Belfast Health and
Social Care Trust

MUCKAMORE ABBEY HOSPTIAL

OCCUPATIONAL THERAPY DEPARTMENT

STANDARDS OF PRACTICE

IN-PATIENTS

SC STANDARDS OF PRACTICE_AUG 2013 REVIEW AUG 2016

INTRODUCTION

> *"The purpose of Occupational Therapy is to enable people to fulfil, or work towards fulfilling their potential as occupational beings. Occupational Therapists promote function, quality of life and realization of potential in people who are experiencing occupational deprivation, imbalance or alienation. They believe that activity can be an effective medium for remediating dysfunction, facilitating adaptation and recreating identity", (College of Occupational Therapists, 2009, p1.)*

Standards of Practice are to help develop and maintain high quality, safe and effective current Occupational Therapy practice, enabling the demonstration of the value and uniqueness of the professions contribution. Auditing services and practice against these standards allows for demonstration of the degree to which individual practitioners and services meet set requirements and the level of quality provided (College of Occupational Therapists, 2011).

Each standard statement defines an expectation or requirement. Each statement has a number of criteria against which services / practice can be audited.

Occupational Therapy Standards of Practice are based on or take into account the following key documents:

- College of Occupational Therapists (2011) Professional Standards for Occupational Therapy Practice, Draft: 2nd January 2011, London: COT.
- College of Occupational Therapists (2010) Code of Ethics and Professional Conduct. London: COT.
- College of Occupational Therapists (2010) Guidance on Record Keeping. London: COT.
- Health & Care Professions Council (2013) Standards of Proficiency – Occupational Therapy. London: HCPC.
- College of Occupational Therapists (2010) Risk management: second edition. London: College of Occupational Therapists.
- College of Occupational Therapist (2013) Briefing 154: Eight core principles for occupational therapist working with people with learning disabilities. London: College of Occupational Therapists.
- College of Occupational Therapist (2012) Quality Briefing 153: Measuring Outcomes. London: College of Occupational Therapists.
- DHSSPSNI (2003) Reference Guide to consent for examination, treatment or care. Belfast: DHPSSPS.
- BHSCT (2013) Adult protection policy and procedures.
- BHSCT (2010) Adverse incident reporting and management policy.

1. REFERRAL

The Occupational Therapist (OT) shall undertake treatment only when the patient has been referred.

1.1 When a referral has been received, it will be prioritised as routine or urgent by Occupational Therapy staff and added to the Occupational Therapy waiting list.

1.2 The OT will prioritise the referrals based on the information on the referral and any new information from ward staff – see appendix 1.

1.3 Routine referrals will be seen within 12 weeks of referral date, if this is not possible the reasons must be documented in the Occupational Therapy progress notes.

1.4 When a referral has been given verbally, the OT should ensure that the referral is made in line with Occupational Therapy procedures for referrals – appendix 1& appendix 2.

1.5 If patient has had previous Occupational Therapy intervention the old notes/reports will be retrieved and reviewed.

1.6 Before contact with the patient, the OT shall read the medical notes and/or nursing care plan as well as the risk management plan. Relevant information should be recorded in the Occupational Therapy Initial Assessment.

2. INITIAL ASSESSMENT

The OT will carry out an initial interview/assessment with patient to establish rapport, give and receive information and obtain consent for treatment.

2.1 The OT will carry out an initial assessment with the patient no later than one working day after receiving an urgent referral – see appendix 1.

2.2 The OT will introduce himself/herself to the patient, explain the role of Occupational Therapy and gain consent for intervention. See section 8 for more standards on consent.

2.3 The OT having carried out an initial interview/assessment and communicated with the medical/nursing staff, will then ascertain if the patient is ready to continue with intervention.

2.4 The OT will gather initial information via a variety of methods (appropriate to the individual) and record information on the initial assessment form.

2.5 The OT will pay particular attention to any risk assessments completed e.g. comprehensive risk assessment, risk assessment screening tool. All relevant information will be documented on the initial assessment and further information sought from MDT as required.

2.6 If unable to gain the required information from the patient, the OT will liaise with other professionals and family/carer, with consent from the patient. This consent should be documented.

2.7 If unable to gain consent from the patient, the OT will proceed in accordance with the professional code of ethics/conduct, Regional and Trust policies and best practice guidelines in relation to consent.

3. ASSESSMENT PROCESS

The Occupational Therapist (OT) will use assessment as a continuous process to gain acquisition of relevant, quantified data about the patient's abilities and deficits and will result in the formulation of treatment aims and objectives.

3.1 The OT will select the most appropriate assessment(s) from the Occupational Therapy assessment toolkit – see appendix 3. The OT will use clinical judgement and observations to supplement assessments selected.

3.2 All assessment results will be shared with the MDT and patient (if appropriate) and summarised in the medical notes and/or nursing care plan.

3.3 An Occupational Therapy report should clearly identify all assessments used, their rationale for use and an interpretation of the results.

3.4 Where further assessment was unable to be completed, the reason for this will be documented in the OT progress notes/discharge report.

3.5 OT staff will review risks specific to OT intervention on an on-going basis and will liaise with MDT re: any additional predictable risks that may be highlighted for OT activities/interventions. These must clearly be documented in the OT progress notes.

4. INTERVENTION PLAN

The OT shall prepare and document an individual intervention plan based on the results of the assessment. This should be appropriate to the patient's needs and goals and should also be consistent with principles of Occupational Therapy practice.

4.1 An individualised intervention plan will be drawn up and recorded in the Occupational Therapy notes or at the end of the Occupational Therapy initial assessment form.

4.2 Where an intervention plan has not been documented following assessment, it should be clearly stated in the patient's Occupational Therapy progress notes why this has not been carried out.

4.3 If the OT has been unable to complete all aspects of the intervention plan, the reasons for any omissions should be clearly recorded in the Occupational Therapy progress notes.

4.4 If it is necessary for the OT to share intervention outcomes with a family member or carer, consent will be obtained from the patient. If unable to gain consent from the patient, the OT will proceed in accordance with the professional code of ethics/conduct, Regional and Trust policies and best practice guidelines.

4.5 The OT will refer the patient to other agencies as appropriate for required follow up assessment and/or intervention.

5. TREATMENT IMPLEMENTATION

The Occupational Therapist (OT) shall implement treatment according to the specified goals and the intervention plan.

5.1 A client centred holistic approach will be used, based on SMART goals or GAS which should be set collaboratively with the service user/patient, when appropriate.

5.2 The OT has a responsibility to ensure that all equipment and techniques used are in accordance with Trust policy, Health and Safety regulations and with the patient's best interests in mind.

5.3 When delegating tasks to an occupational therapy assistant/student, the OT should ensure that the assistants and students have the necessary skills, training and competencies to carry out the tasks delegated.

5.4 All contacts with patient's relatives/carers and any advice given will be recorded in the Occupational Therapy progress notes.

5.5 Outcomes of ward rounds, case conferences and discussions with other team members will be recorded in Occupational Therapy progress notes.

5.6 The OT shall document routinely, the Occupational Therapy intervention provided, the time the intervention was received and the patient's progress in the Occupational Therapy progress notes.

5.7 The OT shall reassess periodically and record the changes in the patient's performance and functional abilities. They will adjust treatment and client centred goals, as appropriate and provide a clinical rationale for same.

5.8 Medical notes/nursing care plans should be updated when any significant change occurs.

5.9 The OT will liaise with members of the MDT as appropriate on a regular basis throughout the patient's treatment process.

5.10 If any client centred goals are not achieved, the reason(s) for this should be clearly identified.

6. DISCHARGE MANAGEMENT

The Occupational Therapist (OT) shall prepare and record a discharge plan for each patient. Bearing in mind the rapid pace of resettlement, the discharge plan and intervention plan may overlap.

6.1 A patient will be discharged when:
* The Occupational Therapy treatment aims have been achieved
* Occupational Therapy intervention is declined
* Discharged to another hospital/service area/team
* The patient's mental state or physical condition prevents them from receiving occupational therapy intervention.

6.2 The OT will document if treatment aims have been achieved. Reasons for unmet treatment aims must be clearly documented

6.3 When patients are being discharged/ transferred to another hospital/team and require on-going Occupational Therapy, a discharge summary will be forwarded or given verbally to the relevant Occupational Therapy Department.

6.4 Where there are concerns regarding the functional ability of a patient to return home, a pre-discharge home visit may be carried out by the OT.

6.5 Where specific requirements e.g. aids, equipment, postural management equipment are identified, the OT will assess and prescribe. In instances, where Community Occupational Therapy follow up is required, a timely referral will be made to the OT in the community learning disability team.

6.6 A discharge report/OT report should be completed on all patients, prior to closing the case. However, if this is not completed a valid reason should be documented e.g. discharged prior to completion of necessary OT intervention.

6.7 If a patient is discharged prior to being seen by an OT, the date of discharge is noted and the unmet need will be recorded by the Lead OT and highlighted to the operational or professional line manager.

6.8 Once discharged, the OT will ensure that the Community OT is informed, discharge reports are completed and forwarded (where appropriate), progress notes completed and contacts/statistics are completed.

7. QUALITY AND AUDIT

The Occupational Therapist (OT) shall periodically and systematically review all aspects of Occupational Therapy interventions for effectiveness, efficiency and outcomes of the service.

7.1 The OT will review the quality and appropriateness of total service delivery at regular intervals using predetermined criteria that reflect professional practice and changes in service delivery.

7.2 To ensure the above, peer reviews, multi-disciplinary discussions, staff development schemes and departmental audits will be on going.

7.3 If modification is required, a programme to improve care will be planned and implemented.

7.4 The service initiative/programme will be reviewed again, after a period of modified practice to assess the success of corrective action.

7.5 The OT is expected to ensure quality of care at all times and must always be up to date with new developments within the profession including research findings.

7.6 The OT is expected to maintain a ‘Continuing Professional Development’ portfolio to ensure his/her fitness to practice.

7.7 The complaints procedure should be clearly displayed within the Occupational Therapy Department and provided to service users and families/carers on request.

8. CONSENT

The Occupational Therapist (OT) must seek informed consent to provide intervention (so far as possible).

8.1 The OT will explain their role and give some indication of treatment format. Written/accessible information should be provided with a contact telephone number, name and designation of the OT. Where required, the OT will provide information in different modalities or use an interpreting service and document same.

8.2 The OT must document that an explanation of their role has been provided and what information has been given.

8.3 Only then, can informed consent be sought from the patient. If consent is given to engage with Occupational Therapy intervention, this must be documented in the Occupational Therapy progress notes.

8.4 Where the patient lacks capacity to make an informed decision regarding Occupational Therapy intervention, the OT will act in the best interests of the patient and in line with Regional, Trust and local policy and guidance. The method of consent must be documented in the Occupational Therapy progress notes.

8.5 When photography, audio-recording or videoing is required, the OT will provide a full explanation regarding the reasons for this and gain written consent from the patient. If the patient is unable to give informed consent, the OT will act in the best interests of the patient and in line with Regional, Trust and local policy and guidance. Consultation and agreement should be sought from the next of kin for patients' who lack capacity.

8.6 The OT will gain consent for student(s) to observe or provide Occupational Therapy intervention, this should be documented in the Occupational Therapy progress notes.

8.7 In cases, where a patient does not consent to intervention, their refusal and reasons for same must be clearly documented in the Occupational Therapy progress notes.

8.8 Where a family member/carer is present during intervention, consent should be obtained from the patient and this should be documented in the progress notes.

9. DOCUMENTATION

The Occupational Therapist (OT) shall ensure that all progress notes and reports are accurate, well structured, clear and concise; to ensure that they are accessible to those who may need to refer to them. High quality information underpins high quality evidence based healthcare.

9.1 The referral should be easily accessible from the patient's Occupational Therapy notes.

9.2 The OT must ensure that progress notes are factual, contemporaneous and concise.

9.3 All progress notes must include the date and time of intervention, those present, the location of the intervention and an accurate account of the intervention provided.

9.4 All note entries must be signed by the OT (full name must be signed), their designation must be recorded and their name printed if their signature is not clear.

9.5 Views and wishes expressed by the patient should be recorded in the treatment plan.

9.6 All correspondence such as telephone calls, discussions with members of the MDT or family must be recorded in the Occupational Therapy progress notes.

9.7 Any non-attendance by the patient for planned treatment sessions must be recorded.

9.8 All advice and information provided in relation to the patient must be recorded, including the nature and source of the information.

9.9 All relevant reports e.g. SI, functional, discharge reports must be enclosed and referred to in the Occupational Therapy progress notes.

9.10 Emails should be enclosed and referred to in the main body of the Occupational Therapy progress notes.

9.11 The OT will use only accepted abbreviations during all forms of documentation.

9.10 Any corrections to notes must be made by inserting a single line through the existing text/word so that it is still legible and then the amendment can be made. All amendments/corrections require initialling by the OT.

9.11 The OT shall be aware of and abide by, legal regulations about confidentiality, storage and disposal of records, and a patient's right to access their own records. The OT shall abide by local and regional policies in relation to these matters.

Appendix 1

Occupational Therapy Referral Guidelines

Occupational Therapists (OTs) work with people of all ability levels to support occupation in education, employment and independent living.

If your client has difficulties in the following areas a referral to occupational therapy should be considered. Please provide a written referral on form provided (see Appendix 2)

Occupational performance area	**Examples**
Self care	Activities of daily living, showering, bathing, dressing, toilet hygiene, feeding.
Productivity (domestic/work/education)	Roles, routines, community living skills, domestic skills, vocational rehabilitation, money management.
Motivation	Strengths and limitations, self esteem, goal setting
Leisure	Structure, opportunities, work/life balance, developing interests
Interpersonal skills	Social and communication skills, assertiveness
Cognitive ability	Memory, planning, organisation, problem solving, judgement
Physical ability	Postural management, seating, wheelchair, motor skills, pressure care, falls
Physical environment	Housing, accessibility, transport, safety, aids and equipment, assistive technology, reducing falls risk
Sensory processing	Impact on engagement in occupation and interaction within environment. May also impact on behaviour.

Please complete written referral and send to OT dept, Rathmore building. Referrals will then be prioritised an allocated according to need.

Referrals will be treated as **urgent** if they meet the following criteria:

- Condition has deteriorated rapidly or there is a sudden change in circumstances resulting in significant risks
- Palliative/end of life

If your client meets any of these criteria please identify this on the referral form.

If you have any questions regarding OT referrals please call Heather, Shelley or Katie on 95044589.

Appendix 2

REFERRAL TO ADULT LEARNING DISABILITY
Occupational Therapy Service

Patient's Name: **Date of admission:**	**Date of Birth**: **Ward:** **Named Nurse:**

Diagnosis:

Reason for OT referral:

☐ Seating

☐ Wheelchair

☐ 24 hour Postural Management

☐ Bathing/ Toileting/showering

☐ Resettlement

☐ Functional Assessment

☐ Sensory Assessment

☐ Falls

Other, please specify

….………………………………………………………………………………

Relevant Medical History:

Relevant Social History:

Other Relevant Info: (e.g. Sensory/MH/Forensic/Other)

Drug History:

Date:	**Signed By:** ……………………………………………………………………	**Routine Request** ☐	**Urgent Request** ☐

Print Name & Designation

Appendix 3

Belfast Health and
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OCCUPATIONAL THERAPY - LEARNING DISABILITY ASSESSEMENT TOOLKIT

Occupational OTs (OTs) working within learning disability services will seek to select the most valid and reliable assessment tool(s) alongside their clinical judgement to ensure the following:

1. **A high quality evidence – based OT service is delivered with a clear rationale to support recommendations**
2. **Impact of OT intervention can be measured**
3. **Functional, environmental, cognitive and postural changes can be measured over time to monitor changes in condition, particularly from baseline**
4. **Clients can be compared to normative populations/data, if relevant**
5. **Clarity re: professional roles**
6. **Evidence from standardised assessments can assist with diagnosis of conditions in collaboration with MDT**

CONTENTS

1.0 Functional/occupation based assessments

Assessment	Description
1.1 AMPS **Assessment of Motor & Process Skills** **(Fisher & Jones, 2012)** *OT specific assessment/devised by OT*	The Assessment of Motor and Process Skills (AMPS) is a standardised observation-based evaluation of occupational performance. It has been standardized on an international sample of 148,158 persons with and without disabling conditions or medical diagnoses. The AMPS measures the **quality** of a person's ADL performance by rating the ***effort, efficiency, safety, and independence*** while a person actually performs chosen, familiar, and life-relevant ADL tasks which include bathing, dressing, meal preparation, house cleaning tasks, outdoor maintenance tasks, and shopping (120 standardised ADL tasks). It is useful as a baseline assessment and can be used over time to highlight improvement or deterioration. This assessment is based on the Model of Human Occupation (MOHO).
1.2 MOHO ExpLOR **(Parkinson et al, …..)** **** awaiting publication** *OT specific assessment/devised by OT*	Objective, theory based assessment which measures occupational participation for those at an exploratory level of functioning. The assessment is designed to guide intervention and service delivery for this client group by rating performance under categories motivation for occupation, pattern of occupation, communication and interaction skills, process function and motor function. It is based on the widely used Model of Human Occupation (MOHO).
1.3 FIM - Functional Independence Measure (Adapted from Hall et al, 1994)	The Functional Independence Measure (FIM) is an 18-item global measure of disability. Each item is scored on 7 ordinal levels. The FIM can be used for measuring disability in a wide range of conditions and is a reliable tool when used by trained clinicians. FIM is the most widely used functional assessment tool and is designed to measure function over time.

1.4 FIM + FAM – Functional Assessment Measure (Adapted from Hall et al, 1994)	The Functional Assessment Measure does not stand alone but adds 12 FAM items to the FIM, specifically addressing cognitive and psychosocial function, which are often the major limiting factors for outcome. Hence the Functional Assessment Measure is abbreviated to (FIM+FAM).
1.5 ABAS-II - Adaptive Behaviour Assessment System (Harrison & Oakland, 2003	Comprehensive norm-referenced assessment of adaptive skills from birth to 89 years. It may be used for diagnosis and classification of disorders and to monitor progress over time. The behavioural rating scale measures daily living skills--what people actually do, or can do, without the assistance of others; addressing 10 adaptive skill areas. It can be completed by a carer or adults can self-rate.
1.6 Functional Living Scale (Cullum et al, 2012) *OT specific assessment/devised by OT*	Ecologically valid performance-based measure of functional competence for use with individuals suffering from a variety of neurodevelopmental disorders; designed to measure instrumental activities of daily living (IADL). The scale assesses domains such as time, money management, communication and memory. It can be used in comprehensive assessments, to support placement decisions, aid treatment planning, evaluate treatment outcomes, and monitor disease progression.
1.7 Model of Human Occupation Screening Tool (MOHOST) (Parkinson et al 2006) *OT specific assessment/devised by OT*	The MOHOST addresses client's motivation for occupation, pattern of occupation, communication/interaction, process, and motor skills, and environment allowing the OT to gain an overview of the client's occupational functioning. The MOHOST was designed to be used to document progress towards occupational therapy intervention goals as well as to screen for occupational therapy services.
1.8 Occupational Circumstance Assessment Interview and Rating Scale (OCAIRS) (Forsyth et al 2005) *OT specific assessment/devised by OT*	A semi-structured interview that reports on the extent and nature of an individual's occupational participation. Appropriate for use with adolescents and adults who have the cognitive and emotional ability to participate in an interview. Questions are centred around a client's roles, habits, personal causation, values, interests, skills, goals, interpretation of past experiences, physical

	environment, social environment and readiness for change.
1.9 Eating and Drinking assessment *OT specific assessment/devised by OT*	Locally devised tool to assess a person's ability when eating and drinking. It considers upper limb function, positioning, perception, sensory issues, behaviour, environment, swallow ability and equipment required.
1.10 Pool Activity Level (Poole 2012) *Devised by OT*	The PAL Instrument contains a valid and reliable tool for assessing level of ability which is recommended in the National Clinical Practice Guideline for Dementia (NICE, 2006), for activity of daily living skill training and for activity planning. The instrument also contains profiling tools for interpreting the assessment in order to plan and deliver effective, enabling care and support. http://www.jackiepoolassociates.org/wp-content/themes/flare-child-theme/pal/index.htm
1.11 Role checklist (accessible) Based on the Role Checklist by Frances Oakley, MS, OTR/L, FAOTA. Adapted by Kim Bogues OT (UK) and Rebecca Wilson OT (UK), with permission. *OT specific assessment/devised by OT*	The role checklist is a reliable and valid assessment tool that provides data on individuals' perception of their participation in roles throughout their lifespan and data regarding the degree to which each role is valued. It also gathers supplemental information regarding an individual's capacity to maintain a balance among roles.

2.0 Environmental assessments

Assessment	**Description**
2.1 REIS – Residential Environmental Impact Survey (short form- UK version) (Parkinson et al, 2011) *OT specific assessment/devised by OT*	Semi–structured assessment, designed to examine the environmental impact of residential facilities on the resident(s). The REIS was designed for adults with a mild to moderate learning disability in mind and aims to provide a conceptualization of the impact of the environment on the functioning of an individual and to generate recommendations to enhance the qualities of the environment. MOHO serves as the theoretical framework for this assessment.

2.2 Dementia Design Audit Tool (Dementia Services Development Centre University of Stirling, 2nd Edition, 2011)	This audit tool provides a framework for making decisions about the design of spaces for people with dementia with particular consideration given to the impact of the environment those with sensory and cognitive impairments. The 2nd edition is based on new research and recent design literature, a field study by researchers from DSDC and the experience of numerous audits.

3.0 Falls assessments

Assessment	**Description**
3.1 FRAT – Falls Risk Assessment Tool (Peninsula health, 2006)	The FRAT has three sections: Part 1 - falls risk status; Part 2 – risk factor checklist; and Part 3 – action plan. The complete tool (including instructions for use) is a complete falls risk assessment tool. However, Part 1 can be used as a falls risk screen. It was developed by the Peninsula Health Falls Prevention Service for a DH funded project in 1999, and is part of the FRAT Pack. A study evaluating the reliability and validity of the FRAT has been published (Stapleton C, Hough P, Bull K, Hill K, Greenwood K, Oldmeadow L , 2009).
3.2 Home FAST - Home Falls and Accident Screening Tool (McKenzie & Byles et al, 2000) *OT specific assessment/devised by OT*	This environmental screening tool can be used to identify hazards within the home. The tool includes 25 questions and a definition for each question. The higher the score the higher the risk of falls due to environmental factors. Home Fast was developed and trialled in Australia by researchers at the University of Newcastle and has been adopted by many service providers in clinical and research settings in Australia, the United Kingdom and Canada

4.0 Cognitive and perceptual assessments

Assessment	**Description**
4.1 CAMDEX – DS Cambridge Examination for Mental Disorders of Older People with Down's Syndrome and Others with Intellectual Disabilities	The CAMDEX -DS is a comprehensive standardised assessment tool for diagnosing dementia in people with Down's syndrome (a group known to be at particular risk of dementia). Based upon CAMDEX-R, CAMDEX-DS has been modified for use with intellectual

(Ball et al, 2006)	disability. The pack is comprised of a structured informant interview, a direct assessment of the patient/participant (CAMCOG), and guidance for diagnosis and post-diagnosis intervention, providing a reliable way to identify dementia (and to differentiate it from other common disorders). It may be used in community settings by mental health professionals as part of the diagnostic process. Use of the CAMCOG provides the means for on-going neuropsychological evaluation and informs future support and intervention strategies.
4.2 CAM - Cognitive Assessment of Minnesota **(Rustad et al, 1993)** *Devised by OT*	Screening tool that assesses a wide range of cognitive skills, covering a variety of cognitive skills which are organized into a hierarchy from simple to complex. The specific subtests are attention span, memory /orientation, visual neglect, following directions, immediate memory, temporal awareness, matching, object identification, visual memory and sequencing, recall/recognition, auditory memory and sequencing, simple money skills, simple math skills, foresight and planning, safety and judgment, concrete problem solving, and abstract reasoning. This test is designed to be used for adult clients who have cognitive impairments due to a CVA or a TBI, although not standardised for LD population proves a useful tool.
4.3 Loewenstein Occupational Therapy Cognitive Battery (LOTCA) **(Itzkovich, Averbuch, Elazar, & Katz, 2000)** *OT specific assessment/devised by OT*	LOTCA is a valid and reliable tool for measuring cognitive abilities and visual perception in people with intellectual disabilities. It includes 25 subtests in 6 cognitive areas, orientation, visual and spatial perception, praxis, visuomotor organization and thinking operations.

5.0 Sensory integration assessments

Assessment	Description
5.1 Sensory Profile - Caregiver Questionnaire **(Dunn, 1999)** *Devised by OT*	A standard method to measure sensory processing abilities and to profile the impact of sensory processing on functional performance. Use the profile's nine factor groupings to characterize by responsiveness to sensory input, sensory seeking, emotional reactive, low

	endurance/tone, oral sensory sensitivity, inattention/distractibility, poor registration, sensory sensitivity, sedentary, and fine motor/perceptual. The manual presents information on administration, scoring, interpretation guidelines, development, and technical properties (reliability and validity).
5.2 Sensory Profile Adult - Self report questionnaire (Brown & Dunn, 2002) *Devised by OT*	A standard method to measure sensory processing abilities and to profile the impact of sensory processing on functional performance. The *Adolescent/Adult Sensory Profile* is designed as a trait measure of sensory processing patterns and effects on functional performance. An individual answers questions regarding how he or she generally responds to sensations. This enables the instrument to capture the more stable and enduring sensory processing preferences of an individual.
5.3 Sensory Integration Inventory – revised for individuals with developmental disabilities (Reisman & Hanschu, 1992) *Devised by OT*	A sensory integration screening tool to assess if individuals will benefit from further assessment and treatment. It is divided into sections associated with sensory integrative processing: tactile, vestibular, proprioceptive, and general reactions. In each section behaviours suggestive of sensory needs are listed as well as the self-stimulatory or self-injurious behaviour associated with that system. A profile of sensory strengths and needs and associated self-injurious and self-stimulating behaviours is elicited through this process that provides a guideline for treatment.

6.0 Postural management assessments

Assessment	Description
6.1 Comprehensive Postural Management Assessment (Crawford, 2012) *OT specific assessment/devised by OT*	Comprehensive assessment divided into 3 parts: initial information, physical/postural evaluation and risk assessment. Incorporates postural competency scales, quality and quantity of lying & sitting scales as well as chest symmetry and joint range of movements. The assessment guides clinical rationale for specialist equipment and handling techniques. It also services as a baseline assessment which can detect changes over time. The main outcome is that each individual has a personalised postural care passport (pictorial and written advice) outlining their specific needs and providing comprehensive advice to

	carers, staff and support workers across settings to ensure a consistent approach to 24 hour postural care for complex disability.
6.2 Critical Measures Seating Assessment **(Crawford, 2009)** *OT specific assessment/devised by OT*	Seating assessment which incorporates joint ranges that are critical to ensuring that an adequate seating solution is provided and that OT staff can justify the allocation and expenditure of seating resources. This assessment also incorporates basic information relevant to seating such as pressure ulcer risk, transfer ability, sitting balance etc. This is the minimum assessment for seating provision and if a client has complex disability e.g. contractures, high extensor tone, the Comprehensive Postural Management Assessment must be used.

7.0 Social and Communication assessments

Assessment	**Description**
7.1 The Assessment of Communication and Interaction Skills (ACIS) **(Forsyth et al 1998)** *OT specific assessment/devised by OT*	The ACIS is an observational assessment that gathers data on the skill that persons demonstrate when communicating and interacting with others in an occupation. The ACIS gathers data on skill as it is exhibited during performance of an occupational form and/or within a social group of which the person is part.
7.2 Evaluation of Social Interaction (ESI) **(Fisher & Griswold, 2008)** *OT specific assessment/devised by OT*	To evaluate a person's ***quality*** of social interaction during natural social exchanges with typical social partners. *The ESI is used to*: • Test the person as he or she engages in relevant social interactions that have been prioritized by the client, and as the person interacts with typical social partners (an unlimited range of social interactions can be observed) • Measure the degree to which a person's social interactions are polite, respectful, well-timed, relevant and mature.

8.0 Vocational assessments

Assessment	**Description**
8.1 Worker Role Interview (WRI) **(Braveman et al 2005)**	The WRI is a semi-structured interview designed to be used as the psychosocial/environmental component of the initial rehabilitation assessment

OT specific assessment/devised by OT	process for the injured worker or the worker with a long term disability and poor/limited work history.
8.2 Work Environment Impact Scale (WEIS) **(Moore et al 1998)** *OT specific assessment/devised by OT*	The WEIS is a semi-structured interview and rating scale designed to assist the OT to gather information on how individuals with physical or psychosocial disabilities experience and perceive their work environments. Typical candidates for this assessment are persons who are experiencing difficulty on the job, and persons whose work is interrupted by an injury or episode of illness. The 17 items reflect the social and physical environment, supports, temporal demands, objects used, and daily job functions

9.0 Other assessments

Assessment	**Description**
8.1 Interest Checklist UK - V6.1 (Heasman D & Brewer P, 2008) *devised by OT*	The Modified Interest Checklist gathers information on a client's strength of interest and engagement in 68 activities in the past, currently, and in the future. The main focus is on leisure interests that influence activity choices. The checklist can be used by adolescents or adults and is based on the Model of Human Occupation.
8.2 Volitional Questionnaire (VQ) (De las Heras et al 1998) *OT specific assessment/devised by OT*	The volitional questionnaire is an observational assessment tool that examines a person's motivation as represented in the concept of volition. By systematically capturing how a person reacts to and acts within his/her environment, the VQ provides insight into a person's inner motives and information about how the environment enhances of attenuates volition. The VQ was designed to be used in conjunction with the re-motivation process.

Guidelines for Occupational Therapy Community Outings

Guidelines for Occupational Therapy Community Outings

The purpose of this document is to provide guidelines for Occupational Therapy staff accompanying clients on community outings. This document is not a policy and therefore there is a degree of clinical judgement to be used by Occupational Therapy staff as well as adherence to documents specific to the area of work.

Community outings are defined as outings outside of the grounds of the hospital. Ground leave refers to periods of time which a client have been given in conjunction with the multidisciplinary team to walk around the hospital grounds accompanied by staff or unaccompanied by staff.

1. Community outings will be carried out as part of a client's individual Occupational Therapy treatment plan

2. Clients will only be selected for community outings by a qualified Occupational Therapist

3. The Occupational Therapist will consider the mental health status/mental state of the client and their level of observations.

4. The Occupational Therapist will book transport in advance.

5. Any untoward incidents must be reported on return to the Occupational Therapy Team Leader who will inform the Occupational Therapy Manager. Nursing and medical staff will also be informed and the Incident recorded as soon as possible on DATIX. Incidents must also be documented on PARIS.

6. It is essential that all staff attend Personal Safety and Disengagement training or MAPA according to area of work.

7. Occupational Therapy staff are required to read the Belfast Health and Social Care Policy entitled "Observation within Mental Health Services" (November 2013).

<u>Acute (Rathlin, Avoca and the Mater)</u>

- The staff – client ratio will be determined by the following:-
    - The mental state of the client on the day of the outing
    - The level of observation i.e. general or continuous
    - The venue/ location
    - Mode of transport
    - Banding levels of staff i.e. qualified or unqualified
    - Physical health status ie mobility issues

- The majority of clients on Occupational Therapy community outings will be on general observation levels.

- A ratio of 2 clients on general observation levels to 1 qualified Occupational Therapist or Occupational Therapy Assistant

  Or

  A ratio of 4 clients to 1 Occupational Therapist and 1 Occupational Therapy Assistant.

- In Avoca ward OT staff rarely accompany clients on community outings. But a minimum of 1 Occupational Therapist and 1 Occupational Therapy Assistant to clients on ground leave

- The Occupational Therapist will discuss the clients identified for community outing with nursing staff and seek Doctor's clarification for an individual to attend if necessary

- In conjunction with clients, the Occupational Therapist will identify the venue/location- depending on the identified needs of the group e.g. mobility, level of observations etc

- The Occupational Therapist will inform Occupational Therapy and nursing staff colleagues verbally and in writing of the clients' names, time of departure, venue of visit, expected time of return and contact telephone numbers (mobile to be taken)

- The Occupational Therapist will check with nursing staff that the clients have received their medication before departing (if applicable). This will include medication for physical conditions

SHANNON

1. Grounds leave: escorted or unescorted to be discussed and agreed at weekly MDT team conference and staff members identified based on individual service user and their care plan.

2. Community leave also to be discussed and agreed at weekly MDT case conference and number/type of staff identified. Occupational therapists to work alongside service user to identify a leave plan. Leave plan to include desired location, purpose of visit (eg assessment/social skills training) time of departure and return, mode of transport, staff to accompany. Leave plan to be recorded in patient notes and community leave risk assessment updated with details.

3. Should a batch of leaves be approved at MDT case conference Occupational Therapist to liaise also with service user's lead nurse to develop leave plan as OT staff may not always be required as staff members.

4. Leave plans to be forwarded to consultant to inform DOJ approval if required. A copy of leave plan also to be placed in service user file on ward. (DOJ approval will be with consultant secretary should nursing staff require same.)

5. Prior to leaving Shannon all patients to receive a 'pat down' and details of purpose of leave clarified. Occupational Therapist to liaise with nursing colleagues to clarify mental state over past 24 hours. Ward restrictions may apply should any incidents have occurred within the previous 48 hours in which case leave is to be postponed and consultant informed.

6. On leaving Shannon patients name and clothing to be recorded on PARIS (OT liaise with nursing staff) nursing staff directed to leave plan in patients folder. Time of return also to be indicated to ward staff. Occupational therapist to take escort mobile phone from reception area and inform ward of mobile number before leaving unit.

7. Whilst on Community Leave all service users to remain in eyesight of Occupational Therapist - should this be breached (eg male visiting toilet) service user to receive 'pat down' and wanding on return to unit.

8. On return from leave Occupational therapist to provide verbal handover to nursing staff and ask service user for their feedback in relation to how their leave went. Both objective and subjective feedback to be provided to consultant to inform DOJ.

Guidelines for an Untoward Incident on a Community Outing

Guidelines for an Untoward Incident on a Community Outing

1. The following are some examples of an untoward incident:

    - Client becomes verbally and/or physically aggressive
    - Client becomes disinhibited and/or an embarrassment to themselves e.g. hypomania or bizarre behaviour
    - Alcohol consumed on outing
    - Drug taken on outing
    - The client becomes suicidal
    - The client has a seizure
    - Becomes physically unwell, falls
    - Threatening to abscond
    - Absconding
    - Panic attack
    - Commits a crime on community leave

2. The Occupational Therapist will try to intervene and diffuse the situation using de-escalation training.

3. If this is not possible the Occupational Therapist will seek assistance from a colleague on the outing.

4. If possible the Occupational Therapist will try to remove the client from the situation and other staff will ensure that the other clients are safe

5. If the client remains unsettled, the Occupational Therapist will ring the ward for further assistance and remain with the client until assistance arrives (either from Occupational Therapy staff/ nursing staff/ PSNI or Security staff etc).

6. Similarly, if the client absconds the Occupational Therapist will ring the ward to inform the nursing staff providing them with the relevant information e.g. the direction the client went and what they were wearing, the clients last conversation and initiate the BHSCT AWOL procedure.

7. If a client has a seizure/ hypoglycemic episode or physical health emergency, first aid will be given at the scene and an appropriate action taken. A member will stay with client and phone for assistance.

8. The Occupational Therapist and/or an Occupational Therapy colleague and Occupational Therapy Assistant will accompany the rest of the clients back to the ward

9. On returning to the ward, the Occupational Therapist will report the incident to nursing and/or medical staff, Occupational Therapy colleagues and the Occupational Therapy Team Leader.

10. The Occupational Therapist will record the incident on Datix and also in the multidisciplinary notes.

11. If possible, a debriefing /refection session will be held with MDT/ Team Leader.

Checklist for Provision and Handover of Weighted Blanket

Clients name: **PARIS ID:**

D.O.B: **Ward:**

Date of assessment:

Weight of client:

Make, model and weight of weighted blanket:

Reason for use:

When should it be used?

Assessment Checklist	**Items Checked and Comments**
Overall health condition of client?	
Have you completed a Sensory Processing assessment?	Yes ☐ No ☐
Can the client remove the blanket independently?	Yes ☐ No ☐
Has the client consented to use of the blanket?	Yes ☐ No ☐
Does the client display any of the following:	
Respiratory problems (Use below torso may be considered)	Yes ☐ No ☐
Cardiac problems	Yes ☐ No ☐
Epilepsy (Must be controlled for Weighted Blanket to be considered)	Yes ☐ No ☐
Serious Hypotonia	Yes ☐ No ☐

Skin problems/allergies	Yes ☐ No ☐
Circulatory problems	Yes ☐ No ☐

Technical Checklist and Handover	
Client to be **supervised at all times** under the blanket	All of the below items discussed with
Weight of blanket a maximum of 10% of client's weight	
Blanket to not be used for longer than 20 minutes at a time	
Weight evenly distributed through blanket	
Head and neck must not be covered	
Respiration must be observable at all times	
Client must not be rolled in blanket – should be placed over them	
If in bed – blanket should not be draped over the sides of the bed	
Must be able to remove/get free of blanket independently	
Weighted blanket must **NEVER** be used as a restraint	
Only for indoor use	
Do not use near a heat source, naked flame or cigarette as it is not fire resistant	
Do not place on radiators or heaters	
Blanket to be stored in ward store or OT dept when not in use.	
Blanket to be removed if any of the following are observed	
Difficulty breathing	
Nausea	
Increase in temp	
Any behavioural/physical reactions demonstrating discomfort or anxiety	

O.T Name(s) (Printed) & Signature(s)	Date:
Client/Carer (Printed) & Signature(s)	Date:

GENERAL RISK ASSESSMENT FORM AS REQUIRED BY THE MANAGEMENT OF HEALTH & SAFETY REGULATIONS (NI) 2000 as amended

Facility/Ward/Department: **PICU, Muckamore Abbey Hospital**
Assessment Completed By: **Katie Carson (OT)/Danielle Quinn (Staff Nurse ICU)**
Date: **03/08/15** reviewed and updated 1/10/15

Brief Description of equipment: Weighted Blankets and weighted lap pad are part of a vast range of tools used for their calming effect in people with difficulties in adjusting to environmental stimuli.

Description of Hazards	Persons Affected by the Work Activity and How	Existing Controls	Likelihood	Severity / Consequence	Risk Rating
Suffocation due to the blanket blocking airway	Client using weighted blanket	Weighted blanket checklist is completed with the client/carer see below for details of same: • When handing over the weighted blanket the staff member is informed that the blanket is NEVER to be placed over the head/neck of a client. • Client is not to be rolled in blanket. • If blanket is being used in bed it should not be draped over the sides of the bed. • The client should be	2	2	low

		supervised at all times when using the blanket. • The blanket should be used for no more than 20 minutes at a time. • The client should be able to remove the blanket independently at any time.			
Allergic reaction to material	Client using blanket if they take a reaction to the material in the blanket	• During initial screening of the medical/ nursing notes check if client has any allergies and document same on checklist.	1	1	low
Impact on medical conditions	Clients that have • Respiratory problems • Cardiac conditions • Circulatory conditions • Epilepsy • Serious hypotonia.	• During initial assessment of client identify if any of these are present and document on checklist. • If client has respiratory problems a weighted blanket may be considered for use below the torso so that respiratory function is not being affected by the pressure of the	1	2	low

		blanket. - If the client has epilepsy it must be well controlled before a weighted blanket is considered. - For cardiac and circulatory conditions a weighted blanket should not be considered as it could have serious health implications. - It is not be considered for someone with severe hypotonia as they would be unable to remove the blanket themselves and it could be considered a restrictive practice.			
Restraint of clients	Client using blanket is affected. Independence and choice would be removed as they are being restricted to move by blanket.	- In the handover checklist it is clearly stated that under no circumstances is the weighted blanket to be used as a restraint for a client. - While assessing the	1	1	low

		client with the blanket it is important to ensure that the client is able to remove the blanket independently and record this in the OT notes and handover form. • Blanket is only to be used for client that can independently remove it.			
Inappropriate weight of blanket	Could lead to the client becoming injured from the weight of the blanket on them. It could also cause breathing or circulatory difficulties if the blanket is too heavy for the client.	• Follow guidelines for blanket to be no heavier than 10% of a client's weight. • Client to be assessed by OT with blanket for the first time to ensure weight is appropriate for client – vital signs do not change and client shows no signs of distress.	2	1	low
Patient to become acutely unwell	Client to begin to feel nauseous or have a temperature change or difficulty breathing while using the blanket and to be unable to remove it.	Checklist for handover to staff to be completed. Precautions to this that are also on the checklist include: • Blanket must still allow	1	2	low

		for clients vital signs to be observed at all times while using the blanket. - If a client shows any signs of distress such as an increase in temp, difficulty breathing, nausea or any behavioural/physical reactions demonstrating anxiety or discomfort the blanket is to be removed.			
Fire Hazard	Patient using the blanket and other people on the ward if blanket was to catch fire.	Checklist to be competed for handover to staff and the following precautions are included on checklist: - Weighted blanket is not fire retardant. - Not to be placed near any heat source, naked flame or cigarette. - Not to be placed on radiators or heaters. - Patient will be supervised at all times when using the blanket.	1	2	low

		• Blankets will be stored ward storage room.			
Infection control	Patients. Risk of spread of infection due to communal use.	• Blanket to be placed in duvet cover before use with individual patient and removed after use and laundered.	1	1	low
Choking hazard	Patients	• Some of the equipment have removable weights which could be ingested with clients who may have conditions such as PICA • All clients are individually risk assessed and specific concerns such as this would be highlighted at that time and measures put in place • Clients are supervised at all times when using the equipment to reduce the risk of this happening	1	1	low
Weights could be used as a weapon	Patients, staff and visitors	• Some of the equipment have removable weights which could be	2	1	low

		used as a potential weapon i.e. to throw at others or objects • All clients are individually risk assessed and specific concerns such as this would be highlighted at that time and measures put in place • Clients are supervised at all times when using the equipment to reduce the risk of this happening • Equipment is locked away and only accessible by staff keys therefore if ward/client is unsettled item can be removed.			

NOTE: There are also specific risk assessment forms for specific Health & Safety issues such as Substances Hazardous to Health (COSHH), Display Screen Equipment Self Assessment Form, Manual Handling Risk Assessment Form (which includes Patient & Load Handling) for particular clients or clinical issues.

Action Plan

Sources of Information / Persons Consulted	Further Action if necessary to control the Risk	Person/s responsible for Co-Ordinating implementation of the Action.	Recommended Timescales	Date Completed	Revised Risk Rating
ROMPA Weighted Blanket safety guidelines College of Occupational Therapists Briefing on "The safe use of weighted blankets" "Sensory modulation & the Environment" book with content relating to risk ax of weighted blankets. Ciaran Connolly (Trust fire officer)	Use of weighted blanket checklist with every patient.	All OT's prescribing the use of a weighted blanket	Immediate	N/A	

Please ensure that you:

1. Communicate this risk assessment with the staff and others affected by the work assessed.
2. Monitor the implementation of any further action identified.
3. Monitor the continued implementation of existing controls.
4. Revise the Risk Rating when additional actions have been implemented.
5. Retain this Risk Assessment in your Health & Safety Policy & Documentation folders.
6. When further action has been identified it is good practice to set a date shortly after measures are likely to be implemented. This will enable you to assess their effectiveness in reducing risk.
7. Review your risk assessment at least every two years or more frequently if required. In certain circumstances it will be necessary to undertake a new assessment eg. following an Accident/Incident, new legislation/guidance/best practice, changes in work activities/location, new hazards/activities identified.

KEY TO RISK RATING: Likelihood x Severity/Consequence = Risk Rating

Likelihood	Severity / Consequence	Risk Rating	
1 Rare	1 Insignificant	**Low Risk (Green)**	**(See Risk Management Strategy on Belfast Trust Intranet for Risk Rating Tables)**
2 Unlikely	2 Minor	**Medium Risk (Yellow)**	
3 Possible	3 Moderate	**High Risk (Amber)**	
4 Likely	4 Major	**Extreme Risk (Red)**	
5 Almost Certain	5 Catastrophic		

Line Manager Signature ____ **Date** ___________________________________

Initial Review Date: ____

Physiotherapy Learning Disability Service Review Of Achievements

May 13

Achievements

- **Change in Structure of Service**
- Dedicated Assistant Manager
- Excellent avenue for Career Progression
- Challenges of recruitment into LD creation of split post LD/Doms to assist with successful recruitment outcome
- Two Geographic Teams
- Movement of Staff from MAH site to facilitate
- Equitable staffing across given resource
- Increased Flexibility Movement of static staff out of Day Centres into Community Teams

- **Learning Disability included in the Band 5 Rot**ation
- Facilitate increased experience in L&D
- Showcase range of skills that are required for working within the service
- Facilitate workforce Planning

Achievements

- **Increased Accountability** regarding activity monitoring across service Community MAH Aids & Appliance Service
- Service compliance with waiting list targets as set by DOH weekly Target Demand Analysis TDA predicted Patient Tracking List PTL
- Referral Rate New / Review
- Capacity Demand in Community service
- Implementation of PCIS in Community / MAH

- **Promotion of EBP**
- Group Work
- Hydro Case Studies/ Hydro Document
- Availability of good quality clinical recording to manage complaint procedures
- Compliments

Achievements

- IST programme for Support Staff
- Student Placements
- Gain Document

Challenges

- Implementation of Trust Policy and Protocol regarding Working Well together and Attendance Management
- Low Staff Morale
- Staff sickness
- Stress on staff to maintain service
- Clinical Risk assessment completed on staffing levels Risk Register
- Changes on MAH site Relocation of services with closure of Rathmore building,resettlement Impact on Physio A&A Service

Plan 14/15 Broad outline

- Improve Morale Team Day TBA GB
- Feedback from Service Review
- Completion of GAIN
- Completion of Caseload analysis spread of Complexity
- Capacity Demand MAH Site / Optimum Staffing
- Capacity/ Demand A&A Review of similar resources across service Maximising resource
- Development of Hydro therapy Service
- Improved AHP working
- User/ carer involvement

Physiotherapy Learning Disability Service

Historic Situation

Hospital / Day Centre based

Recruitment Problems

Lack of structure for supervision

Restricted opportunities for AHP working

Loss of experienced staff due to retirement

New structure and vision for the service

Integration of Aids & Appliance service MAH: this service being reviewed as part of overall Physiotherapy Aids & Appliances Review

Improved staffing 1.5 Band 6, 1.0 Rotational Band 5, 0.5 Band 3, will enable junior staff to gain experience in LD and promote the area in career development and improve skill mix

Improved staffing to offer Trust wide service previously based in N&W sector

Day Centres: Review of skill mix and provision of service commensurate with client need, Audit carried out in Everton to assist with implementation of this change

Greater potential for AHP joint working to impact on best outcome for clients

Improved opportunity for using increased intensity and time limited interventions in order to evaluate physiotherapy input

Development of learning opportunities Band 5/ Student

Opportunities for liaison with other Functional groups within Physiotherapy service e.g. FCH / schools to allow improved and informed transition to Adult services

Promotion of group work using appropriate outcome measures

Improvement in structure for supervision

/DRAFT
15 May 2009

Belfast Health and
Social Care Trust

Pilot
Multidisciplinary Healthy Living Programme

30th August 2007 – 1st November 2007

Finglass Ward
Muckamore Abbey Hospital

Compiled by:
Gillian M Bingham BSc (Hons), Grad Dip Phys, MCSP
Superintendent Physiotherapist / Team Leader
Adult Learning Disability Physiotherapy Services

CONTENTS

Appendices

THE MULTIDICIPLINARY TEAM

Gillian Bingham	Superintendent Physiotherapist/Team Leader
Pat Heaney	Charge Nurse
Marie-Claire Kane	Chief Dietitian
Dr K Ng	Associate Specialist
Dr M McGinnity	Consultant Psychiatrist

Thanks to all the staff who contributed to the programme including:

Rosalind Kyle	SALT
Sylvia Roberts	Dentist
David Lewis	Podiatrist
Elsie Clinghan	Ward Manager
Carmel Tohill	Pharmacist
Carolyn Quinn	Staff Nurse
Kim Murray	Day Care
Joan Roulston	Image Consultant

ACKNOWLEDGEMENTS

Thanks goes to Eileen McIlhagga, Senior Physiotherapist and the physiotherapy technical instructors for their input to the programme. Also to the Ward Staff, who attended and encouraged the patients throughout the programme. Margaret Kennedy for clerical support and Margaret McKeen, Audit Research Officer.

KEY WORDS

Healthy living, health status, exercise, diet, adults with learning disabilities, mental health, multidisciplinary.

SUMMARY

Six adults with learning disabilities (ALD) in a ward for delayed discharge were recruited to take part in a 10-week pilot hospital based programme, designed to improve their health and improve physical function.

Primary outcome measures were weight reduction, walking speed and flexibility.

The effects of lifestyle or self-perceived lifestyle and health status knowledge were also assessed using a pre-pilot questionnaire.

The programme was evaluated by the outcomes in exercise improvement, flexibility, weight reduction, and via a pre and post programme questionnaire. Feedback and comments from participants and staff were very positive in that the programme has helped to educate and raise awareness of the benefits of a healthy lifestyle to the user group.

Feedback indicates that interactive and active modes of delivery for such a programme reinforces the outcomes and gives the participants ownership. Regular group exercise and educational sessions on lifestyle and nutrition, helps improve physical function and health status for adults with learning disabilities. The social interaction was important for this pilot group and as the programme progressed so did the peer support. Recommendations for further groups of this type are made at the end of the paper.

BACKGROUND TO THE PILOT HEALTHY LIVING PROJECT

The pilot healthy living project stemmed from a multidisciplinary discussion regarding the activity and health of patients in a ward where the patients were identified as delayed discharges.

These patients were receiving medical care but were having little or no input from AHPs and some where identified as having health issues including obesity, diabetes and other related problems such as low uptake of physical activity and poor diet. The activities patients undertook needed to be better co-ordinated and provide overall cohesion of patient care. There was a clear indication for a multidisciplinary group to be set up to achieve improved outcomes for health.

It was also felt that to help better prepare the patients for discharge into the community a programme could be devised to address the issues mentioned and promote an overall life style with health benefits.

A meeting was set up in conjunction with the weekly ward meetings and this was chaired by the Consultant Psychiatrist.

Co-ordinating the project was difficult due to AHP staff resources, however, there was commitment to see it through by all the staff involved from the onset.

Staffing levels meant the start date kept getting moved. Finally it was decided to start the 10 week programme and address issues as they arose. This proved a good decision.

INTRODUCTION

There is substantial evidence that regular physical activity is beneficial to many other aspects of health including improved cardio-vascular function; improved strength of muscles, tendons and bones, thus reducing the risk of injury and osteoporosis. Also changes in metabolic function resulting in weight control, reduction in obesity and obesity related disease. Enhanced psychological function affecting self-esteem, mood, memory and reduction of stress and challenging behaviours are also positive outcomes. Regular participation in physical activity may have a beneficial effect on wider aspects of personal lifestyle, as people who exercise habitually have been shown to hold healthier attitudes to other health behaviours, such as smoking, alcohol, and food consumption (Shepherd 1988).

Key highlights of research evidence on the health of people with learning disabilities indicate that this group has an increased risk of death compared to the general population, (Hollins et al 1998). A recent report by the Disability Rights Commission (DRC) has substantiated this fact. Coronary heart disease (CHD) is the most common cause of death among people with learning disabilities 14-20%; (Hollins *et al* 1998) and the rates are increasing due to increased longevity and lifestyle changes (Carter and Jancar 1983). The leading cause of death is respiratory disease being 46-52% (Carter and Jancar 1983; Puri *et al* 1995).

People with intellectual disabilities have substantially lower bone density than the general population (Aspray et al 1998), with increased fractures occurring throughout the life span, particularly combined learning disabilities and epilepsy (Jancar and Jancar 1998). Barr *et al* 1999 also indicates that 36.5% of adults with learning disabilities have unhealthy teeth and gums.

Risk factors associated with poor health for people with learning disabilities indicate that they are more likely to be obese or underweight (Bell and Bhate 1992; Robertson *et al* 2000). Less than 10% of adults with learning disabilities eat a balanced diet with insufficient intake of fruit and vegetables and lack of knowledge and choice about healthy eating, (Robertson *et al* 2000; Rodgers 1998).

Over 80% of adults with learning disabilities engage in levels of physical activity below the minimum recommended by the DOH, a much lower level of physical activity than the general population (53-64%) (Messent et al 1998;

Robertson et all 2000) with people of a lower ability in more restricted environments at increased risk of inactivity (Robertson *et al*, 2000). According to Dr Erika Borkoles (2006) women who are clinically obese do not need to diet to improve their health but to take regular exercise classes and despite minimal weight loss or even gain the women ended up significantly fitter i.e. BP, HR, and cholesterol fell and respiratory fitness increased.

Fewer adults with learning disabilities smoke tobacco or drink alcohol compared to the general population (Fidler *et al* 1993).

Reported prevalence rates for anxiety or depression among people with learning disabilities vary widely but are reported to be at least as prevalent as the general population. (Stavrakaki 1999).

Challenging behaviours (aggression, destruction, self-injury, etc.) are shown by 10-15% of people with learning disability, with prevalence peaking between the ages 20 and 49 (Emerson *et a*l 2001).

It is recommended by the DOH that adults should undertake 30 minutes per day of physical activity 5 or more days per week. It would appear that the learning disability section of the community may not benefit from current government policy.

In order to change behaviour a person must first perceive a relevant reason for doing so. Research has shown that educating people in the potential health benefits of exercise is not enough to influence behaviour (Knapp 1988). For example reducing the risk of CHD is a long term goal and may not be seen as relevant to certain people, whereas the more immediate rewards of weight control, increased energy levels and a more general feeling of well-being are more likely to prove greater incentives.

In the past decades, adults with learning disabilities had not the opportunities to make informed choices regarding health, diet and lifestyle. A multi-disciplinary team (MDT), patient centred educational approach is the most appropriate format when used to inform the individual with a learning disability, and also his/her carers and family. A study by Chapman et al (2005) supports the need for intervention for this patient group, indicating a healthy living programme should be health-practitioner led in order to effect optimum change and reduce obesity and subsequent health risks. This programme aims to address these issues and to facilitate a patient centred healthy lifestyle plan.

AIM

The aim of the Pilot Healthy Living Programme is to help individual group members to improve his or her knowledge thus empowering and motivating them to make positive lifestyle changes.

Objectives

1. To improve individual group member knowledge of general lifestyle issues, which will include exercise, nutrition; topics on cessation of smoking, oral hygiene and looking after their feet.

2. To provide a safe environment to develop group member's motivation to make positive lifestyle changes.

3. To audit and evaluate the programme for effectiveness in terms of patient, carer and staff satisfaction and measurable physical and mental benefits.

4. To educate carers in supporting patients in achieving their health and fitness goals.

5. To provide the programme on a regular basis and accept referrals from wards throughout the hospital.

6. If successful the pilot could lead to the basis for an ongoing programme for adults with learning disabilities in the hospital and community.

Target Group

The Pilot Healthy Living Programme engaged 4 - 6 motivated patients with a BMI equivalent to or greater than 30g/m^2 who consented to 8 -10 weekly motivational and educational sessions on lifestyle, nutrition and exercise. It is hoped that this programme will make more efficient use of time and input for staff in the multidisciplinary team and have a greater impact on outcomes for patients taking part in the scheme. Although it is not a new initiative, it is providing a more co-ordinated approach to patient interventions already taking place. Patients taking part must meet referral criteria set and agreed by the Multidisciplinary Team.

METHOD

Members of the Multidisciplinary Team will be involved in creating and delivering a structured 8-10 week motivation and education programme targeting lifestyle issues such as nutrition, exercise, smoking, attitude and motivation to empower patients to make positive lifestyle changes.

Referral and Consent

Referral criteria were discussed at ward MDT meetings and a referral form drawn up **(Appendix 1)**.

Each patient was selected in accordance with the referral criteria and a referral form and health screen completed by the ward medical officer. Consent was obtained from each patient and recorded on a consent form **(Appendix 2)**.

General

Preparation for the programme (**Appendix 3**) included arranging the speakers, preparing talks and setting out the pre/post-questionnaire with the assistance of the SALT staff.

The dietitian and physiotherapist liased with the ward staff and day care staff to ensure the patients were available for the programme. Liaison with the MDT at this stage was paramount.

The venue for the programme was the manual handling room in the Rathmore Building. This was set up with the equipment that included mats, bicycle, step bench and hoops.

Individual activity files were put together to encourage each patient to record the types of exercise and activities they were able to carry out (**Appendix 4**). Ward staff and day care staff agreed to assist the patients when completing their weekly records.

Each weekly session was preceded by feedback from patients and carers and the lessons learned from the previous weeks activities.

A member of staff from the ward attended with the patients each week; this was invaluable as the staff often took part in the group work and also encouraged the patients to gain their goals when back on the ward.

Bottled water was available and participants encouraged re-hydrating at regular intervals.

Fresh fruit was ordered and provided via the catering department. The patients were encouraged to help prepare the fruit in the kitchen area in the Rathmore building, under the guidance of the dietitian.

The exercise programmes were varied and adapted according to each patient’s ability, coordination and comprehension. Each exercise session was approximately 1 hour. The sessions included a 10 minutes warm-up aerobic (cardiovascular) and anaerobic (strength) exercises followed by a 5 minute cool down. Programme example at **Appendix 5**. No injuries were sustained during the sessions. The exercise was monitored by physiotherapy staff at all times and patients shown how to carry out the tasks safely and accurately for optimum benefit.

Assessment

The assessment consisted of a pre-health questionnaire (**Appendix 6**), a physical assessment (example at **Appendix 7**) that included Flexibility Test, Timed “Get Up and Go” Test, Berg Balance Score, Record of Weight, and BMI.

Individual physical assessments were carried out for patients on the first day by physiotherapy staff. The dietitian, SALT, physiotherapy staff and one ward staff assisted in conducting the questionnaire interviews.

Recording

The activity charts were given to each patient on the first day and they were asked to complete these daily. These allowed the patient’s diet and physical activity levels to be monitored through out the programme.

Throughout the 10 weeks results were recorded for exercise and weight.

Post programme questionnaires were to be completed but only one patient completed this (**Appendix 8).**

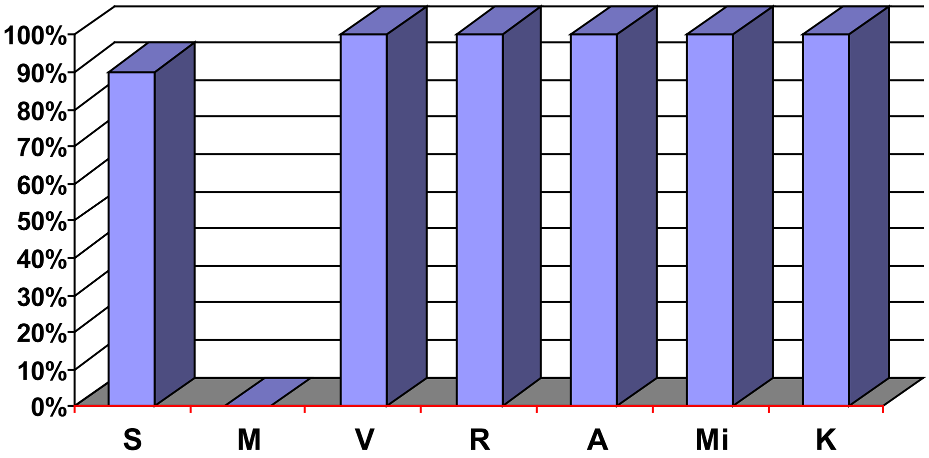
On competition of the 10-week programme, each patient was presented with a certificate of achievement. An Image Consultant was booked for the final day to help the patients look at their overall appearance and how to put ideas into practice for the Christmas season. She then very kindly presented the certificates to each patient and all, including the male participants, said how much they had enjoyed learning more about colour and style.

RESULTS

Attendance

Of those agreeing to take part there was full attendance with one patient joining the group in week 2, taking the place of a patient who refused to attend.

Figure 1: % OF ATTENDENCE PER PATIENT FOR 10 WEEK PROGRAMME



Weight

Each patient was weighed at the start and at intervals throughout the programme. **The starting weights ranged from 86.4 kg – 135 kg with the mean being 106.56 kg. The end weight ranged from 135.4 kg – 86.4 kg with a mean weight of 105.8 kg.**

Table 1. Start / Finish Weight

Serial (a)	Patient (b)	Height	Waist (c)	Start Wt (d)	End Wt (e)	Loss/Gain (f)	Start BMI (g)	End BMI (h)
1.	A	5’6”	57”	135.0	135.4	↑	52.7	52.8
2.	K	5’11”	51”	119.8	116.0	↓	36.9	35.8
3.	Mi	5’4”	55”	105.0	105.8	↑	39.5	39.8
4.	R	4’11”	41”	89.0	88.4	↓	39.2	39.2
5.	S	5’3”	46”	87.0	86.4	↓	34.9	34.9
6.	V	5’7”	49”	103.6	102.8	↓	35.2	35.4
7.	M	-	-	-	--	-	-	-

Table 2: Weight recorded at intervals shows flux throughout programme

Patient (b)	**Serial (a)**	**30/08/07 Ax**	**02/09/07**	**13/09/07**	**20/09/07**	**27/09/07**	**04/10/07**
A	1.	135.0	135.0	135.4	133.2	133.2	134.0
K	2.	119.8	119.8	118.2	118.4	116.0	116.0
Mi	3.	105.0	104.4	105.0	105.0	104.6	103.2
R	4.	89.0	88.0	88.4	87.2	88.4	88.4
S	5.	87.0	86.4	86.4	86.4	86.4	86.4
V	6.	103.6	102.0	102.4	102.2	99.0	100.8
M	7.	-	-	-	-	-	-

Balance, Flexibility And Timed Up And Go Measurements

Flexibility was measured by long sitting with back against a wall and stretching forward from the hips towards toes and keeping knees straight. Berg Balance Test was used to score Balance and the Timed, Up and Go Test to score speed.

Table 3. Flexibility, Berg Balance Score, Timed Up and Go

Serial (a)	**Patient (b)**	**Start Flexibility (c)**	**End Flexibility (d)**	**Berg Balance Test (e)**	**Timed, Up and Go (seconds) (f)**
1.	A	Would not attempt	Would not attempt	Would not attempt	Would not attempt
2.	K	43”	41”	56	11 /12
3.	Mi	37”	35”	55	9 / 8
4.	R	40”	40”	47	12 / 11
5.	S	41”	38”	Not attempted	Not attempted
6.	V	38”	36”	55	12/ 11
7.	M	-	-	-	-

Activity Charts

Patients were asked to complete exercise activity charts each week, therefore should have completed 10.

Table 4: Activity Charts Completed

Serial (a)	Patient (b)	% Completed Charts (c)	Comments (d)
1.	A	20%	
2.	K	50%	Accurately completed charts
3.	Mi	40%	Accurately completed charts
4.	R	10%	Pt preferred to keep own diary privately and refused to complete more than 1 x chart
5.	S	44.4%	Joined group in second week
6.	V	30%	
7.	M	-	Did not take part in programme

Pre And Post Questionnaire Results

5 questionnaires were completed at the start of the programme and only one at the end of the programme. The results and responses are shown in **Appendices 6 & 8.**

The verbal feedback from ward staff and the patients at the weekly sessions was very positive. On the final day 100% of the participants wanted to continue and as one person said the programme “made me feel important and that somebody was interested in me”.

DISCUSSION

All who attended, including the staff, enjoyed the programme. The attendance was excellent with no patients dropping out of the programme and the rapport between the patients and staff was good.

The ‘Timed Get Up and Go Test’ was not refined enough to demonstrate accurately changes in ability and a more objective measure was required.

Not all patients completed the post programme questionnaire and this area lacked the follow up for results.

Each patient was able to complete a more intense cardiovascular programme by the end of the 10 weeks.

All the patients asked if they could continue with the programme as they enjoyed it so much.

One patient stated, “ When I was at home last weekend I wasn’t as angry as I normally am for a very long time and enjoyed it better at home”.

The health checks were not re-measured following the programme resulting in lack of objective outcome measures.

Due to staff resources setting up the programme was logistically difficult and this included co-ordinating the meetings with the core multidisciplinary team.

If planning such an activity again it would be useful to have a more inclusive multidisciplinary discussion group including Day Care staff and more ward staff involved. It would also be helpful to have the objectives shared more widely with day care staff to enable them to assist in helping patients keep their weekly diaries. This would also help patients adhere to the programme and keep them motivated.

Although regular meetings took place with the core team (dietitian, physiotherapist, nurse manager and registrars) it would be helpful to include all other staff including those delivering the programme. This would be more inclusive and also keep staff involved motivated and informed of progress. Health books or passports could be produced for each patient and the content could be reviewed at the patient’s annual review.

It must not be underestimated the benefits of the programme or patients' self esteem and positive indicators for mental health. This is reflected in the comments patients made during the weekly feed back sessions and also in the response and questions to the speakers each week.

In order to maximize the health outcomes for patients the initiative should be co-ordinated across all activities and programmes and the information shared appropriately with a wider staff group.

Qualitative comments and indicators could be developed to allow tutors to feed back on their findings and help corroborate the results.

The patients and staff learned a lot about healthy living and how to achieve this in their daily lives. The patients demonstrated team work and a significant confidence in their appearance, particularly when the image consultant held a very positive and well received practical session. The patients were dressed in their favourite outfits and the lady gave them advice on colours that suited them and the style of clothes to enhance their figures and looks. The two men on the programme also found this really enjoyable and were fully engaged in the sessions.

Qualitative Comments From Ward Based Staff

'I attended two sessions of the healthy living. The group participated in light exercise and were educated about a healthy lifestyle and diet. I feel the group will benefit greatly from these sessions as well as being educated about a proper balanced diet.'

'This diet and fitness exercise was of great benefit to the Group, they very much enjoyed the comradeship. In addition, they enjoyed learning about the amount of bones within the skeleton. Both male and female enjoyed the games and the interaction and it brought out the competitiveness in them. They also took great enjoyment when they had won within their team activities. The girls really enjoyed the 'Colour Me Beautiful', it gave them a good feeling factor because it highlighted their qualities, and to my amazement the boys the same. At the end of the group they requested that they would like to do it again. The group sawit as a more social task, and I personally feel that they gained from learning about their body, and how important it was to exercise, thinking healthy and the fact it was done in a fun way.'

CONCLUSION

The Pilot Healthy Living Programme (HLP) was devised to meet the health needs of identified patients in a hospital ward designed for delayed discharge and awaiting placement in the community. The MD pilot programme aimed to address these health needs by providing patients and staff with the knowledge, experience, motivation and support to develop and lead healthy lifestyles. The programme proved very successful and had positive outcomes for the in-patients involved. The success is demonstrated in the various aspects of the programme, including the attendance rate, improvements in fitness levels, weight reduction, improved activity and diet levels and the consistently positive feedback from the patients and ward staff attending.

It is therefore proposed that the HLP continues and is further developed taking in the recommendations in order to continue to promote a healthy diet and physical activity and improve the health and well being of the adult learning disability population throughout the hospital. The programme should be further developed and implemented to meet quality of life issues and the health needs of the community adults with learning disabilities population in the Belfast Trust. By adopting a more standardized approach in Muckamore Abbey Hospital and within the wider Belfast Trust adult learning disability community this should lead to the development of agreed regional standards and guidelines for exercise and healthy living programmes taking into account the recommendations in the Bamford Review of Mental Health and Learning Disability and the document Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland.

The recommendations that follow will add to the success and outcomes of future programmes. This programme should be health practitioner led and work in partnership with patients, carers and other agencies.

RECOMMENDATIONS FOR FUTURE HEALTHY LIVING PROGRAMMES IN THE HOSPITAL

Health

- Objective fitness test to be used for higher ability groups.

- Patient’s weight to be recorded weekly.

- Patient’s waist measurement to be recorded at start and end.

- All injuries are to be recorded by physiotherapy staff and treatment appropriately given and ward MO informed.

- A single leg balance test with eyes closed and timed could be effectively used to determine balance and measured at the start and end of the programme.

- Physical activity levels should be incorporated into care plans, PCPs, care pathways and be discussed at MD ward reviews on an annual basis.

- As per recommendations in the Equality Commission Review, December 2007 an objective baseline health screen should be commenced and completed for each patient prior to starting a Healthy Living Programme. Where appropriate the health screen should be completed by a medical officer or other health professional and should include some or all of the following: Height, Weight, BMI, waist measurement, HR, RR, Pulse, Blood Sugars, cholesterol, urinalysis, Realflow and O_2 salivation, lipid profile, precautions and allergies. Behaviours may also be monitored and recorded and any changes noted in drug intake. The 10 week pilot programme was too short to show significant weight reduction, however, a six month follow up would be of benefit to determine longer term benefits for each patient.

Organisational

- The room size dictates a maximum of 6 patients per group.

- Encouragement and support to complete the activity and food charts.

- Accurate recording of patient’s individual achievement at each exercise training session.

- Physiotherapy staff to supervise, and ensure that exercises are carried out with precision and accuracy for each patient's needs.

- Evaluation questionnaires to be completed at start and end of programme.

- Equipment failure/ breakages to be reported via physiotherapy staff to faults dept ASAP and recorded. Notices to be attached to faulty equipment as unserviceable.

- Exercise equipment to be cleaned by each patient after use to reduce cross infection. Physiotherapy staff to provide the wipes.

- Any patient requiring treatment for a medical condition will be referred appropriately to the ward Medical Officer.

- Questionnaire set out in different format for evaluation purposes.

- Set MD local standards and guidelines for "Healthy Living" for adults with learning disabilities population to include exercise and healthy eating with a view to influencing regional policy.

- Presentation to Hospital Management Team, Clinical Director, Journal Club, Adults with Learning Disabilities Director and Team

- Publication of outcomes in Trust Newsletter.

- Access to funding to expand the programme to supported living / community.

- A coordinated physical activity strategy should be introduced to inform the writing of policy and guidelines, to help focus on physical activity and its inclusion into other service areas, including Day Care.

- Devise a directory accessible for carers and people with Learning Disability giving information on venues for exercise eg football, gyms, boccia etc and other facilities and agencies that can provide support for healthy living for adults with learning disabilities.

- Role out a biannual road show on HEALTHY LIVING in a central venue in Belfast Trust area working in partnership with external agencies such as the Health Promotion Agency and Mencap. Self referrals could be accepted from areas such as supported living, day centres, residential care etc. It should be more than just a visit but an opportunity to use professionals to advise and consult with users and carers ie a Healthy Living Fair for people with Learning Disabilities. Each patient could be issued with a health book or health passport and this would help address the area within PCP's and highlight the detail needed to address physical and mental health.

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Appendix 1: Referral Form /Criteria:

Patient's Name:
Date of Birth:
Ward:
BMI:

Reason for Referral

Hypertension	**Diabetes**	Weight Reduction ☐	Other CHD Risk ☐
Medication ☐	Medication ☐	Anxiety/Stress ☐	Asthma ☐
No Medication ☐	Oral Medication ☐	Osteoporosis ☐	Osteoarthritis ☐
		Inactive/Sedentary ☐	Epilepsy ☐

Baseline Measurements

BP Supine:
BP Standing:
Resting Heart Rate:

Medication:

Susceptible to:

- Abnormal Muscle Tone ☐
- Angina ☐
- Arrythmia ☐
- Asthma ☐
- Dizziness, Falls ☐
- Hypoglycaemia ☐
- Hypotension ☐
- Impaired Alertness ☐
- Impaired Cognition ☐
- Infection ☐
- Joint Pain ☐
- Osteoporosis ☐
- Skin Irritation ☐
- Urinary Frequency ☐

Behavioural Problems

If '**YES**' give details of any risks to self or others.

Comments

Please add any other comments to assist in exercise prescription.

This patient is referred to the Healthy Living Programme under the guidelines.

Signature of Medical Officer:
Date:

Appendix 2

Belfast Health and
Social Care Trust

Your ref:
Our ref:

Muckamore Abbey Hospital
1 Abbey Road, Muckamore, ANTRIM BT41 4AH
Tel: (028) 9446 3333 Fax: (028) 9446 7770

Dear

RE: Consent for Pilot Healthy Living Programme

I ______________________, following discussion with ______________________ Would like to take part in the above programme. I understand that this may improve my well-being.

The content of the programme has been fully explained to me.

Signature: ______________________________ Date: __________________

Witness: ______________________________ Date: __________________

Appendix 3

BELFAST HEALTH & SOCIAL CARE TRUST – MUCKAMORE ABBEY HOSPITAL

PILOT HEALTHY LIVING PROGRAMME

WEEK NO / DATE	0-10 MINS/WEEK 10.00-10.10	10/15 MINS/WEEK (after speaker)	45-60 MINS/WEEK 10.45-11.45	20 MINS/WEEK 10.10-10.30	TUTOR
START WITH ASSESSMENTS ON 30 AUG 07	**PATIENTS TO COMPLETE QUESTIONNAIRE (R KYLE)**	**ASSESSMENT BY DIETITIAN (M-C KANE)**	**ASSESSMENT BY PHYSIOTHERAPY TEAM**	**PROGRAMME OUTLINE OF TOPICS**	**ACTIVITY BOOKS / DIARIES FOR PATIENTS**
SCHEDULE					
Wk 1 06 Sept 07	INTRODUCTION	DIET ADVICE	EXERCISE TBA	DISCUSSION	THE TEAM
Wk 2 13 Sept 07	FEEDBACK	DIET ADVICE	EXERCISE	DISCUSSION	THE TEAM
Wk 3 20 Sept 07	FEEDBACK	DIET ADVICE	EXERCISE	SMOKING CESSATION	CAROLINE QUINN (CONFIRMED)
Wk 4 27 Sept 07	FEEDBACK	DIET ADVICE	EXERCISE	DENTAL HYGIENE	SYLVIA ROBERTS
Wk 5 04 Oct 07	FEEDBACK	DIET ADVICE	EXERCISE	ALCOHOL	ELSIE CLINGHAN
MID-PROGRAMME EVALUATION – 10 OCT 07 AT 12 00 HRS IN FINGLASS					
Wk 6 11 Oct 07	FEEDBACK	DIET ADVICE	EXERCISE	DISCUSSION	THE TEAM
Wk 7 18 Oct 07	FEEDBACK	DIET ADVICE	EXERCISE	PODIATRY FOOT CARE	DAVID LEWIS
Wk 8 25 Oct 07	FEEDBACK	DIET ADVICE	EXERCISE	LOOK AFTER YOUR BACK & BONES	GILLIAN BINGHAM
Wk 9 01 Nov 07	FEEDBACK	DIET ADVICE	EXERCISE	IMAGE CONSULTANT	JOAN ROLSTON

Appendix 4

PILOT HEALTHY LIVING PROGRAMME

NAME: **DOB:**

WEEK NO: x Date	DESCRIBE ACTIVITY AND TIME
THURSDAY	
FRIDAY	
SATURDAY	
SUNDAY	
MONDAY	
TUESDAY	
WEDNESDAY	

Appendix 5 BELFAST TRUST ADL HEALTH LIVING PROGRAMME – INDIVIDUAL EXERCISE RECORD

Name: DOB:

ACTIVITY	Wk 1 Date	Wk 2 Date	Wk 3 Date	Wk 4 Date	Wk 5 Date	Wk 6 Date	Wk 7 Date	Wk 8 Date	Wk 9 Date	Wk 10 Date
Warm Up and Stretching (10 mins)										
Bridging (2 mins)										
Sit-Ups (2 mins)										
Bkie Distance Resistance Time										
Step-Ups (2 mins)										
Push-Ups (2 mins)										
Weights Repetition Weight										
Cool Down										
Other Activities During Week eg Walking Swimming Dancing Football Cycling Other										
Treadmill: Elevation Kcal HR Time Distance Speed										
Comments:										

Appendix 6

HEALTHY LIVING PRE- PROGRAMME PATIENT QUESTIONNAIRE RESULTS

The aim of this questionnaire is to look at patient knowledge and motivation for change prior to taking part in the healthy living programme. This will be followed up by a patient questionnaire at the end of the healthy living programme for audit purposes to assess patient satisfaction, changes in knowledge and motivation to change in regards to a healthy lifestyle.

This healthy living programme is about healthy lifestyle issues targeting:-

Healthy Diet.	
Regular Exercise:	Walking Swimming Dancing Football Gym Horse-riding Cycling
Alcohol.	
Smoking.	
Image:	Clothes Hairstyle Posture
Attitude to Healthy Living:	Self Confidence Self-Motivation
General Health:	Physical Emotional

Information in this questionnaire is confidential and only those involved in the programme or relevant professionals will have access to this information.

HEALTHY LIVING PRE- PROGRAMME

PATIENT QUESTIONNAIRE - RESULTS

GENERAL QUESTIONS ON HEALTHY LIVING

1. Do you feel a healthy lifestyle is important? (Please circle one)

a. Not Important = 0
b. Important = 1
c. Very Important = 4

What is your idea of a healthy lifestyle?

- To help you

- Helps your heart rate
- Better for muscles
- Makes you feel good

- Health, style and exercise is good
- Friends

- Walk
- Cycle
- Swimming
- Horse-riding
- Makes you feel good

- Eat more fruit and vegetables
- Exercise

2. How happy are you with your current lifestyle? (Please circle one)

a. Not happy = 3
b. Happy = 0
c. Very happy = 2

Give reasons:-

- Feel sad and down at times

- Am motivated to change lifestyle
- Happy because you lose weight
- Family feels happy and that makes you happy

- I want to lose more weight
- Very happy to come to this group

- Overweight
- Out of breath

- Strain on heart

- SOB
- Feeling overweight
- Feeling bloated
- Not having nice clothes
- Smoking too much

3. What would you like to change about your lifestyle?

- Meals in hospital
- New wardrobe
- Eat more salads
- Eat smoothies

- Lose weight and lots

- To lose more weight and go horse-riding

- Swim better
- Less tired

- Try and be more healthy
- To lose weight
- Get fit
- Eat more healthily
- Give up smoking

4. What would you like to achieve?

- Lose weight
- Look good

- New wardrobe
- More fit

- To go back to horse-riding

- Be fitter
- Gym and Swimming

- To lose weight
- Get fitter
- Know more about what I am eating

5. How confident are you to change your lifestyle? (Please circle one)

Not confident Very confident

1	2	3	4	5	6	7	8	9	10
			1	**2**	**1**				**1**

Can you give reasons/comments?

- I need help to do this
- Feel not 100% confident
- I think I will; I probably will do it
- Like to be in a group for support

6. What lifestyle factors help you feel better? (From the list)

- Walking and talking with friends.
- Walking, football, gym, swimming.
- Clothes, hairstyle, posture, healthy diet, walking, swimming, gym, horse-riding, cycling, self-confidence, self-motivation.
- Clothes, posture, gym, cycling, swimming, physical, emotional.

DIET

7. Is a healthy diet important? (Please tick box)

Yes ☐ = **5**
No ☐ = **0**

What is a healthy diet?

- Salads
- Pasta, tomatoes, cheese, cucumber, lettuce, porridge
- Fruit and vegetables
- Eating more fruit and vegetables
- Going for healthy walk
- Eating at right times
- Eating more fruit and vegetables

8. Do you have a healthy diet? (Please tick box)

Yes ☐ = **2**
No ☐ = **3**

Describe it:

- If unhappy eat too much

- Lunch – soup, sandwiches/roll
- Cut down on chips, cut out KFC's

- Some vegetarian food is not healthy

- Crisps, big portions, chocolate, butter

9. What topics would it be useful to know more about?

- Don’t know

- Learn how to be healthy
- Learn how to vary diet
- Portion sizes
- Which foods are high in fat
- How to learn more about good food groups

- Exercise and healthy foods

- The healthy food
- More exercise information

- Giving up cigarettes
- Learn about what is in food and drinks
- How to exercise right

EXERCISE

10. Is regular exercise important? (Please tick box)

Yes ☐ = **5**
No ☐ = **0**

Why?

- To help keep me fit

- Exercises muscles, good for bones, very good for heart, beneficial for breathing

- To keep healthy

11. What forms of exercise/activity do you enjoy?

a. Swimming = **2**
b. Mountain Bikes = **1**
c. Football = **2**
d. Pool = **0**
e. Gym = **2**
f. Walking = **2**

How often do you do these?

a. Swimming - 1/wk (2)

b. Walking – 2/day – half hr/each
c. Football – 1/wk – 1 hr
d. Mountain bike 2/wk – 2 hrs
e. More than 1/wk everyday walk if enough staff
f. Dancing

Do you currently feel you take enough exercise? (Please tick box)

Yes ☐ = **2**
No ☐ = **3**

But would like to do more.

12. Would you like help to know more about regular exercise? (Please tick box)

Yes ☐ = **5**
No ☐ = **0**

- Talk about exercise and what kind of exercise to do
- Feel exhausted when finished

13a How often should you exercise a week? (Please circle one)

a. Once = **1**
b. Three times = **3**
c. Five times = **0**
d. Seven times = **1**

13b And for how long? (Please circle one)

a. Half an hour = **1**
b. One hour = **3**
c. More than one hour = **1**

Half an hour in morning. Half an hour in afternoon.

14. How could we help you to do more activities?

- Teach best exercise to do
- Want help to lose weight
- Like to do it more often and to work out what is preventing from doing more
- Go to the gym, have more activities available.

SMOKING

15. Do you currently smoke? (Please tick box)

Yes ☐ = **1**
No ☐ = **4**

(If no, then you have finished the questionnaire)

16. How many cigarettes do you smoke a day? (Please circle one)

0	1-5	5-10	10-15	15-20	OVER 20	N/A
4		**1**				

17. Do you want to cut down or stop smoking? (Please circle one)

No	A Little	A Lot	N/A
		1	**4**

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE

Appendix 7

TINETTI BALANCE ASSESSMENT TOOL

Tinetti ME, Williams TF, Mayewski R, Fall Risk Index for elderly patients based on number of chronic disabilities. Am J Med 1986:80:429-434

PATIENTS NAME ______________________ **D.o.b.** _____________ **Ward** ______

BALANCE SECTION

Patient is seated in hard, armless chair;

	Date		
Sitting Balance	Leans or slides in chair = 0 Steady, safe = 1		
Rises from chair	Unable to without help = 0 Able, uses arms to help = 1 Able without use of arms = 2		
Attempts to rise	Unable to without help = 0 Able, requires > 1 attempt = 1 Able to rise, 1 attempt = 2		
Immediate standing balance (first 5 seconds)	Unsteady (staggers, moves feet, trunk sway) = 0 Steady but uses walker or other support = 1 Steady without walker or other support = 2		
Standing balance	Unsteady = 0 Steady but wide stance and uses support = 1 Narrow stance without support = 2		
Nudged	Begins to fall = 0 Staggers, grabs, catches self = 1 Steady = 2		
Eyes closed	Unsteady = 0 Steady = 1		
Turning 360 degrees	Discontinuous steps = 0 Continuous = 1		
	Unsteady (grabs, staggers) = 0 Steady = 1		
Sitting down	Unsafe (misjudged distance, falls into chair) = 0 Uses arms or not a smooth motion = 1 Safe, smooth motion = 2		
	Balance score	/16	/16

P.T.O.

TINETTI BALANCE ASSESSMENT TOOL

GAIT SECTION

Patient stands with therapist, walks across room (+/- aids), first at usual pace, then back at rapid pace

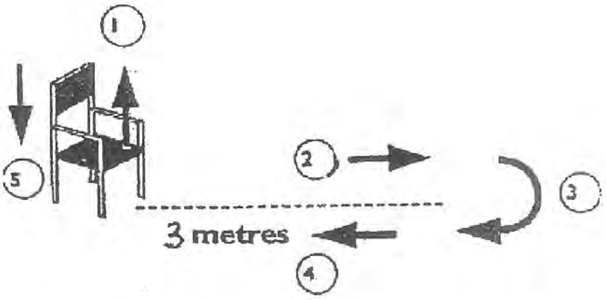
	Date		
Initiation of gait (immediately after told "go")	Any hesitancy or multiple attempts = 0 No hesitancy = 1		
Step length and height	Step to = 0 Step through R = 0 Step through L = 1		
Foot clearance	Foot drop = 0 L foot clears floor = 1 R foot clears floor = 1		
Step symmetry	Right and left step length not equal = 0 Right and left step length appear equal = 1		
Step continuity	Stopping or discontinuity between steps = 0 Steps appear continuous = 1		
Path	Marked deviation = 0 Mild / moderate deviation or uses w. aid = 1 Straight without w. aid = 2		
Trunk	Marked sway or uses w. aid = 0 No sway but flex. knees or back or uses arms for stability = 1 No sway, flex., use of arms or w. aid = 2		
Walking Time	Heels apart = 0 Heels almost touching while walking = 1		
	GAIT SCORE	/ 12	/ 12
	Balance score carried forward	/ 16	/ 16
	TOTAL SCORE = Balance + Gait Score	/ 28	/ 28

Risk Indicators :

Tinetti Tool Score	Risk for Falls
≤ 18	High
19 – 23	Moderate
≥ 24	Low

TIMED 'GET UP AND GO' TEST

INSTRUCTION PROTOCOL



COMPONENTS

1. Getting up from chair
2. Walking 3 metres
3. Turning
4. Walking 3 metres (return)
5. Sitting down

1. Patient is seated with back against the chair, arms resting on the arms of the chair and walking aid (if required) at hand.
2. The test is explained to the patient - **"When I ask you to start, you will get up out of this chair and walk (with your stick / frame) at a comfortable and safe pace to the mark on the floor 3 metres away. Cross the line, turn round and return to the chair and sit down again."**
3. Ask the patient to repeat what she has to do.
4. Tell the patient to **"START now".**
5. Timing starts from the moment the patient is told to start.
6. Timing stops when the patient is fully seated.

The patient should perform the test twice – one practice and the test following sufficient rest. Use a stop watch for the test and standardise the seat height for use consistently with the test. (17 – 19 inches.)

This test is a very useful monitor of medication control in Parkinsons Disease / Syndrome. If used for PD record the time of day and the number of strides in 3 metres.

Podsiado D, Richardson S. The Timed Up and Go test of basic functional mobility for frail elderly persons *J Am Geriatr Soc* 1991 39:142-148

ELDERLY MOBILITY SCORE

Patient Name ______________________ **Date of Birth** ______

	Date			
TASK	**Scoring**			
Lying to Sitting	2 Independent 1 Needs help of 1 person 0 Needs help of 2+ people	2		
Sitting to Lying	2 Independent 1 Needs help of 1 person 0 Needs help of 2+ people	2		
Sitting to Standing	3 Independent in under 3 seconds 2 Independent in over 3 seconds 1 Needs help of 1 person 0 Needs help of 2+ people	3		
Standing	3 Stands without support and able to reach 2 Stands without support but needs support to reach 1 Stands but needs support 0 Stands only with physical support of another person	3		
Gait	3 Independent (+ / - stick) 2 Independent with frame 1 Mobile with walking aid but erratic / unsafe 0 Needs physical help to walk or constant supervision	3		
Timed Walk (6 metres)	3 Under 15 seconds 2 16 – 30 seconds 1 Over 30 seconds 0 Unable to cover 6 metres			
	Recorded time in seconds.			
Functional Reach	4 Over 25 cm. 2 15 - 25 cm. 0 Under 15 cm.			
	Actual reach			
	SCORES	**/ 20**	**/ 20**	**/ 20**
	Staff Initials			

Smith R. Validation and reliability of the elderly mobility scale Physiotherapy 1994; 80(11). 744-747

Scores under 10 – generally these patients are **dependent** in mobility manoeuvres, require help with basic ADL, such as transfers, toileting and dressing.

Scores between 10 – 13 – generally these patients are **borderline** in terms of safe mobility and independence in ADL i.e. they require some help with some mobility manoeuvres.

Scores over 14 – Generally these patients are able to perform mobility manoeuvres alone and safely and are **independent** in basic ADL.

Range of Movement/ Muscle Strength:

	RIGHT		LEFT		PROBLEM IDENTIFIED
	R.O.M	GRADE	R.O.M.	GRADE	
Shoulder					
Elbow					
Wrist					
Hip					
Knee					
Ankle					
Neck					
Trunk					

Balance: (BERG balance score)

	ITEM DESCRIPTION	SCORE 0 – 4
1. Sitting to standing	**Please stand up. Try not to use your hands for support.** 4 - Able to stand without using hands 3 - Able to stand independently using hands 2 - Able to stand using hands after several times 1 - Needs minimal aid to stand 0 - Needs moderate or maximal assist to stand	
2. Standing unsupported	**Please stand for 2 minutes without holding.** 4 – Able to stand safely 2 minutes 3 – Able to stand 2 minutes with supervision 2 – Able to stand 30 seconds unsupported 1 – needs several tries to stand 30 seconds unsupported 0 – unable to stand 30 seconds unsupported	
3. Sitting unsupported	**Please sit with arms folded for 2 mins. (back unsupported)** 4 - Able to sit safely and securely for 2 minutes 3 – Able to sit 2 minutes under supervision 2 – Able to sit 30 seconds 1 – Able to sit 10 seconds 0 – Unable to sit without support 10 seconds	
4. Standing to sitting	**Please sit down** 4 – sits safely with minimal use of hands 3 – controls descent by using hands 2 – uses back of legs against chair to control descent 1 – sits independently but has uncontrolled descent 0 – needs assistance to sit	
5. Transfers	**Transfer between bed and a chair** 4 – able to transfer safely with minor use of hands 3 – able to transfer safely with definite need of hands 2 – able to transfer with verbal cuing and / or supervision 1 – needs one person to assist 0 – needs 2 people to assist or supervise to be safe	
6. Standing unsupported with eyes closed	**Please close your eyes and stand still for 10 seconds** 4 – able to stand 10 seconds safely 3 – able to stand 10 seconds with supervision 2 – able to stand 3 seconds 1 – unable to keep eyes closed 3 seconds but stands safely 0 – needs help to keep from falling	

7. Standing unsupported with feet together	**Place your feet together and stand without holding** 4 – able to place feet together indep. and stand 1 min safely 3 – able to place feet together indep. and stand 1 min with supn. 2 – able to place feet together indep. but unable to hold for 30 secs. 1 – needs help to attain position but unable to stand 15 secs feet tog. 0 – needs help to attain posn. But unable to hold for 15 secs.	
8. Reaching forward with outstretched arm	**Lift arms to 90 degrees. Reach forward as far as you can.** 4 – can reach forward confidently 25cm (10 inches) 3 – can reach forward 12cm (5 inches) safely 2 – can reach forward 5cm (2 inches)safely 1 – reaches forward but needs supervision 0 – loses balance while trying / requires external support	
9. Pick up object from floor (standing)	**Pick up shoe / slipper that is placed in front of your feet** 4 – able to pick up slipper safely and easily 3 – able to pick up slipper but needs supervision 2 – unable to pick up but reaches 2-5cm from slipper and keeps balance indep. 1 – unable to pick up and needs supervision while trying	
10. Turning to look behind	**Turn to look directly behind you over your left shoulder. Repeat to the right.** 4 – looks behind from both sides and weight shifts well 3 – looks behind one side only, other side shows less weight shift 2 – turns sideways only but maintains balance 1 – needs supervision when turning 0 – needs assist to keep from losing balance	
11. Turning 360 degrees	**Turn completely around in a full circle. Pause. Then turn a full circle in the other direction.** 4 – able to turn 360 dergrees safely in 4 secs or less 3 – able to turn 360 degrees safely one side only in 4 secs or less 2 – able to turn 360 degrees safely but slowly 1 – needs supervision when turning 0 – needs assistance while turning	
12. Placing alternate foot on stool	**Place each foot alternately on the step. Continue until each foot has touched the step 4 times.** 4 – able to stand indep. and safely and complete 8 steps in 20 secs 3 – able to stand indep. and safely and complete 8 steps > 20 secs 2 – able to complete 4 steps without aid with supervision 1 – able to complete >2 steps needs minimal assistance 0 – needs assistance to keep from falling / unable to try	
13. Standing unsupported one foot in front	**Place one foot directly in front of the other. If you feel that you cannot place your foot directly in front, try to step far enough ahead that the heel of your forward foot is ahead of the toes of the other foot.** 4 – able to place foot tandem indep. and hold 3 secs 3 – able to place foot ahead of other indep. and hold for 3 secs 2 – able to take small step indep. and hold 30 secs 1 - needs help to step but can hold 15 secs 0 – loses balance while stepping or standing	
14. Standing on one foot	**Stand on one leg as long as you can without holding** 4 – able to lift leg indep and hold >10 secs 3 – able to lift leg indep. and hold 5 – 10 secs 2 – able to lift leg and hold = or >3 secs 1 – tries to lift leg unable to hold 3 secs but remains standing indep. 0 – unable to try or needs assist to prevent fall	
RISK VALUE : **> 45/56 Indicates a very low risk of falling** **< 36/56 Indicates 100% fall risk in community**	**TOTAL SCORE** (56 max.)	

O/P Assessment May '03

Appendix 8

PILOT HEALTHY LIVING POST-PROGRAMME PATIENT QUESTIONNAIRE

The aim of this questionnaire is to look at patient knowledge and motivation for change prior to taking part in the healthy living programme. This will be followed up by a patient questionnaire at the end of the healthy living programme for audit purposes to assess patient satisfaction, changes in knowledge and motivation to change in regards to a healthy lifestyle.

This healthy living programme is about healthy lifestyle issues targeting issues such as:-

Healthy Diet:	
Regular Exercise:	Walking Swimming Dancing Football Gym Horse-riding Cycling
Alcohol:	
Smoking:	
Image:	Clothes Hairstyle Posture
Attitude to Healthy Living:	Self Confidence Self Motivation
General Health:	Physical Emotional

Information in this questionnaire is confidential and only those involved in the programme or relevant professionals will have access to this information.

HEALTHY LIVING POST-PROGRAMME

PATIENT QUESTIONNAIRE - RESULTS

GENERAL QUESTIONS ON HEALTHY LIVING

1. Do you feel a healthy lifestyle is important? (Please circle one)

a. Not Important = **0**
b. Important = **0**
c. Very Important = **1**

What is your idea of a healthy lifestyle?

- **Good for health**
- **Exercises good**
- **Style and make-up – personal appearance**
- **“Made me feel great and like a new person”**
- **I felt better doing the exercises and enjoyed going over there**
- **I enjoyed it all, the healthy eating, exercises and it all**

2. How happy are you with your current lifestyle? (Please circle one)

a. Not Happy = **0**
b. Happy = **0**
c. Very happy = **1**

Give reasons:-

- **Doing healthy living and helping to get weight and all off**
- **Feel better**

3. What would you like to change about your lifestyle?

- **Would like to do it again.**
- **Enjoyed the talks and drinking a lot of water.**
- **Drank some water before but now drinks more water.**

4. What would you like to achieve?

- **Like to keep up with healthy living.**

5. How confident are you to change your lifestyle? (Please circle one)

Not Confident									Very Confident
1	2	3	4	5	6	7	8	9	10
							1		

Can you give reasons/comments?

- **Because I have help.**
- **Can help to achieve me by keep doing it.**

6. What lifestyle factors help you feel better? (From the list)

- **Felt more fitter**
- **Enjoyed the walks around grounds.**
- **Activity books**.

DIET

8. Is a healthy diet important? (Please tick box)

Yes ☐ = **1**
No ☐ = **0**

What is a healthy diet?

- **Eating salads**
- **Eating fruit**
- **Drinking water**
- **Not have too much weight on**
- **Avoid cake and crisps**

8. Do you have a healthy diet? (Please tick box)

Yes ☐ = **1**
No ☐ = **0**

Describe it:

- **a.m. - Porridge**
- **Toast with a little butter – Flora**
- **Tea and plain biscuit**
- **Fruit/yoghurt**
- **Dinner – Stew, potatoes – normal portions**
- **Trying not to eat as much now as used to**

9. What topics would it be useful to know more about?

- **Cannot think at the moment**
- **Teaches how to do exercises as well as losing weight**

EXERCISE

10. Is regular exercise important? (Please tick box)

Yes ☐ = **1**
No ☐ = **0**

Why?

- **For health**
- **For fitness**
- **Keeps heart stable**
- **Keep bones strong and stops getting lungs tired.**

11. What forms of exercise/activity do you enjoy?

- **Mat exercises**
- **Bicycle**
- **Walking**
- **Swimming**

How often do you do these?

- **Walk to work**
- **Out for walks with work**
- **Swimming l/wk.**

Do you currently feel you take enough exercise? (Please tick box)

Yes ☐ = **0**
→ **Sometimes well**
No ☐ = **0** **Did not do it because no one to go with me and short staffed**

12. Would you like help to know more about regular exercise? (Please tick box)

Yes ☐ = **1**
No ☐ = **0**

13a How often should you exercise a week? (Please circle one)

a. Once = **0**
b. Three times = **0**
c. Five times = **0**
d. Seven times = **1**

13b And for how long? (Please circle one)

a. Half an hour = **0**
b. One hour = **1**

c. More than one hour = **0**

14. How could we help you to do more activities?

- **Have the exercise group longer**
- **Start the exercise group again**
- **Would like it twice a week**

SMOKING

15. Do you currently smoke? (Please tick box)

Yes ☐ = **0**
No ☐ = **1**

(If no, then you have finished the questionnaire)

16. How many cigarettes do you smoke a day? (Please circle one)

0	1-5	5-10	10-15	15-20	OVER 20	N/A
1						

17. Do you want to cut down or stop smoking? (Please circle one)

No	A Little	A Lot	N/A
			Does not smoke

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE

Physiotherapy Staffing MAH site
2008 v 2021

MAH Physiotherapy Staffing

2021

Band 8a Clinical Team Lead (0.5 WTE)

Band 7 Physiotherapist

(0.5WTE)

Band 6 Physiotherapist

(1.0WTE) MAH monies

(1.0WTE) MAH monies

Rotational Band 5 Physiotherapist

(1.0WTE)

Technical Instructor B4

Vacant (1.0 WTE)

(1.0WTE)

Total 6 incl vacancy

AIDS AND APPLIANCES-
Orthotic and Helmet Clinic
2021

Staffing under review

Healthcare Scientist Practitioner B6

(0.1 WTE)

Senior Assistant Technical Officer B3

(0.6 WTE) MAH / 0.4 RVH

Total = 0.7 wte

MAH Physiotherapy Staffing
2008

Band 7 Team Lead 1.0 wte
uplifted to Band 8a

Band 6 Physiotherapist 0.2 wte

Band 4 Assistants/ Staff technical Instructors

0.8 wte x2

Total 2.8 wte

Aids & Appliances
Orthotic and Helmet Clinic
2008

Band 5 Medical Technical Officer (MTO)
1.0 wte
Band 3 1.0 wte Assistant MTO
Band 1 0.53 wte Sewing Room Assistant

Total = 2.53 wte

HSC Belfast Health and Social Care Trust

caring supporting improving together

Activity	Definition	Health Related Physical fitness component Outcome Measure
Physical Activity **Promoted by everyone**	***Any bodily movement produced by the contraction of skeletal muscles that results in a substantial increase in caloric requirement over resting energy expenditure*** Promotion of mobility in wards / outside Walking groups Walk and talk therapy session Motivational skills Visual prompts / feedback	**1. Cardio Vascular Treadmill Test** **Timed lap MAH site** **2. Body Composition BMI** **3. Muscle Strength Muscle Testing** **4. Muscle Endurance Push up test** **Wall sit test** **Plank Test** **5. Flexibility Sit / Reach Test** **Shoulder Range of Movement** **Hamstring Flexibility**
Physical Exercise **Training required to deliver**	***A type of Physical activity consisting of planned structured and repetitive bodily movement done to improve and or maintain one or more components of physical fitness*** Chair based / wheelchair Aerobics Physiotherapy Exercise Prescription / follow up programme Circuit type exercises Walking Groups Individual sessions	
Improvement of Physical Fitness	***A set of attributes or characteristics individuals have or achieve that relates to their physical ability to perform physical activity*** Gym based activity Treadmill Cross Trainer Day care / Physio gym / outside of MAH site Group/ Indivicdual sessions	

🟥	🟥	

Background

Physiotherapy Walking Groups MAH site

The physio department currently run male and female walking groups which aids in the promotion and deliverance of physical activity on the Muckamore site in line with national recommendations. Along with the well-known physical benefits of exercises helping with mood, sleep and weight mgmt; we also feel the walking groups help patients establish a routine, gain discipline and develop social skills. We love taking these groups and feel our patients really enjoy participating in them.

The male walking group named "THE EARLY BIRDS" takes place each Tuesday and Thursday morning at 8am and is welcome to all male pts. The size of the group has varied depending on referrals- before Christmas (prior to many discharges) we were getting 10-12 participants and required 2 groups on Thursday mornings. Presently we have 4-6 participants who take part but this will likely increase with new patients been identified.

The female group takes place on Wednesdays at 11:30am- it is more difficult to get girls to engage but we are getting approx. 3-5 participants regularly.

Each walk lasts 45 mins and encompasses a moderate paced walk around hospital grounds with 3 x stops at different intervals where the physio leads aerobic activities including step ups (on kerb), star jumps, high knees etc and stretching exercises. At the end of the walk we finish with a timed lap of pre-measured route where patients are encouraged to walk/run at their fastest pace to beat their time from previous day. If weather is too bad the patients are brought up to Portmore and circuits based exercises are completed.

Feedback from Nursing staff

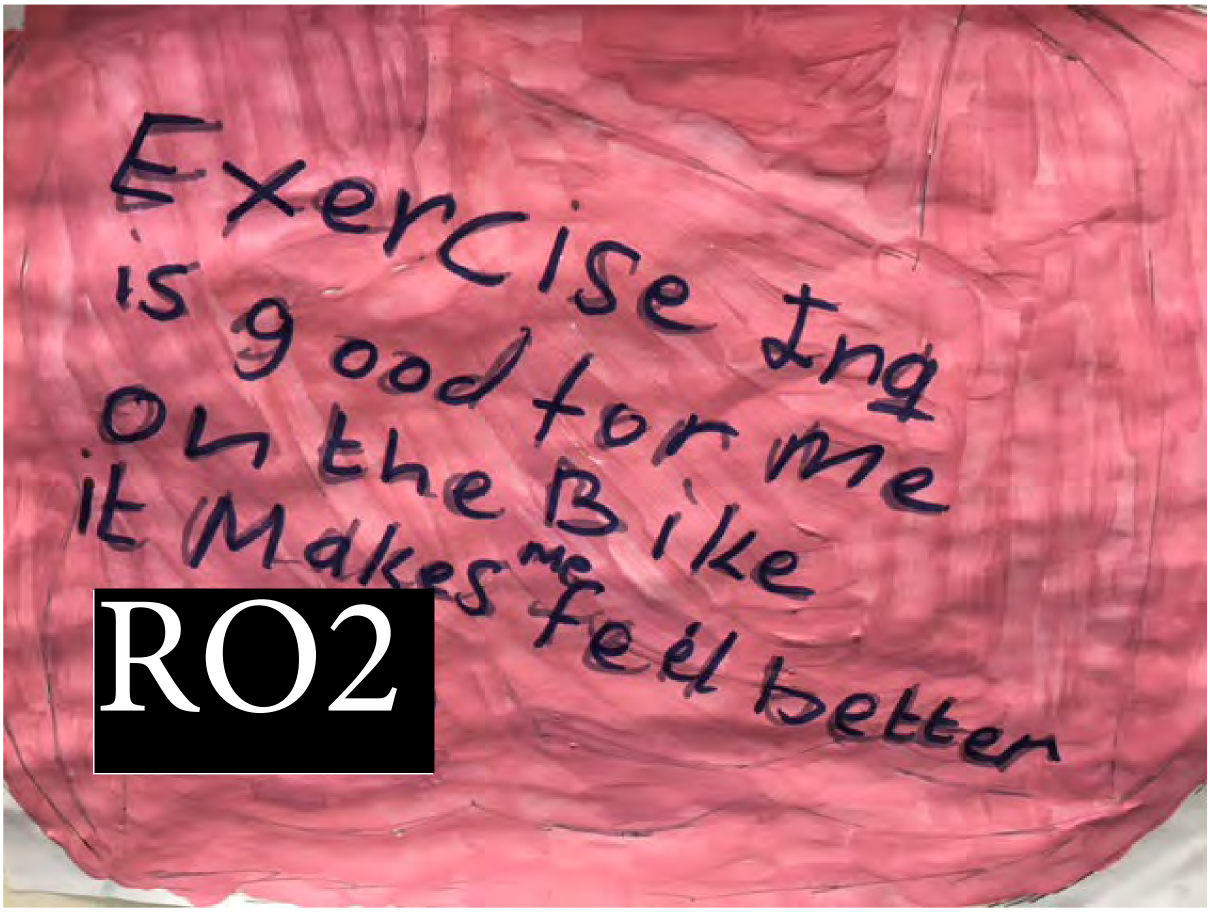
[redacted], [redacted], [redacted] and [redacted] have all benefited greatly since commencing the walking group. It has proved great structure and routine, that they rise in the morning and have purpose. It has also been noted that sleep pattern has improved by all patients. [redacted] feels healthlier and records his weight. [redacted], [redacted] and [redacted] all have fitbits which record there steps/heart rate, and they all compare how much they have achieved during the walking group. The walking group has given all patients the incentive to be active and eat healthier. They all have spoke highly of the walking group, and look forward to it before attending their daycare sessions.

All patients mood appear happier following the walking group and tends to avoid confrontation within the ward.

[redacted] has been participating in Thursday afternoon physio session cooperated into his daily schedule for some time. [redacted] thoroughly enjoys his session with Nicky and participates well with encouragement. This helps [redacted] with his mobility and encourage overall physical health and wellbeing. [redacted] states that “He loves it to bits” It is not only beneficial to [redacted] for physical rewards but it also helps with his social skills and social participation also.

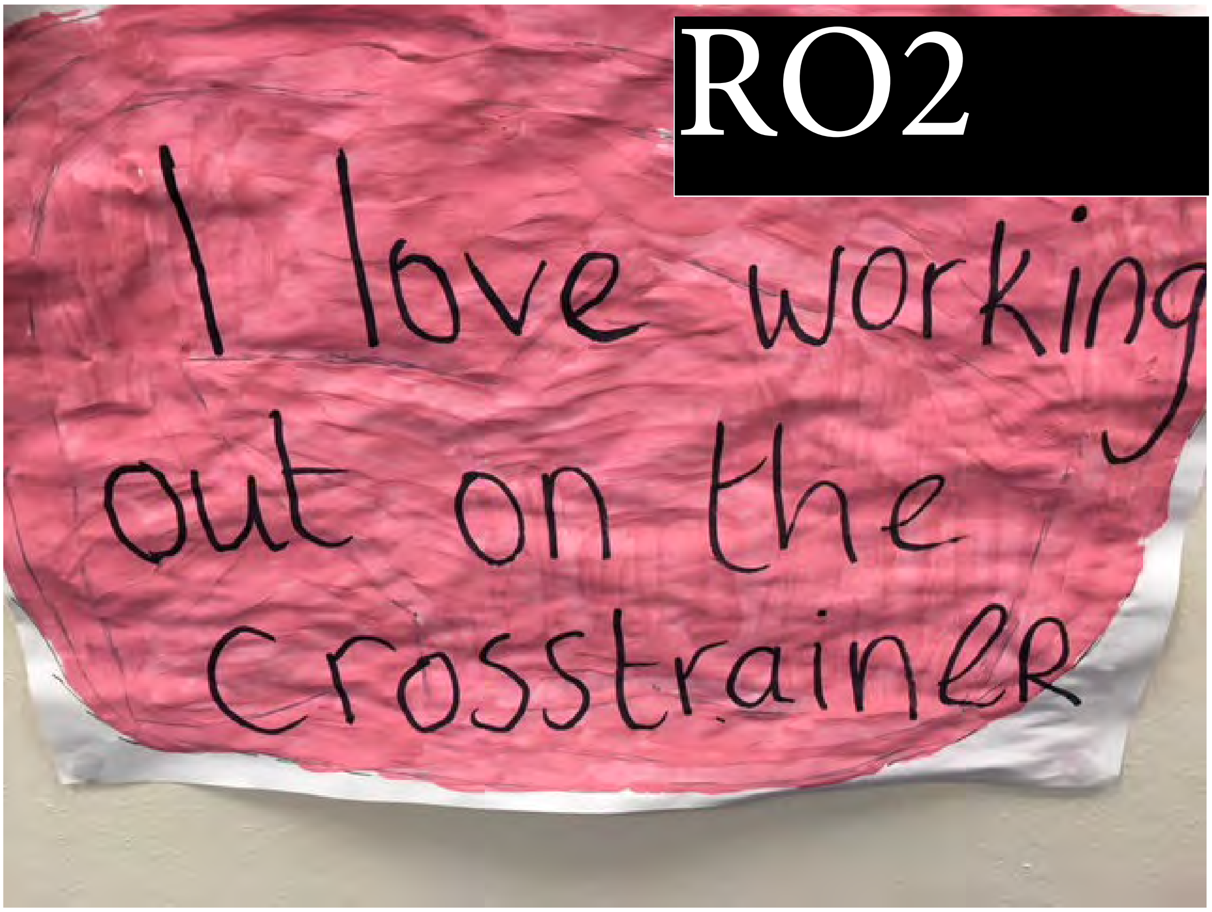
[redacted] has been participating in the walking group every Tuesday, Thursday and Friday mornings. [redacted] loves walking and being outside. He looks forward to his 3 weekly sessions and enjoys the social aspects as well. This definitely benefits [redacted] as he sometimes finds it difficult waiting on day-care to start so the walking group gives him a structure to his morning.

Patient Feedback



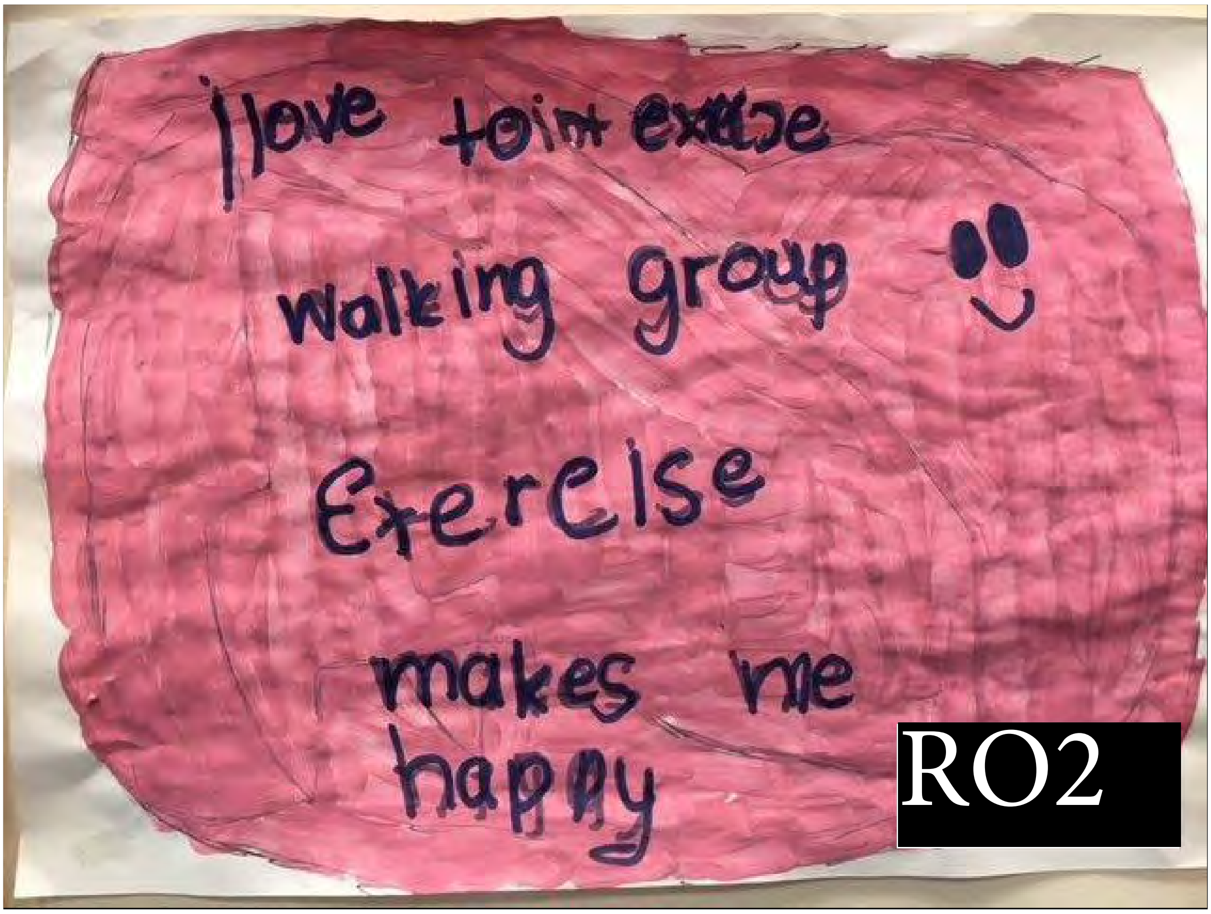
Exercise Ing
is good for me
on the Bike
it Makes me feel better

RO2



RO2

I love working
out on the
crosstraineR



I love toint exase
walking group
Exercise
makes me
happy

RO2

Move More Challenge

- Everyone is welcome!
- We have planned an activity "*MOVE MORE CHALLENGE" - A TOUR OF IRELAND.* This will be led by Physiotherapy, in conjunction with the Dietetics department, alongside their Weight Watchers initiative. Our main aim is to promote and increase physical activity and fitness levels across the hospital site. It will run up until Christmas**.**
- Each ward/ department will work as a team, and together in MAH we will aim to complete the number of miles required to go around the coastline of Ireland **(total 1970 miles)**
- We encourage all patients and staff to walk, run, cycle, swim or move in an active way to reach this goal.
- We aim to support each patient to participate and enjoy their exercise.
- If anyone (either patient or staff) would like ideas for alternative physical activities, please contact the Physiotherapy department and we will help: ext. no: **52295.**

Each ward will be given a mile tracker with slots for both staff and patients.

This must be updated and filled in once each mile is complete.

As example: 2 full laps of site = 1 mile = 1 dot

15 mins moderate exercise = 1 mile = 1 dot

1) The miles completed must be recorded on the mile tracker using a coloured dot, or a single tick.
2) When recording the miles for each patient/ staff, do so above their slot on the tracker sheet.
3) If there are any questions/ issues or guidance required, please contact Physiotherapy department ext. **52295**
4) The Physiotherapy team will collect the tracker sheets from the ward each week, and will update the overall record, which will be displayed in Moyola daycare, so that everybody can see the whole site progress on a weekly basis.

hcpc health & care professions council

Standards of proficiency

Physiotherapists

Contents

Foreword

We are pleased to present the Health and Care Professions Council's standards of proficiency for physiotherapists.

We first published standards of proficiency for physiotherapists when our Register opened in July 2003. We published revised standards in 2007. We review the standards regularly to look at how they are working and to check whether they continue to reflect current practice in the professions we regulate.

These new revised standards are a result of our most recent review of the standards of proficiency. As a result of the first stage of the review, and the results of a public consultation, we have revised our generic standards which apply to all the professions we regulate. The revised standards are now based around 15 generic statements. This new structure means that we can retain the standards which are shared across all the professions we regulate, whilst allowing us more flexibility in describing the detailed standards which are specific to individual professions.

The profession-specific standards for physiotherapists included in this document were developed with the input of the relevant professional body and the views of all stakeholders during a further public consultation. The review process and consultation produced valuable feedback and we are grateful to all those who gave their time to help us in shaping the new standards.

We have made a small number of changes to the standards overall, mainly to reflect developments in education and practice, to clarify our intentions and to correct any errors or omissions. We have also made some minor changes to the introduction, in particular, to explain the language we use in the standards.

We are confident that the standards are fit for purpose and reflect safe and effective professional practice in physiotherapy.

These standards are effective from Tuesday 28 May 2013.

Introduction

This document sets out the standards of proficiency. These standards set out safe and effective practice in the professions we regulate. They are the threshold standards we consider necessary to protect members of the public. They set out what a student must know, understand and be able to do by the time they have completed their training, so that they are able to apply to register with us. Once on our Register you must meet those standards of proficiency which relate to the areas in which you work.

We also expect you to keep to our standards of conduct, performance and ethics and standards for continuing professional development. We publish these in separate documents, which you can find on our website.

The standards of proficiency in this document include both generic elements, which apply to all our registrants, and profession-specific elements which are relevant to registrants belonging to one of the professions we currently regulate. The generic standards are written in **bold**, and the profession-specific standards are written in plain text.

We have numbered the standards so that you can refer to them more easily. The standards are not hierarchical and are all equally important for practice.

A note about our expectations of you

You must meet all the standards of proficiency to register with us and meet the standards relevant to your scope of practice to stay registered with us.

It is important that you read and understand this document. If your practice is called into question we will consider these standards (and our standards of conduct, performance and ethics) in deciding what action, if any, we need to take.

The standards set out in this document complement information and guidance issued by other organisations, such as your professional body or your employer. We recognise the valuable role played by professional bodies in providing guidance and advice about good practice which can help you to meet the standards in this document.

Your scope of practice

Your scope of practice is the area or areas of your profession in which you have the knowledge, skills and experience to practise lawfully, safely and effectively, in a way that meets our standards and does not pose any danger to the public or to yourself.

We recognise that a registrant's scope of practice will change over time and that the practice of experienced registrants often becomes more focused and specialised than that of newly registered colleagues. This might be because of specialisation in a certain area or with a particular client group, or a movement into roles in management, education or research. Every time you renew your registration, you will be asked to sign a declaration that you continue to meet the standards of proficiency that apply to your scope of practice.

Your particular scope of practice may mean that you are unable to continue to demonstrate that you meet all of the standards that apply for the whole of your profession. As long as you make sure that you are practising safely and effectively within your given scope of practice and do not practise in the areas where you are not proficient to do so, this will not be a problem. If you want to move outside of your scope of practice, you should be certain that you are capable of working lawfully, safely and effectively. This means that you need to exercise personal judgement by undertaking any necessary training and experience, before moving into a new area of practice.

Meeting the standards

It is important that you meet our standards and are able to practise lawfully, safely and effectively. However, we do not dictate how you should meet our standards. There is normally more than one way in which each standard can be met and the way in which you meet our standards might change over time because of improvements in technology or changes in your practice.

We often receive questions from registrants who are concerned that something they have been asked to do, a policy, or the way in which they work might mean they cannot meet our standards. They are often worried that this might have an effect on their registration.

As an autonomous professional, you need to make informed, reasoned decisions about your practice to ensure that you meet the standards that apply to you. This includes seeking advice and support from education providers, employers, colleagues, professional bodies, unions and others to ensure that the wellbeing of service users is safeguarded at all times. So long as you do this and can justify your decisions if asked to, it is very unlikely that you will not meet our standards.

Language

We recognise that our registrants work in a range of different settings, which include direct practice, management, education, research and roles in industry. We also recognise that the use of terminology can be an emotive issue.

Our registrants work with very different people and use different terms to describe the groups that use, or are affected by, their services. Some of our registrants work with patients, others with clients and others with service users. The terms that you use will depend on how and where you work. We have used terms in these standards which we believe best reflect the groups that you work with.

In the standards of proficiency, we use phrases such as ‘understand’, ‘know’, and ‘be able to’. This is so the standards remain applicable to current registrants in maintaining their fitness to practise, as well as prospective registrants who have not yet started practising and are applying for registration for the first time.

These standards may change in the future

We have produced these standards after speaking to our stakeholders and holding a formal public consultation.

We will continue to listen to our stakeholders and will keep our standards under continual review. Therefore, we may make further changes in the future to take into account changes in practice.

We will always publicise any changes to the standards that we make by, for instance, publishing notices on our website and informing professional bodies.

Standards of proficiency

Registrant physiotherapists must:

1 be able to practise safely and effectively within their scope of practice

1.1 know the limits of their practice and when to seek advice or refer to another professional

1.2 recognise the need to manage their own workload and resources effectively and be able to practise accordingly

2 be able to practise within the legal and ethical boundaries of their profession

2.1 understand the need to act in the best interests of service users at all times

2.2 understand what is required of them by the Health and Care Professions Council

2.3 understand the need to respect and uphold the rights, dignity, values, and autonomy of service users including their role in the diagnostic and therapeutic process and in maintaining health and wellbeing

2.4 recognise that relationships with service users should be based on mutual respect and trust, and be able to maintain high standards of care even in situations of personal incompatibility

2.5 know about current legislation applicable to the work of their profession

2.6 understand the importance of and be able to obtain informed consent

2.7 be able to exercise a professional duty of care

3 be able to maintain fitness to practise

3.1 understand the need to maintain high standards of personal and professional conduct

3.2 understand the importance of maintaining their own health

3.3 understand both the need to keep skills and knowledge up to date and the importance of career-long learning

4 be able to practise as an autonomous professional, exercising their own professional judgement

4.1 be able to assess a professional situation, determine the nature and severity of the problem and call upon the required knowledge and experience to deal with the problem

4.2 be able to make reasoned decisions to initiate, continue, modify or cease techniques or procedures, and record the decisions and reasoning appropriately

4.3 be able to initiate resolution of problems and be able to exercise personal initiative

4.4 recognise that they are personally responsible for and must be able to justify their decisions

4.5 be able to make and receive appropriate referrals

4.6 understand the importance of participation in training, supervision and mentoring

5 be aware of the impact of culture, equality, and diversity on practice

5.1 understand the requirement to adapt practice to meet the needs of different groups and individuals

5.2 be able to recognise the need to identify and take account of the physical, psychological, social and cultural needs of individuals and communities

6 be able to practise in a non-discriminatory manner

7 understand the importance of and be able to maintain confidentiality

7.1 be aware of the limits of the concept of confidentiality

7.2 understand the principles of information governance and be aware of the safe and effective use of health and social care information

7.3 be able to recognise and respond appropriately to situations where it is necessary to share information to safeguard service users or the wider public

8 be able to communicate effectively

8.1 be able to demonstrate effective and appropriate verbal and non-verbal skills in communicating information, advice, instruction and professional opinion to service users, colleagues and others

8.2 be able to communicate in English to the standard equivalent to level 7 of the International English Language Testing System, with no element below 6.5[1]

8.3 understand how communication skills affect assessment and engagement of service users and how the means of communication should be modified to address and take account of factors such as age, capacity, learning ability and physical ability

8.4 be able to select, move between and use appropriate forms of verbal and non-verbal communication with service users and others

8.5 be aware of the characteristics and consequences of verbal and non-verbal communication and how this can be affected by factors such as age, culture, ethnicity, gender, socio-economic status and spiritual or religious beliefs

8.6 understand the need to provide service users or people acting on their behalf with the information necessary to enable them to make informed decisions

8.7 understand the need to assist the communication needs of service users such as through the use of an appropriate interpreter, wherever possible

8.8 recognise the need to use interpersonal skills to encourage the active participation of service users

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[1] The International English Language Testing System (IELTS) tests competence in the English language. Applicants who have qualified outside of the UK, whose first language is not English and who are not nationals of a country within the European Economic Area (EEA) or Switzerland, must provide evidence that they have reached the necessary standard. Please visit our website for more information.

9 be able to work appropriately with others

9.1 be able to work, where appropriate, in partnership with service users, other professionals, support staff and others

9.2 understand the need to build and sustain professional relationships as both an independent practitioner and collaboratively as a member of a team

9.3 understand the need to engage service users and carers in planning and evaluating diagnostics, and therapeutic interventions to meet their needs and goals

9.4 be able to contribute effectively to work undertaken as part of a multi-disciplinary team

9.5 understand the need to agree the goals, priorities and methods of physiotherapy intervention in partnership with the service user

10 be able to maintain records appropriately

10.1 be able to keep accurate, comprehensive and comprehensible records in accordance with applicable legislation, protocols and guidelines

10.2 recognise the need to manage records and all other information in accordance with applicable legislation, protocols and guidelines

11 be able to reflect on and review practice

11.1 understand the value of reflection on practice and the need to record the outcome of such reflection

11.2 recognise the value of case conferences and other methods of review

12 be able to assure the quality of their practice

12.1 be able to engage in evidence-based practice, evaluate practice systematically and participate in audit procedures

12.2 be able to gather information, including qualitative and quantitative data, that helps to evaluate the responses of service users to their care

12.3 be aware of the role of audit and review in quality management, including quality control, quality assurance and the use of appropriate outcome measures

12.4 be able to maintain an effective audit trail and work towards continual improvement

12.5 be aware of, and be able to participate in, quality assurance programmes, where appropriate

12.6 be able to evaluate intervention plans using recognised outcome measures and revise the plans as necessary in conjunction with the service user

12.7 recognise the need to monitor and evaluate the quality of practice and the value of contributing to the generation of data for quality assurance and improvement programmes

12.8 be able to evaluate intervention plans to ensure that they meet the physiotherapy needs of service users, informed by changes in circumstances and health status

13 understand the key concepts of the knowledge base relevant to their profession

13.1 recognise the role of other professions in health and social care

13.2 be aware of the principles and applications of scientific enquiry, including the evaluation of the efficacy of interventions and the research process

13.3 understand the concept of leadership and its application to practice

13.4 understand the structure and function of the human body, together with knowledge of health, disease, disorder and dysfunction, relevant to their profession

13.5 understand the theoretical basis of, and the variety of approaches to, assessment and intervention

13.6 understand the following aspects of biological science:

- normal human anatomy and physiology, including the dynamic relationships of human structure and function as related to the neuromuscular, musculoskeletal, cardio-vascular and respiratory systems
- patterns of human growth and development across the lifespan
- factors influencing individual variations in human ability and health status
- how the application of physiotherapy can cause physiological and structural change

13.7 understand the following aspects of physical science:

- the principles and theories from physics, biomechanics, applied exercise science and ergonomics that can be applied to physiotherapy
- the means by which the physical sciences can inform the understanding and analysis of movement and function
- the principles and application of measurement techniques based on biomechanics or electrophysiology
- the application of anthropometric and ergonomic principles

13.8 understand the following aspects of clinical science:

- pathological changes and related clinical features commonly encountered in physiotherapy practice
- physiological, structural, behavioural and functional changes that can result from physiotherapy intervention and disease progression
- the specific contribution that physiotherapy can potentially make to enhancing individuals' functional ability, together with the evidence base for this
- the different concepts and approaches that inform the development of physiotherapy intervention

13.9 understand the following aspects of behavioural science:

- psychological, social and cultural factors that influence an individual in health and illness, including their responses to the management of their health status and related physiotherapy interventions
- how psychology, sociology and cultural diversity inform an understanding of health, illness and health care in the context of physiotherapy and the incorporation of this knowledge into physiotherapy practice
- theories of communication relevant to effective interaction with service users, carers, colleagues, managers and other health and social care professionals
- theories of team working

14 be able to draw on appropriate knowledge and skills to inform practice

14.1 understand the structure and function of health and social care services in the UK

14.2 be able to deliver and evaluate physiotherapy programmes

14.3 be able to gather appropriate information

14.4 be able to select and use appropriate assessment techniques

14.5 be able to undertake and record a thorough, sensitive and detailed assessment, using appropriate techniques and equipment

14.6 be able to undertake or arrange investigations as appropriate

14.7 be able to analyse and critically evaluate the information collected

14.8 be able to form a diagnosis on the basis of physiotherapy assessment

14.9 be able to demonstrate a logical and systematic approach to problem solving

14.10 be able to use research, reasoning and problem solving skills to determine appropriate actions

14.11 be able to formulate specific and appropriate management plans including the setting of timescales

14.12 be able to apply problem solving and clinical reasoning to assessment findings to plan and prioritise appropriate physiotherapy

14.13 recognise the need to discuss, and be able to explain the rationale for, the use of physiotherapy interventions

14.14 be able to set goals and construct specific individual and group physiotherapy programmes

14.15 be able to conduct appropriate diagnostic or monitoring procedures, interventions, therapy, or other actions safely and effectively

14.16 be able to select, plan, implement and manage physiotherapy interventions aimed at the facilitation and restoration of movement and function

14.17 know how to position or immobilise service users for safe and effective interventions

14.18 be able to select and apply safe and effective physiotherapy-specific practice skills including manual therapy, exercise and movement, electrotherapeutic modalities and kindred approaches

14.19 be able to change their practice as needed to take account of new developments or changing contexts

14.20 recognise the value of research to the critical evaluation of practice

14.21 be aware of a range of research methodologies

14.22 be able to evaluate research and other evidence to inform their own practice

14.23 be able to use information and communication technologies appropriate to their practice

15 understand the need to establish and maintain a safe practice environment

15.1 understand the need to maintain the safety of both service users and those involved in their care

15.2 know and be able to apply appropriate moving and handling techniques

15.3 be aware of applicable health and safety legislation, and any relevant safety policies and procedures in force at the workplace, such as incident reporting and be able to act in accordance with these

15.4 be able to work safely, including being able to select appropriate hazard control and risk management, reduction or elimination techniques in a safe manner and in accordance with health and safety legislation

15.5 be able to select appropriate personal protective equipment and use it correctly

15.6 be able to establish safe environments for practice, which minimise risks to service users, those treating them and others, including the use of hazard control and particularly infection control

Notes

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CHARTERED
SOCIETY
OF
PHYSIOTHERAPY

Quality Assurance Standards

for physiotherapy service delivery

Contents

Foreword

As the Chair of Council, I am pleased to introduce the Society's new Quality Assurance (QA) Standards for physiotherapy service delivery. These replace the original Core and Service Standards developed in 2000 and updated in 2005. The QA Standards provide an integrated and person-centred approach to practice and service delivery which reflects the complexity of service delivery and physiotherapy practice. They are intended to support members in meeting their legal, ethical and regulatory requirements.

These QA Standards have been developed in response to Member feedback that the CSP Standards continue to be relevant to member's working lives and integral to delivering and assuring the high quality of physiotherapy services. The project to develop them involved extensive consultation with CSP members throughout the UK working in a range of organisations and roles and was overseen by a steering group representing members.

The QA Standards provide statements of expected levels for service delivery which members, through consultation, agree are set at a level which is reasonable and achievable by a CSP member, or physiotherapy service in the UK. They apply regardless of an individual's role, grade or experience and apply to individual members, physiotherapy teams delivering services and those, including managers or employers whose background may not be physiotherapy, with a responsibility for overseeing service delivery. The QA standards are a tool for members to use collectively or as individuals as part of a quality assurance process. They will also be useful for service users and those purchasing services. The QA standards resource includes a QA tool which enables the comparison of actual services with these standards.

Dr Helena Johnson EdD MEd PgDHE BSc Hons MCSP FHEA
Chair of CSP Council

August 2012

Introduction

Purpose of the Quality Assurance Standards

These Quality Assurance (QA) Standards have been developed by the Chartered Society of Physiotherapy (CSP) for its members; qualified members, associates and students.

The QA Standards together with the Quality Assurance (QA) Audit Tool have been developed to:
- promote and assure quality in clinical practice and service delivery
- support CSP members in assuring and demonstrating the standard of physiotherapy care and services
- support CSP members in delivering safe and effective physiotherapy services
- provide a marker for CSP members and those who purchase or use physiotherapy services on which to assess the standard of a local physiotherapy service or care
- support CSP members in meeting the expectations of the Society as articulated in the *Code of Professional Values and Behaviour* (1)
- Support qualified Members in meeting the requirements of the Health and Care Professions Council as set out in the *Standards of Proficiency – Physiotherapists* (2) and *Standards of Conduct, Performance and Ethics.*(3)

Development of the Quality Assurance Standards

Physiotherapy is a healthcare profession that works with people to identify and maximise their ability to move and function. Functional movement is a key part of what it means to be healthy. This means that physiotherapy plays a key role in enabling people to improve their health, wellbeing and quality of life.(4)

The CSP has the responsibility for leading the physiotherapy profession in the UK. It provides a range of resources for its members and others interested in the practise of physiotherapy. It is anticipated that a wide range of individuals and organisations will use these resources to inform their knowledge of physiotherapy and the physiotherapy profession.

These QA Standards build on and replace the former CSP Core Standards(5) and Service Standards(6) produced in 2000 and the Core Standards of Physiotherapy Practice updated in 2005.(7) The QA Standards have been developed in consultation with CSP members working in a range of organisations and roles and in response to member feedback that the CSP Standards have remained a tool which is used and valued by them. The key changes, seen in this document, has been to develop a single resource which integrates and builds on the Core and Service Standards, applies to all CSP members and places greater emphasis on their role in promoting and assuring quality clinical practice and service delivery. In response to feedback a range of formats are available to enable members to access the QA Standards in the depth required at any given time.

Interpretation of the Quality Assurance Standards

The QA Standards are set at a level which, members through consultation agree, is reasonable and achievable by a CSP member or physiotherapy service in the UK. The QA Standards apply to individual members, physiotherapy teams delivering services and those, including managers or employers whose background may not be physiotherapy, with a responsibility for overseeing physiotherapy service delivery. The QA Standards have been developed to reflect the complexity of service delivery and physiotherapy practice. As such, although accessing a section of the resource may be relevant at times, each section should be considered as part of a whole.

The QA Standards apply regardless of an individual's role, grade or experience. Their interpretation will vary for different member groups or levels of practice and not all of the standards will be applicable in all situations or at all times of an individual's career. CSP members should critically reflect on their role and individual scope and the context of their practice and the service within which it is delivered to determine when standards do not apply.

The QA Standards are organised into 10 sections. Within each section are a number of standards. These QA standards provide clear statements on expected features of physiotherapy service delivery provided by members of the physiotherapy profession. Each of the standards has a number of measurable criteria relating to them which present the components of how a standard may be met. These are provided for quality assurance purposes. These criteria are not exhaustive and it is likely that there may be other ways in which to demonstrate that a standard has been met and these should be agreed locally.

A quality assurance audit tool (QA tool) has been developed to facilitate the comparison of actual service delivery with the criteria in the QA standards. There are links throughout the standards to this tool.

Terminology

The term ‘organisation’ has been used throughout the QA Standards to refer to the context within which the physiotherapy service is delivered, e.g. a single handed independent practitioner delivering a service, or a service within a large organisation.

The term service user has been used to include all those in receipt of physiotherapy including patients, clients, carers and others.

The term ‘intervention’ has been used to include all aspects of service delivery, clinical care and physiotherapy management.

Responsibility for implementation

CSP members are responsible for the implementation and audit of these QA Standards. There is no intention to monitor the implementation of them as they are a tool for members to use either collectively or as individuals as part of a quality assurance process. Individuals and services are advised to identify locally where responsibility for ensuring the actual implementation of a specific standard and criteria lies.

It is likely that the QA Standards will be used at a local level for reference and support in organisational governance systems and used nationally for reference, in cases heard by the Health and Care Professions Council (HCPC). Where appropriate, in a fitness to practice case the regulator looks for evidence of what is a reasonable standard of practice and what the average professional would do. The QA Standards, along with other documents produced by the CSP, in particular the Code(1), the Physiotherapy Framework(4) and the Learning & Development Principles(8), may also be used to form part of this professional framework.

Participation in audit should be part of a member’s continuing professional development (CPD) and use of the QA tool supports CSP members’ activity in this way. The link to the ePortfolio(9) provides the individual member with a tool for recording participation in the quality assurance process. The ePortfolio profile tool allows members to add evidence to demonstrate how they fulfil the criteria in each standard and therefore becomes a log of development of practice and service delivery.

Quality Assurance audit tool(10)

The QA audit tool has been developed to facilitate the comparison of physiotherapy service delivery with that presented in the QA standards. The QA, through the QA audit tool, enable the audit of the standards in either their entirety or in sections if required. The QA audit tool uses the criteria beneath the standard to identify whether the actual standard has been met. The majority of the criteria are measurable and information can be gathered from records or policies, or may be observed or assessed. However, there are some criteria which may require reflection by the physiotherapist or physiotherapy team member through, for example, peer review or gathering service users' experiences to demonstrate that the criteria have been met.

The QA audit tool comprises three elements which enable the triangulation of information;

- a data collection tool to gather information from the service user or physiotherapy records and organisational policies
- a structure for gathering service user's experiences
- a tool for peer review

Use of the QA Standards as a framework for quality assurance will provide one method through which actions can be identified for service improvement and will support members in complying with the legal, moral and ethical obligations placed on them when practising physiotherapy in the UK. Use of the QA audit tool will provide evidence that physiotherapy service delivery is of a standard quality; and will provide useful information as part of a cyclical quality assurance process. This information may be shared, both within the service as part of the quality improvement cycle and with those outside the service to assure the quality of a service being delivered. Where the process identifies variations from the standard, the physiotherapist or physiotherapy team member is responsible for communicating this information to the responsible person(s).

At times the organisational policy may conflict with the QA Standards and prevent a standard being met. In analysing the results of the QA process these discrepancies should be identified action taken to explore this further. In this situation the individual member and the organisation are advised to consider legal responsibilities, organisational responsibilities HCPC requirements, and responsibilities to service users.

The annex on related resources includes a range of resources to support the understanding and implementation of these QA standards.

1 Autonomy and accountability

Quality Assurance Standards

1.1 Members work within the scope of practice of the profession and their individual scope of practice
1.2 Members demonstrate the behaviours, skills and knowledge to fulfil the responsibilities of their role
1.3 Members fulfil their duty of care to service users
1.4 Members demonstrate professionalism at all times

Introduction

Maintaining autonomy and accountability to the service user, the patient, the profession and the public requires each CSP member to be aware of the many environmental factors underpinning these: such as the need to practice within the legal obligations of the country and the organisation in which they work.

As an autonomous profession, physiotherapists can accept referrals for assessment from a range of sources: from an individual themselves (self-referral) or from other people involved with that individual. Professional autonomy means that a member makes decisions and acts independently within a professional context and is responsible and accountable for these decisions and actions. A key element of professional autonomy is understanding and working within the limits of personal competence and scope of practice.

Neither physiotherapy students nor support workers hold professional autonomy. Both groups of members undertake physiotherapy-related activity with appropriate forms of supervision. Physiotherapy students are prepared through their qualifying education to assume the responsibilities of professional autonomy on qualification. While not autonomous practitioners, physiotherapy support workers take responsibility for undertaking the tasks delegated to them in delivering a physiotherapy service.

As the professional body for physiotherapy, the CSP defines scope of practice for physiotherapy in the UK. Scope of practice relates strongly to competence and professionalism. The concept recognises the profession's scope of practice is evolving, and needs to evolve, in line with changing patient and population needs, developments in the evidence base, changes in service design and delivery and changing opportunities for professional and career development. Individual members have a responsibility to be aware of how their practice may challenge the boundaries of the scope of practice of UK physiotherapy and to take appropriate action. Individual members also have a responsibility to limit their activity to those areas in which they have established and maintained their competence.

Professionalism defines what is expected of a professional, and what it means to be a professional. Broadly, it can be summarised as; a motivation to deliver a service to others, adherence to a moral and ethical code of practice, striving for excellence, maintaining an awareness of limitations and scope of practice and a commitment to empowering others (rather than seeking to protect professional knowledge and skills).

1.1 Members work within the scope of practice of the profession and their individual scope of practice

Criteria

1.1.1 Members demonstrate an understanding of their personal scope of practice and the scope of the profession
1.1.2 Members practise within their individual scope of practice
1.1.3 Members identify their learning needs and put in place learning opportunities which consider the needs

of the service and service users
1.1.4 Members are insured for the activities that they undertake

1.2 Members demonstrate the behaviours, skills and knowledge to fulfil the responsibilities of their role

Criteria

1.2.1 Members reflect on their role and evaluate their learning needs
1.2.2 Members identify areas of learning required to develop and maintain competence in their role
1.2.3 There is a policy which includes:
  a. checking physiotherapists are registered with the HCPC on initial employment and annually
  b. checking physiotherapy team members have undergone relevant disclosures
  c. assessing the suitability of new physiotherapy team members using the relevant person specification and job description
  d. holding personnel files which include a CV where applicable, references, records of appraisal, and evidence of engagement in CPD
  e. an appraisal system to evaluate learning needs
1.2.4 A signature, job title and work area is recorded in the signature book for all physiotherapy team members and retained in line with record keeping legislation

1.3 Members fulfil their duty of care to service users

Criteria

1.3.1 Members demonstrate an understanding of their duty of care responsibility, including how this relates to organisational, regulatory and professional standards
1.3.2 Members take responsibility for fulfilling their duty of care to the service users
1.3.3 Members take responsibility for identifying where factors, including implementation of organisational decisions and structures, have the effect of compromising their duty of care to individual service users
1.3.4 There is a policy in place to ensure that CSP members are supported in identifying and addressing factors that may compromise their fulfilment of their duty of care to service users

1.4 Members demonstrate professionalism at all times

Criteria

1.4.1 Members demonstrate practice that is ethical and in accordance with relevant organisational, legal and regulatory requirements
1.4.2 Members behave in such a way that their manner, attitudes and actions instil confidence in the profession
1.4.2 There is a policy in place which includes:
  a. an appearance policy
  b. duty to report
  c. the use of social media
  d. physiotherapy team members working excessive hours
  e. physiotherapy team members working in roles outside of physiotherapy

2 Delivering a safe and effective service

Quality Assurance Standards

2.1 There is a planned orientation and induction programme for members working in new roles
2.2 Physiotherapy staffing and skill mix is sufficient to support the services being provided
2.3 Physiotherapy services are delivered in a safe environment
2.4 There is a systematic, proactive and responsive approach to risk management that follows the organisation's overall strategy
2.5 All medical devices are safe and fit for purpose, ensuring service user, carer and physiotherapy team safety
2.6 The risks of lone working are minimised

Introduction

Delivering a safe and effective service requires a range of activities to assure the safety of service users and those who work within it and the effectiveness of the service delivered. A comprehensive range of policies and procedures are required to underpin this service delivery. The requirements and emphasis on specific aspects of this will vary according to the organisation, service delivered, service users and the context of care. The CSP provides a broad range of resources to support members in these areas.

2.1 There is a planned orientation and induction programme for members working in new roles.

Criteria

2.1.1 There is an accessible and planned orientation and induction programme for all members working in new environments, e.g. returners, new starters and members going to new sites etc
2.1.2 Members attend the induction programme and identify where components of it are omitted
2.1.3 Members provide feedback on the induction programme to ensure its continued relevance
2.1.4 There is a policy in place for the induction programme which includes:
  a. content and structure of the programme
  b. a named person responsible for planning and for implementation
  c. a named person responsible for evaluation and review to ensure the programme continues to fulfil its intended purpose
  d. completion of the programme within locally agreed time-scales
  e. issue of the programme to each new member of the physiotherapy team
2.1.5 Mandatory training is completed within agreed timescales
2.1.6 Members receive training in:
  a. fire procedures
  b. life support
  c. moving and handling
  d. dealing with violence and aggression
  e. control and prevention of infection
  f. confidentiality
  g. information governance
  h. safeguarding children
  i. safeguarding vulnerable adults
  j. familiarisation with record keeping systems (eg storage of paper records or electronic access)
  k. an approach to record keeping within the team (style/use of acronyms and short forms etc)

2.2 Physiotherapy staffing and skill mix is sufficient to support the services being provided

Criteria

- 2.2.1 There is a policy which includes;
  - *a.* an appropriate recruitment and selection procedure
  - *b.* staffing commensurate with delivering a safe and effective service which makes best use of existing resources in terms of:
    - grade
    - skill mix
    - experience
    - staff numbers
  - *c.* managing:
    - situations where staffing levels fall below locally agreed minimum levels
    - the regular review of staffing levels
    - the regular review of skill mix
  - *d.* prioritisation of workload if demand exceeds staffing levels
    - flexibility in both service provision and the needs of CSP members
    - a system to ensure all physiotherapy team members have skills and experience in the areas in which they are required to work
    - arrangements for identifying and addressing learning needs arising from changing service requirements
    - arrangements for the delegation of activities within teams
    - arrangements for clinical leadership
    - arrangements for the clinical leadership of services
    - a procedure to recognise and correct poor performance

2.3 Physiotherapy services are delivered in a safe environment

Criteria

- 2.3.1 The physiotherapy service acts on health and safety guidance
- 2.3.2 The physiotherapy service (where part of a larger organisation) is considered, and if appropriate included, in the wider organisational plans for emergency incidents which could affect provision of normal services
- 2.3.3 Physiotherapy services comply with policy on;
  - *a.* safeguarding children
  - *b.* safeguarding vulnerable adults
  - *c.* national child protection guidance
- 2.3.4 Service users receiving physiotherapy are made aware of how to summon assistance
- 2.3.5 There are systems in place to identify, report and learn from service user safety incidents and other notifiable incidents, using appropriate local and/or national governance systems and to demonstrate resulting improvements in practice
- 2.3.6 There is a health and safety policy which includes procedures to manage;
  - *a.* fire
  - *b.* waste disposal
  - *d.* disposal of medical waste
  - *e.* resuscitation
  - *f.* first aid
  - *g.* control and prevention of infection
  - *h.* disposal of sharps
  - *i.* lone working
  - *j.* chaperoning arrangements

- *k.* interpreters
- *l.* working outside normal hours
- *m.* control of substances hazardous to health
- *n.* safe moving and handling of loads
- *o.* reporting of industrial diseases and dangerous occurrences
- *p.* planned maintenance
- *q.* rehabilitation e.g. practising stairs policy
- *r.* the summoning of urgent assistance when required

2.3.7 There are policies in place for the maintenance of:

- *a.* temperature
- *b.* humidity
- *c.* lighting
- *d.* ventilation

2.4 There is a systematic, proactive and responsive approach to risk management that follows the organisation's overall strategy

Criteria

2.4.1 Care is taken to minimise risks to physiotherapy team members and service users

2.4.2 Regular health and safety audits are undertaken in accordance with locally defined time-scales

2.4.3 Notices of hazards to service user are prominently displayed in areas of known risk

2.4.4 There are policies for risk management which include:

- *a.* clearly defined procedures for the management of risks
- *b.* training in undertaking risk assessments which include identification and effective management of risks
- *c.* the indications for a documented risk assessment
- *d.* indications for a risk assessment carried out for every service user, prior to each procedure or treatment
- *e.* indications for a risk assessment carried out for every activity involving a physiotherapy team member
- *f.* the analysis of findings from risk assessments to make recommendations for changed work practices.
- *g.* action taken on the results of a risk assessment, to minimise any hazards identified

2.5 All medical devices are safe and fit for purpose, ensuring service user, carer and physiotherapy team safety

Criteria

2.5.1 There is a process in place for;

- *a.* registration to receive by email patient safety and MRHA (Medicines and Healthcare products Regulatory Agency) alerts
- *b.* cascading information on 'Patient Safety Alert' notices
- *c.* for acting upon Patient Safety Alerts and other communications that relate to the safe provision of physiotherapy
- *d.* ensuring that action is taken on new guidance about medical devices safety and on 'Patient Safety Alert' notices issued on treatments/ interventions that affect practice

2.5.2 There are policies in place which include;

- a. the use of medical devices according to manufacturer's instructions
- b. regular servicing of medical devices, whereby servicing is undertaken and action taken

when indicated
c. visual and physical safety checks of medical devices prior to use or issue to service users
d. the identification, reporting and recording of action taken regarding faults of medical devices
e. cleaning of medical devices according to manufacturer's instructions and policies for control and prevention of infection
f. removal of faulty medical devices
g. evaluation of new medical devices in the context of a clinical trial to meet the requirements of research governance
h. safe equipment for the care of bariatric service users (to include visible maximum weight of furniture e.g., treatment couches, waiting room chairs, department toilets and upstairs flooring)
i. weighing and recording of the weight of service users where indicated

2.5.3 There are polices in place which ensure;
a. training is provided in issuing and maintaining medical devices
b. a training record is kept
c. a record is kept of medical devices and/ or products loaned to service users
d. a record is kept of medical devices and/ or products purchased by the service user
e. where medical devices and/ or products are loaned or sold to service users instructions on the safe use are provided

Standard 2.6 The risks of lone working are minimised

Criteria

2.6.1 There are policies in place for lone working which include:
a. members working alone
b. communication links between members working alone and their base
c. the use of personal alarms
d. home visiting
e. home visiting where a known risk exists
f. the indications for and use of chaperones.

3 Learning and Development

Quality Assurance Standards

3.1 Members actively engage with and reflect on the continuing professional development (CPD) process to maintain and develop their competence to practise
3.2 Members offer quality CPD opportunities that help others learn and develop
3.3 Members actively engage with supporting students' practice education and the development of their professional socialisation
3.4 There are recognised structures, processes and resources in place that support learning and development in the workplace and enable members to meet the requirements of their role and meet professional and regulatory CPD requirements

Introduction

Learning and development is integral to physiotherapy practice. The CSP expects its members to actively engage with the two faces of learning and development; as learners through the process of continuing professional development (CPD), and as facilitators of others' learning and development.

Active engagement with CPD ensures that CSP members can maintain and develop their competence to practice and continue to work within an evolving scope of practice. CPD is therefore a professional and regulatory requirement. By enabling members to actively engage with CPD opportunities appropriate to their individual learning needs, organisations can ensure that the physiotherapy workforce is able to provide person-centred, ethical and effective services that reflect (and shape) developments in research and practice. It also means that the behaviours, knowledge and skills of the physiotherapy workforce are deployed safely and effectively by ensuring that physiotherapy team members can take responsibility for delegation of tasks. Support for CSP members' CPD therefore enables employers to address governance issues by assuring that the physiotherapy workforce fulfilling professional and regulatory requirements for practice.

The CSP's outcomes-based approach to CPD means that members are expected to demonstrate how their learning through CPD supports the development of practice. This outcomes-based approach also recognises that learning can occur through a wide range of activities (both formal and informal) and in a variety of spaces (e.g. workplace, classroom or online), and encourages the integration of learning and practice.

The behaviours, knowledge and skills required to engage in CPD are the same as those required to help others learn and develop. Both processes are about learning: CPD is about being a learner, while helping others learn and develop is about being a teacher, or facilitator of learning (e.g. by offering mentorship/ preceptorship, practice learning or supervised practice opportunities). The process of helping others learn and develop can offer a valuable CPD opportunity that supports the development of individuals, the service and physiotherapy practice.

3.1 Members actively engage with and reflect on the continuing professional development (CPD) process to maintain and develop their competence to practise

Criteria

3.1.1 Members assess their learning and development needs and preferences
3.1.2 Members develop and engage in a personalised plan to meet their learning and development needs
3.1.3 Members critically evaluate their learning in terms of how it relates to their current/future practice
3.1.4 Members record and evidence the outcomes of the learning process

3.2 Members offer quality CPD opportunities that help others learn and develop

Criteria

3.2.1 Members work with learner(s) to establish learning outcomes for any CPD opportunity provided
3.2.2 Members design and deliver materials/experiences that facilitate an individual's learning and development
3.2.3 Members evaluate the effectiveness of the CPD opportunity provided
3.2.4 Members critically reflect on the learning and development process

3.3 Members actively engage with supporting students' practice education and the development of their professional socialisation

Criteria

3.3.1 Members work collaboratively with colleagues, other health professions and Higher Education Institutions (HEIs) to plan and provide mechanisms, resources and activities to facilitate students' learning as an integral part of service development and delivery
3.3.2 Members actively engage with, and reflect on the CPD opportunities available to them that exist to develop their ability to support students' learning and development
3.3.3 Members strive to provide opportunities for students to learn and develop including by:
  a. ensuring that multidisciplinary working promotes understanding of the roles and the value of other professions involved in delivering high quality healthcare
  b. working collaboratively with other colleagues to ensure appropriate models of supervision
  c. critically evaluating their own learning and development needs and preferences as well as their students, in order to adapt their teaching styles appropriately
  d. sharing their own learning appropriately with other colleagues involved in supporting students, and with the students themselves
3.3.4 Members ensure consistency and transparency in the assessment of student learning

3.4 There are recognised structures, processes and resources in place that support learning and development in the workplace and enable individuals to meet the requirements of their role and meet professional and regulatory CPD requirements

Criteria

3.4.1 The development needs of the service are evaluated on an annual basis and used to inform the learning and development needs of physiotherapy team members
3.4.2 There are policies in place to ensure;
  a. that CPD policies and processes are inclusive and equitable, and implemented in ways that accommodate all members' learning and development needs
  b. Members have protected personal learning time of at least ½ day/month for informal CPD activities in addition to study leave arrangements for formal CPD and mandatory training
  c. Members have access to advice, guidance, and a variety of learning and development resources that enable the individual to implement their CPD plan.

4 Working in partnership

Quality Assurance Standards

4.1 Services are designed, planned and delivered with the aim of promoting and improving the health of individuals and the local population and decreasing health inequalities
4.2 Service users are respected as individuals and placed at the centre of service planning and physiotherapy management
4.3 Information is provided to enable service users to participate fully in their care

Introduction

To ensure effective and efficient services, at an individual or service level, physiotherapy care must be delivered in partnership with the service user(s).

Person-centred practice is an approach to health care within which the goals, expectations, preferences, capacity and needs of service users form the focus of all activity. In delivering the service consideration needs to be given to respecting and promoting diversity, that is the process of recognising, respecting and valuing people's differences (e.g. age, disability, gender, race, religion and belief, sexuality) and including this in the decision making process.

Person-centred practice includes acknowledging and understanding that, at times, the view of an individual may conflict with the view of a member, the profession or the organisation within which a service is being delivered. Consideration should also be given to the service user as an individual and the degree of involvement they would like to have in planning their care and services as this will vary according to individuals.

4.1 Services are designed, planned and delivered with the aim of promoting and improving the health of individuals and the local population and decreasing health inequalities

Criteria

4.1.1 Service users and carers are involved in the planning, development and delivery of services
4.1.2 Service development and delivery is informed by local demographic/epidemiological data
4.1.3 Processes are in place to explore the effect of rationing and other measures on the sufficiency and quality of care received by service users
4.1.4 There is a system in place for obtaining feedback from service users about existing services
4.1.5 There is evidence of action taken as a result of service users' feedback and experiences

4.2 Service users are respected as individuals and placed at the centre of service planning and physiotherapy management

Criteria

4.2.1 Service users are involved in service planning and service evaluation through service user experience surveys, focus groups and ongoing service user feedback
4.2.2 Service users are informed of the contact name of the physiotherapist responsible for their episode of care where appropriate
4.2.3 The service user's privacy and dignity is respected
4.2.4 The service user is offered a chaperone where appropriate
4.2.5 Members;
  a. demonstrate care and compassion in their interaction with service users.
  b. are courteous and considerate
  c. address the service user by the name of their choice

d. consider the service user's lifestyle, cultural beliefs and practices
e. respect and respond appropriately to an individual's lifestyle, personal and cultural beliefs and practices

4.3 Information is provided to enable service users to participate fully in their care

Criteria

4.3.1 Appropriate information is available to service users on:
a. the range of services and options of intervention available
b. arrangements for the first contact with the physiotherapist
c. access to services
d. costs of care where appropriate
e. transport and access
f. did not attend / cancellation policies
g. access to medical records
h. access to physiotherapy records
i. hazards related to clinical care
j. discharge planning
k. how to provide feedback on the physiotherapy service
l. how to make a complaint

Consent

Quality Assurance Standards

5.1 Members obtain and document the service user's informed consent before any advice, assessment, examination, intervention, treatment or procedure
5.2 Where written consent is obtained a copy of the consent record is included in the service user's records
5.3 Where a service user lacks capacity to consent for themselves the appropriate process is in place to allow a 'best interests decision' to be made under the relevant Mental Health or In/Capacity Acts(11-15)

Introduction

Consent is the voluntary agreement given by a person to allow something to happen to them and /or to allow their participation in something. It is a fundamental right that every adult with capacity has the absolute right to determine what happens to their own body and this right is protected in law. Physiotherapists should ensure that service users have the capacity to consent, give consent voluntarily without coercion, and have sufficient information on which to make this decision. Consent should be reaffirmed throughout therapeutic interaction where there are significant changes to the service user's treatment plan or condition or the service user reports new information.

Consent may be written or oral and the law does not require written consent for physiotherapy treatment. However, it is recommended that written consent is obtained for any intervention that is invasive e.g. acupuncture or injection therapy.

5.1 Members obtain and document the service user's informed consent before any advice, assessment, examination, intervention, treatment or procedure

Criteria

5.1.1 The service user's consent is obtained and documented before giving advice or beginning an assessment, examination, intervention, treatment or procedure
5.1.2 The consent process includes:
  a. consideration of the service user's age, capacity to consent, emotional state and cognitive ability,
  b. discussion of treatment options, including significant benefits, risks side effects and alternatives to proposed intervention
  c. opportunity for the service user to ask questions
  d. establishing the service user's consent or otherwise to sharing information to others directly involved in their care
  e. informing the service user of their right to decline physiotherapy at any stage
  f. specific recording in the notes when a service user declines physiotherapy, including a note as to the service user's rationale for the decision if known
  g. informing the service user that their physiotherapy may be observed or delivered by another healthcare professional/ student
  h. giving the service user the opportunity to decline observation of their physiotherapy treatment by another healthcare professional confidentially
  i. provision of written information, where possible, to assist in the consent process
5.1.3 Where written information/ leaflets are used this is documented in the notes
5.1.4 Versions of written information/ leaflets are stored in line with legislation for the retention of medical records
5.1.5 There are policies for the consent process which include;

a. induction and training in gaining consent
b. indications of appropriate situations for the delegation of the gaining of consent
c. members undertake the delegated task of gaining service user's consent only when it is appropriate to do so
d. those interventions requiring written consent forms
e. situations where the service user declines treatment by a student or support worker
f. safeguarding children
g. safeguarding vulnerable adults
h. situations where a formal assessment of capacity may need to be made by an appropriate practitioner

5.2 Where written consent is obtained, a copy of the consent record is included in the service user's records

Criteria

5.2.1 A policy is in place detailing those physiotherapy procedures where written consent is to be obtained
5.2.2 Where written consent is gained, a copy is retained in the service user's records and a copy is given to the service user

5.3 Where a service user lacks capacity to consent for themselves the appropriate process is in place to allow a 'best interests decision' to be made under the relevant Mental Health In/Capacity Acts(11-15)

Criteria

5.3.1 There are polices in place for identifying when a service user may lack the capacity to give consent for treatment themselves
5.3.2 Qualified members are aware of the process for invoking the relevant Mental Health or In/Capacity Act(11-15) where a service user lacks the capacity to give consent for themselves
5.3.3 Where consent is gained by the service user's advocate under the relevant Mental Health or In/Capacity legislation, a record is retained in the service user's records
5.3.4 Where a valid Lasting Power of Attorney (LPOA) is in place its directions are followed
5.3.5 Where there is a valid advanced directive its directions are followed

6 Record keeping and information governance

Quality Assurance Standards

6.1 Every service user who receives physiotherapy has an appropriate record
6.2 Records are stored while current and disposed of according to legal requirements
6.3 Data capture systems are designed and maintained to provide effective and secure transfer of patient identifiable information
6.4 There is evidence that regular audits of record keeping are planned, undertaken and action taken asla result

Introduction

CSP members have a professional and legal obligation to keep an accurate record of their interaction with service users in whatever system or format (paper or electronic) the organisation specifies.

A 'health record' is any record which:

- consists of information relating to the physical or mental health condition of an individual, and
- has been made by or on behalf of a health professional in connection with the care of that individual.

A record can be in paper or electronic format, or a mixture of both, and includes all the information relating to the health status and management of the individual service user. There are various types of records in practice: for example, summary/full record; shared record; uni-professional record; and service user record.

The record may contain information about the current episode of care only, or may be a compilation of every episode of care for that individual in a given time-frame. Depending on the needs of the service user, and the care setting(s) involved, the record may be maintained by an individual health care professional or a group of different professionals across the care pathway.

Members involved in recording, accessing, and storing health records must be aware of the legal context within which they work, and comply with regulatory, national, professional body and local employer guidance on record keeping.

CSP members must be aware of, and adhere to the relevant information[1] or governance framework when dealing with service user identifiable information. Audit serves as a learning process rather than merely a compliance tool, and organisations should plan and deliver audit as part of a planned audit cycle through which individuals and teams are helped to learn from mistakes, etc.

6.1 Every service user who receives physiotherapy has an appropriate record

Criteria

6.1.1 Records;

a. are started at the time of the initial contact
b. written immediately after the contact with the service user or before the end of that working day
c. include a reference in each entry to the date and time of treatment or advice
d. include a reference to the date and time that the entry into the record was made
e. are legible, factual, consistent and accurate such that service users and other health professionals can understand the content
f. are attributable to the individual completing them
g. provide evidence of the care planned, the decisions made, the care delivered and the information shared
h. identify problems that have arisen and the action taken to rectify them
i. provide evidence of actions agreed with the service user (including consent to treatment and/or consent to

disclose information)
j. are written, wherever appropriate, with the involvement of the service user
k. use standard coding techniques and protocols for electronic records where appropriate

6.1.2 Records comply with policies which include:
- *a.* a locally agreed short forms glossary
- *b.* disclosure of information
- *c.* service user access to records, including charges for viewing or receiving a copy of a health record

6.2 Records are stored while current and disposed of according to legal requirements

Criteria

6.2.1 There are policies for:
- *a.* the retention of records
- *b.* the secure storage of records while current so that they can be easily retrieved
- *c.* the secure storage of records once they are no longer current
- *d.* the disposal of records in accordance with statutory requirements
- *e.* identification of who has storage and access rights over the record
- *f.* access to records by service users and others .

6.2.2 Records are kept in accordance with relevant legal and regulatory requirements

6.2.3 The local policy is followed when the service user asks for the record.

6.2.4 There is:
- *a.* a signature book to ensure physiotherapy team members can be recognised and traced by their signature, job title and work area or other identifiable information
- *b.* information available to ensure that the service user is aware of their right to access their records
- *c.* a glossary of short forms describing the allowable abbreviations and their meaning
- *d.* a process for destroying service user records in a secure manner after the (lapse of the) required time

6.3 Data capture systems are designed and maintained to provide effective and secure transfer of patient identifiable information

Criteria

6.3.1 There is a policy for IT (Information Technology) and data security which is updated annually.

6.3.2 Systems are configured to meet information governance standards around maintaining the security and confidentiality of service user identifiable data, including encryption of emails and use of mobile/portable device.

6.3.3 Members are made aware of their responsibilities under the Data Protection Act (1998).(16)

6.3.4 Members comply with local health informatics/ IT security policies

6.4 There is evidence that regular audits of record keeping are planned, undertaken and action taken as a result

Criteria

6.4.1 Members are clear of the standards in place for governing their record keeping practice

6.4.2 Audit of record keeping is planned and undertaken annually to monitor compliance with relevant legislation and ensure best practice guidance is being upheld

6.4.3 There is evidence that the results of audit are disseminated and recommendations made for action

6.4.4 There is evidence that action is taken as a result of the outcomes of audit

7 Communication

Quality Assurance Standards

7.1 **Mechanisms exist to ensure effective communication within and outside the physiotherapy service**
7.2 **Members communicate effectively with service users to ensure effective and efficient services**
7.3 **Members communicate effectively with other health professionals and relevant outside agencies to ensure effective and efficient services**
7.4 **Members treat all information in the strictest confidence**

Introduction

Communication is the interactive process of constructing and sharing information, ideas and meaning through the use of a common system of symbols, signs and behaviours. It includes the sharing of information, advice and ideas with a range of people, using a variety of media (including spoken, non-verbal, written and e-based) and modifying this to meet service user's preferences and needs

Effective communication requires consideration of the context and nature of the information to be communicated and engagement with technology, particularly the effective and efficient use of Information and Communication Technology

Where the service user does not have capacity reference should be made to Section 5 Consent.

7.1 Mechanisms exist to ensure effective communication within and outside the physiotherapy service

Criteria

7.1.1 The organisation has
- *a.* an organisational chart available
- *b.* locally agreed systems for referral
- *c.* locally agreed processes for the provision of information for multidisciplinary assessments, planned transfers and discharges
- *d.* policies which govern the use of electronic communication to ensure it is appropriate, secure and confidential
- *e.* policies for the use of social media professionally, socially and responsibly

7.2 Members communicate effectively with service users to ensure effective and efficient services

Criteria

7.2.1 Members communicate openly and honestly with service users and consider the wishes of those who do not want themselves or other's e.g. a relative to know the diagnosis
7.2.2 Members assess the recipient's understanding of the information given
7.2.3 Members use active listening skills, providing opportunities for the service user to communicate effectively
7.2.4 The service user is aware of the role of any other member of the physiotherapy team, allied health professional, or social services staff involved in their care
7.2.5 All communication, written and oral, is clear, unambiguous and modified, where appropriate, to meet the needs of the service user
7.2.6 Methods of communication are modified to meet the needs of the service user e.g. where there is a language barrier an interpreter is used
7.2.7 Information is available on condition-specific support groups and networks
7.2.8 Where written information is provided to service users;

- *a.* a copy or reference is kept in the service user's record
- *b.* all information provided identifies the author, production date and review date
- *c.* superseded versions of information documents for service users are retained for the same length of time as health records

7.3 Members communicate effectively with other health professionals and relevant outside agencies to ensure effective and efficient services

Criteria

7.3.1 There are organisational policies in place for the;

- *a.* referral and transfer of care
- *b.* use of electronic communication to ensure appropriate information is conveyed and that such communications are secure and confidential
- *c.* delegation of treatment to outside agencies
- *d.* use of multi-professional record keeping and service user-held records

7.3.2 Members;

- *a.* are aware of lines of communication within and outside the organisation
- *b.* inform others of their own specific role
- *c.* are involved in regular team meetings/ briefings
- *d.* are represented at organisation-wide meetings where these exist
- *e.* are involved in senior management policymaking and the business planning process
- *f.* are aware of the roles of members of the multidisciplinary team
- *g.* provide information for multidisciplinary assessments, planned transfers and discharges
- *h.* ensure that the information supplied to other professionals is directly relevant to their role with the service user
- *i.* communicate with other health professionals and agencies involved in the service user's care
- *j.* communicate relevant information clearly and promptly
- *k.* agree common goals with the service user, multidisciplinary team and wider carers and family
- *l.* when delegating a task, ensure that the line of responsibility is understood and clear
- *m.* ensure that where a task has been delegated, the outcome is clearly communicated

7.4 Members treat all information in the strictest confidence

Criteria

7.4.1 Members ensure that;

- *a.* there is privacy when discussing personal details e.g. communication of a sensitive nature
- *b.* service user identifiable information is transmitted securely
- *c.* service user's information is only released to sources, other than those immediately involved in the plan for intervention, with permission or when there is a signed consent form to allow this process
- *d.* the written consent of service users is obtained before using identifiable clinical information (photographs, videos etc) for purposes other than the treatment of the patient
- *e.* where confidentiality cannot be guaranteed, the service user is informed of this fact and given the option to decline giving information
- *f.* when it is of benefit to the service user and in discussion with the service user, other healthcare workers may be given access to the physiotherapy record
- *g.* consent is sought from the service user before discussing confidential details with carers, friends or relatives

7.4.2 There are policies in place, which are followed to;

- *a.* ensure the confidentiality of service user identifiable data held, or transmitted, in electronic formats
- *b.* ensure the confidentiality of service user identifiable data seen by members but intended for other professional team members

8 Physiotherapy management and treatment

Quality Assurance Standards

8.1 **There is fair and equitable access to physiotherapy services according to need**
8.2 **There is a system to ensure that physiotherapy care is based on the best available evidence of effectiveness**
8.3 **Appropriate information relating to the service user and the presenting problem is collected**
8.4 **Analysis is undertaken following information gathering and assessment in order to formulate a treatment plan, based on the best available evidence**
8.5 **Appropriate treatment options are identified based on the best available evidence, in order to deliver effective care**
8.6 **The plan for intervention is constantly evaluated to ensure that it is effective and relevant to the service user's changing circumstances and health status**
8.7 **On completion of the treatment plan, arrangements are made for discharge or transfer of care**

Introduction

Delivering effective clinical care is a process undertaken in partnership with the service user to ensure the treatment plan is individualised to meet the individual's goals. This includes the systematic collection of information from a wide variety of sources relevant to the decision making situation; the processing and analysis of the information collected; an analysis of the intervention and reflection of the effectiveness of it; discussion with the service user to identify the most acceptable management plan and critical evaluation of the plan and its outcomes during implementation.

Where treatment or assessment highlights that a service user may lack capacity, the relevant policies should be followed.

8.1 There is fair and equitable access to physiotherapy services according to need

Criteria

8.1.1 There is evidence within the organisation of
- *a.* stakeholder engagement specifically to support the planning and design of services
- *b.* access routes to physiotherapy services being promoted to all referrers and appropriate service user groups or within appropriate service user environments
- *c.* transparent and ethical protocols governing waiting list management and the prioritisation of service users
- *d.* service features which support service user's choice; these may include for example appointment times or place of treatment
- *e.* a clearly communicated procedure for managing referrals which have not been seen within a locally agreed time-scale
- *f.* protocols that ensure effective and appropriate discharge arrangements

8.2 There is a system to ensure that physiotherapy care is based on the best available evidence of effectiveness

Criteria

8.2.1 Members;
- *a.* actively engage with the evidence base through critical appraisal of available evidence
- *b.* have access to;
  - library and library search facilities
  - internet facilities

8.2.2 There are systems in place;
- *a.* for disseminating information about effective practice
- *b.* for providing links with external agencies to identify good practice
- *c.* to demonstrate implementation of evidence-based clinical guidelines and the use of research evidence
- *d.* that support the integration of research activity within day-to-day practice
- *e.* that enable and encourage members to develop evidence and to share their research findings through appropriate channels

8.3 Appropriate information relating to the service user and the presenting problem is collected

Criteria

8.3.1 Where appropriate, standardised datasets are in use that facilitate benchmarking of data and respond to national good practice initiatives and requirements

8.3.2 There is evidence that information is collected to inform the physiotherapeutic process which, where appropriate, includes:
- *a.* the service user's demographic details
- *b.* presenting condition/problems
- *c.* history of the presenting condition including management of the problem to date
- *d.* the service user's perception of their needs
- *e.* the service user's expectations of intervention
- *f.* past medical history
- *g.* current medication/treatment
- *h.* contra-indications/precautions/allergies/red flags
- *i.* social and family history/lifestyle
- *j.* documentation and evaluation of relevant clinical investigations/results to assist the diagnosis and management process

8.3.3 There is written evidence of a physical examination carried out including measurable data which includes:
- *a.* observation
- *b.* use of specific assessment tools/techniques
- *c.* handling/palpation

8.3.4 Where the required information is missing or unavailable, the reasons are documented

8.3.5 Appropriate outcome measures are identified and implemented at assessment including, where possible and appropriate;
- *a.* one recommended condition/disease specific patient (service user) reported outcome measures (PROM)
- *b.* *one disease specific performance measure (clinical outcome measure)*
- *c.* one patient (service user) reported experience measure (PREM)

8.4 Analysis is undertaken following information gathering and assessment in order to formulate a treatment plan, based on the best available evidence

Criteria

8.4.1 There is consideration and critical evaluation of information about effective interventions relating to the presenting condition
8.4.2 There is evidence of a clinical reasoning process with identified needs/problems, formulated from the information gathered
8.4.3 A working hypothesis/diagnosis is formed, with relevant signs and symptoms recorded
8.4.4 The clinical impression is documented and discussed with the service user
8.4.5 Subjective markers are agreed with the service user
8.4.6 Objective markers are agreed with the service user
8.4.7 Analysis is undertaken following information gathering and assessment in order to formulate a plan for intervention, based on the best available evidence
8.4.8 Where there is no intervention indicated, this information is relayed to the referrer, where there is one
8.4.9 Information relating to options for intervention is identified, based on the best available evidence, in order to deliver effective care
8.4.10 The findings of the clinical assessment are explained to the service user.

8.5 Appropriate treatment options are identified, based on the best available evidence, in order to deliver effective care.

Criteria

8.5.1 Clinical reasoning is recorded that explains why a specific approach has been implemented.
8.5.2 The service user is enabled to make an informed choice about their care, based on the best available evidence on effective and appropriate interventions
8.5.3 Goals are agreed with the service user, multidisciplinary team including outside agencies and wider carers and family
8.5.4 Where clinical guidelines or local protocols are used this is recorded in the records
8.5.5 A treatment plan is included in the physiotherapy record
8.5.6 All interventions are implemented according to the treatment plan
8.5.7 Members contribute to the development of evidence by gathering information throughout the treatment of service users
8.5.8 All advice/information given to the service user is recorded, signed and dated.
8.5.9 A record is made of medical devices loaned and issued to the service user
8.5.10 When it is in the best interest of the service user a referral is made to another professional and the reasons discussed with the service user

8.6 The plan for intervention is constantly evaluated to ensure that it is effective and relevant to the service user's changing circumstances and health status

Criteria

8.6.1 At each treatment session there is a review of:
  a. the treatment plan
  b. subjective markers
  c. objective markers
  d. results of relevant investigations.
8.6.2 All relevant changes, subjective and objective, are documented.
8.6.3 Any changes to the intended plan are recorded in the record with the reasons given
8.6.4 Any changes to the treatment plan are documented

8.6.5 Outcome is measured as appropriate to each indicator to assess the effect of intervention
8.6.6 Information derived from the use of outcome measures is shared with the service user
8.6.7 Adverse and unexpected effects occurring during treatment are reported and evaluated using the relevant mechanisms

8.7 On completion of the treatment plan, arrangements are made for discharge or transfer of care

Criteria

8.7.1 The service user is involved with the arrangements for their transfer of care/discharge and offered copies of transfer or discharge summaries
8.7.2 Arrangements for the transfer of care/discharge are recorded in the record
8.7.3 When the care of a service user is transferred, information is relayed to those involved in their on-going care in the most appropriate manner and format
8.7.4 A discharge summary is sent to the referrer upon completion of the episode of care in keeping with agreed local policies
8.7.5 Where service user’s information is transferred this meets the requirements of consent, confidentiality and disclosure

9 Evaluation of clinical care and services

Quality Assurance Standards

9.1 Effective quality improvement processes are in place, which are integrated into existing organisation-wide quality programmes
9.2 There is a clinical audit programme to ensure continuous improvement of clinical quality with clear arrangements for ensuring that clinical audit monitors the implementation of clinical effectiveness
9.3 There is a clear and responsive procedure for making and dealing with complaints
9.4 The effect of the physiotherapeutic intervention and the treatment plan is evaluated to ensure that it is effective and relevant to the goals

Introduction

The process of developing and (re)designing services and improving the effectiveness, efficiency and quality of current services requires a critical evaluation of physiotherapy service delivery. This involves a cyclical process of information gathering, analysis and action.

Quality improvement processes are necessary to maintain the effectiveness, efficiency and quality of a service provided, to recognise situations where elements of the service are compromised and facilitate action to ensure improvement and learning takes place.

9.1 Effective quality improvement processes are in place, which are integrated into existing organisation-wide quality programmes.

Criteria

9.1.1 Members identify and contribute to progressing service improvements
9.1.2 There is a strategy for the implementation of clinical governance, which is linked to the organisation's overall strategy
9.1.3 There are locally agreed standards of practice for common conditions developed by multi-professional groups in order to implement national guidance
9.1.4 The physiotherapy service produces an annual clinical governance report that contributes to the organisation's overall clinical governance report
9.1.5 Members are supported to identify and contribute to service improvement processes as an integral part of the process of service improvement

9.2 There is a clinical audit programme to ensure continuous improvement of clinical quality, with clear arrangements for ensuring that clinical audit monitors \ the implementation of clinical effectiveness

Criteria

9.2.1 Members participate in a regular and systematic programme of clinical audit
9.2.2 Members participate in multi-professional clinical audit, where it is undertaken
9.2.3 The clinical audit programme takes account of service user, organisational, service and national priorities,
9.2.4 The documented results and recommendations from clinical audit are made available through the clinical governance process
9.2.5 Changes in practice are implemented as part of the clinical audit cycle, in order to rectify any deficiencies identified

9.3 There is a clear and responsive procedure for making and dealing with complaints

Criteria

9.3.1 All members understand their role within the complaints procedure.

9.3.2 There are policies in place which ensure;

- *a.* service users have access to information about the service's complaints procedure
- *b.* complaints are managed within a locally defined time-scale
- *c.* complaints are monitored in order to identify trends and to inform the process of service improvement and risk management
- *d.* complaints inform the process of service improvement

9.4 The effect of the physiotherapeutic intervention and the treatment plan is evaluated to ensure that it is effective and relevant to the goals

Criteria

9.4.1 There is a policy;

- *a.* to support members in engaging with service improvement initiatives
- *b.* for the use of service user experience surveys
- *c.* for the use of measures to evaluate clinical effectiveness

9.4.2 An appropriate measure is used to evaluate the effect of physiotherapeutic intervention(s);

- *a.* the measure chosen is published, standardised, valid, reliable and responsive
- *b.* the measure used is the most relevant to the service user's problems to evaluate the change in the service user's health status
- *c.* the measure is acceptable to the service user
- *d.* the metric is used in an appropriate way for that specific measure (possibly at the start and end of treatment and at appropriate intervals including follow up)
- *e.* members ensure they have the necessary skill and experience to use, administer and interpret the measure
- *f.* members take account of the service user's welfare during the administration of the measure
- *g.* the result of the measurement is recorded
- *h.* information derived from the evaluation and the use of the outcome measure is shared with the service user and documented
- *i.* written instructions in the manufacturer's manual, test designer's manual or service guidelines are followed during the administration and scoring of the measure if applicable

10 Promoting, marketing and advertising physiotherapy services and products

Quality Assurance Standards

10.1 **Information provided on services accurately reflects those offered**
10.2 **Information provided on products accurately reflects those offered**
10.3 **Products sold or supplied to service users are necessary in delivering effective care**
10.4 **The endorsement of a product or service is based on sound clinical reasoning, evidence, and consideration of cost and quality**

Introduction

CSP members are increasingly involved in promoting services or products to those who will use or purchase them. In doing so at all times the professionalism of the CSP member and the needs of the service user is central to this relationship. At times the CSP member may feel compromised and further guidance may be sought from the CSP as a professional body and the HCPC as a regulator.

10.1 Information provided on services accurately reflects those offered

Criteria
10.1.1 Information accurately reflects the service(s) offered and supports the decision making process
10.1.2 The promotion of services is based on evidence
10.1.3 The use of benchmarking and comparative statements is based on fact

10.2 Information provided on products accurately reflects those offered

Criteria
10.1.2 Information accurately reflects the products offered and supports the decision making process
10.1.2 The promotion of products is based on evidence
10.1.3 The use of benchmarking and comparative statements is based on fact

10.3 Products sold or supplied to service users are necessary in delivering effective care

Criteria
10.3.1 Medical devices and products sold or supplied are appropriate to the presenting condition to support the achievement of expected treatment outcomes
10.3.2. The costs, to the service user (or service), of supplying medical devices are considered
10.3.3 Where possible, service users are offered information on sourcing products and a choice in the goods recommended and the retail outlet for these goods

10.4 The endorsement of a product or service, by a member, is based on sound clinical reasoning, evidence, and consideration of cost and quality

Criteria
10.4.1 When exploring the endorsement of a product, members consider:
- *a.* the appropriateness of the product or service in respect of presenting conditions
- *b.* member's own experience of the effectiveness of the product or service
- *c.* the evidence presented by the manufacturer with regard to the stated purpose and benefits of the medical device
- *d.* a reasonable assessment of the quality and cost of the service or product

Glossary

Accountability taking responsibility for, and accepting the consequences of, a personal decision or action

Advocacy acting on behalf, and in the best interests, of an individual or group of individuals with the intention of having a positive influence on a decision or action affecting that individual or group

Associate member a support worker who has joined the CSP as a member

Autonomy the ability to make decisions and act independently

Client a person in receipt of a service; where the term uses 'individual' or 'client', this should be interpreted to include any other responsible person such as a carer, parent or guardian, as appropriate to circumstances; in the case of animal physiotherapy, the term may be interpreted to mean an animal and its owner/carer

Code of Professional Values and Behaviour or **'The Code'** The Code sets out the CSP's expectations of all members: qualified physiotherapists, associates and students

Compassion a human emotion initiated by the experiences or suffering of others and leading to a desire to alleviate their suffering

Competence the synthesis of knowledge, skills, values, behaviours and attributes that enables members to work safely, effectively and legally within their particular scope of practice at any point in time.

Consent the process by which an individual allows something to occur to themselves

Continuing professional development (CPD) a wide range of learning activities through which members' abilities are maintained and developed throughout their career to ensure the capacity to practise safely, effectively and legally within an evolving scope of practice (including, in the case of qualified, practising members, fulfilment of the CPD requirements of the Health and Care Professions Council (HCPC)) formerly Health Professions Council (HPC)

CSP Chartered Society of Physiotherapy

CSP member a person who is a member of the CSP in one of the following categories: as a qualified (chartered) physiotherapist, physiotherapy student, or associate (as a physiotherapy support worker)

CSP membership open to physiotherapists who hold registration with the Health and Care Professions Council (HCPC) and are therefore eligible to practise physiotherapy in the UK, physiotherapy students, and physiotherapy support workers; physiotherapists who have been eligible for and Care Professions registration but who have retired, are taking a career break, or who reside/work outside the UK may also be members, as may physiotherapists who practise on animals

Delegation the process through which one person allocates work to another person on the basis of deeming that individual competent to undertake that task, with the delegated individual then carrying responsibility for undertaking the delegated task

Disclosure an organisation will ask for a disclosure to ensure that necessary legal information for recruitment and placement decisions can be made especially in positions involving children & the vulnerable (i.e. Protection of Children & Protection of Vulnerable Adults). There are a number of mechanisms through which this is undertaken in the United Kingdom

- England and Wales: The criminal records bureau
- Northern Ireland: Access NI is a Criminal History Disclosure Service within the Department of Justice In Northern Ireland.
- Scotland : Scotland Protecting Vulnerable Groups (PVG) scheme www.disclosurescotland.co.uk/pvg/pvg_index.html

Dignity an individual being respected and esteemed

Duty of care the responsibility held by members to ensure that their decisions and actions are in the interests of the individuals receiving or affected by physiotherapy services that they deliver

Empowerment the process of giving someone power or authority over a decision or action

Ethics issues of correct conduct informed by moral principles

Evidence different forms of valid and relevant information that are used to underpin decision-making; and action that are often, but not exclusively, the outcome of research activity

Fairness reasonable behaviour that is motivated by a consideration of the needs of others and the delivery of services equitably

Health and Care Professions Council (HCPC) formerly the Health Professions Council (HPC) the statutory regulatory body for the allied health professions (AHPs), formed in 2002 (as the successor to the Council for Professions Supplementary to Medicine (CPSM))

A 'health record' any record which: consists of information relating to the physical or mental health condition of an individual, and has been made by or on behalf of a health professional in connection with the care of that individual

Individual a person receiving a service from a CSP member (as a patient or client, or as the carer of a patient or client), or a person who is affected by a CSP member's delivery of a service; e.g. deriving from research, education or management activity

Informed consent in the UK this is taken as meaning that the patient/ service user has been told of the 'nature and purpose of the proposed treatment, together with all significant and material risks, benefits and outcomes of the proposed treatment AND has been told of all the alternative and comparative treatments that are available for the condition being treated.'

Intervention a term used to include all aspects of service delivery, clinical care and physiotherapy management.

Leadership an act or instance of providing guidance or direction

Lone working individuals who work alone – whether on a regular or permanent basis or for a short period of time each day

Member a member of the CSP

Medical devices an instrument, apparatus or other which is intended for use in the diagnosis of disease or treatment or management of conditions.

Organisation the structure(s) within which a member undertakes his or her physiotherapy activity, within the public, private, independent and third sectors

Person-centred practice putting the person at the centre of practice describes the behaviour, knowledge and skills required to: demonstrate respect for the individual; provide information and support that enables an individual to make informed choices; involve individuals in shaping the design and delivery of their service

Physiotherapy service the physiotherapy service delivered to the service user including advice, assessment, examination, intervention, treatment or procedure at an individual, group or organisational level.

Physiotherapy practice the practical (psycho-motor) skills used by the physiotherapy workforce. These include manual therapy, electro-physical modalities and other physical approaches. As with physiotherapy knowledge, an individual's skill-base will evolve according to their experiences and context of practice, but individual's must demonstrate how their skills relate to physiotherapy and their personal scope of practice

PREM Patient reported experience measure

Professional autonomy the application of the principle of autonomy whereby a Member makes decisions and acts independently within a professional context and is responsible and accountable for these decisions and actions

Professionalism defines what is expected of a professional, and what it means to be professional. Broadly, it can be summarised as; A motivation to deliver a service to others, Adherence to a moral and ethical code of practice, Striving for excellence, maintaining an awareness of limitations and scope of practice and A commitment to empowering others (rather than seeking to protect professional knowledge and skills)

PROMS Patient reported outcome measures

Quality Assurance the process by which services or care are monitored to ensure that mandatory standards are being met

Record a physiotherapy record is a health record. That is any record which: (a) consists of information relating to the physical or mental health or condition of an individual, and (b) has been made by or on behalf of a health professional in connection with the care of that individual. A record can be in paper or electronic format, or a mixture of both, and includes all the information relating to the health status and management of the individual service user. The record may contain information about the current episode of care only, or may be a compilation of every episode of care for that individual in a given timeframe. There are various types of records in practice; for example, summary/full record; shared record; uni-professional record; and patient-held record. Depending on the needs of the patient, and the care setting(s) involved, the record may be maintained by the CSP member or a group of different professionals across the care pathway.

Referral when one health professional asks another health professional to take over the care of the service user

Risk Assessment a logical process of identifying hazards and putting in place sensible measures to prevent or control them

Reasoning the ability to make logical inferences from available information

Service user an individual or individuals in receipt of a service from a member to include patients, clients, carers and others.

Scope of practice the scope of practice of physiotherapy is defined as any activity undertaken by an individual physiotherapist that may be situated within the four pillars of physiotherapy practice where the individual is educated, trained and competent to perform that activity

Support worker anyone in a direct or indirect clinical support role. They are not subject to professional registration

Valid consent an individual being in receipt of sufficient knowledge of all relevant facts and factors to agree to, or refuse, a particular course of action

Value the importance or worth of something (an outcome, intervention or service) for an individual

Values ideals that individuals or a profession find morally compelling

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Annex 1

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Thank-you for all those who coordinated the focus groups (named below) and to those who contributed to the development of the QA Standards through attendance at the focus groups.

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Annex 2

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Code of Members' Professional Values and Behaviour

2019

The purpose of the Code

The Code defines the professional values and behaviour that the CSP expects of ALL of its members. The Code applies to all roles in all membership categories, sectors and settings and at all career stages. It reinforces the imperative that members adhere to the law, regulatory requirements and the requirements of their employing organisations and education institutions. The Code promotes professionalism and supports members in taking responsibility for their decision-making and actions and fulfilling their duty of care to individuals with whom they interact, in their physiotherapy roles. Members agree to adhere to the Code in choosing to take up membership of the CSP (in all membership categories).

The Code's underpinning ethics, values and concepts

The Code's four principles are underpinned by contemporary healthcare ethics and by professional values and concepts derived from these. These are summarised in Table A at the end of the document.

Principle 1.

CSP members take responsibility for their actions

1.1 Members are responsible and accountable

Members

1.1.1 Exercise professional autonomy appropriate to their role, recognising the responsibilities and accountability that this carries

1.1.2 Recognise and respect the autonomy of individuals and service users

1.1.3 Act on their duty of care and duty of candour, raising concerns when situations could cause harm or distress, and being open about when things go wrong

1.1.4 Engage with quality assurance, clinical governance and service improvement processes to uphold safe, effective practice

1.1.5 Are responsible and accountable for their decisions and actions, including when they delegate activity to others

1.1.6 Justify and account for their decisions and actions, including decisions not to act

1.1.7 Ensure their physiotherapy activity has appropriate indemnity cover

1.1.8 Hold the appropriate registrations to practise e.g. annotations to HCPC registration for prescribers.

1.2 Members act within their scope of practice

Members

1.2.1 Limit their physiotherapy activity to those areas in which they can demonstrate current education, training and competence

1.2.2 Delegate and refer to others appropriately, ensuring delegated activities are

  a) Within the other person's scope of practice, with the parameters of the delegated activity being clear

  b) Appropriately supervised and supported to provide safe, effective, person-centred care

  c) Kept under review to maintain the quality of service delivery and identify how the nature of delegated activity could appropriately be extended

1.2.3 Act appropriately on delegated activities or referrals received

1.2.4 Undertake continuing professional development (CPD) to establish, maintain and develop their competence

1.2.5 Understand and be able to explain how their individual scope of practice sits within the scope of physiotherapy practice in the UK

1.2.6 Recognise that their individual scope of practice will evolve and must be supported by appropriate CPD

1.2.7 Take account of population health, service and workforce needs in how they develop their competence, scope of practice and role.

1.3 Members make informed decisions

Members

1.3.1 Exercise sound professional judgment in their physiotherapy activity

1.3.2 Can explain how their professional judgement and decisions are informed by the profession's evolving evidence base

1.3.3 Use available information and evidence to assess risk and make decisions

1.3.4 Evaluate the impact of their decisions and use their reflections and learning to inform their subsequent approach to physiotherapy activity.

Principle 2.

CSP members behave ethically

2.1 Members adhere to legal, regulatory and ethical requirements

Members

2.1.1 Adhere to all legal, regulatory, ethical and organisational requirements relevant to their physiotherapy activity (including requirements relating to General Data Protection Regulations [GDPR], equality and research)

2.1.2 Ensure confidential information created, obtained or received through their physiotherapy activity remains secure

2.1.3 Comply with local clinical governance and quality assurance processes in how they engage in physiotherapy activity and contribute to service delivery

2.1.4 Can explain, justify and reflect on their response to ethical issues, including specific decisions and actions that they take.

2.2 Members act with integrity, honesty, respect and openness

Members

2.2.1 Understand and manage the impact of their own beliefs, values and behaviours, including in their interaction with others

2.2.2 Are open and candid about all aspects of their service delivery, including when things go wrong

2.2.3 Act to facilitate an appropriate investigation if they need to raise concerns about service delivery or individuals' care

2.2.4 Use their professional judgment when endorsing, advertising, supplying or selling particular services or products

2.2.5 Provide truthful, honest and accurate information, including when advertising or promoting services

2.2.6 Disclose any financial benefit that they expect to receive through endorsement or advertising services

2.2.7 Declare any conflict of interest in their physiotherapy activity

2.2.8 Recognise the potential impact of their personal behaviour, life-style, and activities outside work (including social media use) on their physiotherapy role.

2.3 Members fulfil their responsibilities within relevant professional and social contexts

Members

2.3.1 Strive to challenge and address health inequalities in how services are delivered

2.3.2 Contribute to the health of individuals and population groups, including through engaging in health promotion and illness and injury prevention

2.3.3 Adhere to ethical business practices

2.3.4 Recognise their role as an advocate for the physiotherapy profession

2.3.5 Recognise the potential impact of their personal behaviour, life-style and activity on the reputation of the physiotherapy profession

2.3.6 Uphold their professional responsibilities in how they communicate both in a professional and personal capacity

2.3.7 Optimise use of digital technologies to enable the delivery of accessible, timely care, in line with individuals' needs and preferences

2.3.8 Deliver services within available resources, being clear when the care of individuals could be compromised by insufficient resources.

Principle 3.
CSP members deliver an effective service

3.1 Members put individuals at the centre of what they do

Members

3.1.1 Seek to understand and take account of individuals' specific needs, preferences, expectations and goals in providing a service to them

3.1.2 Advocate for individuals' quality of care and safety and raise concerns if there is a risk of individuals' care being compromised

3.1.3 Seek to understand individuals' situations and circumstances and the significance of these factors for how individuals engage with physiotherapy activity

3.1.4 Respond to individuals compassionately and sensitively, being aware of individuals' vulnerability in the context of their receipt of healthcare

3.1.5 Respect individuals' rights, dignity, cultural differences, beliefs and identity in seeking to act in an individuals' best interests

3.1.6 Behave in non-discriminatory, non-oppressive ways.

3.2 Members respect and promote individuals' autonomy

Members

3.2.1 Promote and uphold individuals' rights and choices, including their right not to consent to options available to them

3.2.2 Share all relevant information to support individuals to make decisions, including issues of risk and consent

3.2.3 Enable individuals to give valid consent to any decision or action affecting them

3.2.4 Share their knowledge and skills with individuals and colleagues to inform decision-making, planning, goal-setting and evaluation

3.2.5 Enable and support individuals to self-manage in ways that are relevant and responsive to individual needs and priorities.

3.3 Members communicate effectively

Members

3.3.1 Use appropriate methods to ensure effective communication with others

3.3.2 Adapt their communication approach according to individuals' communication needs, preferences and expectations

3.3.3 Provide full, accurate and truthful information about the services that they deliver, including the outcomes of physiotherapy activity

3.3.4 Consult with colleagues and share information appropriately, respecting confidentiality, in line with individuals' interests and needs.

3.4 Members work effectively with others

Members

3.4.1 Engage and collaborate with colleagues within and across settings, sectors and professions in the best interests of service users

3.4.2 Respect colleagues' perspectives and contribution to service delivery

3.4.3 Promote a safe, positive and healthy working environment

3.4.4 Support and enable others to practise within their individual scope of practice

3.4.5 Use all available information and evidence sources to assess risk, to themselves and others, and take appropriate action if they have cause for concern.

Principle 4.

CSP members strive to achieve excellence

4.1 Members contribute to continuous improvement

Members

4.1.1 Maintain, promote and support high standards of physiotherapy practice in how they perform their physiotherapy role and activity

4.1.2 Engage in data collection, audit and service evaluation to demonstrate the value and impact of service delivery, in order to identify any need for service improvement

4.1.3 Consider the relevance of new developments, research findings, evidence and measures of effectiveness, applying them appropriately to their physiotherapy activity and service delivery

4.1.4 Critically reflect upon and evaluate their own practice

4.1.5 Engage in career-long learning, identifying their own development needs and taking appropriate action to address these

4.1.6 Maintain and develop their knowledge, understanding and skills in response to individual, service and practice needs.

4.2 Members demonstrate innovation and leadership

Members

4.2.1 Apply their knowledge and skills to different situations and settings, taking account of the relevance and value of this within service improvement and meeting individual needs

4.2.2 Respond appropriately to new and changing needs within the scope of UK physiotherapy practice

4.2.3 Question, articulate and demonstrate the value and impact of their care

4.2.4 Demonstrate leadership through their contribution to service improvement and delivery.

4.3 Members support others' learning and development

Members

4.3.1 Contribute to creating and maintaining a learning culture and to meeting the identified learning needs of individuals and groups

4.3.2 Share their own learning with others, including reflections and evidence of its value and impact

4.3.3 Recognise the value of contributing to others' learning for their own development.

4.4 Members contribute to the development of physiotherapy practice

Members

4.4.1 Contribute to developing physiotherapy through building the evidence base of physiotherapy practice and implementing new evidence, to meet changing needs

4.4.2 Recognise and take appropriate action where plans for personal practice could push the boundaries of physiotherapy scope of practice

4.4.3 Engage with factors impacting on physiotherapy's responsiveness to changing needs and the implications of these factors for their own practice, service delivery and development

4.4.4 Respond to developments in research and the evidence base that may raise questions about the safety or efficacy of specific elements of physiotherapy practice

4.4.5 Engage with developments in research and the evidence base that present new clinically and cost-effective ways to respond to individuals' needs

4.4.6 Contribute to identifying evidence gaps and priorities for research in order to build the evidence base for physiotherapy's value and impact for meeting population and individual healthcare needs.

Table A: Underpinning ethics, values and concepts

Underpinning ethics	Underpinning values	Core professional concepts
Respect for individual autonomy Promoting what is best for an individual Avoiding harm Fairness in how services are delivered	Altruism, in terms of giving priority to the interests of individuals Advocacy Honesty and integrity Compassion and caring Accountability for decision-making and actions Fulfilment of duty of care and social responsibility Commitment to excellence	Competence Professional autonomy Professionalism Scope of practice

Code
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THE CHARTERED SOCIETY OF PHYSIOTHERAPY
is the professional, educational and trade union body for the United Kingdom's 58,000 chartered physiotherapists, physiotherapy students and support workers.

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SO YOUR NEXT PATIENT HAS A LEARNING DISABILITY?

A GUIDE FOR PHYSIOS NOT SPECIALISING IN LEARNING DISABILITIES

A learning disability is a significant, lifelong condition that started before adulthood, that affected the person's development and which means they need help to understand new or complex information, learn new skills and cope independently.*

*The Same as You, 2000; Valuing People, 2001

The majority of people with a learning disability can successfully access mainstream physiotherapy services when reasonable adjustments are made.

Planning and preparation for your appointment

A person with a learning disability has individual needs like everyone else, however, the following suggestions may be helpful when preparing for your appointment.

Try to find out in advance

- Relevant medical history - they might not be able to remember or explain all the details you need
- Information relating to the particular condition or syndrome they may have
- If the person has a Health Action Plan, Health Passport or communication passport and request a copy
- If the person has specific likes or dislikes, which may affect the appointment

Appointment planning

- If possible consider the location of the appointment, and where the person is most likely to be relaxed and comfortable. For community visits try to choose a location which limits disruption to the person's routine. In a clinic setting choose a separate quiet room to reduce distractions; curtained cubicles are not ideal.
- Provide longer appointments so that you can take your time with the person and avoid rushing them. Alternatively, if you are aware that someone has a short attention span, it may be better to offer several short appointments.
- Some people with learning disabilities may be unable to read. Consider arranging appointments via telephone and back this up with a letter, using an accessible format.
- Where appropriate ask for a carer who knows the person well to attend with them.
- Check whether the person needs specialist equipment for the appointment (e.g. hoist).
- If your location is difficult to find offer to meet them at front door.

Don't forget about consent!

Many people with learning disabilities are able to give consent to treatment, however, some may not. Assume a person has capacity to give consent until an assessment indicates otherwise.

Remember

- A capacity assessment is not a blanket decision, it relates to a specified task/activity.
- A person can have capacity for one decision and not for another.
- Capacity can fluctuate – it may be necessary to review the decision or wait until capacity returns.

Where someone is unable to give informed consent, you will need to adhere to the Mental Capacity Act 2005 or the Adults with Incapacity (Scotland) Act 2000, depending on your location. You should also refer to your own organisational policies for further guidance.

How to get the best outcome from your appointment

Time Start your appointment on time. Many people with a Learning Disability don't understand the concept of waiting and may find waiting areas stressful.

Environment Consider the environment. Minimise sensory stimulation, limit the likelihood of interruption and remove unnecessary equipment. Enclosed and noisy waiting rooms, and the smell of clinical environments may be unsettling for some people. A number of short pre-visits might help them relax.

Communication

- Think about how you will speak to the person. Use short sentences, avoiding using abstract ideas and jargon. Using words the person is familiar with can help to get ideas across more effectively.
- Always talk directly to the person using their chosen name, even if they are unable to answer. Include the carer in the discussion to confirm information and advice. A good balance of involving both is needed.

Flexibility Be prepared to work from the person's perspective. A flexible and relaxed approach is essential. Encourage the person to look at and touch equipment, as appropriate.

Assessment Think about your assessment from a practical point of view. Plan the order of your assessment to minimise frequent positional changes.

Functional and fun

- If you want to observe their movement ask the person to perform functional activities that make sense, or make the task fun and relevant to their interests. Be creative! Dance, music, iPads, puzzles are just a few examples that could be effective.
- Use imitation and role modelling; asking them to copy you or including their carer in demonstrations can be a good strategy.

Making communication work Use visual aids to explain what you want the person to do and what will happen. Pictures, photographs, symbols and video can be helpful. If you need to give them information to take home try to make it accessible, and refer to their communication passport if available.

Difficult behaviour Difficult behaviour is not part of having a learning disability. It can often be someone's way of communicating information. Use your assessment, carers advice and specialist tools, such as DisDAT, to rule out potential physical causes before assuming these are behavioural issues.

Lack of success If your appointment doesn't go to plan don't despair, just stop the session and schedule a follow up. Continuing with a negative experience may make future sessions more difficult. Discuss this with the carer and think about alternative approaches you could use next time.

CHARTERED
SOCIETY
OF
PHYSIOTHERAPY

The professional, educational and trade union body for the United Kingdom's 54,000 chartered physiotherapists, physiotherapy students and support workers.

Who can help?

Your local Community Learning Disability Team (CLDT) should have a specialist physiotherapist who provides specialist support to people with a learning disability who are unable to cope in mainstream physiotherapy services. They will be happy to discuss any concerns you may have and will be able to give you further advice on working with people with learning disabilities.

Further advice and information

http://acppld.csp.org.uk
www.enable.org.uk
http://mencap.org.uk
www.pamis.org.uk
www.pmldnetwork.org
www.pcpld.org
www.easyhealth.org.uk
www.downs-syndrome.org.uk
www.knowledge.scot.nhs.uk/learningdisabilities
www.bild.org.uk
www.cafamily.org.uk

This leaflet was written by the ACPPLD - April 2016.

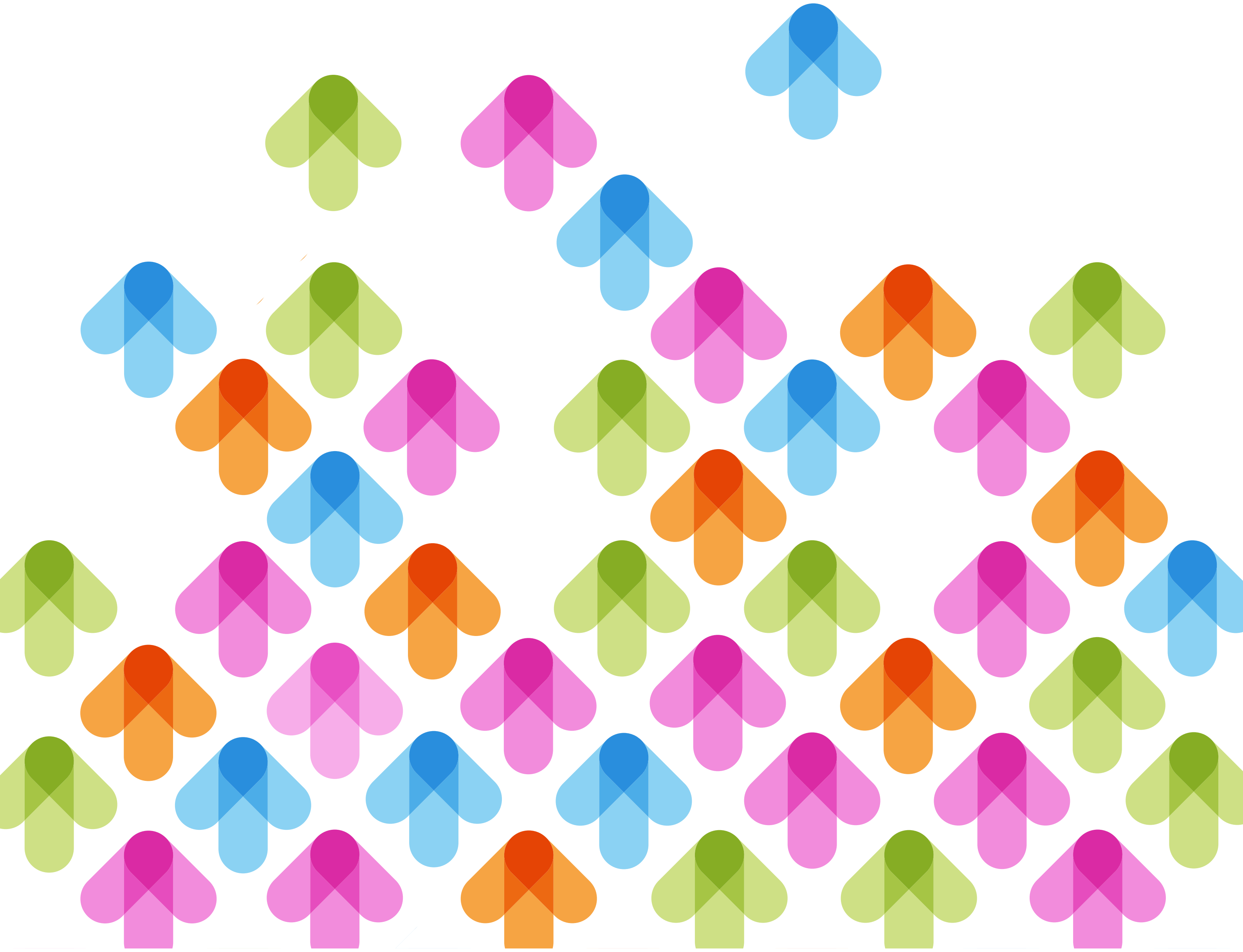
ASSOCIATION OF CHARTERED PHYSIOTHERAPISTS FOR PEOPLE WITH LEARNING DISABILITIES
ACPPLD

001342 SPED 5/2016 5k

Standards of Practice for Physiotherapists

Working with adults with a learning disability

Sarah Bruce & David Standley



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Introduction

Adults with a learning disability experience poorer health than the general population.

(Emerson et al. 2010).

They have a shorter life expectancy and are at greater risk of premature death.

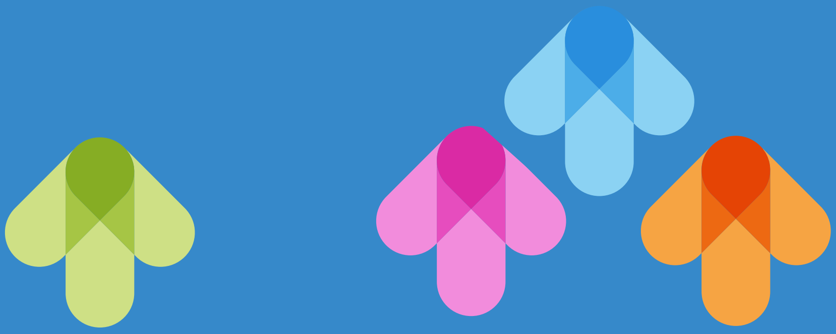
(Hollins et al. 1998; Heslop et al. 2013).

Adults with a learning disability have the same rights to access mainstream health services as the general population but may require reasonable adjustments to facilitate positive access and outcomes.

(Equality Act 2010).

However, they regularly receive inadequate health care.

(Mencap 2004, 2007 and 2012; Michael and Richardson 2008; Department of Health 2009; Heslop et al. 2013).



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Introduction

There are a number of potential barriers to adults with a learning disability successfully accessing mainstream health care. All public services, including the health sector have a legal obligation to make reasonable adjustments to overcome these barriers. Specialist learning disability health professionals have an important role to play in supporting the health and wellbeing of people with a learning disability. They are required to both support mainstream practice and directly serve those with the most complex needs (Department of Health 2000 and 2009; RCGP 2013; Learning Disability Professional Senate 2015). Specialist learning disability teams should be delivering person centred services within the community that respect and promote the rights of people with a learning disability as full citizens. To do this, there needs to be in place good commissioning, a competent workforce and a robust system to check quality and outcomes (Moore and Thorley 2011).

It is estimated that there are around 1.4 million people in the United Kingdom (UK) who have a learning disability (Mencap n.d.). Adults with a learning disability are likely to require access to physiotherapy at some point over their lifetime. There are a number of factors that predispose them to developing physiotherapy related problems. These include associated physical impairments and conditions, premature aging, increased risk of injuries and falls, poor health literacy, and leading sedentary and unhealthy lifestyles. Many people will be able to access mainstream services with reasonable adjustments (ACPPLD 2016). However, some people will require adjustments that go beyond what is reasonable and will require access to specialist learning disability physiotherapy to achieve successful outcomes.

One group of adults with a learning disability that are very likely to require regular life-long access to specialist physiotherapy are people with a complex physical disability, such as individual's with severe cerebral palsy and profound and multiple learning disabilities (PMLD). Research conducted by the Centre for Disability (2009) estimated that in an 'average' area in England with a population of 250,000 the number of adults with PMLD needing health and social care services will rise by 1.8% per year from 78 in 2009 to 105 in 2026; and the number of young people with PMLD becoming adults in any given year will rise from 3 in 2009 to 5 in 2026. This growth is attributed to more young people surviving into adulthood and an increase in life expectancy due to improvements in medical care. Although this is a relatively small increase, this population of people are among the most disabled and vulnerable individuals in our community (Mansell 2010) and are likely to require intensive access to specialist learning disability physiotherapy services to manage their health needs throughout their lives.

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Without a clear definition and national standards, specialist learning disability physiotherapy services have evolved guided by local priorities and pressures, dependent on local commissioning. This has led to individuals and local teams developing their own standards, resulting in wide variations in the commissioning and delivery of services across the UK. The researchers have anecdotal evidence and received feedback from specialist learning disability physiotherapists across the UK that highlighted a number of concerning emerging themes relating to individual specialist learning disability physiotherapists and physiotherapy services.

These include:

- Poor understanding of the role of physiotherapy for adults with a learning disability, especially amongst commissioners; service managers and policy makers.
- Specialist physiotherapy posts being downgraded and, in some areas, completely decommissioned.
- Physiotherapists being asked to take on roles that are outside of their scope of practice and divert them from their primary roles.
- Limited access to adequate supervision with a suitably qualified and experienced clinician.
- A lack of standards regarding the training and education that specialist learning disability physiotherapists require to become competent professionals.
- A paucity of skilled and experienced specialist learning disability physiotherapists in positions of management and influence to advocate the need for commissioning and retention of specialist physiotherapy posts.
- Published research, local evidence and wider anecdotal information indicates an increase in the numbers of adults with a learning disability who have complex health needs who require specialist 24 hour postural management.

In response, the researcher's conducted a five round Modified Delphi Technique study to develop a definition and standards of practice for specialist learning disability physiotherapists. This involved a systematic review of the current literature pool and four rounds of questionnaires to explore the views and opinions of an expert panel recruited via the Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD).

Research Methodology and Results

Literature review

The results of the research have led to the development of the 'standards of practice' which aim to:

- enhance specialist learning disability physiotherapists in their everyday clinical practice through supporting clinical reasoning and evidence based arguments;
- to provide support and evidence for specialist learning disability physiotherapists to influence service leads, managers and commissioners to improve, standardise and shape the delivery, development and commissioning of services across the UK; and
- raise awareness of the role of the specialist learning disability physiotherapist to commissioners, service managers, the multidisciplinary team and mainstream health and social care professionals.

> *It is the researcher's belief that proactive specialist learning disability physiotherapy can deliver high-quality cost-effective interventions that are person centred and needs led.*

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Standards of practice

Physiotherapists must meet the standards of proficiency to become registered with the Health and Care Professions Council (HCPC) (HCPC 2018). The HCPC, regulates the physiotherapy profession and clinicians must work within the standards in order to maintain their registration to practice. As an autonomous professional, the physiotherapist needs to make informed, reasoned decisions about their practice. This includes seeking advice and support from education providers, employers, colleagues, professional bodies, unions and others to ensure that the wellbeing of service users is always safeguarded.

The HCPC recognises the role played by the Chartered Society of Physiotherapy (CSP), in providing guidance and advice about good practice that help physiotherapists meet the HCPC standards. There are more than thirty physiotherapy professional networks that are self-governing bodies responsible for providing the clinical leadership for their specialism, as well as managing their own financial and organisational liabilities.

The Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD) is the professional network for specialist learning disability physiotherapists. The group aims to provide a platform for information update and exchange; national networking; support; promotion of evidence-based practice and research; and to improve the awareness of the rights and needs of people with a learning disability. The authors have worked in collaboration with members of the ACPPLD to develop the standards of practice.

The standards of practice and definition of the specialist learning disability physiotherapist detailed within this document were derived through analysis of the available evidence and expert opinion of experienced specialist learning disability physiotherapists. They are systematically developed statements about the role of the specialist learning disability physiotherapist. The statements are not a mandate for practice but assist service development, delivery and commissioning; and clinical reasoning about appropriate health care for specific circumstances. Regardless of the strength of the evidence on which the recommendations are made, it is the responsibility of the individual clinician and service to interpret their application for each situation, taking account of the individual needs, preferences and values of service users, as well as the local context.

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Definition of a learning disability

> *"Adults with a learning disability are people first, who should be valued and respected for their differences. They have the same rights as any other citizen."*

(Joint committee of Human Rights 2008 – Life like any other)

For the purposes of this standards of practice document the term 'learning disability' will be adopted throughout. People can often find the term learning disability confusing because there are many different definitions and terms which are used interchangeably. In the UK, the most common definition for learning disability is from Valuing People: a new strategy for learning disability for the 21st century. This government White Paper for England about health and social care support for people with a learning disability (Department of Health 2001) states that a learning disability includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence); with
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with lasting effect on development.

It is internationally recognised that three criteria must be met before a learning disability can be identified or diagnosed.

1. Intellectual impairment (Intellectual quota (IQ) <70)
2. Social or adaptive dysfunction combined with IQ <70
3. Early onset.

Learning disability; intellectual disability or learning difficulty

The words we use to describe a particular impairment or disability change as a result of listening to people with personal experience; and as a result of changing values and attitudes in society. There have been many different terms used to describe a person with a learning disability from mental sub-normality, mental retardation, mental handicap and to eventually, in the 1990's, learning disability.

The same words can have different meanings in different countries. Although we share a common language with countries such as America and Australia the words we use to describe particular disabilities related to learning are different. An increasing number of international organisations and countries such as the USA, Canada and Australia use the term 'intellectual disability'. This term has also been used in Professor Mansell's report on services for people with severe and profound learning disabilities (Mansell 2010).

Another term that is frequently used is 'learning difficulty'. The terms 'learning difficulty' and 'learning disability' are often confused, or even used interchangeably. It is important to understand that in the education system in the UK, the term learning difficulty relates to specific conditions such as dyslexia, dyspraxia, developmental co-ordination disorder, dyscalculia and attention deficit hyperactivity disorder (ADHD). Unlike a learning disability, these conditions do not affect general intelligence (IQ).

As a child develops and their learning needs become acknowledged, there is no formal process for diagnosing a learning disability. This can cause challenges for young people and services as they transition into adult services. In the UK, adults with a learning disability should have their

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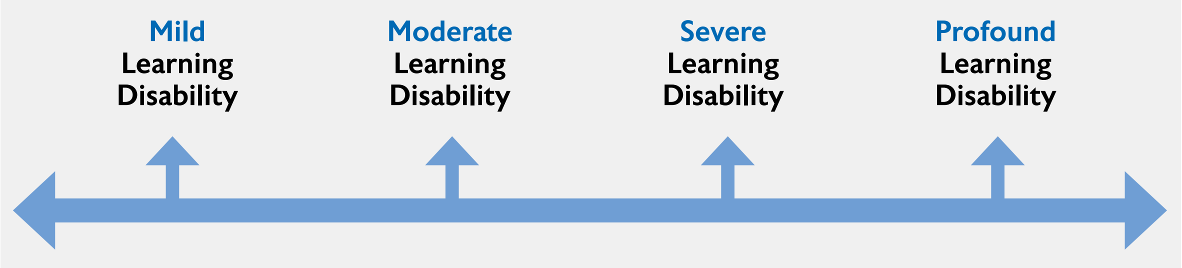
diagnosis coded on the general practitioner register. Unfortunately, due to the confusion around the terminology they are not always accurate resulting in most adult services requiring some form of eligibility pathway.

The term learning disability is used to describe a varied group of individuals from those requiring a high level of support to those who only need support in a few areas. The UK categorises people with a learning disability in relation to their needs or level of cognition. Degrees of learning disability are conventionally estimated by standardised intelligence tests which can be supplemented by scales assessing social adaptation in a given environment. These measures provide an approximate indication of the degree of learning disability. In an attempt to explain the wide range of different abilities the British Institute of Learning Disabilities (n.d.) adopt the idea of a continuum of learning (Figure 1).

Figure 1: The continuum of learning disability



Mild:	People with an IQ score of 50-70. Many people with a mild learning disability will be able to work and maintain good social relationships. They may require support to understand complex ideas.
Moderate:	People with an IQ score of 35-50. People with a moderate learning disability can communicate their day-to-day needs and wishes. They may need some assistance and guidance with their personal care and may require longer time to learn new skills.
Severe:	People with an IQ score of 20-35. They often use basic words and gestures to communicate their needs. They may need a high level of support with activities of daily living. Some may have additional medical needs and require more support with mobility.
Profound:	A person with a profound learning disability will have an IQ score under 20, with severely limited understanding.

The definitions of the different categories of the continuum of a learning disability are not rigid. For example, some people who have a complex physical disability and multiple health needs who require full support for all daily living activities may have an IQ in the 'mild' range. Therefore, it is important to always see the person first; not make assumptions about a person's cognitive and functional abilities; and adapt communication and intervention to that person's individual needs.

Causes of a learning disability

There are many factors that may cause a person to have a learning disability. A learning disability occurs when a person's brain development is affected. A child may be diagnosed at birth, or during early childhood. But for some people it may be many years before they receive a diagnosis, while others may never receive a diagnosis at all.

The causes of a learning disability include genetic factors, infections and brain injury or damage.

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For many who are diagnosed with having a learning disability the cause remains unknown. There are three critical events where a learning disability could become present:

1. Before birth

Chromosomal conditions

Chromosomes make up the genetic blueprint for humans. Everyone has 23 pairs of chromosomes in their cells. Abnormality in chromosomes can result in a learning disability. For example, conditions such as Down's syndrome, Fragile-X syndrome, Williams syndrome, Wolf-Hirschhorn syndrome and Prader-Willi syndrome have a high prevalence of an associated learning disability.

Maternal factors

Infections such as cytomegalovirus, toxoplasmosis and rubella may be passed on to the unborn child and may lead to a learning disability. Other maternal factors that can cause a learning disability include diet deficiencies and excessive consumption of alcohol (foetal alcohol syndrome) during pregnancy.

Metabolic disorders

A person's metabolism controls all the chemical reactions in the body. Certain conditions affecting metabolism can result in a learning disability. For example, phenylketonuria (PKU) is a rare but potentially serious inherited disorder that increases the levels of an amino acid called phenylalanine. People with PKU can't break down phenylalanine which then builds up in the blood and brain. This can lead to brain damage and a learning disability.

2. During birth

Oxygen deprivation is a significant risk for babies during the labour and delivery process. Lack of oxygen at birth can have long-term effects for the infant and can cause long-term disabilities, developmental delays and a learning disability.

3. After birth

Some childhood illnesses and infections such as encephalitis and meningitis can cause a learning disability. Neurological events such as stroke, traumatic brain injury and haemorrhage can also cause a learning disability. Social and environmental factors, such as poor housing conditions, poor diet and health care, malnutrition, lack of stimulation and all forms of child abuse may also lead to learning disability.

Numbers of people with a learning disability

It is estimated that there are around 1.4 million people in the UK who have a learning disability (Mencap n.d.). The number of adults with a learning disability known to Clinical Commissioning Groups in England; Health and Social Care Trusts in Northern Ireland; National Health Service (NHS) boards in Scotland; and local authorities in Wales are significantly less (Northern Ireland Assembly 2014; Public Health England 2016; Scotland Commission for Learning Disability 2017; Welsh Government 2018). The data used in this document to reference the numbers of people with a learning disability is related to England. The researchers acknowledge that the population numbers will vary in Northern Ireland, Scotland and Wales but the trends described are likely to be similar and thus should not detract from the application of the Standards of Practice in these countries.

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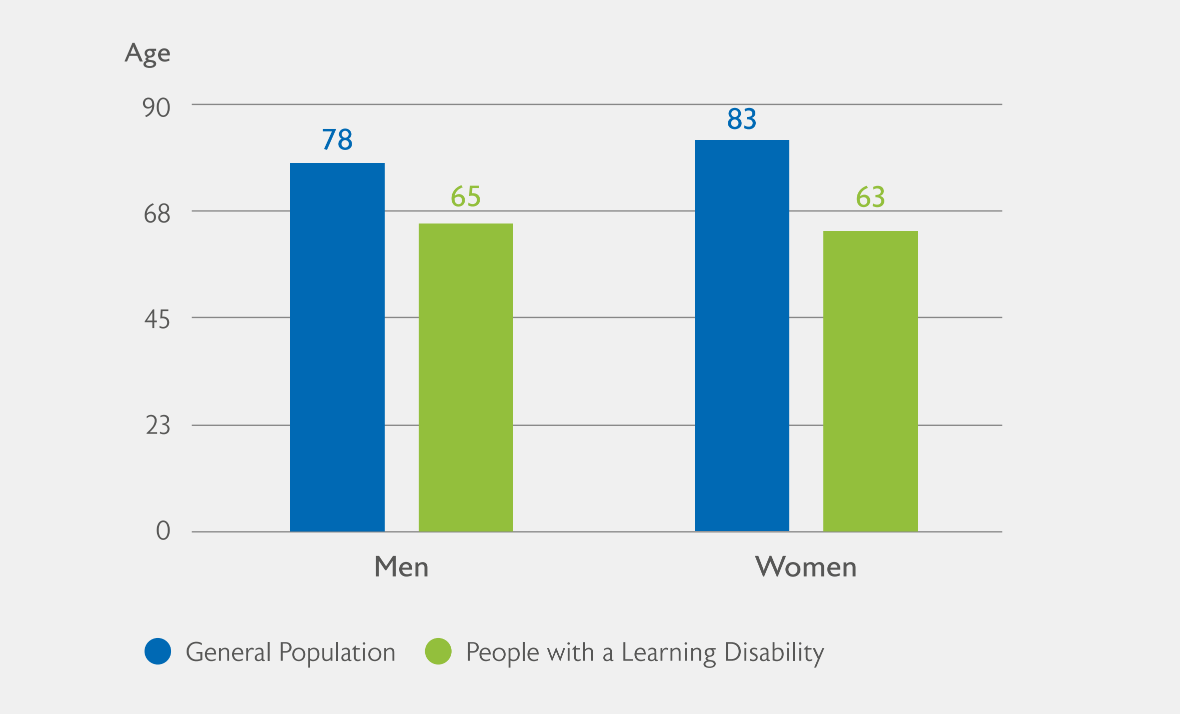
Public Health England recognises that there is no definitive record of the number of people with a learning disability in England. As a result, population estimates are made using particular services, overall population predictions for England and the results of epidemiological research (Public Health England 2016).

In 2016-17, 0.46% people were recorded by clinical commissioning groups as having a learning disability (NHS Digital 2017). However, the prevalence of a learning disability is estimated to be 2.16% of the English adult population (Public Health England 2016a). The number of people with a learning disability are expected to rise steadily. Emerson and Hatton (2008) recognise that it is not possible to accurately determine whether the numbers of people with a learning disability are changing and by how much. However, they acknowledge that several factors are likely to result in the growth of this population. These include the future size and composition of the English population; potential changes in the incidence and prevalence of a learning disability; the increase in proportion of younger English adults who belong to South Asian minority ethnic communities; an increase in survival rates among young people with severe and complex disabilities; and reduced mortality among older adults with a learning disability.

Health outcomes

Adults with a learning disability have higher morbidity rates than the general population. They have higher incidence of cancer, coronary heart disease, respiratory disease, diabetes, reflux, and constipation (Emerson and Baines 2011). Many people have multiple health problems and long-term conditions. As a result, people with a learning disability often die younger. The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) found that 42% of the 247 deaths reviewed were premature. On average men die 13 years younger than the general population and women 20 years (Figure 2). The average age of death of people with PMLD was significantly lower at 41. Life expectancy was linked to severity of learning disability and the number of multi-morbidities. The most common reasons for these findings were delays or problems with diagnosis or treatment; difficulties with identifying needs; and challenges in providing appropriate care in response to changing needs (Heslop et al. 2013).

Figure 2: Life expectancy of people with a learning disability vs. general population (Heslop et al. 2013)



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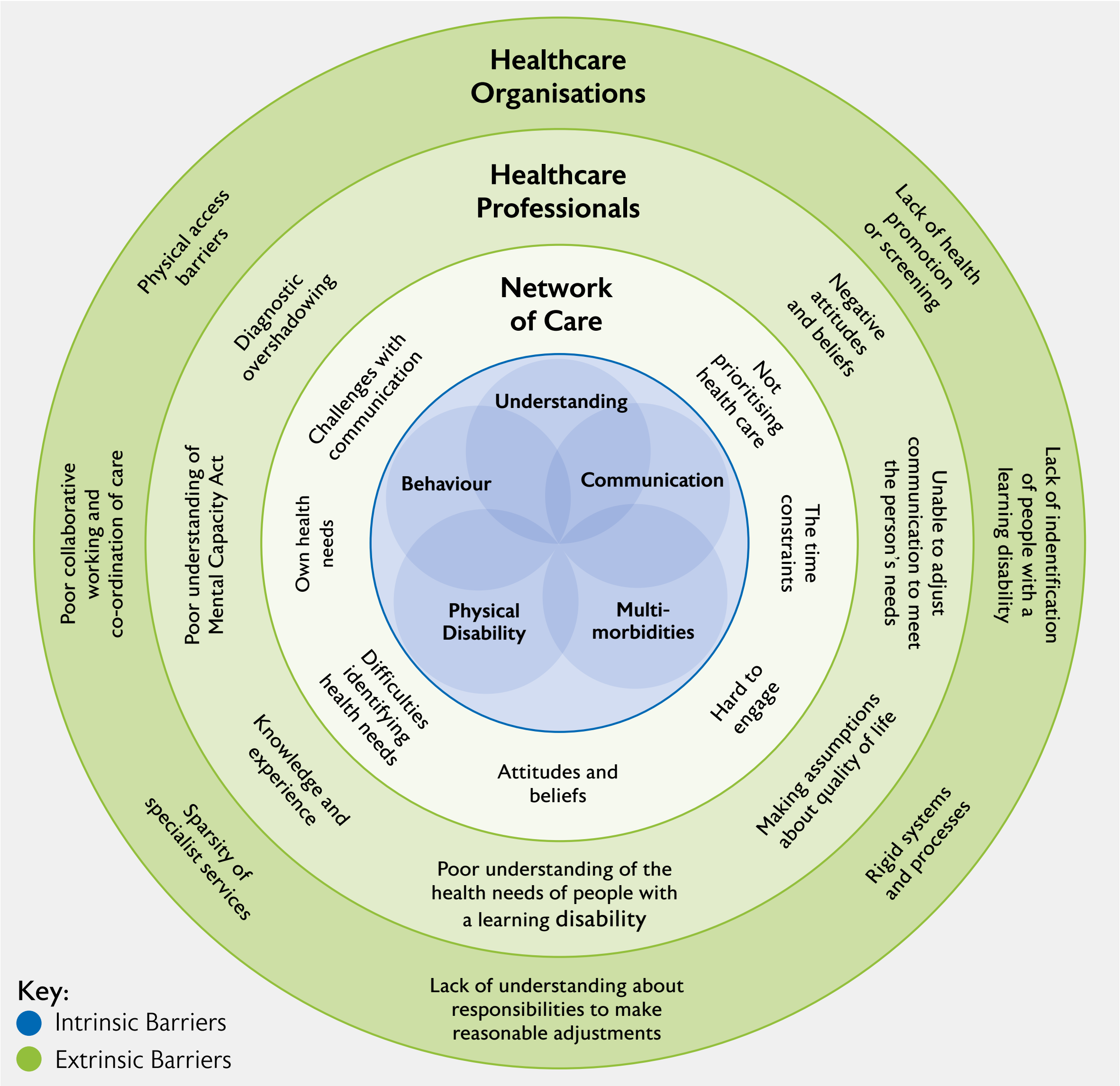
Barriers to adults with a learning disability accessing healthcare

Adults with a learning disability have the same right as the general population to access mainstream healthcare services and to receive the most current evidence-based treatments and techniques (Department of Health 2001). However, there are often a number of barriers that prevent someone with a learning disability having equal access to care (Department of Health 2009; Equalities Act 2010; Heslop et al. 2013). Barriers to accessing health services are factors that prevent an individual gaining access to successful healthcare. These can manifest as physical, psychological, financial, graphical, cultural, language and resource barriers.

Barriers can be categorised into intrinsic and extrinsic. The intrinsic barriers to adults with a learning disability accessing successful healthcare are those related to the person, usually as a result of the individual's communication difficulties, limited understanding and ability to learn new information, physical disability, and complex health background. The extrinsic barriers to adults with a learning disability accessing successful healthcare arise from factors outside of the individual's control such as the person's network of care, the professionals that provide care, and health and social care organisations (Figure 3).

Figure 3: Diagram illustrating the barriers to providing successful healthcare to adults with a learning disability

Barriers to adults with a learning disability accessing healthcare



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Reasonable adjustments

Under the Equality Act (2010), all disabled people have the right to reasonable adjustments when using public services, including healthcare. These adjustments aim to overcome the barriers that disabled people would otherwise face ensuring they have equal access to good quality healthcare (Mencap 2018).

Public Health England (2016) states that reasonable adjustments can mean alterations to buildings by providing lifts, wide doors, ramps and tactile signage, but may also mean changes to policies, procedures and staff training to ensure that services work equally well for people with a learning disability. Public sector organisations should not simply wait and respond to difficulties as they emerge, the duty on them is 'anticipatory'. This means they have to think about what is likely to be needed in advance. In addition, all organisations that provide NHS or adult social care must follow the accessible information standard by law. This standard aims to make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand with support, so they can communicate effectively with health and social care services (Public Health England 2016).

There is a body of literature that evidences that when the appropriate adjustments are made, adults with a learning disability can have successful outcomes from accessing mainstream healthcare services (Michael and Richardson 2008; Heslop et al. 2013; RCGP 2013). Public Health England have produced a series of guidance papers on making reasonable adjustments to manage some of the key health problems of people with a learning disability. These include constipation, dementia, dysphagia, obesity and weight management, oral care and postural care and falls.

Mencap (2018) produced guidance for healthcare professionals on making reasonable adjustments for people with a learning disability in hospital. They report that 1,200 people with a learning disability die avoidably every year, when good healthcare could have saved their lives. Thus, making reasonable adjustments in hospital is important. Reasonable adjustments can be simple changes made by one healthcare professional, or they can be more complex and need multiple teams to work together. Mencap states that making reasonable adjustments can mean removing barriers that people with a learning disability face or providing something extra for someone to enable them to access the healthcare they need. Mencap recognise that every person is different, therefore the adjustments people with a learning disability need will differ from person to person. However, there are common adjustments that help lots of people with a learning disability such as speaking clearly and using simple words; taking time; working with the person's network of care; being flexible with appointment times; listening to specialist learning disability professionals; providing written information in an accessible format; and not making assumptions.

In 2017 the ACPPLD launched the 'so your next patient has a learning disability' campaign. This involved publishing an information booklet and poster providing advice and guidance for physiotherapists not specialising in learning disability services on making reasonable adjustments to support people with a learning disability to access mainstream physiotherapy. The advice covers a range of intrinsic and extrinsic adjustments mainstream physiotherapists may need to make through the service user's journey to directly support adults with a learning disability to access successful physiotherapy.

➡ **The reasonable adjustments to support adults with a learning disability to access successful physiotherapy outcomes.**

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Some adults with a learning disability are unable to access mainstream services even when reasonable adjustments are made. The intrinsic and extrinsic barriers to these individuals accessing mainstream services are often wide ranging and to overcome them requires individually tailored adjustments. As a result, the adjustments required to provide successful healthcare and physiotherapy may go beyond what is reasonable and possible for mainstream services. To implement this level of adjustments requires specialist knowledge, skills and services. Therefore, individuals will require support from specialist learning disability physiotherapists to either support positive access to and responses from services; or to provide direct assessment and intervention (Department of Health 2009; Heslop et al. 2013; Learning Disability Professional Senate 2015; National Quality Board 2017).

Physiotherapy

Physiotherapy is an allied health care profession which promotes and restores movement and function when someone is affected by injury, illness or disability. Physiotherapy is a science-based profession and takes a 'whole person' approach to health and wellbeing, which includes the patient's general lifestyle (CSP 2019). Physiotherapists are autonomous practitioners who provide expert, holistic interventions to help restore movement or, in the case of permanent injury or disease, to lessen the effects of any dysfunction (WHO n.d.).

Physiotherapists have worked with adults with a learning disability since before the 1960's. Although there have been many changes in attitudes and beliefs, laws, legislation, government and local policy, models of care, and significant advancement in technology and health care the core functions of the role of the specialist physiotherapist remain mostly the same. Physiotherapists continue to predominantly support adults with a learning disability with the most severe and complex physical disabilities; those with mobility problems and at risk of falls; and those who are unable to successfully access mainstream healthcare services.

➔ History of physiotherapy for adults with a learning disability.

➔ 20th century timeline of key legislation, publications, national developments, policies, guidelines and labelling related to the health needs of adults with a learning disability.

Physiotherapy for adults with a learning disability

Adults with a learning disability have a number of factors and associated conditions that increase the prevalence of developing **physiotherapy related problems** either from an early age or within their lifetime. These manifest due to:

1. Associated conditions that result from the initial neurological event or genetic abnormality
2. The impact of the person's physical and neurological disability such as increased risk of injuries and falls and premature aging
3. The person's learning disability and cognitive impairment
4. Making poor lifestyle choices, such as leading sedentary and unhealthy lifestyles
5. Poor access to healthcare due to intrinsic and extrinsic barriers and health inequalities

➔ Physiotherapy needs of adults with a learning disability.

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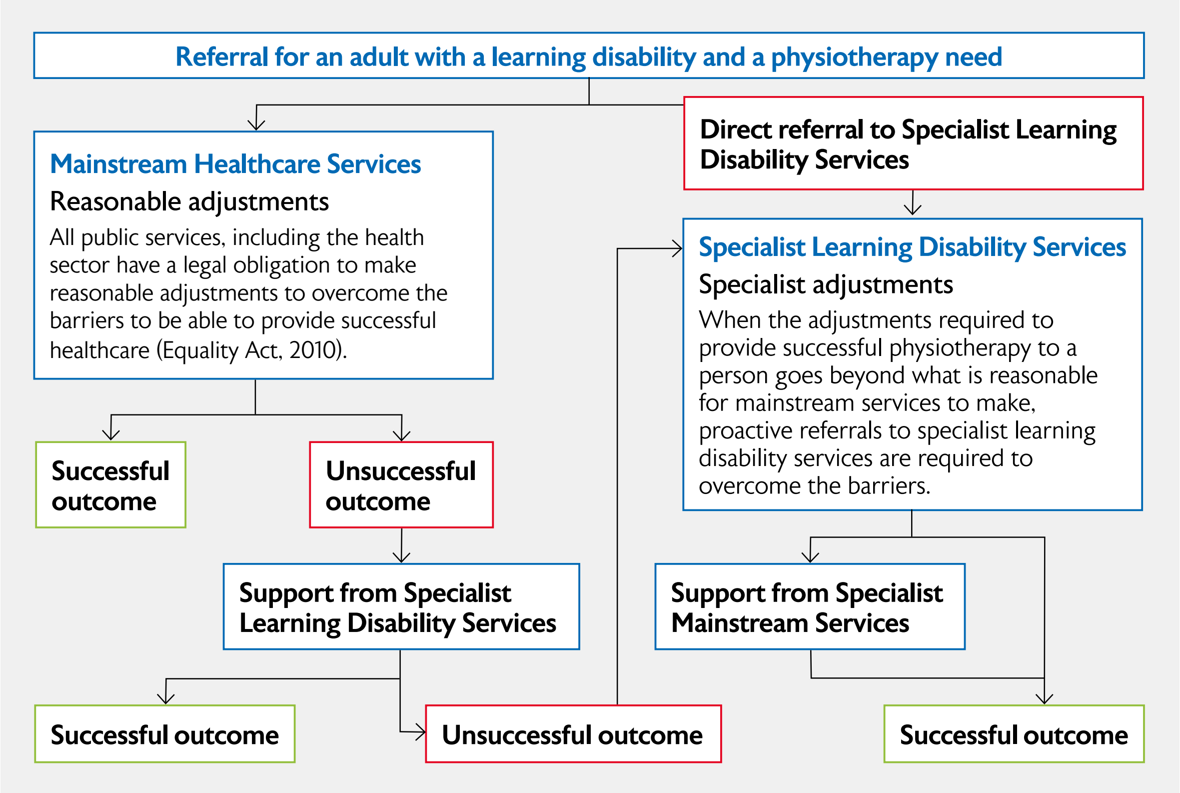
As a result, many adults with a learning disability will require access to physiotherapy at some point within their lifetime. The pathway to people receiving a successful outcome can occur via mainstream physiotherapy services or through specialist learning disability physiotherapy services. Often mainstream and specialist services are required to work in collaboration to share and combine their knowledge and skills to deliver a successful outcome (Figure 4).

Figure 4: Pathway to providing successful physiotherapy to adults with a learning disability

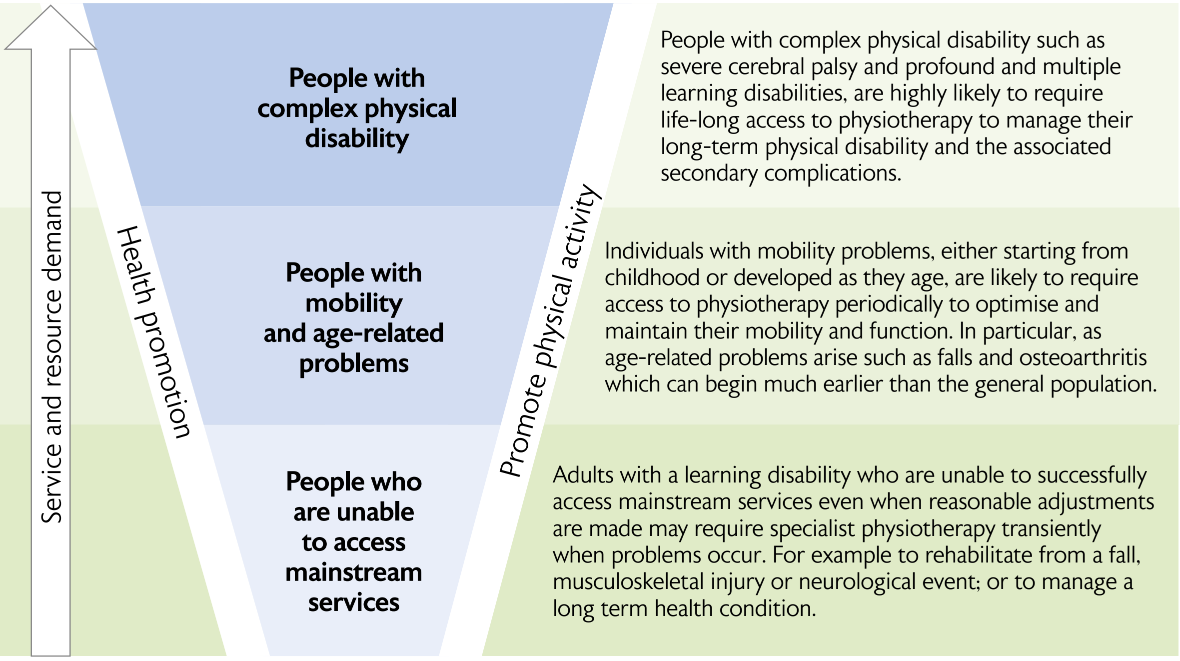


All public services, including the health sector have a legal obligation to make reasonable adjustments to overcome the barriers to be able to provide successful healthcare (Equality Act, 2010).

When the adjustments required to provide successful physiotherapy to a person goes beyond what is reasonable for mainstream services to make, proactive referrals to specialist learning disability services are required to overcome the barriers.

The main areas where specialist learning disability physiotherapists provide services fall within three groups (Figure 5). There are likely to be some variations to this model depending on local drivers, populations and services.

Figure 5: The main areas where specialist learning disability physiotherapists provide services



People with complex physical disability such as severe cerebral palsy and profound and multiple learning disabilities, are highly likely to require life-long access to physiotherapy to manage their long-term physical disability and the associated secondary complications.

Individuals with mobility problems, either starting from childhood or developed as they age, are likely to require access to physiotherapy periodically to optimise and maintain their mobility and function. In particular, as age-related problems arise such as falls and osteoarthritis which can begin much earlier than the general population.

Adults with a learning disability who are unable to successfully access mainstream services even when reasonable adjustments are made may require specialist physiotherapy transiently when problems occur. For example to rehabilitate from a fall, musculoskeletal injury or neurological event; or to manage a long term health condition.

A new definition for the ‘Specialist Learning Disability Physiotherapist’

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A new definition for the 'Specialist Learning Disability Physiotherapist'

> *'Learning disability physiotherapists provide specialist assessment, treatment and management to adults with a learning disability whose needs cannot be successfully met by mainstream services, even when reasonable adjustments are made. Physiotherapists will work in collaboration with the person, their network of care, mainstream health services, and the multidisciplinary team to enhance, optimise and maintain the person's physical presentation, function and quality of life."*

Supporting Evidence

For specialist learning disability physiotherapy service leads and physiotherapists to deliver the new definition it is ESSENTIAL they:

- Be accessible and equitable to ALL adults with a learning disability with a physiotherapy need that cannot be met successfully by mainstream services even when reasonable adjustments are made. This includes:
  - Where mainstream physiotherapy services provide the appropriate reasonable adjustments but are unable to successfully meet the person's physiotherapy needs.
  - Where mainstream physiotherapists lack the specialist skills required to provide successful physiotherapy to the adult with a learning disability.
  - When the adjustments required for the adult with a learning disability to successfully access mainstream physiotherapy services go beyond what is reasonable.
  - Where mainstream physiotherapy services are not available and accessible locally to meet the physiotherapy needs of adults with a learning disability.
- Be based on clinical need, not on an assumed level of a person's learning disability.
- Consider whether mainstream services are best placed to successfully meet the individual's physiotherapy needs and support positive access to and responses from mainstream services where appropriate.
- Work in collaboration with mainstream physiotherapy and other relevant healthcare services in the assessment, management and monitoring of adults with a learning disability to ensure positive access and successful outcome.
- Support mainstream physiotherapy and relevant health services to make the reasonable adjustments required to ensure adults with a learning disability have positive access to and responses from services where extra support from specialist learning disability services is indicated.
- Make the adjustments required to provide successful physiotherapy to adults with a learning disability that go beyond what is reasonable for mainstream services.
- Seek specialist support from mainstream physiotherapy and other related healthcare services to provide physiotherapy to adults with a learning disability where appropriate.

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- Work in collaboration with the multidisciplinary team to provide a co-ordinated approach to care and contribute to local co-ordination processes and pathways through supporting communication and providing appropriate documentation as required.
- Develop links, open lines of communication and direct referral pathways with local health and social care services critical to the effective delivery of physiotherapy services to adults with a learning disability. This aims to support collaborative working and positive access to and response from services.
- Support the development of local integrated multi-disciplinary and agency pathways for adults with a learning disability who have or are at high risk of developing physiotherapy and health problems.
- Develop and target service provision, delivery and priorities on the changing and evolving physiotherapy needs of adults with a learning disability locally.

Conclusion

To deliver the new evidenced based definition effectively, specialist learning disability physiotherapists and services have the responsibility to ensure local practice meets the expected level of performance outlined in this document. As a minimum, it is essential that specialist learning disability physiotherapy services be based on clinical need not on an assumed level of a person's learning disability; are accessible and equitable to all adults with a learning disability and a physiotherapy need which cannot be met successfully by mainstream services, even when reasonable adjustments are made; make the adjustments required to provide successful physiotherapy to adults with a learning disability that go beyond what is reasonable for mainstream services; and offer and deliver the different aspects of the role of the specialist learning disability physiotherapist to the standards outlined within this document. To achieve this expected level, it is essential that specialist learning disability services are commissioned and resourced appropriately. Staff must have the knowledge, skills and experience to provide physiotherapy to adults with a learning disability in all settings, providing specific and additional input as required to respond to their health care needs.

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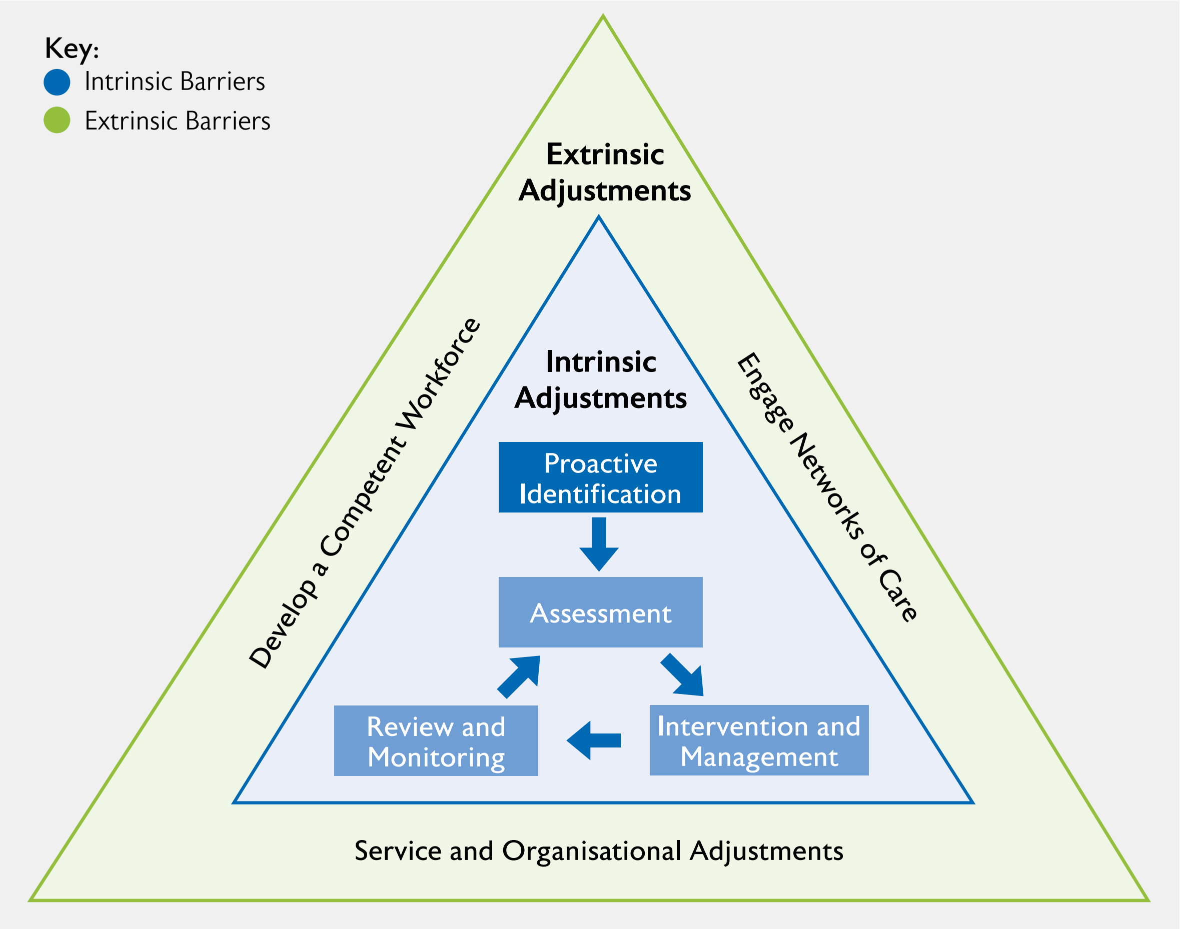
Specialist adjustments

The unique attributes of the specialist learning disability physiotherapist.

> *"Learning disability physiotherapists provide specialist assessment, treatment and management to adults with a learning disability whose needs cannot be successfully met by mainstream services even when reasonable adjustments are made. Physiotherapists will work in collaboration with the person, their network of care, mainstream health services, and the multidisciplinary team to enhance, optimise and maintain the person's physical presentation, function and quality of life."*

To successfully deliver the definition, it is essential that specialist learning disability physiotherapists make the adjustments required to provide successful physiotherapy to adults with a learning disability. Providing these adjustments requires specialist knowledge and skills and a model of working which facilitates the development of relationships with adults with a learning disability and their network of care. Adjustments are required at a strategic level to develop a competent network of care and local workforce, as well as the systems to support adults with a learning disability to access the healthcare they need in a timely manner (Figure 5). This level of adjustment are not possible or reasonable for mainstream services and it is essential they are be delivered by specialist learning disability physiotherapy services to achieve successful outcomes.

Figure 6: The domains where specialist learning disability physiotherapists make adjustments to provide successful physiotherapy



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NB: The following statements were developed through thematic analysis of the available evidence, the roles, statements of each role and qualitative data extrapolated through the questionnaire rounds. They outline the unique attributes of the specialist learning disability physiotherapist compared to mainstream physiotherapy services. These statements overarch all the roles and standards of practice within this document.

Intrinsic adjustments

Proactive Identification

Specialist learning disability physiotherapists:

1. Be proactive in identifying, managing and monitoring high risk groups of adults with a learning disability who have, or are at risk of developing physiotherapy problems. For example, people with complex physical disabilities, profound and multiple learning disabilities, cerebral palsy, Down's syndrome, adults with a learning disability and dementia, and young people transitioning from paediatric to adult services.
2. Work in collaboration with health and social care professionals in the early detection and treatment of health problems to address the health inequalities experienced by adults with a learning disability. For example, dementia in people with Down's syndrome, recognition of the signs of dysphagia and aspiration, and the early detection of falls and risk of falls.

During Assessment

Specialist learning disability physiotherapists:

1. Offer assessments over a prolonged period and multiple contacts where required to ensure that they are able to accurately assess and diagnose physiotherapy and other health related problems. This supports the development of long term relationships and builds knowledge and understanding of the individual and their network of care.
2. Develop an understanding of the person's comprehension, communication style and needs and adapt communication appropriately.
3. Where available use specialist assessment tools and outcome measures that are specifically designed and validated for use with adults with a learning disability.
4. Adapt mainstream physiotherapy assessments to meet the specific needs of the adult with a learning disability taking into consideration evidence-based assessments, assessment protocols, their learning disability, and social circumstances.
5. Complete assessments in the different environments and situations adults with a learning disability access. Adults with a learning disability often present differently dependent on the environment and support provided; and assessments are often not reliably transferable between settings.
6. Gain subjective information by proxy from many sources such as the network of care, family members, and external agencies to accurately assess and diagnose adults with a learning disability. Use a proxy reporter who has the most day to day contact with the person and knows them well such as a key worker/family member where the person is unable to self-report.
7. Individually tailor assessments to the person's diagnosis, learning disability, social circumstances, behaviour, specific risk factors, drug history, past medical history.
8. Link information from different sources to form part of the assessment process and provide an overview and summary to the adults with a learning disability and their network of care in a way that they can understand.
9. Make assessments flexible, adaptable and creative where the adult with a learning disability is unable to tolerate standardised assessment methods and tools.

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During intervention and management

Specialist learning disability physiotherapists:

1. Work in collaboration with mainstream physiotherapy and other related health services to develop and adapt management plans that take into consideration the person's learning disability, home environment, social circumstances, daily routines and activities.
2. Develop individually tailored management plans that take into consideration the person's learning disability, complex physical disability, behavioural presentation, home environment, social circumstances, daily routines and activities. Plans should be integrated into the person's and their network of care's daily routine, activities and lifestyle. This aims to improve compliance with recommendations and not increase the care burden or impact on quality of life.
3. Offer a holistic long term disability management approach which enhances engagement with physiotherapy and takes a long term view of rehabilitation, intervention and management.
4. Set functional and long-term goals and work over a prolonged period of time to achieve the goals.
5. Disseminate management plans that are written in an accessible format to ensure that they are can be understood and implemented.
6. Make onward referrals to relevant health and social care services and support positive access to and responses from services where extra support from the specialist learning disability physiotherapy team is indicated and critical to the outcome.
7. Offer specialist interventions to address physiotherapy goals which are creative, fun and enjoyable to improve compliance and outcomes. For example, group exercise, hydrotherapy/aquatic therapy and physiotherapy on a trampoline/rebound therapy. Adults with a learning disability are often unable to complete specific exercise programmes and/or understand the benefits which impacts on compliance. Therefore, utilising specialist interventions can help to overcome these problems.
8. Support a positive risk management approach to ensure that the needs of the adult with a learning disability are met in a person-centred manner, that maximises personal choice and quality of life as well as evidence based intervention.

Review and monitor

Adults with a learning disability are often unable to express when their needs have changed or when they experience side effects of treatments or management plans. They may also be unable to seek medical support and are reliant on others to identify and meet their health needs. Changes can be very subtle making it difficult for the person's network of care to detect. Therefore, reviews are required to monitor the person's physical presentation and following any treatment, especially in people with communication difficulties, and complex presentations and social situations.

1. Offer regular monitoring and reviews for adults with a learning disability in a timely manner as clinically indicated depending on the level of risk; and the complexity of the person's disability, associated health problems and social circumstances.
2. Offer access to regular reviews, monitoring and supervision where management plans have been delegated in line with the CSP guidance on the delegation of tasks to support workers.
3. Provide monitoring and review immediately after implementation of new or changes to management plans to ensure that there is no adverse impact.
4. Contribute to reviewing and monitoring of mainstream physiotherapy and relevant healthcare service management plans to ensure that adults with a learning disability and their network of care implement treatment plans correctly and feedback as needed.

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Extrinsic Adjustments

Engage the person's network of care

Specialist learning disability physiotherapists:

1. Invest time into developing relationships with the network of care and engaging them in physiotherapy. Adults with a learning disability are often reliant on their network of care to provide physical care and to advocate on their behalf. Hence, are integral to providing successful physiotherapy to adults with a learning disability.
2. Develop physiotherapy management plans that consider their impact on the person's network of care.
3. Engage networks of care in service development and design to ensure local specialist learning disability physiotherapy teams are serving the needs of the local population.
4. Delegate management and treatment plans to the person's network of care for completion on a daily and sustainable basis. Adults with a learning disability often require support from their network of care to complete their management plans either due to their learning disability or physical limitations.

Develop a competent local workforce

Specialist learning disability physiotherapists:

1. Provide training and education to healthcare professionals, networks of care and the local community workforce to
   a. develop a competent local workforce that supports adults with a learning disability;
   b. raise awareness of the physiotherapy needs of adults with a learning disability;
   c. provide advice on how to make reasonable adjustments; and
   d. promote the role of the specialist learning disability physiotherapist.

Service and Organisational

Specialist learning disability physiotherapists:

1. Offer a model of service delivery which facilitates the development of relationships with adults with a learning disability and their network of care. This includes offering extended episodes of care; allowing more time to assess and treat; providing a continuity of care; taking a proactive approach; and being able to review and monitor people regularly.
2. Offer flexible working patterns to take account of the individual's and their network of care's needs. For example, a late appointment to observe an evening routine.
3. Deliver bespoke learning disability physiotherapy services to meet the needs of the local population of adults with a learning disability were mainstream services are not available or accessible. For example:
   - 24 hour postural service where there is a lack of local mainstream service provision.
   - Falls prevention and intervention, where mainstream services are commissioned to only see people over the age of 65.
4. Support adults with a learning disability and their network of care to have positive access to and responses from health and social care services where attendance is critical to the outcome of the appointment. This includes supporting communication of the person's health needs to healthcare professionals; improving understanding of the rationale behind assessment and treatment options; and facilitating the implementation of recommendations into the community.
5. Use specialist knowledge, skills and experience in working with adults with a learning disability to support the development of local healthcare services, activities and environments.
6. Work in collaboration with the person's network of care, multidisciplinary team, social services, mental health, and external agencies to provide a co-ordinated approach to care.

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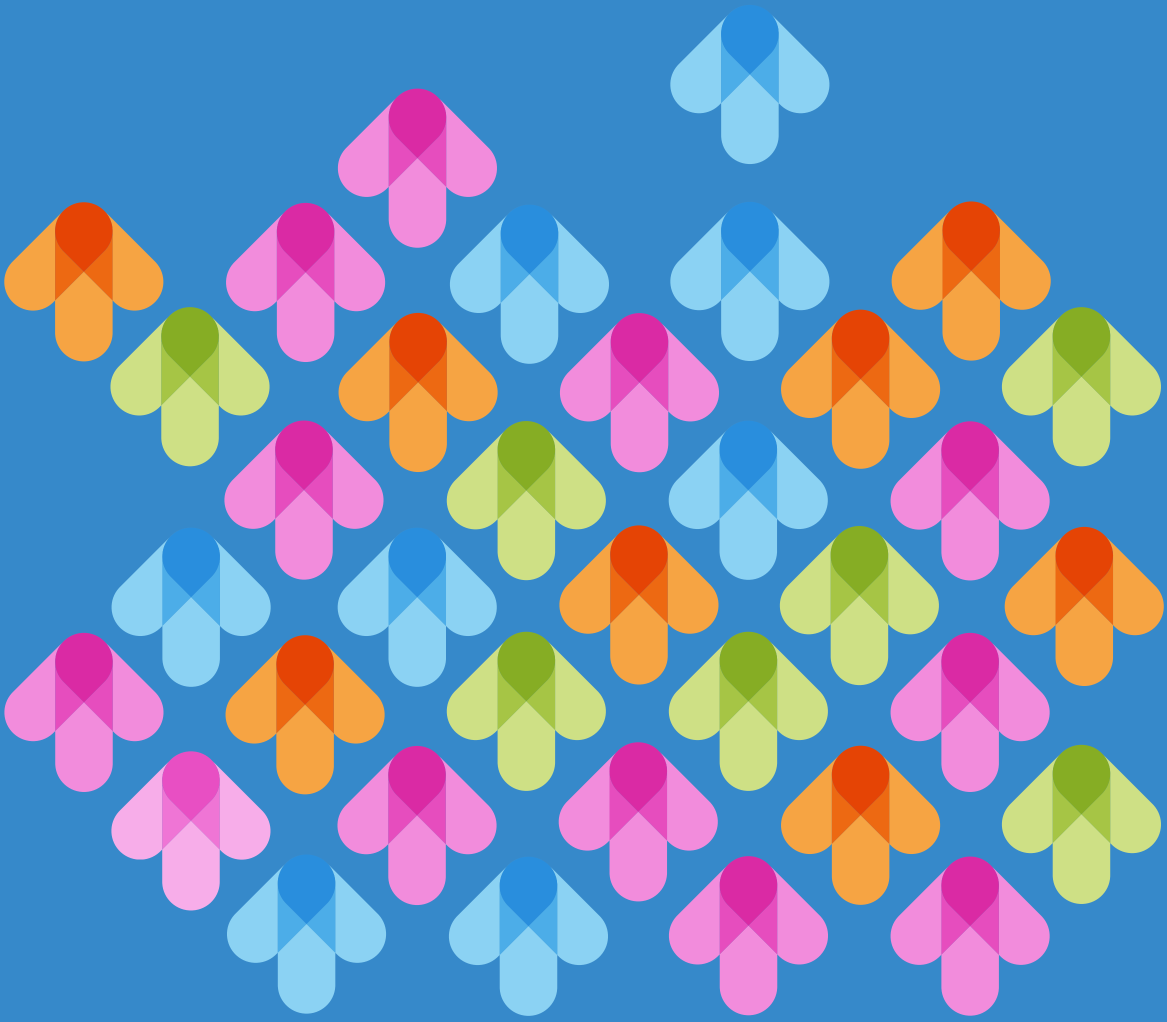
The role of the specialist learning disability physiotherapy service



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The role of the specialist learning disability physiotherapy service

> *"Learning disability physiotherapists provide specialist assessment, treatment and management to adults with a learning disability whose needs cannot be successfully met by mainstream services even when reasonable adjustments are made. Physiotherapists will work in collaboration with the person, their network of care, mainstream health services, and the multidisciplinary team to enhance, optimise and maintain the person's physical presentation, function and quality of life."*

To successfully deliver the definition, it is essential that specialist learning disability physiotherapists offer and deliver the roles within this document to the standards outlined. The 15 different facets of the roles of the specialist learning disability physiotherapist have been categorised further into **Lead**, **Contributory** and **Supporting** roles. These have been developed into an Onion Diagram representing the roles of the Specialist Learning Disability Physiotherapy Service. The evidence for each of the roles is documented in the supporting information.

LEAD roles

These are the roles that are ESSENTIAL for the specialist learning disability physiotherapist to take lead responsibility for providing where the adult with a learning disability is unable to successfully access mainstream services, even when reasonable adjustments are made. The provision of these roles is likely to depend on the physiotherapy needs of the local population of adults with a learning disability and the accessibility and provision of mainstream local physiotherapy and healthcare services.

It is ESSENTIAL that physiotherapists develop specialist knowledge, skills and experience in these areas to be able to successfully deliver physiotherapy to adults with a learning disability.

CONTRIBUTORY roles

The specialist learning disability physiotherapist will contribute to and work in collaboration with members of the multidisciplinary team or mainstream services to deliver the contributory roles. Physiotherapists will contribute their specialist knowledge, skills and experience and be versatile in developing new skills and competence. The provision of these roles is likely to depend on the physiotherapy needs of the local population of adults with a learning disability and the accessibility and provision of mainstream physiotherapy and healthcare services.

SUPPORTING roles

The supporting roles underpin the successful provision of the lead and contributory roles of the specialist learning disability physiotherapist. The provision of these roles is likely to depend on the physiotherapy needs of the local population of adults with a learning disability and the accessibility and provision of mainstream local physiotherapy and healthcare services.

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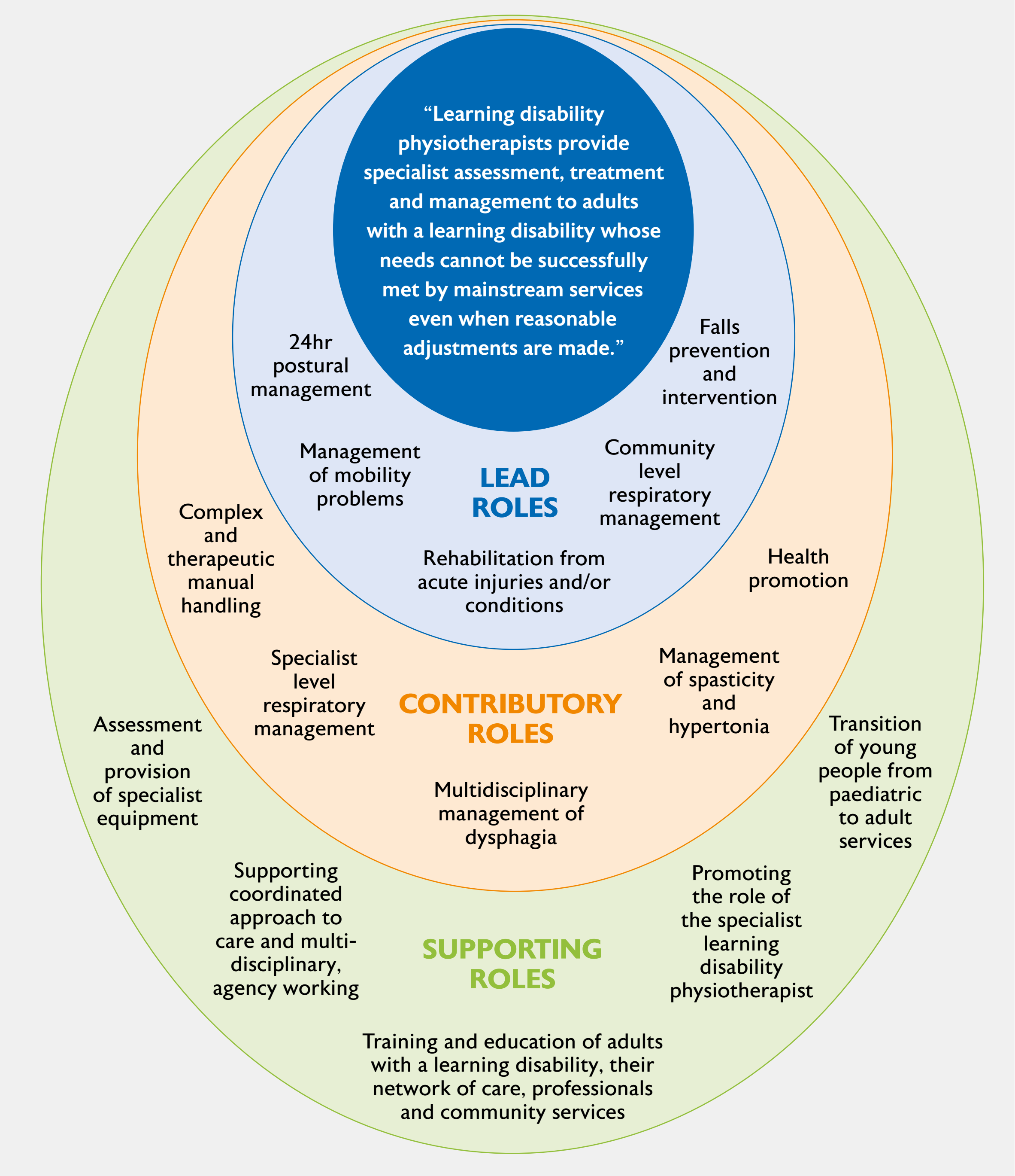
Onion Diagram

The Roles of Specialist Learning Disability Physiotherapy Services



Click on the individual roles within the diagram to take you to the relevant section.

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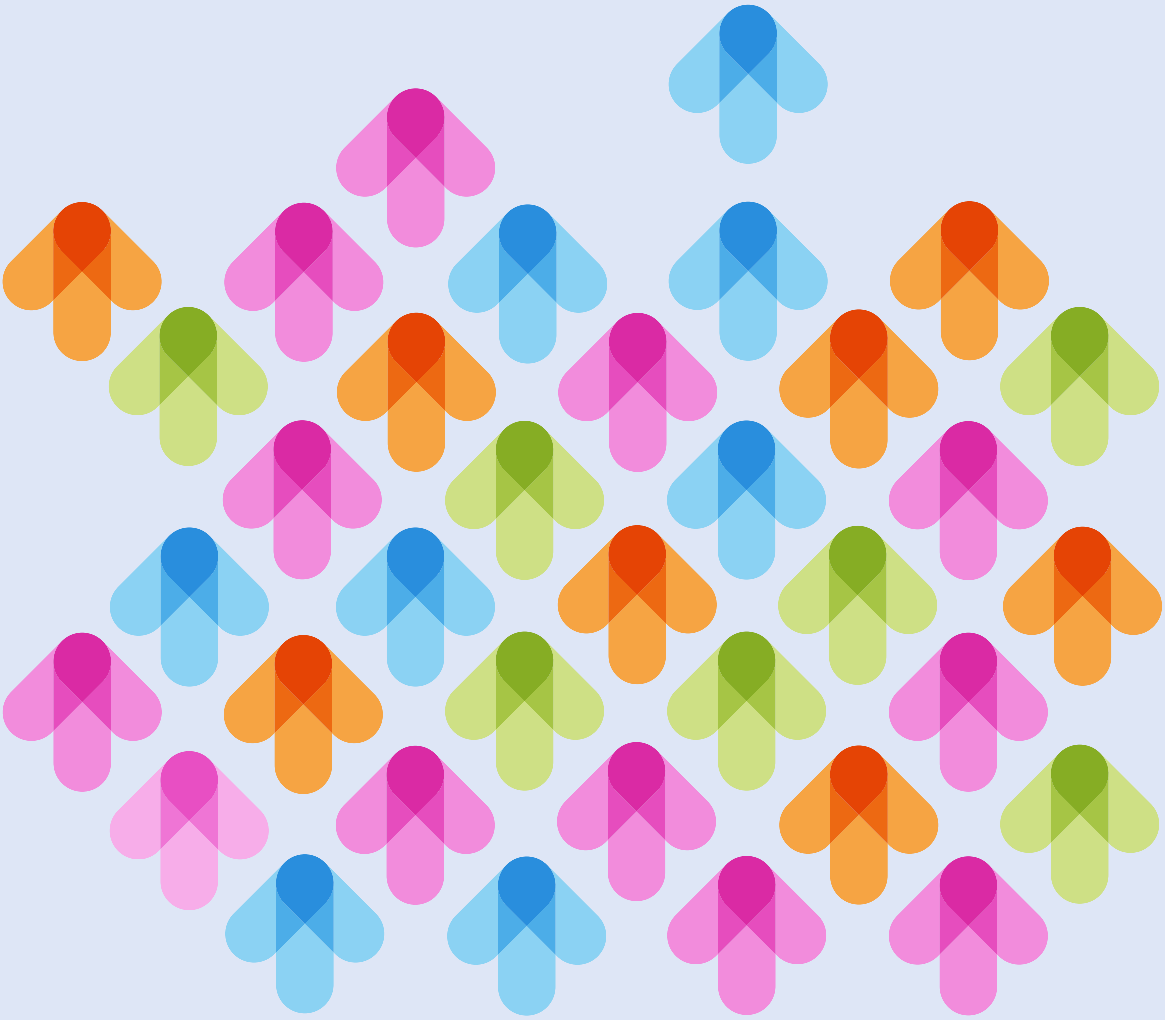
LEAD roles

These are the roles that are ESSENTIAL for the specialist learning disability physiotherapist to take lead responsibility for providing where the adult with a learning disability is unable to successfully access mainstream services, even when reasonable adjustments are made. The provision of these roles is likely to depend on the physiotherapy needs of the local population of adults with a learning disability and the accessibility and provision of mainstream local physiotherapy and healthcare services.

It is ESSENTIAL that physiotherapists develop specialist knowledge, skills and experience in these areas to be able to successfully deliver physiotherapy to adults with a learning disability.

Onion Diagram



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24 hour postural management

It is ESSENTIAL that specialist learning disability physiotherapy services offer 24hr postural management to adults with learning and complex physical disabilities whose needs cannot be met successfully by mainstream services even when reasonable adjustments are made.

➡ Onion Diagram

➡ Supporting Evidence

Standard of Practice Statements

*NB: **Readers should also consider standard of practice statements under the management of spasticity and hypertonia; and the assessment and provision of equipment when providing 24hr postural management.***

Assessment

Specialist learning disability physiotherapists:

1. Complete comprehensive holistic and person-centred postural assessments for adults with complex physical and learning disabilities. This may include using a standardised assessment tool such as the Management of Physical Disability 24-7 assessment tool for purposes of repeatability and ongoing monitoring.
2. Use validated objective outcome measures to determine the effectiveness of postural management interventions. The recommended measures that are consistently used in practice are: The Goldsmith indices of body symmetry; range of motion (ROM) measures using a goniometer and a measuring protocol; repeated measures from baseline assessment; Goal Attainment Scale (GAS); Therapy Outcome Measures (TOMs).
3. Complete postural assessments that are flexible and adaptable where people are unable to tolerate standardised assessment tools because of their complexity, compliance or behaviour.
4. Assess the causes of the person's physical and neurological presentation to project any future deterioration and the development of secondary complications.
5. Assess for the presence and risk of developing secondary complications of complex physical disabilities.
6. Assess the person's neurological presentation including hypertonia, spasticity, dystonia, movement disorders, retained reflexes and sensory impairment; and how this may be impacting on the person's physical and functional presentation.
7. Screen the person's respiratory and chest health as part of the postural assessment and complete a community respiratory assessment where indicated.
8. Assess the person's hand management including their function, hygiene, skin integrity and range of movement and make onward referral to hand therapy and/or orthotic services where indicated.
9. Assess day-to-day levels of pain and discomfort as part of postural assessments. Where the person is unable to self-report, use a proxy reporter who has the most day to day contact with the person and knows them well. For example, a key worker or family member. Consider using a validated pain and discomfort assessment tool such as DisDAT (Disability Distress Assessment Tool) and the Paediatric Pain Profile.
10. Assess whether a medical issue is contributing to the person's presentation. Where a medical cause is suspected or indicated make an onward referral to the person's GP and/or relevant healthcare professionals for further assessment and management, and support positive access to and responses from services.

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11. Assess bowel elimination habits and identify any signs and symptoms of constipation. Where indicated, work with the multidisciplinary team and the person's network of care to develop a constipation care plan. This includes non-pharmacological treatments such as healthy diets, hydration, regular exercise, movement, good toilet habits and abdominal massage. Make onward referrals to the GP or specialist services for advice on pharmacological management.

Abdominal massage for constipation

12. Assess and monitor spinal position and deformities as indicated using objective measurements as well as taking into consideration the impact of the person's spinal position on their function, respiratory health and pain.

Intervention and Management

Specialist learning disability physiotherapists:

1. Develop postural management plans that aim to promote and maintain function and quality of life; prevent and reduce body shape distortion; and reduce the impact of associated secondary complications.
2. Develop a person centred realistic postural management plan based on the outcome of a postural assessment. Postural management plans may require multi-disciplinary and multi-professional involvement and includes:
   - Identifying the optimal positioning for sitting, lying and standing (if applicable) in relation to the person's physical and neurological presentation.
   - Recommendations for regular changes of position over a 24-hour period that effectively supports the person's posture whilst facilitating function, comfort, engagement and quality of life.
   - Contributing to and advising on the medical management. For example, the person's neurological presentation, orthopaedic conditions, respiratory health.
   - The management of the person's critical range of movement.
   - Optimising function and quality of life.
   - Therapeutic activities. For example, movement and counter movement programmes, physiotherapy on a trampoline/rebound therapy, gym programmes, and community activities.
   - Considering the impact of the programme on the person's network of care.
3. Postural management plans should consider the person's '24-hour profile'; the different environments the person's accesses; and be integrated into the person daily activities and lifestyle.
4. Document any recommendations that have not been possible to deliver including the reasons and rationale for the actions not implemented.
5. Disseminate postural management plans in an accessible format to ensure that they are fully understood and embedded into daily routines.
6. Make recommendations for and support the assessment and provision of specialist equipment assessed as essential to the individual's postural management plan. This may include equipment such as wheelchairs, alternative seating, standing frames, sleep systems and orthotic devises.

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7. Work in collaboration with relevant healthcare professionals to support the assessment and provision of specialist equipment. Develop funding applications for equipment and resources assessed as essential to the individual's postural management plan. These should include sound clinical reasoning and justification considering the cost versus benefit as well as the impact on the person and their network of care.

8. Make onward referrals to relevant health and social care professionals and services as indicated by assessment and support positive access to and responses from health and social care professionals and services where required.

9. Work in collaboration with local wheelchair and special seating services to support the successful assessment and provision of equipment. Wheelchairs should support the person's posture and facilitates function whist providing comfort; and be practical for the families and carers to use within their daily lives and routines.

10. Develop a person-centred management plan of the person's spinal position where indicated by spinal assessment. This should include:

- Conservative physiotherapy interventions and techniques in the management of the person's spinal deformities such as postural management, positioning, stretching and muscle strengthening.
- Making onward referrals to specialist orthotics services and orthopaedic consultants for assessment and consideration of spinal bracing and surgery as clinically indicated and support positive access to and responses from services as required.
- Contributing to post surgery physiotherapy management in collaboration with the spinal consultant and relevant mainstream physiotherapy services.

11. Work in collaboration with specialist orthotic services to support the successful assessment and provision of orthotics where indicated. This may include assisting in the monitoring of orthotics following prescription to ensure that they are introduced and implemented correctly and that they are not causing any adverse effects such as pressure sores, pain or discomfort.

12. Work in collaboration with district nursing, tissue viability nursing, occupational therapy, dietetics and the network of care in the management of pressure ulcers. This will include advising on the positioning and repositioning of people with complex postural needs and making recommendation for appropriate equipment as indicated.

13. Delegate postural management plans and specialist interventions to the person's network of care adhering to the CSP guidance on the delegation of task to support workers to ensure that programmes and plans are delivered competently and in a regular sustained manner.

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Review and Monitoring

Specialist learning disability physiotherapists:

1. Offer regular monitoring and reviews of postural assessments and management plans to monitor functional and postural needs; to manage potential deterioration; and to assess the effectiveness of current postural management intervention. Reviews should be conducted in a timely manner as clinically indicated depending on the level of risk; and the complexity of the person's disability, associated health problems and social circumstances.
2. Provide the person and their network of care with the relevant information to recognise decline and deterioration in an individual's postural presentation to encourage timely re-referral back to the team.

Knowledge and Skills

To deliver this role successfully it is essential that physiotherapists develop specialist knowledge and skills in providing 24hr postural management to adults with a learning disability.

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Community level respiratory management

It is ESSENTIAL that specialist learning disability physiotherapy services offer community level respiratory management services to adults with a learning disability whose needs cannot successfully be met through mainstream services even when reasonable adjustments are made; and to people with complex physical disability who have respiratory problems and/or at risk of developing respiratory complications.

➡ Onion Diagram ➡ Supporting Evidence

Standard of Practice Statements

Assessment

Specialist learning disability physiotherapists:

1. Complete community level respiratory assessments of adults with a learning disability who have/are at risk of developing respiratory complications.

   Community Level Respiratory Assessment includes:

   - A subjective assessment including history of present condition, baseline respiratory measures, past medical history, social history and drug history.
   - An objective assessment including colour, alertness, perfusion, peripheral or central oedema, chest wall deformity, body posture and tone, work of breathing, breathing pattern, temperature and clamminess.
   - Auscultation where appropriately trained.
   - Clinical observations such as respiratory rate, heart rate, oxygen saturations, blood pressure, temperature, sputum volume, viscosity, colour, odour/foul breath, and previous chest X rays.
   - Cough effectiveness, strength, productive, reflexive or voluntary.

2. Work in collaboration with speech and language therapists and the multidisciplinary team to identify adults with a learning disability who have saliva management dysfunction and make onward referrals to GP's or specialist respiratory services for further assessment and consideration for medical management where clinically indicated.

Intervention and Management

Specialist learning disability physiotherapists:

1. Develop, implement and delegate community level respiratory management plans working in collaboration with the multidisciplinary team where indicated.

   Community Level Management plans may include:

   - Treatment techniques aimed at maintaining or improving airway clearance dysfunction including:
     - Positioning
     - Movement programmes
     - Therapeutic activities such as physiotherapy on a trampoline/rebound therapy and hydrotherapy/aquatic therapy
     - Chest physiotherapy
     - Oral suction
     - Positive Expiratory Pressure (PEP)

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- Treatment programmes aimed at maintaining or improving thoracic deformity including:
  - Postural management
  - Positioning
  - Therapeutic activities such as physiotherapy on a trampoline/rebound therapy and hydrotherapy/aquatic therapy
  - Exercise
  - Onward referrals to orthotics and orthopaedics
- Treatment programmes to maintain or improve pulmonary fitness such as:
  - Movement programmes
  - Therapeutic activities such as physiotherapy on a trampoline/rebound therapy and hydrotherapy/aquatic therapy
  - Supported walking
  - Standing programmes
  - Pulmonary rehabilitation
- Making onward referrals to relevant health and social care professionals as indicated by assessment such as specialist respiratory services and support positive access to and responses from services as required.

Review and Monitoring

Specialist learning disability physiotherapists:

1. Provide regular monitoring and reviews of adults with a learning disability assessed at risk of developing respiratory complications. Reviews should be conducted in a timely manner as clinically indicated depending on the severity of the person’s respiratory health and its impact on the person’s function, independence and care needs.

2. Offer regular monitoring and reviews to adults with a learning disability and respiratory complications who have been delegated respiratory care plans that have been developed by the learning disability physiotherapy team in line with the CSP guidance on the delegation of tasks to support worker.

Knowledge and Skills

To deliver this role successfully it is essential that physiotherapists working with adults with a learning disability develop appropriate knowledge and skills to conduct community level respiratory assessments and management plans.

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Falls prevention and intervention

It is ESSENTIAL for specialist learning disability physiotherapy services to consider whether mainstream falls prevention and intervention services are better placed to successfully meet the physiotherapy needs of the adult with a learning disability in the first instance and support positive access to and responses from mainstream services where appropriate.

It is ESSENTIAL for specialist learning disability physiotherapy services to support mainstream falls services to make person centred reasonable adjustments to facilitate adults with a learning disability to have positive access to and responses from services.

It is ESSENTIAL for specialist learning disability physiotherapy services to offer specialist learning disability falls services to adults with a learning disability whose needs cannot be successfully met by mainstream service even when reasonable adjustments are made.

➔ Onion Diagram   ➔ Supporting Evidence

Standard of Practice Statements

Assessment

Specialist learning disability physiotherapists:

1. Include falls screening tools within multidisciplinary assessments with the aim to identify people who have fallen/are at high risk of falling and may benefit from further support and/or intervention.
2. Offer individually tailored multifactorial falls assessments to adults with a learning disability that require access to specialist learning disability falls services.
3. Administer evidence based outcome measures that have been validated for use with adults with a learning disability as part of assessment and for evaluation of intervention.
   For example:
   - Timed up and go test.
   - One-leg stance test.
   - Tinnetti Balance Assessment.
   - Berg Balance Score.
   - Rivermead Mobility Index.
   - Barthel Activities of Daily Living Index.
4. Screen for fear of falling during assessments. If the person reports fear of falling assess using an appropriate recognised tool such as Falls Efficacy Scale (FES).

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5. Refer people to their GP or specialist services for assessment of fracture risk and consideration for bone sparring treatment if they are a:
   - Women aged 65 years and over
   - Man aged 75 years and over
   - Women aged under 65 years and men aged under 75 years in the presence of risk factors, for example:
     - Previous fragility fracture.
     - Current use or frequent recent use of oral or systemic glucocorticoids.
     - History of falls.
     - Family history of hip fracture.
     - Other causes of secondary osteoporosis.
     - Low body mass index (BMI) (less than 18.5 kg/m2).
     - Smoking.
     - Alcohol intake of more than 14 units per week for women and more than 21 units per week for men.

   Use a standardised osteoporosis risk assessment tool such as FRAX or Q fracture to support this referral where appropriate.
6. Assess whether pain is a contributing factor to the person's falls and deterioration in function. Where pain is suspected or indicated this may involve a multidisciplinary assessment using specialist pain assessments for people with a learning disability such as DISDAT or Paediatric Pain Profile.
7. Assess whether medical causes are contributing to the person's falls such as dizziness on standing and black outs. Where a medical cause is suspected make an onward referral to the person's GP and/or relevant healthcare professionals for further assessment and management and support positive access to and responses from services.
8. Develop joint SMART goals with the person and/or their network of care to evaluate the outcomes of interventions.

Management

Specialist learning disability physiotherapists:

1. Develop an individualised falls rehabilitation and prevention programme based on the outcome of the assessment taking into consideration the person's learning disability, physical disability, behavioural presentation, home environment, social circumstances and daily routines and activities.
2. Delegate programmes to the person and their network of care where indicated in line with the CSP guidance on the delegation of tasks to support workers.
3. Contribute to the development of risk assessments which support adults with a learning disability to lead as active and as inclusive lives as possible in their communities. This may involve positive risk taking.

   A POSITIVE RISK MANAGEMENT APPROACH: *ensures that the needs of the adult with a learning disability are met in a person-centred manner, to maximise personal choice, quality of life as well as evidence based falls intervention.*

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4. Offer specialist interventions such as specialist falls groups, physiotherapy on a trampoline/rebound therapy, hydrotherapy/aquatic therapy and gym programmes as part of the person's falls prevention and management plans.
5. Make onward referrals to local health and social care services such as general practitioner and/or specialist falls services for medical reviews, orthotics, social services and occupational therapy as clinically indicated and support positive access to and responses from services where required.
6. Make recommendations for the provision of specialist equipment to reduce the risk of falls and promote functional independence. This may require collaborative working with occupational therapy colleagues and depend on local equipment provision agreements.
7. Support adults with a learning disability to access community-based exercise groups and activities where appropriate and available to ensure long term sustainable falls prevention and as part of health promotion.

Review and Monitoring

Specialist learning disability physiotherapists:

1. Offer timely monitoring and reviews to people who are frequent fallers or at high risk falls and where falls management plans are delegated. The frequency of reviews should be proportional to the level of risk of injury and may depend on associated health problems and social circumstances.
2. Provide the person and their network of care with the relevant information to recognise decline and deterioration in an individual's mobility to make timely re-referrals back to the team.

Knowledge and Skills

To deliver this role successfully it is essential that physiotherapists working with adults with a learning disability develop specialist knowledge and skills to offer evidence-based falls prevention and intervention services to adults with a learning disability whose needs cannot be successfully met by mainstream services. It is also essential that physiotherapists have specialist knowledge of the risk factors that increase the prevalence of falls in adults with a learning disability. Evidence suggests that these include:

1. Abnormal patterns of walking because of neurological impairment.
2. Concurrent medical problems.
3. Impulsiveness and distractibility.
4. Visual deficits.
5. Taking more than four medications, especially epilepsy and antipsychotic medications.
6. Epilepsy.

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Management of mobility problems

It is ESSENTIAL that specialist learning disability physiotherapy services consider whether mainstream mobility and rehabilitation services are better placed to successfully meet the physiotherapy needs of adults with a learning disability in the first instance and support positive access to and responses from services where appropriate.

It is ESSENTIAL that specialist learning disability physiotherapy services support mainstream mobility and rehabilitation services to make reasonable adjustments to support adults with a learning disability to have positive access to and responses from services.

It is ESSENTIAL that specialist learning disability physiotherapy services offer services to manage the mobility problems of adults with a learning disability whose needs cannot be successfully met by mainstream services even when reasonable adjustments are made.

Onion Diagram   Supporting Evidence

Standard of Practice Statements

NB: Readers should also consider standard of practice statements under the management of spasticity and hypertonia; and the assessment and provision of equipment when providing management of mobility problems.

Assessment

Specialist learning disability physiotherapists:

1. Offer comprehensive mobility assessments using evidence-based outcome measures where applicable. Outcome measures that have been validated for use with adults with a learning disability include:
   - Timed up and go test,
   - Two-leg stance test,
   - Rivermead Mobility Index,
   - Barthel Activities of Daily Living Index.
2. Refer people to their GP or specialist services for assessment of fracture risk and consideration for bone sparring treatment if they are a:
   - Women aged 65 years and over,
   - Men aged 75 years and over,
   - Women aged under 65 years and men aged under 75 years in the presence of risk factors, for example:
     - Previous fragility fracture.
     - Current use or frequent recent use of oral or systemic glucocorticoids.
     - History of falls.
     - Family history of hip fracture.
     - Other causes of secondary osteoporosis.
     - Low body mass index (BMI) (less than 18.5 kg/m2).
     - Smoking.
     - Alcohol intake of more than 14 units per week for women and more than 21 units per week for men.

   Use a standardised osteoporosis risk assessment tool such as FRAX or Qfracture to support this referral where appropriate.

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3. Assess whether pain is a contributing factor to the person's mobility problems and deterioration in function. Where pain is suspected or indicated this may involve a multidisciplinary assessment using specialist pain assessments for adults with a learning disability such as DISDAT or Paediatric Pain Profile.
4. Assess whether a medical issue is contributing to the person's change in presentation as part of physiotherapy assessments. Where a medical cause is suspected or indicated make an onward referral to the person's GP and/or relevant healthcare professionals for further assessment and management and support positive access to and responses from services.
5. Complete assessments of the person's mobility in different environments to consider extrinsic factors such as busy environments, uneven surfaces and changes in light.

Intervention and Management

Specialist learning disability physiotherapists:

1. Develop individualised management plans based on the outcome of the assessment taking into consideration the person's learning disability, physical disability, behavioural presentation, home environment, social circumstances and daily routines and activities.
2. Offer specialist interventions such as exercise groups, physiotherapy on a trampoline/rebound therapy, hydrotherapy/aquatic therapy, gym programmes as part of the person's mobility management plan.
3. Set functional SMART goals with the person and/or their network of care to evaluate intervention.
4. Work in collaboration with occupational therapy colleagues to make recommendations to improve any environmental factors assessed to be contributing to the person's mobility problems.
5. Support adults with a learning disability to access community-based exercise groups and activities where available, to facilitate long term outcomes and management of mobility problems.
6. Develop, disseminate and delegate accessible individualised mobility management plans to the person and their network of care.
7. Make recommendations for the provision of specialist equipment to improve mobility and promote functional independence. This may require collaborative working with occupational therapy colleagues and depend on local equipment provision agreements.
8. Develop funding applications to justify the provision of essential specialist equipment, increased support hours and funding for community activities where they are deemed essential to physiotherapy management.
9. Make onward referrals to local health and social care services such as spasticity clinics, wheelchair services, orthotics, social services, occupational therapy, and orthopaedics as clinically indicated and support positive access to and responses from services where required.
10. Work in collaboration with specialist orthotic services in the assessment and provision of orthotics assessed as clinically needed to enhance and optimise the person's function and/or physiotherapy management. This may include assisting in the monitoring of orthotics following prescription to ensure that they are introduced and implemented correctly; and that they are not causing any adverse effects such as pressure sores, pain or discomfort.

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Review and Monitoring

Specialist learning disability physiotherapists:

1. Offer timely monitoring and reviews to people who have ongoing mobility problems and are at risk of deterioration. The frequency of reviews should be proportionate to the level of risk of injury and the risk of deterioration; and could depend on associated health problems and social circumstances.
2. Provide the person and their network of care with the relevant information to recognise decline and deterioration in an individual's mobility to encourage timely re-referral back to the team.

Knowledge and Skills

To deliver this role successfully it is essential that physiotherapists develop specialist knowledge and skills to manage the mobility needs of the adult with a learning disability. This includes developing in depth understanding of the mobility problems of high risk groups and how to successfully manage these issues including:

1. People with cerebral palsy (GMFCS Level I, II and III).
2. People with Down's syndrome.
3. People with severe epilepsy.
4. People taking antipsychotic medication.
5. People with conditions which predispose them to develop mobility problems.
6. Older adults with a learning disability.
7. People aging with physical disabilities.

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Rehabilitation from acute injuries and/or conditions

It is ESSENTIAL that specialist learning disability physiotherapy services work in collaboration with mainstream physiotherapy and other related healthcare services in the rehabilitation from acute injuries and conditions of adults with a learning disability whose needs cannot be met successfully by mainstream services even when reasonable adjustments are made. For example, fractures, musculoskeletal injuries and neurological events. This will involve:

1. Mainstream physiotherapy services leading on rehabilitation with support of the specialist learning disability physiotherapist.
2. Specialist learning disability physiotherapists and mainstream services working in collaboration to provide rehabilitation to the person.
3. Specialist learning disability physiotherapists leading on the rehabilitation with support from mainstream physiotherapy and other related healthcare services.

➡ Onion Diagram   ➡ Supporting Evidence

Standard of Practice Statements

Assessment

Specialist learning disability physiotherapists:

1. Complete or contribute to assessments taking into consideration evidence-based practice, any protocols in place, and the person’s learning disability.

Intervention and Management

1. Develop or contribute to a person-centred treatment programme taking into consideration the recommended treatment protocols for the injury and the person’s learning disability.
2. Make recommendations for the provision of equipment to facilitate rehabilitation with support from mainstream services where appropriate.
3. Make onward referrals to relevant health and social care services where appropriate and support positive access and responses from services.
4. Delegate individualised management plans to the person’s network of care.
5. Support mainstream services to provide accessible information to the person and their network of care to enhance their understanding of recommended rehabilitation; any proposed surgery or procedures; to maximise their capacity to make decisions; and to contribute to best interest decisions where needed.
6. Support adults with a learning disability to have successful hospital admissions and to facilitate safe and timely discharges where extra support from the specialist learning disability team is indicated and critical to the outcome. This includes supporting assessments and rehabilitation; providing advice on the postural management of people with complex physical and learning disabilities; sharing information about baseline presentations and previous physiotherapy input; and advocating and supporting access to appropriate post discharge rehabilitation services.

Knowledge and Skills

It is ESSENTIAL that specialist learning disability physiotherapists apply their specialist skills in providing physiotherapy to adults with a learning disability; supporting them to access mainstream services; and supporting mainstream services to make reasonable adjustments. They will also need to be versatile in developing new skills and competence in the specific area of physiotherapy depending on the reason for referral.

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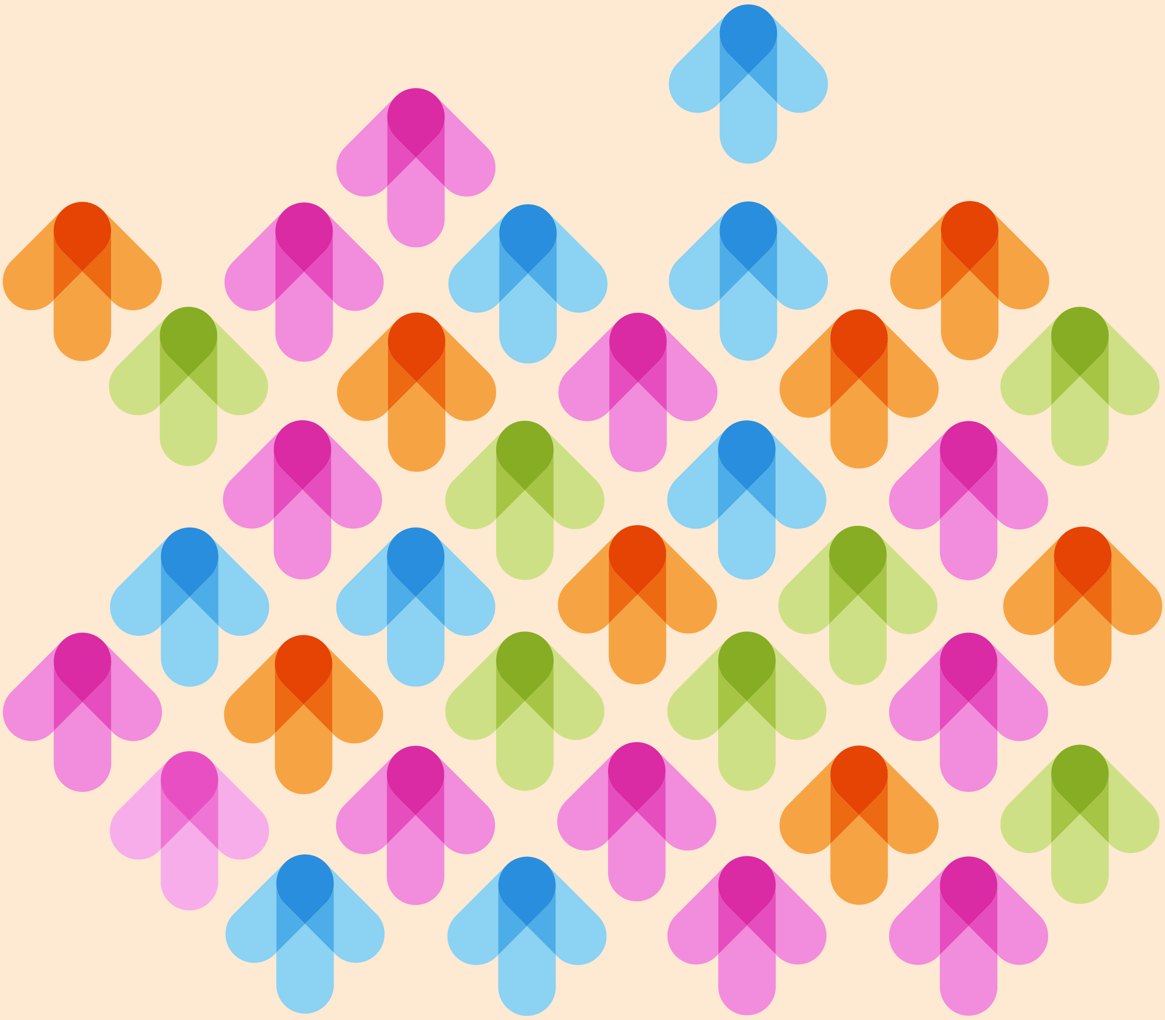
CONTRIBUTORY roles

The specialist learning disability physiotherapist will contribute to and work in collaboration with members of the multidisciplinary team or mainstream services to deliver the contributory roles. Physiotherapists will contribute their specialist knowledge, skills and experience and be versatile in developing new skills and competence. The provision of these roles is likely to depend on the physiotherapy needs of the local population of adults with a learning disability and the accessibility and provision of mainstream physiotherapy and healthcare services.

➔ Onion Diagram



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Multidisciplinary management of dysphagia

It is ESSENTIAL that specialist learning disability physiotherapy services work in collaboration with speech and language therapists and the wider multi-disciplinary team in the identification of potential signs of dysphagia and aspiration, and the assessment and management of dysphagia in adults with a learning disability.

➡ Onion Diagram

➡ Supporting Evidence

Standard of Practice Statements

Assessment

Specialist learning disability physiotherapists:

1. Identify potential signs of dysphagia and aspiration in adults with a learning disability and make onward referrals to appropriate services to ensure their needs are addressed in a timely manner.
2. Work in collaboration with speech and language therapists and the wider multi-disciplinary team to complete meal time and dysphagia assessments for adults with a learning disability. This includes completing assessments:

   - of the optimal position for a safe and effective swallow; and
   - to facilitate and optimise independent eating and drinking.
3. Complete community level respiratory assessments for adults with a learning disability and dysphagia where clinically indicated and make onward referrals to specialist respiratory services if required.

Intervention and Management

Specialist learning disability physiotherapists:

1. Contribute to the development of multidisciplinary, person-centred dysphagia and mealtime care plans.
2. Work in collaboration with speech and language therapists and wider multidisciplinary team to develop an individualised positioning plan based on the outcome of the assessment. This aims to optimise a safe and effective swallow to reduce the risk of aspiration.
3. Contribute to the development of multi-disciplinary risk assessments and management strategies that support a positive risk management approach to ensure that the needs of adults with a learning disability are met in a person-centred manner, to maximise personal choice, quality of life as well as evidence-based dysphagia intervention.
4. Work in collaboration with the multidisciplinary team to implement advice on the optimal position to reduce risk of reflux where the person has complex positioning needs.
5. Advise on physiotherapy management techniques to aid saliva clearance such positioning to encourage anterior loss of saliva and/or the use of oral suction.

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Review and Monitoring

Specialist learning disability physiotherapists:

1. Monitor the effects of any changes made to the individual's position during their meal time to ensure there is no negative impact on their ability to swallow safely or increase the risk of aspiration or choking. People may use compensatory movements of their body and head to improve their swallow efficiency and safety thus changing their position may impact of their ability to utilise these strategies.
2. Provide the person and their network of care with the relevant information to identify signs of aspiration and changes in dysphagia to encourage them to make timely re-referrals to back to the team.
3. Work in collaboration with speech and language therapists and the multidisciplinary team to review dysphagia and mealtime care plans and risk assessments as clinically indicated.

Knowledge and Skills

To deliver this role successfully it is essential that specialist learning disability physiotherapists develop the appropriate knowledge, skills and experience in the physiotherapy aspects of the assessment and management dysphagia. This includes:

1. The assessment and development of an individualised positioning plan for the optimal position for safe and effective swallowing; reducing the risk of reflux; and promoting anterior loss of saliva.
2. Optimising independent eating and drinking skills.
3. Community level respiratory assessments.

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Health promotion

It is ESSENTIAL that specialist learning disability physiotherapy services support adults with a learning disability to lead an active lifestyle in line with the public health agenda and offer long-term preventative management of physiotherapy related problems.

Onion Diagram

Supporting Evidence

Standard of Practice Statements

Specialist learning disability physiotherapists:

1. Work in collaboration with health and social care professionals, the person's network of care, service providers, leisure centres, voluntary and charity organisations, local healthy lifestyle initiatives, and local disability sports and activity groups to support adults with a learning disability to lead an active lifestyle in line with the public health agenda.
   This may include:
   - Developing knowledge of the exercise groups and activities available locally.
   - Acting as specialist advisors to support services to make reasonable adjustments for adults with a learning disability.
   - Sign posting people to activities where indicated.
   - Facilitate engagement in physical activities and exercise opportunities where there are specific physiotherapy related barriers to inclusion and access.
   - Contributing to training and education to improve awareness of the needs of adults with a learning disability.
2. Develop and maintain local directories of community activities and groups that people and their network of care may access to lead an active lifestyle and support preventative long-term disability management.

Knowledge and Skills

To deliver this role successfully it is essential that learning disability physiotherapists develop specialist knowledge, skills and experience in supporting adults with a learning disability to engage in physical activity and lead an active and healthy lifestyle in line with the public health agenda. To achieve this physiotherapist will need to understand:

1. The reasons why adults with a learning disability lead sedentary lives.
2. The barriers to adults with a learning disability engaging in the recommended amount of daily physical activity.
3. How to support adults with a learning disability and their network of care to lead an active lifestyle.
4. How to support local community services, facilities and groups to make reasonable adjustments to support adults with a learning disability to access physical activity.
5. The availability and accessibility of local community services, facilities and groups for adults with a learning disability.

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Specialist level respiratory management

It is ESSENTIAL that specialist learning disability physiotherapy services work in collaboration with mainstream and specialist respiratory services where available, to provide specialist level respiratory management to adults with a learning disability with complex respiratory presentations.

Where specialist respiratory services are not available, physiotherapy services should proactively seek to develop links and pathways with local specialist and community respiratory services. For example, respiratory services for people with neurological conditions with a respiratory component such as Duchenne Muscular Dystrophy or Motor Neuron Disease; or services who manage people who require long-term ventilation and/or tracheostomies.

Onion Diagram   Supporting Evidence

Standard of Practice Statements

NB: Readers should also consider standard of practice statements under 24hr postural management and community respiratory management.

Assessment

Specialist learning disability physiotherapists:

1. Work in collaboration with mainstream and specialist respiratory services to provide specialist level respiratory assessments.

Intervention and Management

Specialist learning disability physiotherapists:

1. Specialist respiratory management plans may include:
   - Specialised physiotherapy treatment techniques aimed at maintaining or improving airway clearance dysfunction. Including:
     - Airway clearance devices such as cough assists, lung volume recruitment bags, vest.
     - The assessment, provision and implementation of specialist respiratory equipment.
     - Medication.
2. Work in collaboration with healthcare professionals to support end of life planning such as facilitating and contributing to the development of advance and escalation of care plans where extra support from the specialist learning disabilities physiotherapist is indicated. For example, where there is an established relationship with a person and their network of care; or where deterioration in health is likely to impact on physiotherapy management such as respiratory complications in people with complex physical disability.

Review and Monitoring

Specialist learning disability physiotherapists:

1. Work in collaboration with mainstream or specialist respiratory services to provide regular monitoring and reviews of adults with a learning disability assessed at risk of developing respiratory complications. Reviews should be conducted in a timely manner as clinically indicated depending on the severity of the person's respiratory health and its impact on the person's function, independence and care needs.

Knowledge and Skills

To deliver this role successfully it is essential that physiotherapists working with adults with a learning disability develop the knowledge of specialist respiratory assessment and treatment options to inform onward referrals to and support access to specialist respiratory services.

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Management of hypertonia and spasticity

Specialist learning disability physiotherapy services will work in collaboration with specialist neurology services and the multidisciplinary team in the assessment, treatment and monitoring of hypertonia and spasticity in adults with a learning disability.

Specialist learning disability physiotherapists will lead on community level assessment, treatment and monitoring of hypertonia and spasticity, usually through postural management, management of mobility problems and falls services.

Specialist learning disability physiotherapists will support specialist services to deliver, optimise and monitor medical management plans for hypertonia and spasticity in adults with a learning disability. This may involve:

1. Supporting specialist services to make the appropriate reasonable adjustments to support positive access to and outcomes for adults with a learning disability and their network of care.
2. Supporting the person and their network of care to understand the positive and negative implications of proposed medical treatment options and to contribute to capacity assessments and best interest decisions regarding the management approach.
3. Supporting the optimisation of treatments to manage hypertonia and spasticity such as stretching post Botox injection or optimisation of medication dosage.
4. Monitoring any adverse effects of treatment and providing feedback.

Onion Diagram

Supporting Evidence

Standard of Practice Statements

NB: Readers should also consider standard of practice statements under 24hr postural management and management of mobility problems.

Assessment

Specialist learning disability physiotherapists:

1. Complete assessments of hypertonia and spasticity as part of postural and mobility assessments using a validated outcome measure, such as Motor Assessment Scale or Tardieu Scale, taking into consideration the impact of the person's neurological presentation on their function and independence.
2. Assess whether pain is a contributing factor to the person's hypertonia and spasticity. Where pain is suspected or indicated this may involve a multidisciplinary assessment using specialist pain assessments for adults with a learning disability such as DISDAT or Paediatric Pain Profile.

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Intervention and Management

Specialist learning disability physiotherapists:

1. Develop individualised physiotherapy management plans in collaboration with the multidisciplinary team to treat and manage hypertonia and spasticity considering:
    - Conservative physiotherapy interventions and management techniques such as positioning, stretching, casting, splinting and muscle strengthening before proposing medication and medical interventions.
    - The positive and negative features of the person's hypertonia and spasticity when developing spasticity management plan.
    - The impact of the management approach and treatment on the person's physical presentation, health, care needs and quality of life.
2. Delegate individualised management plans to the person's network of care.
3. Make onward referrals to general practitioner and specialist neurology services for further assessment of hypertonia and spasticity, and consideration of medical management where a conservative approach is not achieving agreed outcomes and goals. Supporting positive access to and responses from services as required.

Review and Monitoring

Specialist learning disability physiotherapists:

1. Monitor and review adults with a learning disability with an ongoing hypertonia and spasticity problems as clinically indicated.
2. Provide the person and their network of care with the relevant information to recognise changes and/or deterioration in an individual's hypertonia and spasticity to encourage timely re-referral to back to the team.

Knowledge and Skills

To deliver this role successfully it is essential that specialist learning disability physiotherapists develop the appropriate knowledge, skills and experience of physiotherapy assessment, treatment and monitoring of hypertonia and spasticity and understand the medical treatments available to support appropriate onward referrals to specialist services.

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Complex and therapeutic manual handling

Specialist learning disability physiotherapists will work in collaboration with the occupational therapy team, multidisciplinary team, family members, network of care, and service providers to contribute to manual handling assessments, management and training of adults with a learning disability with complex manual or therapeutic handling needs.

➡ Onion Diagram

➡ Supporting Evidence

Standard of Practice Statements

Assessment

Specialist learning disability physiotherapists:

1. Work in collaboration with the occupational therapy team, multidisciplinary team, and network of care to complete individualised manual handling assessments for adults with a learning disability where they have complex manual handling needs. Such as people with complex body shapes and movement disorders; or where there are therapeutic handling requirements to maximise functional abilities or rehabilitation.

Intervention and Management

1. Specialist learning disability physiotherapists work in collaboration with the occupational therapy team, wider multidisciplinary team and network of care to:
   - Develop person centred accessible manual handling guidelines for adults with a learning disability with complex manual or therapeutic handling needs as indicated by assessment and delegate them to the person’s family and/or network of care.
   - Advice on the provision of manual handling equipment for adults with a learning disability where they have complex manual and/or therapeutic handling requirements. The assessment and provision of manual handling equipment may depend on local equipment pathways and agreements.
2. Make onward referrals to relevant services where manual handling issues and concerns are identified. Where these issues put the person, and/or their network of care at risk of injury; develop and implement risk management plans to reduce the level of immediate risk.

Review and Monitoring

Specialist learning disability physiotherapists:

1. Provide the person and their network of care with the relevant information to be able to identify manual handling problems and risks to encourage timely referrals to the appropriate services as required.

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Knowledge and Skills

To deliver this role successfully it is essential that specialist learning disability physiotherapists apply their knowledge and skills in contributing to the assessment of adults with a learning disability and complex manual or therapeutic handling needs. This will involve:

1. Developing an understanding of manual handling legislation.
2. Maintaining up to date manual handling training.
3. Keeping up to date with manual handling equipment and products available locally.
4. Developing knowledge, skills and experience in postural management, the management of mobility problems and falls intervention and prevention, and how these impact on a person's manual handling.

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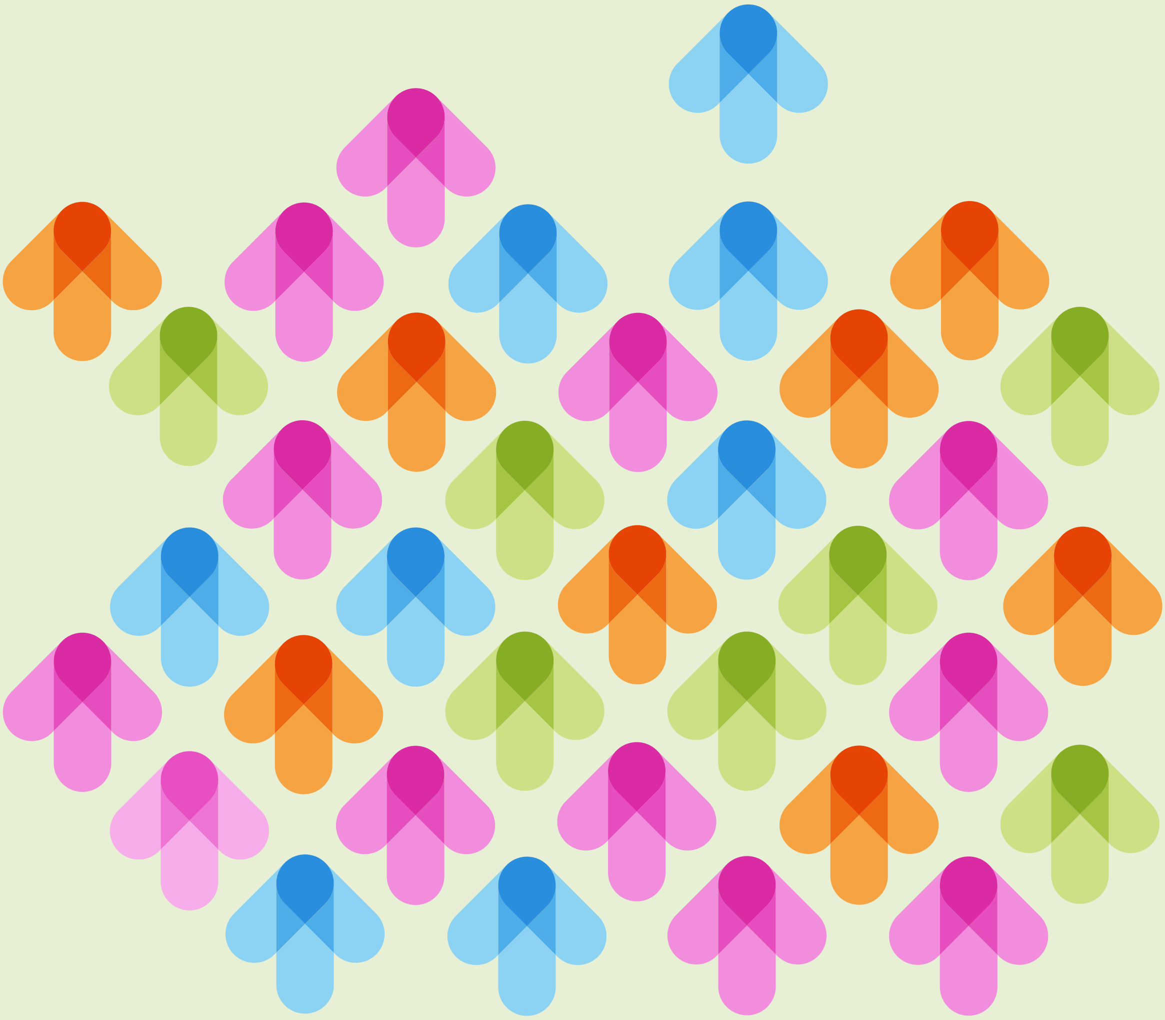
SUPPORTING roles

The supporting roles underpin the successful provision of the lead and contributory roles of the specialist learning disability physiotherapist. The provision of these roles is likely to depend on the physiotherapy needs of the local population of adults with a learning disability and the accessibility and provision of mainstream local physiotherapy and healthcare services.

➡ Onion Diagram



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Assessment and provision of specialist equipment

Specialist learning disability physiotherapy services will complete the assessment and provision of specialist equipment as part of the lead or contributory roles.

➡ Onion Diagram

➡ Supporting Evidence

Standard of Practice Statements

Specialist learning disability physiotherapists:

1. Complete comprehensive assessments for the provision of specialist equipment taking into consideration the clinical need, the cost versus benefit, the available evidence, the competence of the network of care, compliance of the person and the practicality of the equipment.
2. Develop funding applications for specialist equipment. These should include sound clinical reasoning and justification considering the cost versus benefit of the equipment as well as the impact it may have on the person and their network of care.
3. Liaise with equipment manufacturers and providers to trial specialist equipment as part of an assessment and consider available options.
4. Provide training, demonstration and education to the person and their network of care to ensure that specialist equipment is implemented and used competently.
5. Develop or contribute to the development of specific manual handling plans to ensure the equipment is used safely and effectively.
6. Keep abreast of the available research and evidence that supports the provision and clinical benefits of specialist equipment.
7. Develop an accessible treatment plan and delegate to the person’s network of care to ensure that specialist equipment is used competently and integrated into the person’s daily routines and management plans.
8. Make onward referral to health and Social care professionals and services as indicated by assessment to support the use and implementation of specialist equipment such as orthotics, spasticity services and social services.

Knowledge and Skills

To deliver this role successfully specialist learning disability physiotherapists will:

1. Apply their specialist knowledge, skills and experience in providing physiotherapy to adults with a learning disability, in particular 24hr postural management, management of mobility problems, and falls prevention and intervention to inform the appropriate prescription of specialist equipment.
2. Need to develop a breadth of knowledge of the specialist equipment available to be able to effectively support the assessment and provision of equipment to adults with a learning disability.

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Training and education: Adults with a learning disability and their network of care; health and social care professionals; and local community services

It is ESSENTIAL that specialist learning disability physiotherapy services deliver and contribute to multi-disciplinary training and education of health and social care professionals, commissioners, and service providers to raise the awareness of the physiotherapy needs of adults with a learning disability and support positive access to and responses from services and providers.

It is ESSENTIAL that specialist learning disability physiotherapy services deliver and contribute to the training and education of adults with a learning disability and their network of care as part of providing safe and successful physiotherapy.

➡ Onion Diagram   ➡ Supporting Evidence

Training and Education of health and social care professionals and non-professionals, commissioners, and service providers

Topics could include

Health inequalities and reasonable adjustments	Deliver and/or contribute to training and education to raise aware of the health inequalities of adults with a learning disability and the barriers to accessing healthcare. This includes advice on the reasonable adjustments that mainstream services and professionals are legally obligated to make to overcome these barriers. In addition, highlight the adjustments specialist learning disability physiotherapists make that go beyond what is reasonable to provide successful physiotherapy to adults with a learning disability.
Role of the specialist learning disability health and physiotherapy team	Deliver training and education to raise awareness of the role of the specialist learning disability health and physiotherapy teams to promote appropriate referrals and improve the profile of the service.
Supporting adults with a learning disability	Deliver and/or contribute to the training and education to raise the awareness of the needs of adults with a learning disability to facilitate positive access to and responses from healthcare services including providing advice on making appropriate reasonable adjustments.
Postural management	Contribute to the delivery of multi-disciplinary, multi-agency postural management training to raise the awareness of the postural needs of adults with complex physical and learning disabilities and the importance of delivering postural management.
Respiratory management	Work in collaboration with mainstream and specialist respiratory services to deliver multi-disciplinary training and education to highlight the incidence and impact of respiratory problems for people with a learning disability; raise awareness of the risk factors that contribute to the development of respiratory complications; and to promote the importance of respiratory management.
Fall prevention and intervention	Contribute to training and education to raise the awareness of the incidence and impact of falls; the risk factors that are specific to adults with a learning disability; and on the importance of falls prevention.

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Training and Education of adults with a learning disability where applicable, and their network of care

1. Provide training and education to adults with a learning disability and their network of care in areas where physiotherapy provide assessment and intervention to enhance knowledge, skills and competence. This may include contributing to multidisciplinary or external agency training and education sessions where appropriate.

Topics could include

Postural management	Deliver training and education to raise the awareness of the postural needs of adults with complex physical and learning disabilities; the importance of 24 hour postural management; and the role of the network of care.
Respiratory management	Deliver training and education to highlight the incidence and impact of, and risk factors for respiratory complications in adults with a learning disability. Teaching sessions should raise awareness of: • the importance of respiratory care; • the role of the multidisciplinary team; • the role of the network of care in the person's management; and • where to seek appropriate support and advice.
Falls prevention and intervention	Contribute to training and education to raise awareness of the importance of falls prevention and the management of ongoing falls risk.
Adults with a learning disability and dementia	Contribute to person centred multidisciplinary training and education to the families, support teams and service providers of adults with a learning disability and a diagnosis of dementia where there are physiotherapy related needs. Training should focus on the physiotherapy related secondary complications such as mobility problems, falls, sudden deterioration in mobility and function, postural changes, and respiratory complications as their dementia progresses.
Preventative management of mobility problems	Contribute to training and education to promote healthy lifestyles and management of ongoing mobility problems.
Health promotion	Include information about health promotion into education and training sessions to promote the benefits of physical activity and healthy lifestyle; and highlight the consequences of physical inactivity.
Hypertonia and spasticity management	Contribute to multi-disciplinary training and education to improve awareness and knowledge of hypertonia and spasticity; the impact this can have on a person's presentation and function; and raise the awareness of the different treatment and management approaches available.

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2. Provide training and education to the person's network of care to teach the theoretical background to the specific treatments or techniques that are delegated to ensure competent performance of the task. It is essential that training and education is delivered in an accessible language and format.

   Treatments and techniques may include:

   - Hydrotherapy/aquatic therapy
   - Exercise programmes
   - Physiotherapy on a trampoline/rebound therapy
   - Gym programmes
   - Movement programmes
   - Passive movement programmes
   - Complex manual or therapeutic handling programmes in collaboration with occupational therapy services
   - Postural management programmes
   - Respiratory management plans
   - Falls management programmes
   - Mobility management programmes
   - Hypertonia and spasticity management plans
   - Dysphagia management plans
   - Provision of specialist equipment

3. Support and contribute specialist knowledge of providing physiotherapy to adults with a learning disability in the development of training and education packages provided by mainstream physiotherapy and other related health services.

4. Evaluate training and education sessions to ensure the content is appropriate and accessible for the audience; that the learning objectives are met; and the participants apply new knowledge into practice.

Knowledge and Skills

To deliver this role successfully it is essential that specialist learning disability physiotherapists develop competence in developing, presenting and evaluating training and education packages for adults with a learning disability and their network of care; health and social care professionals; and local community services.

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Transition of young people with a learning disability from paediatric to adult services

It ESSENTIAL that specialist learning disability physiotherapy services work in collaboration with paediatric physiotherapy teams, special education college physiotherapy teams and the multi-disciplinary team to support the smooth transition of young people with a learning disability and ongoing physiotherapy needs from paediatric to adult services in line with National Institute of Clinical Excellence (NICE) recommendations.

Onion Diagram Supporting Evidence

Standard of Practice Statements

Specialist learning disability physiotherapists:

1. Proactively identify and transition young people with a learning disability and long-term physiotherapy needs from paediatric to adult services.
2. Support young people with a learning disability to access mainstream physiotherapy services where appropriate and clinically indicated.
3. Work in collaboration with the young person's "named worker" to facilitate a smooth transition of care from paediatric to adult services where the person has ongoing physiotherapy needs.
4. Work in collaboration with paediatric physiotherapy teams to provide young people and their families or carers with information about what to expect from the adult specialist learning disability physiotherapy services following transition.
5. Aim to meet the young person with a learning disability and their family or network of care before they transition where their primary needs are physiotherapy related and they will require ongoing, long term physiotherapy support.
6. Contribute to local multidisciplinary and multiagency transition pathways and processes to support the smooth transition of young people with a learning disability and ongoing physiotherapy needs.
7. Contribute to and support the smooth transition of young people with a learning disability and their families or network of care from special education colleges to community specialist learning disability physiotherapy services where the person has ongoing physiotherapy needs. For example, make recommendations for suitable day service provision and community activities; and support the continuation of physiotherapy programmes delivered at college into the community.
8. Work in collaboration with paediatric and special education college physiotherapy teams to support the smooth transition of young people with a learning disability and ongoing physiotherapy needs between education settings where appropriate.
9. Contribute to the development of Education Health Care Plans (EHCP) for young people with a learning disability and ongoing physiotherapy needs where requested and appropriate.

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Knowledge and Skills

To deliver this role successfully it is essential that specialist learning disability physiotherapists develop appropriate knowledge, skills and experience to support the transition of young people with a learning disability from paediatric to adult services. This involves:

1. Keeping abreast with government and NICE recommendations regarding transition.
2. Understanding the changing needs of young people with a learning disability transitioning from paediatric to adult services.
3. Partnership working in line with CSP recommendations.

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Promoting the role of the physiotherapist working with adults with a learning disability

A key role of specialist learning disability physiotherapists is to raise the awareness and improve the understanding of the physiotherapy needs of adults with a learning disability and promote the role of the specialist learning disability physiotherapy team at a local, regional and national level. This aims to support the delivery, development and commissioning of specialist learning disability physiotherapy services.

To achieve this specialist learning disability physiotherapists:

1. Develop relationships with local commissioners, mainstream services and service managers.
2. Contribute to special interest groups; research studies and opportunities; NICE publications and quality standards; and nationally recognised campaigns that address and explore topics relevant to the physiotherapy needs of adults with a learning disability.
3. Support the development of literature and resources regarding the physiotherapy needs and management of adults with a learning disability.
4. Play an active role in research, service development and quality improvement projects with the view to improve the delivery of physiotherapy services to adults with a learning disability and disseminate the results.

Onion Diagram

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Co-ordinated approach to care and multi-disciplinary, multi-agency working

Adults with a learning disability will often have multi-morbidities that require a co-ordinated approach to care and multi-disciplinary and multi-agency partnership working to successfully manage their physiotherapy and wider health needs.

Onion Diagram   Supporting Evidence

Standard of Practice Statements

Specialist learning disability physiotherapists:

1. Identify adults with a learning disability who may benefit from a co-ordinated approach to care. For example; individuals with multi-morbidities; young people transitioning from paediatric to adult services; or people with dementia.
2. Work in collaboration with the multidisciplinary team to provide a co-ordinated approach to care for adults with a learning disability who have complex physical disabilities and health issues requiring long term physiotherapy management.
3. Contribute to local co-ordination processes and pathways through supporting communication, providing appropriate documentation and attending co-ordination meetings as required.
4. Develop links, open lines of communication and direct referral pathways with local health and social care services critical to the effective delivery of physiotherapy services to adults with a learning disability. This includes:
   - Mainstream and specialist respiratory services.
   - Falls prevention and intervention services.
   - Local neurological services that provide assessment and management of hypertonia and spasticity.
   - Community rehabilitation services.
   - Paediatric physiotherapy teams.
   - Specialist education college physiotherapy teams.
   - Wheelchair services.
   - Orthotic services.
   - Social services occupational therapy.
   - Commissioners.
   - Equipment providers.
5. Support and develop of local integrated multi-disciplinary and multi-agency pathways for adults with a learning disability who have or are at high risk of developing physiotherapy and health problems. This should include:
   - Integrated care pathway for the delivery of 24-hour postural management.
   - Integrated care pathway for adults with a learning disability and dysphagia.
   - Integrated care pathway for adults with a learning disability and dementia.
   - Physiotherapy transition pathways for young people with a learning disability and ongoing physiotherapy needs.
   - Integrated falls and mobility pathway.

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6. Work in collaboration with commissioning and local healthcare providers to support the development of local specialist healthcare services where there is a lack of local access or provision for adults with a learning disability. In particular:
- specialist respiratory services.
- postural management services.
- local mainstream falls and rehabilitation services.

7. Work in partnership with other physiotherapists from mainstream services, education and paediatric services to ensure that the person is receiving optimal management across all settings. Where the person is receiving therapy from more than one physiotherapy service, professionals will develop local working agreements following the recommendations set out in the CSP information paper '*Concurrent and subsequent treatment: advice to physiotherapists working in the NHS and private sector.*'

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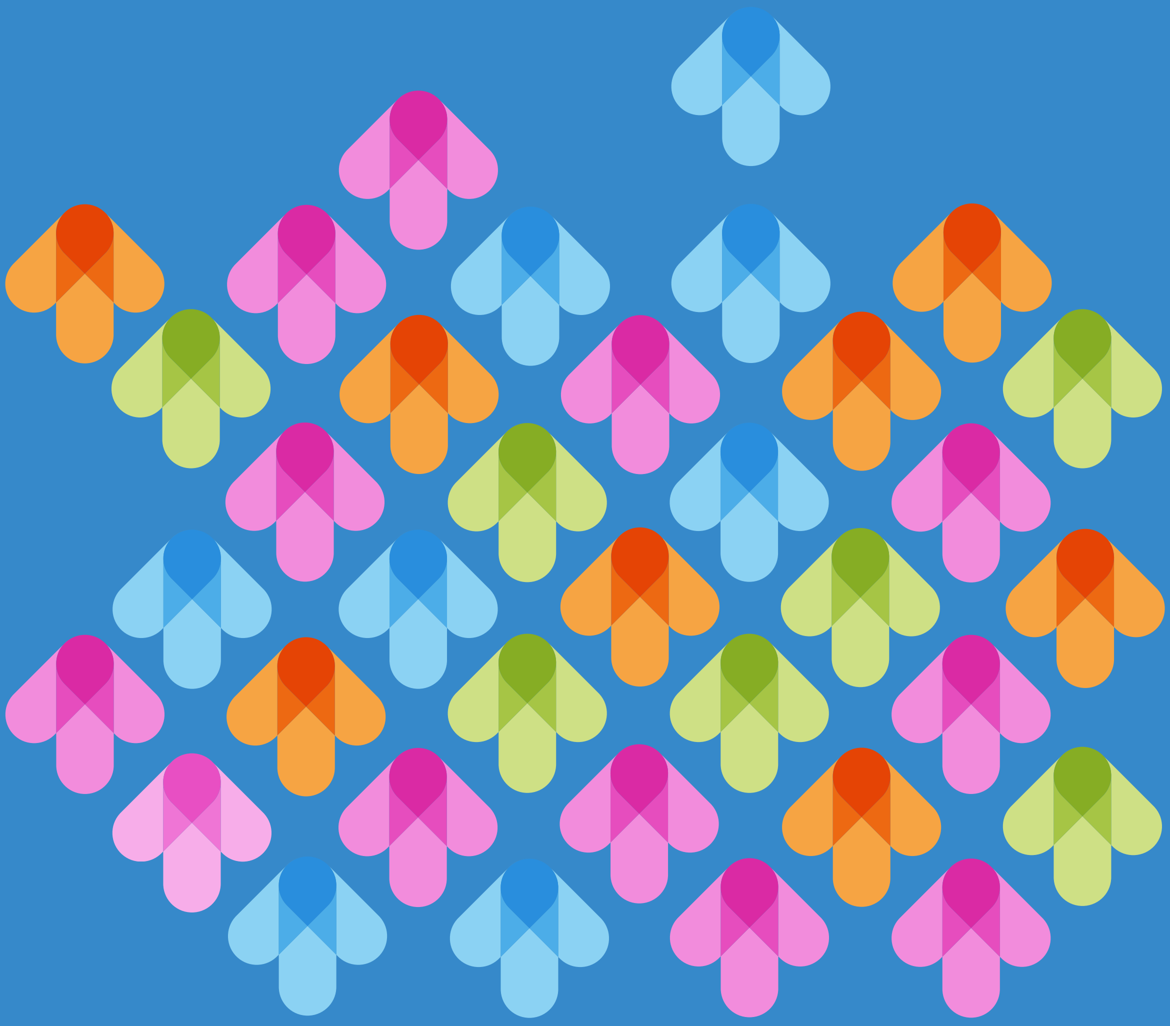
THERAPUETIC MODALITIES



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Therapuetic Modalities

Therapeutic modalities are used to augment therapy and help achieve physiotherapy goals. These include aphysiotherapy on a trampoline/rebound therapy and therapeutic riding or hippotherapy. They are recommended and delivered by a physiotherapist with specialist knowledge and skills in the area. Treatment modalities are particularly valuable and important when providing physiotherapy to adults with a learning disability as they offer the physiotherapist a tool to conduct assessments and deliver treatments that are engaging and fun which can enhance compliance. Adults with a learning disability are often non-compliant with specific exercises because they are not enjoyable, or they do not understand the reason for completing the task. Therefore, engaging people in activities rather than specific exercises can be an effective way deliver physiotherapy treatment and goals.

➔ Hydrotherapy/aquatic therapy

➔ Physiotherapy on a trampoline/rebound therapy

➔ Therapeutic riding or hippotherapy

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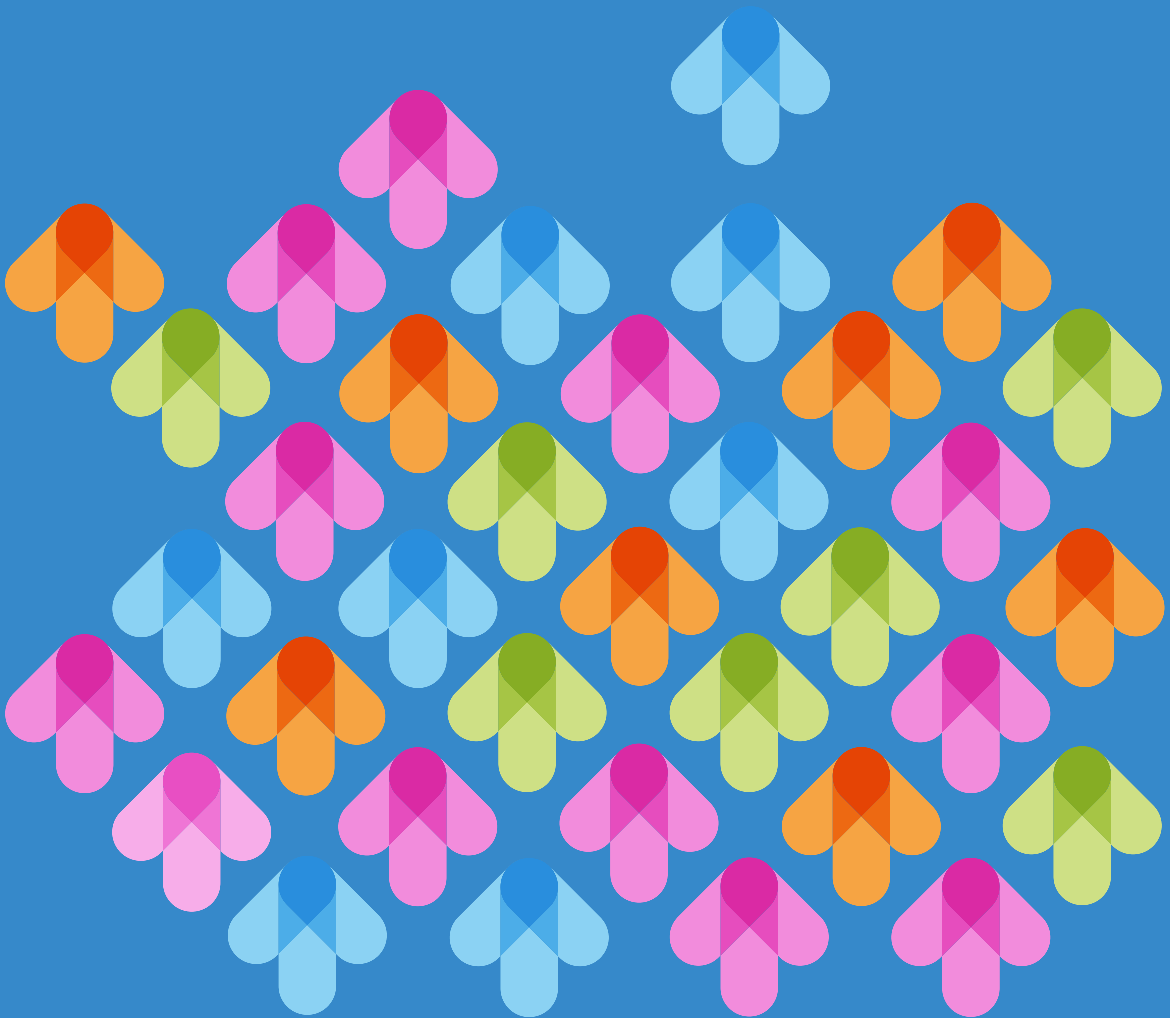
Training, education and development of specialist learning disability physiotherapists



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Training, education and development of specialist learning disability physiotherapists

Introduction

Physiotherapists working with adults with a learning disability are specialist in providing physiotherapy to adults with a learning disability who are unable to access mainstream services even when reasonable adjustments are made. To achieve this it is essential that physiotherapists have specialist knowledge and skills in:

- the health, social, learning and physiotherapy needs of adults with a learning disability;
- making the adjustments required to successfully provide physiotherapy;
- supporting positive access to and responses from mainstream physiotherapy and relevant healthcare services; and
- supporting mainstream physiotherapy and relevant healthcare services to make reasonable adjustments required to provide successful physiotherapy.

To manage the physical needs of adults with a learning disability it is essential that learning disability physiotherapists develop specialist knowledge and skills in specific areas of physiotherapy critical to delivering successful outcomes. In particular 24hr postural management, falls intervention and prevention and the management of mobility problems.

It is essential that specialist learning disability physiotherapist also have general knowledge and skills in a broad range of aspects of physiotherapy and other areas of healthcare. And be versatile in applying their specialist knowledge to meet the physiotherapy needs of an individual. Physiotherapists must acknowledge when the physiotherapy needs of an individual are beyond the scope of their knowledge and skills and then seek further support from healthcare professionals from different specialisms. Thus, it is essential that services focus on developing links and direct referral pathways with local mainstream physiotherapy and relevant healthcare services to ensure that adults with a learning disability can access the specialist knowledge and skills they require as needed.

Specialist learning disability physiotherapists are required to undertake specific and targeted training and education programmes to develop their specialist and generalist knowledge and skills of the role to become a competent and capable practitioner. It is essential that this be completed in line with and alongside the training and development requirements to be compliant with the HCPC standards of proficiency for physiotherapists; the CSP professional's value codes; and their employer's mandatory training. Training, education and development is everyone's responsibility and should occur at an individual, organisational, regional and national level.

➡ Specialists, Generalists and Generalising Specialists

➡ Training, Education and Development Responsibilities

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Training and education requirements of the specialist learning disability physiotherapist

1. **The health, social and learning needs of adults with a learning disability:**

   It is essential that learning disability physiotherapists develop specialist knowledge and skills in the following areas:

   - Tier 3 in the learning disability core skills education and training framework (Skills for Health 2019).
   - The rights of adults with a learning disability and the relevant legislation such as:
     - Human Rights Act 1998.
     - Valuing People (Department of Health 2001).
     - Valuing People Now (Department of Health 2009).
     - Autism Act 2009.
     - Equality Act 2010.
   - Communication with adults with a learning disability.
     - It is essential that Specialist learning disability physiotherapists are able to identify the communication needs of adults with a learning disability and develop a wide range of communication styles and formats to communicate effectively depending on the individual's communication support needs. For example accessible written documentation, simple verbal communication, talking mats, using pictures, Makaton, facial expression, and demonstration.
   - The Mental Capacity Act (England and Wales); Adults with incapacity (Scotland) and Mental Capacity Act Northern Ireland (Northern Ireland).
     - Specialist learning disability physiotherapists need to be aware of and compliant with the Acts as well as how they apply to clinical practice and their own role in implementing the guidance.
   - Safeguarding Vulnerable Adults (England); Adult Support and Protection (Scotland); Adult Safeguarding (Northern Ireland) and Safeguarding Adults (Wales).
     - Specialist learning disability physiotherapists need to be aware of and compliant with the legislation as well as how they apply to clinical practice and their own role in implementing the guidance.
   - The CSP guidance on Supervision, Accountability and Delegation (CSP 2017).
   - The evidence and literature addressing the health, learning and physiotherapy needs of adults with a learning disability.

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2. Supporting adults with a learning disability to have positive access to and responses from mainstream physiotherapy and relevant healthcare services including supporting services to make the reasonable adjustments required to provide successful physiotherapy:

It is essential that specialist learning disability physiotherapists develop specialist knowledge and skills in the following areas:

- The legislation, policies and guidance relevant to adults with a learning disability accessing healthcare including:
  - Healthcare for all (Michael and Richardson 2008).
  - Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report (Heslop et al. 2013).
  - Delivering Effective Specialist Community Learning Disabilities Health Team Support to People with Learning Disabilities and their Families or Carers (Learning Disability Professional Senate 2015).
  - Improving the health and wellbeing of people with learning disabilities: An evidence-based commissioning guide for Clinical Commissioning Groups (CCGs)-revised. Improving Health and Lives (RCGP 2013).
  - Learning Disabilities Mortality Review (LeDeR) Programme (NHS England 2016 and 2018).
- The role and function of different healthcare professionals and services that an adult with a learning disability may need to access.
- The issues that an adult with a learning disability may face when accessing a variety of healthcare services.

3. Specific areas of physiotherapy that are critical to managing the physical needs of the adult with a learning disability

It is essential that learning disability physiotherapists develop specialist knowledge and skills in the following areas:

- 24 hour postural management.
- Management of mobility problems associated with adults with a learning disability.
- Falls prevention and intervention.

Learning disability physiotherapists have become specialists in the 24 hour postural management of people with complex physical and learning disabilities. The evolution of this aspect of the role has resulted from a significant increase in the number and complexity of people with complex physical and learning disabilities entering into adulthood; an increase in the life expectancy of adults with a learning disability with complex disability; and a dearth in the availability of specialist postural management services across the UK. The latter was recently acknowledged by Murphy et al. (2010) who advocates for the development of specialist services across the British Isles dedicated to the 24 hour postural management of people with complex physical disability. The other specialist areas are falls intervention and prevention; and the management of mobility problems. This is due to the significantly increased incidence of falls and impairment of gait in this population of people. Dr. Janet Finlayson and Jennifer Crocket lead the way in this particular area of practice within the UK (Finlayson et al. 2010 and 2014; Crocket et al. 2015; Finlayson et al. 2015).

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4. General training and education requirements:

It is essential that learning disability physiotherapists develop general knowledge, skills and competence in a broad range of aspects of physiotherapy and other related healthcare disciplines including:

- Assessment and management of hypertonia and spasticity
- Community and specialist level respiratory assessment and management
- Dementia
- Dysphagia
- End of life care
- Epilepsy
- Health promotion
- Manual handling
- Musculoskeletal physiotherapy
- Neurological rehabilitation
- Orthopaedic surgery and rehabilitation
- Pain management
- Specialist equipment such as standing and walking frames, sleep systems and night time positioning aids
- Specialist interventions such as hydrotherapy/aquatic therapy and physiotherapy on a trampoline/rebound therapy
- Supporting adults with a learning disability who display behaviours that challenge successfully such as positive behavioural support training, de-escalation, restraint and self-protection techniques; and sensory integration training
- Wheelchair assessment and provision

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Continued professional development

The HCPC standards of proficiency for physiotherapists states that registrant professionals must understand the key concepts of the knowledge base relevant to their profession and be able to draw on appropriate knowledge and skills to inform practice. To achieve this mandate, physiotherapists are obligated to complete and evidence that they complete regular continued professional development (CPD) as part of their HCPC registration. The HCPC reports that "CPD is the way in which registrants continue to learn and develop throughout their careers so they keep their skills and knowledge up to date and are able to practise safely and effectively."

The HCPC state that it is the responsibility of professionals to keep up CPD themselves. The HCPC regulates individual professionals, which means their employers do not have a responsibility to keep up CPD themselves, but as employers are responsible for the safety of their employees' practice. Therefore, they may want to encourage CPD upkeep amongst their staff. The CSP support this view, stating that members are required to engage in CPD in order to remain registered with the HCPC. They also expect that all employers, whether in the NHS or other sectors, will facilitate CPD opportunities for their employees, and that all CSP members, whatever their working context, will allocate time to their learning.

In order to deliver excellent healthcare, members need access and engage with learning opportunities and then to consolidate and integrate their learning into practice. The NHS constitution for England (Department of Health and Social Care 2015) pledges that all NHS employers will "provide all staff with personal development, access to appropriate education and training for their jobs, and line management support to enable them to fulfil their potential." Therefore, it is crucial, for employers to facilitate individuals' learning and development in the form of physical access to learning communities, materials and technologies and/or time out of their working role to engage in learning and development activity.

The researchers support the views of the HCPC and CSP. Concurring that regular CPD ensures services deliver high standards of care that is progressive and innovative; and provide evidence-based practice. This improves the delivery of healthcare and health outcomes for adults with a learning disability. CPD ensures physiotherapists keep up to date with evidence and practice; develop their knowledge and skills; and maintain their generalist and specialist competences.

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Supervision

The HCPC and CSP recognise the importance of supervision as part of CPD; and the development and maintenance of competent physiotherapists. The HCPC standards of proficiency for physiotherapists states that registrant professionals must be able to practise as an autonomous professional, exercising their own professional judgement. To achieve this standard, physiotherapists must understand the importance of participation in training, supervision and mentoring.

The CSP recognises the Butterworth and Faugier (1992) definition for clinical supervision which states that it is ‘an exchange between practising professionals to enable the development of professional skills’. The CSP states that this is a useful definition because of how it aligns with an outcomes-based approach to CPD which is consistent with the HCPC’s expectations of registrants and the CSP’s expectations of its members.

The CSP recognises that clinical supervision in practice must strike a balance between professional development and organisational governance. The CSP has published a brief overview paper on clinical supervision in which it outlines the aims and principles of good supervision (CSP 2017b).

It is critical that specialist learning disability physiotherapists receiving adequate supervision with a suitably qualified and experienced clinician. Ideally, this would be a specialist learning disability physiotherapist. In addition to one to one clinical supervision, professionals should develop opportunities for multidisciplinary and peer group supervision; and training and support with local professionals with an expertise in working with adults with a learning disability.

Conclusion

The specialist and generalist nature of the specialist learning disability physiotherapist makes developing and maintaining the appropriate knowledge and skills challenging. Professionals will need to attend appropriate training and education courses, undertake extensive CPD, actively seek learning opportunities, and have access to appropriate supervision. They will have to keep abreast of the literature and evidence pool for their chosen area of specialism and be proactive to supporting the learning of others. There is currently no structured framework to inform the training and education of the clinical area. The standards of practice can be used as a framework to design, plan and deliver training, education and CPD opportunities that are focused and targeted. Learning opportunities should be planned at an organisational, regional and national level and be accessible for all, including students, to ensure that the broad range of topics and roles are covered regularly for new professionals entering the area as well as to refresh and update the knowledge and skills of established physiotherapists.

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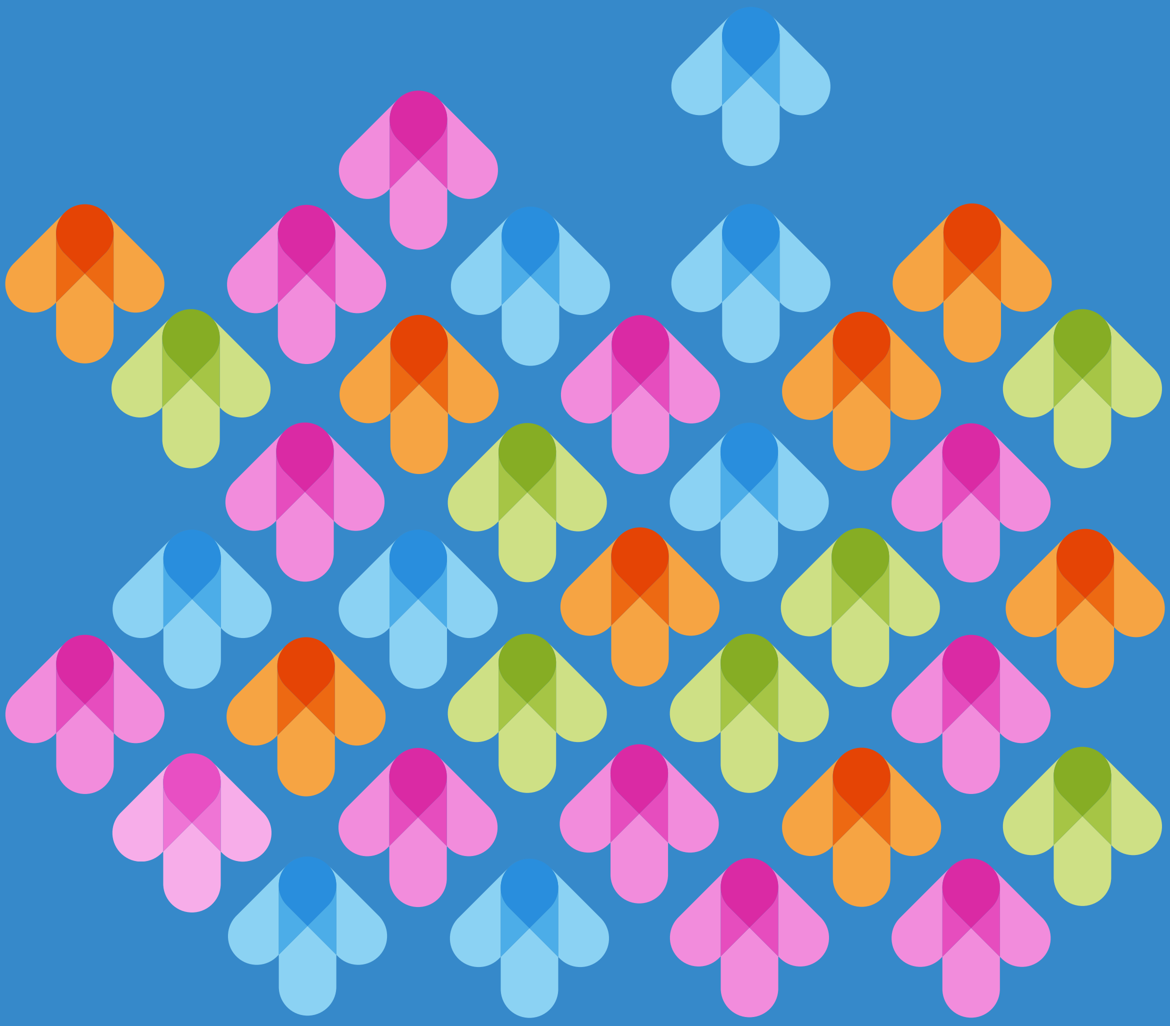
Implementing the standards of practice



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Implementing the standards of practice

Introduction

The standards of practice outline the optimal role of specialist learning disability physiotherapy services based on the available evidence and opinion of an expert participants. However, in reality, there are often a range of local drivers that impact the way specialist learning disability services are delivered. These include local employers' agendas; staffing resources; service commissioning; local mainstream health and social care services; and population variations and needs. As a result, it is essential that specialist learning disability physiotherapy services develop an in-depth understanding of current physiotherapy provision; the local population of adults with a learning disability; and the availability and accessibility of local mainstream physiotherapy and other relevant healthcare services. It is important to take these into consideration when implementing the standards of practice.

Understanding current physiotherapy service provision

Before starting to plan changes to services or implementing new guidance, it is important to understand how the service currently works. This is the baseline and can be used to measure the effect of any change. It is possible to find out about how the service works in lots of different ways. Informal discussions, online questionnaires, workshops or a review of local policies and procedures could help. It is also important to look outside of the organisation and see how the service fits into the wider community. The following methods can be used to develop an understanding of current physiotherapy provision:

1. **Referral numbers and trends:**

   A yearly referral audit can be very useful to understand current service provision and specific areas of demand. This can then provide a baseline to measure any change that may impacts on service delivery and demand.

2. **Job planning:**

   Job planning is an effective method of profiling the clinical workforce to match available clinical resources to the organisation's objectives and clinical priorities. A job plan is a prospective, professional agreement describing each staff member's duties, responsibilities, accountabilities and objectives. It aims to articulate how much of each physiotherapist's role will be allocated to clinical care and how much to any other supporting professional activities, so trusts can manage their capacity and demand.

   NHS Improvement have developed a best practice guide for allied health professionals job planning.

➔ NHS Improvement: **Allied health professionals job planning: a best practice guide**

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3. Staff workload tracker tool:

Conducting a time limited analysis of staff day to day activities can provide valuable information about daily demands on physiotherapy staff. There are a number of limitations to this methodology, in particular whether the chosen period of time during which the tool is completed truly represents a 'typical' working week. However they can develop some understanding and reduce dependence on anecdotal evidence.

NHS Improvement have developed a staff workload tracker tool to allow staff groups such as multidisciplinary team co-ordinators to track their activity. Teams and their leaders can identify the important areas of their activity and assess the time spent on each during the course of a week. This can identify those activities more appropriately performed by another person or role, and facilitate discussions about team development, expansion or modification.

NHS Improvement: **Staff workload tracker tool: user guide**

4. Baseline assessment tool:

Baseline assessment tools can be used to evaluate whether practice is in line with national recommendations and can help to plan activity to meet any identified gaps. Tools can be used by services and organisations to develop a picture of activity either on an individual level or within the local area.

The researchers have developed a baseline assessment framework to support readers to develop an understanding of their current physiotherapy services against the guidelines and recommendations in the standards of practice. The baseline assessment tool includes:

- Analysis of current physiotherapy provision against the standards of practice.
- Analysis of the training and education needs of the members of the physiotherapy team.
- The development of an action plan to implement any identified gaps in services into practice.

Toolkit: **Baseline assessment tool**

Understanding the local population

The learning disability professional senate recognise that specialist community learning disability services must be commissioned with sufficient capacity to support individuals across their life-course, and target adults with a learning disability who have additional severe, complex or recognises support needs (Learning Disability Professional Senate 2015). The government recognise that commissioning, and staff skill mix and resources must reflect the health and social care needs of the local population of adults with a learning disability (Department of Health 2007 and 2009; Learning Disability Professional Senate 2015; National Quality Boards 2017). To achieve these aims, it is essential that services develop an in-depth understanding of their local population of adults with a learning disability.

Michael and Richardson (2008) in Healthcare for All recommends that all health care organisations should ensure that they collect the data and information necessary to allow people with a learning disability to be identified by the health service and their pathways of care tracked. Mansell (2010) in Raising Our Sights specifically supports the need to develop an understanding of people with profound and multiple learning disabilities who are a relatively small population of people, and should therefore be easily identifiable within society, in order to shape services

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for this group of people. Mansell recommends that health partners, “should keep up-to-date information about the number, needs and circumstances of people with profound intellectual and multiple disabilities in their area currently and projected in future to enable effective planning of services.” It is beyond the scope of the specialist learning disability physiotherapist to have an understanding of the whole local population of adults with a learning disability but they do have a role to play in identifying high risk groups of people with physiotherapy needs such as those with specific diagnosis such as cerebral palsy and dementia; and people with postural needs or recurrent falls.

Understanding the needs of the local population helps to inform and guide the development and planning of safe, effective and fit for purpose physiotherapy workforce and services. This improves effectiveness and quality of physiotherapy provision. There are a range of resources available to develop an understanding of the number of people with a learning disability living locally.

Resources to develop an understanding of the local population of adults with a learning disability.

The researchers have developed a database which provides an estimated number of people with a learning disability in each region and CCG in England, Health and Social Care Trust in Northern Ireland, region of Scotland and local health boards in Wales. The database includes evidence based population estimates for the numbers of adults with a learning disability with health problems that are relevant to physiotherapy. The data was developed from the following sources:

- Population of people (Office of National Statistics 2011).
- Number of adults with a learning disability (Public Health England 2016; Northern Ireland Assembly 2014; Scotland Commission for Learning Disability 2017; Welsh Government 2018).
- Common causes of death (NHS England 2018).
- Falls (Cox et al. 2010; Finlayson et al 2010; Hsieh et al. 2012).
- Cerebral Palsy (Westbom et al. 2011; NICE 2012; Australian cerebral palsy register (ACPR) 2013; NICE 2017).
- Numbers of people with profound and multiple learning disabilities (Hogg et al. 2007; Emerson 2009).
- Levels of physical inactivity (Diaro et al. 2016; NHS Digital 2017).

It is important to understand that these are estimates based on research and data. Therefore the results need to be compared to local data for accuracy. However, they provide a platform to develop evidence based arguments for discussions with commissioners and building business cases.

Toolkit: **Population estimates**

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Understanding the availability and accessibility of local mainstream physiotherapy and other relevant healthcare services

The learning disability professional senate recognises that effective community learning disabilities health teams should be able to establish a detailed understanding of all local resources relevant to support individuals with a learning disability and their network of care. They should promote effective integrated working maximising the health and well-being outcomes of individuals. This role supports one of the key functions of the community learning disability team to enable others to provide effective person-centred support to people with a learning disability (Learning Disability Professional Senate 2015).

The integral relationship between specialist learning disability and mainstream health services means that it is critical for physiotherapists to develop an understanding of the availability and accessibility of local provision. There are number of mainstream physiotherapy and other relevant services that are critical to the delivery of the different roles of the specialist learning disability physiotherapist. The researchers have developed a tool to map out the relevant services locally.

➡ Toolkit: Local services map

Prioritising and rationing service delivery

Prioritising some individuals and interventions over others are difficult choices faced by most health care systems. There is no obvious set of ethical principles or analytical tools to determine what decisions should be made at which level of the health system, or how to allocate limited resources. The researchers explored the views of the expert participants on how they would prioritise the roles of the learning disability physiotherapist if there were restrictions on service provision and resources.

Participants were asked to prioritise the roles that reached consensus using the MUST, SHOULD, COULD method of prioritisation and justify their choice. Participants categorised all the roles under either must or should.

The definition for each category for the study is:

Must do:	Roles that are essential to the successful delivery of specialist learning disability physiotherapy services to adults with a learning disability. Without these roles the service would not be viable.
Should do:	Roles that are important and would have a positive impact on the overall delivery of successful physiotherapy services to adults with a learning disability but are not essential or vital. The omission of these roles would have a negative impact on service provision but it would be viable.
Could do:	Roles that would improve delivery of specialist learning disability physiotherapy services to adults with a learning disability, but if left out, they would not have a significant negative impact on service provision. These are roles that would be desirable resource permitting.

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MUST

Definition	‘Learning disability physiotherapists provide specialist assessment, treatment and management to adults with a learning disability whose needs cannot be successfully met by mainstream services, even when reasonable adjustments are made. Physiotherapists will work in collaboration with the person, their network of care, mainstream health services, and the multidisciplinary team to enhance, optimise and maintain the person’s physical’.
Delivering the Definition	1. Support adults with a learning disability to have positive access to and responses from mainstream physiotherapy and relevant healthcare services. 2. Support mainstream physiotherapy and related healthcare services to make appropriate reasonable adjustments to facilitate adults with a learning disability to have positive access to and outcomes from services.
Lead Roles	1. 24-hour postural management. 2. Community level respiratory management. 3. Falls assessment and intervention: delivering a reactive service. 4. Management of mobility problems: delivering a reactive service. 5. Rehabilitation of acute injuries and conditions for adults with a learning. disability whose needs cannot be met successfully by mainstream services. even when reasonable adjustments are made.
Contributory Roles	1. Contribute to multidisciplinary manual handling assessments and management of adults with a learning disability with complex manual or therapeutic handling needs. 2. Contribute to the management of hypertonia and spasticity. 3. Contribute to the multidisciplinary management of dysphagia.
Supporting Roles	1. Assessment and provision of specialist equipment. 2. Deliver training and education to adults with a learning disability and their network of care. 3. Provide a co-ordinated approach to care. 4. Transition of young people with a learning disability from paediatric to adult services.

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SHOULD

Lead Roles	1. Falls prevention: delivering a proactive service. 2. Management of mobility problems: delivering a proactive service.
Contributory Roles	1. Health promotion. 2. Specialist level respiratory assessment and management.
Supporting Roles	1. Deliver training and education to health and social care professionals and non-professionals, commissioners, and service providers. 2. Develop links and direct referral pathways with local health and social care services. 3. Play an active role in research, service development and quality improvement projects. 4. Work in collaboration with commissioning and local healthcare providers to support the development of and improve access to relevant local specialist healthcare services. 5. Work in collaboration with multi-disciplinary and multi-agency teams to develop local integrated care pathways to improve the physiotherapy management and health outcome of adults with a learning disability. 6. Work in partnership with other physiotherapists from mainstream services, educational settings and paediatric services in the provision of physiotherapy to adults with a learning disability.
Specialist Interventions	1. Aquatic therapy/hydrotherapy/aquatic therapy. 2. Physiotherapy on trampolines/ rebound therapy.

NB: Falls prevention and intervention, and management of mobility problems have been divided into providing reactive or proactive physiotherapy services. The definition of these terms are:

Delivering a reactive service: Physiotherapy management of falls or mobility problems post event based on referral. For example:

- Post falls
- Near miss
- Sudden deterioration in mobility
- Insidious change in mobility

Delivering a Proactive Service: Actively identifying people at risk of falls and developing mobility problems and offering physiotherapy intervention and management aimed at preventing an incident or event.

The factors to consider when prioritising and rationing specialist learning disability physiotherapy services are multifactorial (figure 7). The results of questionnaire four found that the vast majority of participants prioritise service provision due to expert opinion developed through personal experience and reflective practice. Participants stated that physiotherapists with experience of working with adults with a learning disability are well placed to design services because of their expert knowledge and understanding of the population's physiotherapy needs.

A number of participants prioritised based on the unique specialist knowledge and skills set of the learning disability physiotherapist because these services cannot be delivered by mainstream services. Thus prioritising and rationing services towards these roles result in all adults with a learning disability receiving some form of physiotherapy intervention, either through specialist or mainstream services. This prioritisation method targets services towards high risk groups of people and where physiotherapy is most effective. These include adults with a learning disability who are unable to access mainstream services; and those with long term physiotherapy needs such as people with postural needs and mobility problems.

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Another important consideration for prioritisation was the quality, willingness, availability and accessibility of local mainstream healthcare services, care providers, activities, and facilities to meet the physiotherapy needs of people with a learning disability. As discussed, there are wide variations across the UK therefore developing an understanding of local services is essential.

Some participants stated that they would prioritise based on the demand for specialist physiotherapy services locally. They would develop an understanding of this need through analysis of referral trends and caseload pressures. One potential risk of prioritising based on current service provision is that it does not take account of potential gaps in current service delivery.

Participants recognised that it is essential that services always consider national best practice guidelines, government white papers, acts and publications, and the available evidence base which can add weight to prioritisation and rationing decisions. The experts recognised that prioritisation would need to be balanced with the available funding, staffing levels, resources and commissioning.

Figure 7: Factors to consider when prioritising and rationing specialist learning disability physiotherapy services

It is critical where prioritisation and rationing of physiotherapy occurs that the resulting gaps in services are highlighted to managers and commissioners along with the potential risks of not providing this aspect of physiotherapy. This information and data is critical when developing evidence based arguments that will resonate with managers and commissioners to influence service development and provision.

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Evidencing the impact of specialist learning disability physiotherapy

Evidence states that physiotherapists are an integral part of specialist learning disability teams (RCGP 2013; Learning Disability Professional Senate 2015). There is widespread anecdotal evidence and opinion that the profession has a positive impact on health outcomes; quality of care; and experiences of the adult with a learning disability and their network of care, as well as having potential cost implications and savings for health and social care. However, there is a lack of research or literature that evidences the impact of specialist learning disability physiotherapy. In the current landscape it is essential that services can evidence the impact of specialist learning disability services on quality, experience and the cost of health and social care.

➔ Recommendations of further research

Conclusion

The aim of the standards of practice are to improve and standardise the delivery, development and commissioning of specialist physiotherapy to adults with a learning disability across the UK. To achieve this, physiotherapists working in community learning disability teams will need to implement the standards of practice into their local area. They will need to develop an understanding of the demand and gaps in current services; the local population; and relevant mainstream services. This information is critical to be able to target and prioritise resources appropriately; manage risk; and offer timely intervention within the limitations of services.

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Final Comments

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Final Comments

The aim of the 'Standards of Practice for Physiotherapists Working with Adults with a Learning Disability' are to influence a range of people, professionals and organisations to improve and standardise the delivery, development and commissioning of specialist physiotherapy to adults with a learning disability across the UK. As specialist learning disability physiotherapists, we have a passion for working with adults with a learning disability, we therefore hope we have achieved our aim. This document has evolved beyond our initial expectations, however we felt it important to share the learning we gained throughout the research process. It can be very difficult to find the time to complete this level of background reading whilst completing clinical work. Therefore, it is our intention, at the very least, to guide people in the right direction.

We believe and have evidence that the role of the specialist learning disability physiotherapist is not always fully understood and valued by some commissioners and service managers. This has resulted in the decommissioning and downgrading of posts, and professionals being asked to take on roles that are outside of their scope of practice or that divert them from their lead roles. This has led to wide variations in the provision of specialist learning disability physiotherapy services around the UK. Some services are well resourced, led by experienced physiotherapists and managers. Whilst, others have one physiotherapist who may not have the time, supervision and support to manage the day to day clinical caseload as well as promote and develop service provision. This has had a significant impact on the provision of physiotherapy services for adults with a learning disability. We believe the reasons for this are multi-factorial. However, we hope that the standards of practice will help to change the current situation by providing an evidence based outline of the role and provide the tools for professionals to develop the arguments to highlight the essential services physiotherapists provide for adults with a learning disability.

We explore the adjustments that specialist learning disability physiotherapists make to provide successful physiotherapy to adults with a learning disability that go beyond what is reasonable for mainstream services. There is significant literature that documents what adjustments are reasonable but very little that explores what is required when these are not sufficient to achieve a successful outcome. To our knowledge we are the first to explore this concept in physiotherapy. We feel strongly that we should use the concept of specialist adjustments to articulate the unique selling point of the specialist learning disability physiotherapist. Delivering these adjustments is what makes us different from mainstream services.

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We hope we have done justice to specialist learning disability physiotherapists across the UK and have outlined our role in a way that supports the profession into the future. We have started the conversation on a national level, but this needs to continue locally. It is essential that we promote the role of the specialist learning disability physiotherapist at every opportunity. This may be time consuming and may take away from clinical work in the short term, however, this is an essential aspect of our role. It raises the awareness of the needs of adults with a learning disability; supports the development of a competent workforce; and cultivates systems to improve access to healthcare and community services. Adults with a learning disability, especially the population physiotherapists tend to manage, often do not have a voice and are unable to advocate for themselves. Thus, it is our responsibility to promote services on their behalf. In the past, this would have been the responsibility of more senior physiotherapists and service managers. But in a culture where this level has disappeared from some community learning disability teams the responsibility is on all physiotherapists.

We believe that it is a good time to promote the role of the specialist learning disability physiotherapist. There has been investment into the NHS for the first time in a number of years; the NHS 10 year plan includes recommendations directly for people with a learning disability; LeDeR continues to highlight areas where services must improve; and the health and social care of people with a learning disability remains in the public forum. We hope that the standards of practice provide the evidence, knowledge and tools to have the conversations with service managers and commissioners to improve the quality and performance of physiotherapy services for adults with a learning disability across the UK. Indeed, the researchers have already received feedback of how the results have been used to secure physiotherapy posts, influence training and education opportunities, and to develop service specifications. We hope that the document will result in many more of these cases and improves the health needs and quality of life of adults with a learning disability.

Sarah Bruce and David Standley

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Standards of Practice for Physiotherapists

Working with adults with a learning disability

SUPPORTING INFORMATION

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Research methodology and results

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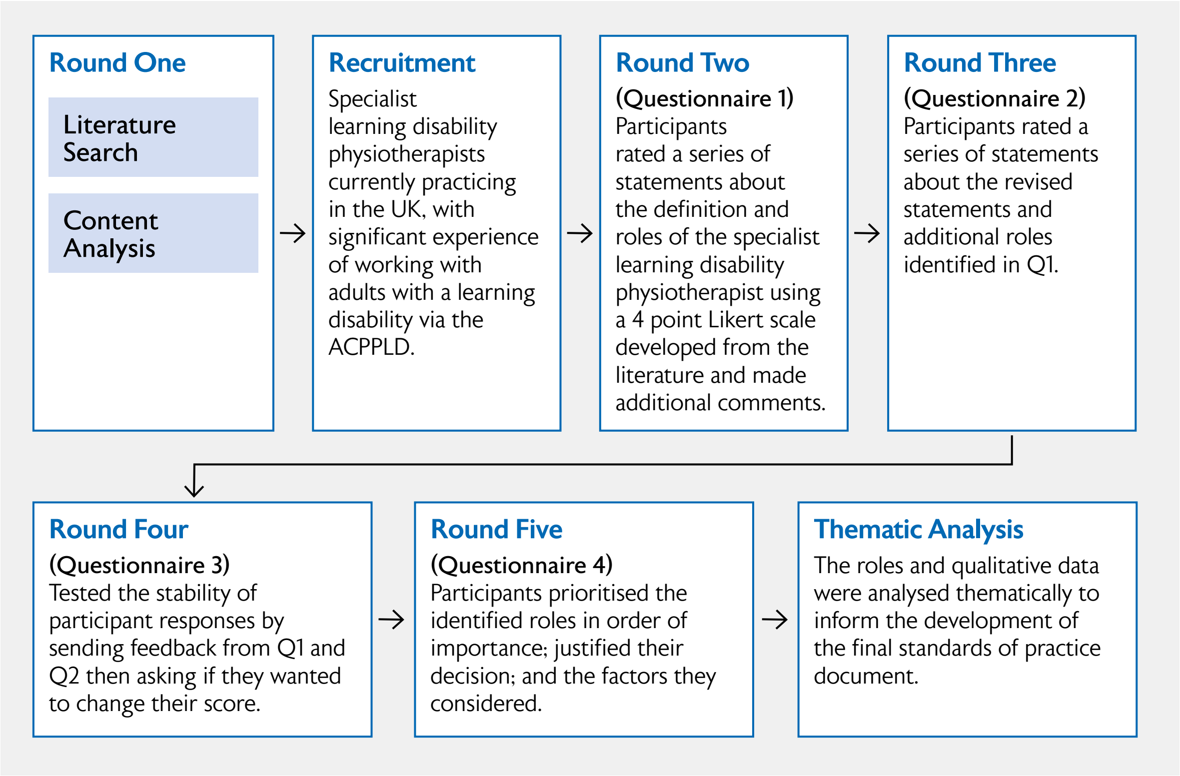
Methodology

The researchers conducted a five round Modified Delphi Technique study to develop the standards of practice for physiotherapists working with adults with a learning disability. This involved a review of the current literature; four rounds of questionnaires to explore the views and opinions of an expert panel recruited via the ACPPLD; and thematic analysis of the data. Figure 8 outlines the structured and stringent research process.

Figure 8: Research methodology flowchart



Round One

Literature Search

Content Analysis

Recruitment

Specialist learning disability physiotherapists currently practicing in the UK, with significant experience of working with adults with a learning disability via the ACPPLD.

Round Two

(Questionnaire 1)
Participants rated a series of statements about the definition and roles of the specialist learning disability physiotherapist using a 4 point Likert scale developed from the literature and made additional comments.

Round Three

(Questionnaire 2)
Participants rated a series of statements about the revised statements and additional roles identified in Q1.

Round Four

(Questionnaire 3)
Tested the stability of participant responses by sending feedback from Q1 and Q2 then asking if they wanted to change their score.

Round Five

(Questionnaire 4)
Participants prioritised the identified roles in order of importance; justified their decision; and the factors they considered.

Thematic Analysis

The roles and qualitative data were analysed thematically to inform the development of the final standards of practice document.

Data analysis: The research team used Statistical Package for Social Sciences (SPSS) to manage and analyse the quantitative data and Microsoft Word the qualitative data. Descriptive statistics were used to analyse the demographics; participant scores on the Likert scale; and prioritisation of role. Consensus was set a priori at 90% scoring the roles slight, somewhat or very important; and 80% scoring agree or strongly agree for the standard of practice statements for each role. Stability of responses in round four was analysed for statistical significance using Wilcoxon Signed Rank test ($p>0.05$). Qualitative data was analysed thematically.

Blinding: Participants were anonymised to the researcher handling the data to reduce the risk of bias. Questionnaires were anonymised using a unique coding system before data analysis.

Ethical considerations: The research involved NHS staff therefore an Ethics Committee review was not required for the research study.

Sponsorship and approval: Guy's and St Thomas' NHS foundation Trust sponsored the study and the Health Research Authority approved the study.

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Results

Literature Search:

84 relevant publications including 16 government publications, 13 NICE guidelines, 27 research papers and 28 grey literature met the inclusion criteria for the research study. Content analysis resulted in a draft definition for physiotherapists working with adults with a learning disability; 14 different roles; and statements outlining the features of these roles.

Participants:

53 physiotherapists returned questionnaire one. 39 participants completed questionnaire two and three, and 37 completed questionnaire four. The mean number of years' experience working as a physiotherapist was 18.6 and 11.8 working with adults with a learning disability. The majority of participants were working at band 7 level. There was an even distribution across the regions of the UK

Consensus rating:

Definition:

The 9 statements which made up the definition developed in round one reached consensus but a number of amendments were recommended. These were taken into consideration and sent to the participants for rating in questionnaire two in form of two statements. Consensus score increased for the two statements. Therefore, this was adopted as the new definition for the specialist learning disability physiotherapist.

Roles:

In round two, all 14 roles identified in the literature review reached consensus (93.7% to 100%). Participants identified 14 additional roles which were distributed for rating in the second questionnaire. 12 out the 14 reached consensus (92.3% - 100%). Two were rejected (82.1% and 84.6%). Stability of responses was achieved for 25/28 roles demonstrating that participants were not influenced in their decision by their peers for the majority of the scores.

Consensus was demonstrated for the definition and 26 out of the 28 different roles of the specialist learning disability physiotherapist identified by the research and participants. This highlights that the profession covers a wide scope of practice; that there are significant variations in delivery across the UK; and that the research and literature does not accurately represent the clinical picture.

The researchers conducted thematic analysis to group the 26 roles into 15 under the three main categorises to develop the Onion model which outlines the roles of the specialist learning disability physiotherapist. Agreement was also reached for the features of each role which have been developed into the standards of practice statements. These outline the expected level of performance for each role.

Thematic Analysis:

The qualitative data in the form of the comments made by participants were thematically analysed by the researchers to derive:

1. Standards of practice that outline an expected and achievable level of performance for specialist learning disability physiotherapy services across the UK;
2. The specialist adjustments learning disability physiotherapists make to provide successful outcomes to adults with a learning disability;
3. The specialist and generalist knowledge and skills of the learning disability physiotherapist and the training and education requirements for the profession; and
4. The recommendations for implementing the standards of practice into practice.

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Literature review

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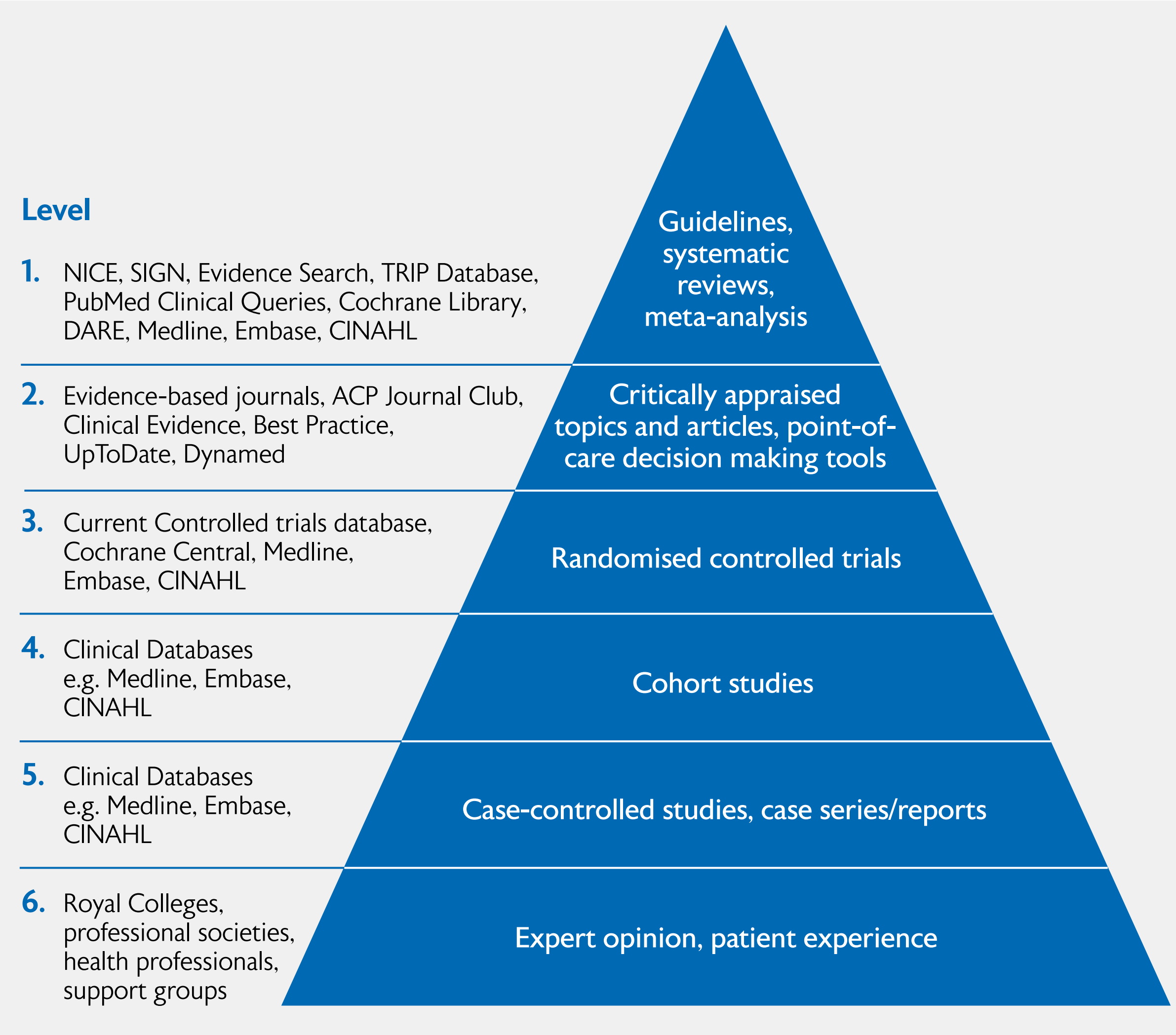
Figure 9: Hierarchy of evidence pyramid



Level

1. NICE, SIGN, Evidence Search, TRIP Database, PubMed Clinical Queries, Cochrane Library, DARE, Medline, Embase, CINAHL
2. Evidence-based journals, ACP Journal Club, Clinical Evidence, Best Practice, UpToDate, Dynamed
3. Current Controlled trials database, Cochrane Central, Medline, Embase, CINAHL
4. Clinical Databases e.g. Medline, Embase, CINAHL
5. Clinical Databases e.g. Medline, Embase, CINAHL
6. Royal Colleges, professional societies, health professionals, support groups

Adapted from DiCanso A, Bayley L and Haynes RB 2009. Accessing pre-appraised evidence: fine tuning the 5S model into a 6S model. Evidence-Based Nursing, 12(4), 99-101 in Brun CD. 2013 Finding the evidence: A key step in the information production process. The Information Standard Guide. Available at https://www.england.nhs.uk/wp-content/uploads/2017/02/tis-guide-finding-the-evidence-07nov.pdf lasted accessed on the 08.08.17

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<table>
<tr><th>Ref</th><th>Name</th><th>Journal</th><th>Date</th><th>Type of Publication</th><th>Hierarchy of Evidence</th><th>Roles informed</th></tr>
<tr><td colspan="7">Research Papers</td></tr>
<tr><td>Bott et al.</td><td>Guidelines for the physiotherapy management of the adult, medical, spontaneously breathing patient</td><td>Thorax</td><td>2009</td><td>Systematic Review</td><td>1</td><td>• Respiratory Management</td></tr>
<tr><td colspan="7">Bott J, Blumenthal S, Buxton M, Ellum S, Falconer C, Garrod R, Harvey A, Hughes T, Lincoln M, Mikelsons C and Potter C 2009. Guidelines for the physiotherapy management of the adult, medical, spontaneously breathing patient. Thorax, 64 (Suppl 1), i1-i52.</td></tr>
<tr><td>Burt</td><td>Physiotherapy for service users: a personal account.</td><td>Learning Disability Practice</td><td>2014</td><td>Professional Opinion</td><td>6</td><td>• Supporting access from mainstream health services
• Training and Education</td></tr>
<tr><td colspan="7">Burt JA 2014. Physiotherapy for service users: a personal account. Learning Disability Practice, 17(6).</td></tr>
<tr><td>Castle et al.</td><td>A 24-hour postural care service: Views, understanding and training needs of referring multidisciplinary staff</td><td>International Journal of Therapy and Rehabilitation</td><td>2014</td><td>Mix method – questionnaire and focus groups</td><td>5</td><td>• 24hr Postural Management
• Training and Education</td></tr>
<tr><td colspan="7">Castle D, Stubbs B, Clayton S and Soundy A 2014. A 24-hour postural care service: Views, understanding and training needs of referring multidisciplinary staff. International Journal of Therapy and Rehabilitation, 21(3), 132-139.</td></tr>
<tr><td>Crockett et al.</td><td>Promoting Exercise as Part of a Physiotherapy-Led Falls Pathway Service for Adults with Intellectual Disabilities: A Service Evaluation</td><td>Journal of applied research in intellectual disabilities</td><td>2015</td><td>Test - Restest Study</td><td>4</td><td>• Falls Prevention and Intervention</td></tr>
<tr><td colspan="7">Crockett J, Finlayson J, Skelton DA and Miller G 2015. Promoting Exercise as Part of a Physiotherapy-Led Falls Pathway Service for Adults with Intellectual Disabilities: A Service Evaluation. Journal of applied research in intellectual disabilities, 28(3), 257-264.</td></tr>
<tr><td>Diaro et al.</td><td>Physical activity levels in adults with intellectual disabilities: A systematic review</td><td>Preventive medicine reports</td><td>2016</td><td>Systematic Review</td><td>1</td><td>• Health Promotion</td></tr>
<tr><td colspan="7">Dairo YM, Collett J, Dawes H and Oskrochi GR 2016. Physical activity levels in adults with intellectual disabilities: A systematic review. Preventive medicine reports, 4, 209-219.</td></tr>
<tr><td>Emerson</td><td>Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England</td><td>Journal of Intellectual Disabilities</td><td>2005</td><td>Cohort Study</td><td>4</td><td>• Health Promotion</td></tr>
<tr><td colspan="7">Emerson E 2005. Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England. Journal of Intellectual Disability Research, 49(2), 134-143.</td></tr>
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Ref	Name	Journal	Date	Type of Publication	Hierarchy of Evidence	Roles informed
Research Papers						
Farley et al.	What is the evidence for the effectiveness of postural management?	British Journal of Therapy and Rehabilitation	2007	Literature review	4	• 24hr Postural Management
Farley R, Clark J, Davidson C, Evans G, Maclennan K, Michael S, Morrow M and Thorpe S 2003. What is the evidence for the effectiveness of postural management? British Journal of Therapy and Rehabilitation, 10(10), 449-455.						
Foran et al.	Expanding assessment of fear of falling among older adults with an intellectual disability: A pilot study to assess the value of proxy responses	Geriatrics	2013	Interview	4	• Falls Prevention and Intervention
Foran S, McCarron M and McCallion P 2013. Expanding assessment of fear of falling among older adults with an intellectual disability: A pilot study to assess the value of proxy responses. ISRN Geriatrics.						
Finlayson et al.	Understanding predictors of low physical activity in adults with intellectual disabilities	Journal of applied research in intellectual disabilities	2009	Prospective cohort design	4	• Health Promotion
Finlayson J, Jackson A, Cooper SA, Morrison J, Melville C, Smiley E, Allan L and Mantry D 2009. Understanding predictors of low physical activity in adults with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 22(3), 236-247.						
Finlayson at el.	Injuries, falls and accidents among adults with intellectual disabilities. Prospective cohort study.	Journal of Intellectual Disability Research	2010	Prospective cohort design	4	• Falls Prevention and Intervention
Finlayson J, Morrison J, Jackson A, Mantry D and Cooper SA 2010. Injuries, falls and accidents among adults with intellectual disabilities. Prospective cohort study. Journal of Intellectual Disability Research, 54(11), 966-980.						
Finlayson et al.	Measuring the actual levels and patterns of physical activity/inactivity of adults with intellectual disabilities	Journal of applied research in intellectual disabilities	2011	Observational Cohort Study	4	• Health Promotion
Finlayson J, Turner A and Granat MH 2011. Measuring the actual levels and patterns of physical activity/inactivity of adults with intellectual disabilities. J. Appl. Res. Intellect. Disabil. 6, 508–517.						
Finlayson et al.	The provision of aids and adaptations, risk assessments, and incident reporting and recording procedures in relation to injury prevention for adults with intellectual disabilities: cohort study	Journal of intellectual disability research	2015	Qualitative methodology using mixture of questionnaires and interviews	4	• Management of Mobility Problems • Falls Prevention and Intervention
Finlayson J, Jackson A, Mantry D, Morrison J and Cooper SA 2015. The provision of aids and adaptations, risk assessments, and incident reporting and recording procedures in relation to injury prevention for adults with intellectual disabilities: cohort study. Journal of intellectual disability research, 59(6), 519-529.						

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Ref	Name	Journal	Date	Type of Publication	Hierarchy of Evidence	Roles informed
Research Papers						
Finlayson et al.	The circumstances and impact of injuries on adults with a learning disability	The British Journal of Occupational Therapy	2014	Qualitative methodology using Interveiws	4	• Falls Prevention and Intervention
Finlayson J, Morrison, J, Skelton DA, Ballinger C., Mantry, D., Jackson, A. and Cooper, S.A., 2014. The circumstances and impact of injuries on adults with learning disabilities. British Journal of Occupational Therapy, 77(8), pp.400-409.						
Hawkins and Look	Levels of engagement and barriers to physical activity in a population of adults with a learning disability	British Journal of Learning Disabilities	2006	Cohort Study	4	• Health Promotion
Hawkins A and Look R 2006. Levels of engagement and barriers to physical activity in a population of adults with learning disabilities. British Journal of Learning Disabilities, 34(4), 220-226.						
Hallawell et al.	Physical activity and learning disability	British Journal of Nursing	2012	Scholar Paper	6	• Health Promotion
Hallawell B, Stephens J and Charnock D 2012. Physical activity and learning disability. British Journal of Nursing, 21(10). 609-612.						
Humphrey and Pountney	The development and implementation of an integrated care pathway for 24-hour postural management: a study of the views of staff and carers.	Physiotherapy	2006	Qualitative methodology using focus groups	5	• 24hr Postural Management
Humphreys G and Pountney T 2006. The development and implementation of an integrated care pathway for 24-hour postural management: a study of the views of staff and carers. Physiotherapy, 92(4), 233-239.						
Katalinic et al.	Stretch for the treatment and prevention of contractures	Cochrane Database	2010	Cochrane Meta-Analysis Review	1	• 24hr Postural Management
Katalinic OM, Harvey LA, Herbert RD, Moseley AM, Lannin NA and Schurr K 2010. Stretch for the treatment and prevention of contractures. Cochrane Database of Systematic Reviews, (9).						
McKeon	A pilot survey of physical activity in men with an intellectual disability	Journal of Intellectual Disabilities	2013	Observational cohort study	4	• Health Promotion
McKeon M, Slevin E and Taggart L 2013. A pilot survey of physical activity in men with an intellectual disability. Journal of Intellectual Disabilities, 17(2), 157-167.						
Middleton and Kitchen	Factors affecting the involvement of day centre care staff in the delivery of physiotherapy to adults with intellectual disabilities: An exploratory study in one London borough.	Journal of applied research in intellectual disabilities	2007	Interview	6	• Training and Education
Middleton MJ and Kitchen SS 2008. Factors affecting the involvement of day centre care staff in the delivery of physiotherapy to adults with intellectual disabilities: An exploratory study in one London borough. Journal of Applied Research in Intellectual Disabilities, 21(3), 227-235.						

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Ref	Name	Journal	Date	Type of Publication	Hierarchy of Evidence	Roles informed
Research Papers						
Petropoulou et al.	Injuries reported and recorded for adults with intellectual disabilities who live with paid support in Scotland: A comparison with Scottish adults in the general population.	Journal of Applied Research in Intellectual Disabilities	2016	Service Evaluation	4	• Falls Prevention and Intervention
Petropoulou E, Finlayson J, Hay M, Spencer W, Park R, Tannock H, Galbraith E, Godwin J and Skelton DA 2017. Injuries reported and recorded for adults with intellectual disabilities who live with paid support in Scotland: a comparison with Scottish adults in the general population. Journal of applied research in intellectual disabilities, 30(2), 408-415.						
Proesmans et al.	Respiratory morbidity in children with profound intellectual and multiple disability	Paediatric pulmonology	2015	Observational Cohort Study	4	• Respiratory Management
Proesmans M, Vreys M, Huenaerts E, Haest E, Coremans S, Vermeulen F and Feys H 2015. Respiratory morbidity in children with profound intellectual and multiple disability. Pediatric pulmonology, 50(10), 1033-1038.						
Robertson et al.	Postural care for people with intellectual disabilities and severely impaired motor function: A scoping review	Journal of Applied Research in Intellectual Disabilities	2018	Literature Review	2	• 24hr Postural Management
Robertson J, Baines S, Emerson E and Hatton C 2018. Postural care for people with intellectual disabilities and severely impaired motor function: A scoping review. Journal of applied research in intellectual disabilities, 31, 11-28.						
Sackley et al.	The reliability of balance, mobility and self-care measures in a population of adults with a learning disability known to a physiotherapy service	Clinical rehabilitation	2002	Reliability Study	4	• Falls Prevention and Intervention
Sackley C, Richardson P, McDonnell K, Ratib S, Dewey M and Hill HJ 2005. The reliability of balance, mobility and self-care measures in a population of adults with a learning disability known to a physiotherapy service. Clinical rehabilitation, 19(2), 216-223.						
Standley	The aquatic therapy competency assessment tool for support workers.	Aqualines	2010	Professional Opinion	6	• Training and Education
Standley D 2010. The aquatic therapy competency assessment tool for support workers. Aqualines: Journal of the Aquatic Therapy Association of Chartered Physiotherapists. 22 (2): 5-10.						
Standley	Respiratory Care in People with PMLD and Complex Physical Disability	PMLD Link	2016	Professional Opinion	6	• Respiratory Management
Standley D 2016. Respiratory Care in People with PMLD and Complex Physical Disability. PMLD Link. 28(3): 85; 23-28.						

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Ref	Name	Journal	Date	Type of Publication	Hierarchy of Evidence	Roles informed
Research Papers						
Stewart et al.	Residential carers' knowledge and attitudes towards physiotherapy interventions for adults with a learning disability	British Journal of Learning Disabilities	2009	Interview	5	• Supporting access from mainstream health services • Management of Mobility Problems • Health Promotion
Stewart S, Macha R, Hebblethwaite A and Hames A 2009. Residential carers' knowledge and attitudes towards physiotherapy interventions for adults with learning disabilities. British Journal of Learning Disabilities, 37(3), 232-238.						
Wolff et al.	Development and evaluation of a community respiratory physiotherapy service for children with severe neuro-disability	BMJ quality improvement reports	2015	Retrospective Service Evaluation	3	• Respiratory Management
Wolff A, Griffin H, Flanigan M, Everest S, Thomas D and Whitehouse W 2015. Development and evaluation of a community respiratory physiotherapy service for children with severe neurodisability. BMJ Open Quality, 4(1), u208552-w3411.						

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Ref	Name	Date	Type of Publication	Hierarchy of Evidence	Roles informed
NICE Guidelines					
NICE CG42	Dementia: supporting people with dementia and their carers in health and social	2006	Clinical Guidelines	1	• Adult with Learning Disabilities and Dementia
NICE 2006. Dementia: supporting people with dementia and their carers in health and social care (CG42). London					
NICE CG145	Spasticity in under 19s: management	2012	Clinical Guidelines	1	• 24hr Postural Management • Falls Prevention and Intervention • Management of Mobility Problems • Spasticity Management • Transition
NICE 2012. Spasticity in under 19s: management (cg145). London					
NICE CG146	Osteoporosis: assessing the risk of fragility fracture	2012	Clinical Guidelines	1	• Falls Prevention and Intervention • Management of Mobility Problems
NICE 2012. Osteoporosis: assessing the risk of fragility fracture (cg 146). London					
NICE CG 161	Falls in older people: assessing risk and prevention	2013	Clinical Guidelines	1	• Falls Prevention and Intervention • Management of Mobility Problems
NICE 2013. Falls in older people: assessing risk and prevention (cg161). London					
NICE CG 179	Pressure Ulcers: prevention and management	2014	Clinical Guidelines	1	• 24hr Postural Management
NICE 2014. Pressure Ulcers: prevention and management (cg179). London					
NICE CG11	Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges	2015	NICE Guidelines	1	• Behaviour that Challenge
NICE 2015. Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (NG11). London					
NICE NG16	Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset	2015	NICE Guidelines	1	• Health Promotion
NICE 2015. Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset (NG16). London					
NICE QS86	Falls in older people	2015	Quality Standards	1	• Falls Prevention and Intervention
NICE 2015. Falls in older people (qs86). London					

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Ref	Name	Date	Type of Publication	Hierarchy of Evidence	Roles informed
NICE Guidelines					
NICE CKS	Osteoporosis - prevention of fragility fractures	2016	Clinical Knowledge Summary	1	• 24hr Postural Management
NICE Clinical Knowledge Summaries 2016. Osteoporosis - prevention of fragility fractures. London					
NICE NG 43	Transition from children's to adult's services for young people using health or social care services	2016	NICE Guidelines	1	• Transition • Case Co-ordination
NICE 2016. Transition from children's to adult's services for young people using health or social care services (ng43). London					
NICE NG56	Multimorbidity: clinical assessment and management	2016	NICE Guidelines	1	• Management of Mobility Problems • Case Co-ordination
NICE 2016. Multimorbidity: clinical assessment and management (ng56). London					
NICE NG62	Cerebral palsy in under 25s: assessment and management	2017	NICE Guidelines	1	• 24hr Postural Management • Spasticity Management • Dysphagia Management • Transition • Case Co-ordination
NICE 2017. Cerebral palsy in under 25s: assessment and management (NG62). London					
NICE QS149	Osteoporosis	2017	Quality Standards	1	• Falls Prevention and Intervention • Management of Mobility Problems
NICE 2017. Osteoporosis (qs149). London					

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Reference	Name	Date	Type of Publication	Hierarchy of Evidence	Roles informed
Government Publications					
CSP	Supervision, Accountability and Delegation	2017	Information Paper	1	• Training and Education
Chartered Society of Physiotherapy 2017. Supervision, Accountability and Delegation. London. Available at: https://www.csp.org.uk/system/files/supervision_accountability_delegation_final.pdf Last accessed 04.04.19					
CSP	Safe practice in rebound therapy	2016	Best Practice Guidance	6	• 24hr Postural Management • Respiratory Management • Management of Mobility Problems • Falls Prevention and Intervention • Health Promotion
Chartered Society of Physiotherapy 2016. Safe Practice in Rebound Therapy (2016). Rebound Therapy Association for Chartered Physiotherapists					
Department of health	Valuing people	2001	Strategy	6	• Supporting access from mainstream health services • Health Promotion • Case Co-ordination • Training and Education
Department of Health 2001. Valuing People: A New Strategy for Learning Disability for the 21st Century. London. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf					
Department of health	Commissioning specialist adult Learning disability health services	2007	Best Practice Guidance	6	• Supporting access from mainstream health services • Training and Education
Department of Health 2007. Commissioning Specialist Adult Learning Disability Services: Good Practice Guidance. London. http://www.debramooreassociates.com/Resources/DH%20Commissioning%20Specialist%20LD%20Adult%20health%20services.pdf					
Department of health	Valuing people now	2009	Strategy	6	• Supporting access from mainstream health services • Health Promotion • Case Co-ordination • Training and Education
Department of Health 2009. Valuing People Now: A New Three Year Strategy for People with Learning Disabilities. London					
Heslop et al.	Confidential inquiry into premature deaths of people with learning disabilities	2013	Inquiry	2	• Supporting access from mainstream health services • 24hr Postural Management • Respiratory Management • Case Co-ordination • Training and Education
Heslop P, Blair P, Fleming P, Hoghton M, Marriott A and Russ L 2013. Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Bristol: Norah Fry Research Centre.					

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Reference	**Name**	**Date**	**Type of Publication**		**Roles informed**
Government Publications					
RCGP et al.	Evidence-based commissioning guide for clinical commissioning groups	2013	Best Practice Guidance	6	• Supporting access from mainstream health services • 24hr Postural Management • Health Promotion • Transition • Training and Education
Royal College of General Practitioners (RCGP) 2013. Improving the health and wellbeing of people with learning disabilities: An evidence-based commissioning guide for Clinical Commissioning Groups (CCGs)-revised. Improving Health and Lives: Learning Disabilities Observatory, Durham.					
Learning Disability Professional Senate	Delivering effective specialist community learning disabilities health team support to people with learning disabilities and their families or carers	2015	Best Practice Guidance	6	• Supporting access from mainstream health services • 24hr Postural Management • Respiratory Management • Management of Mobility Problems • Transition • Behaviours that Challenge • Case Co-ordination • Manual handling • Training and Education
Learning Disability Professional Senate 2015. Delivering effective specialist community learning disabilities health team support to people with learning disabilities and their families or carers. London. Available at: http://acppld.csp.org.uk/documents/national-ld-professional-senate-briefing-paper last accessed 10.06.19					
Mansell	Raising our sights	2010	Strategy	6	• 24hr Postural Management • Respiratory Management • Transition • Training and Education
Mansell J 2010. Raising our sights: services for adults with profound intellectual and multiple disabilities. Tizard Learning Disability Review, 15(3), 5-12					
Michael and Richardson	Healthcare for all	2008	Inquiry	6	• Supporting access from mainstream health services
Michael J and Richardson A 2008. Healthcare for all: the independent inquiry into access to healthcare for people with learning disabilities. Tizard Learning Disability Review, 13(4), pp.28-34.					
National Quality Board	Safe, sustainable and productive staffing: An improvement resource for learning disability services	2018	Best Practice Guidance	6	• Supporting access from mainstream health services • 24hr Postural Management • Health Promotion • Transition • Training and Education • Manual handling
National Quality Board 2018. Safe, Sustainable and Productive staffing: An improvement resource for learning disability services. London. Available at: https://improvement.nhs.uk/documents/588/LD_safe_staffing20171031_proofed.pdf last accessed 28/07/19.					
NHS England	Right care pathway for adults with dysphagia	2017	Best Practice Guidance	1	• Respiratory Management • Dysphagia Management
NHS England 2017. Right Care Pathway for adults with Dysphagia (DRAFT). London.					

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Reference	Name	Date	Type of Publication		Roles informed
Government Publications					
NHS Quality Improvement	Quality indicators learning disabilities	2004	Quality Improvement Paper	6	• Supporting access from mainstream health services • 24hr Postural Management • Respiratory Management • Transition • Training and Education
NHS Quality Improvement Scotland (2004) Quality Indicators Learning Disabilities. Scotland. Available at: https://www.choiceforum.org/docs/qualindic.pdf last accessed 01/08/19.					
Public Health England	Postural care services: making reasonable adjustments	2018b	Best Practice Guidance	1	• 24hr Postural Management • Respiratory Management • Training and Education
Public Health England 2016. Dysphagia in people with a learning disability: reasonable adjustments guidance. Available at: https://www.gov.uk/government/publications/dysphagia-and-people-with-learning-disabilities/dysphagia-in-people-with-learning-difficulties-reasonable-adjustments-guidance last accessed 13.06.19					
Truesdale and Brown	People with learning disabilities in Scotland: Health needs assessment update report	2017	Health Needs Assessment	6	• Supporting access from mainstream health services • Falls Prevention and Intervention • Health Promotion • Training and Education
Truesdale M and Brown M 2017. People with a learning disability in Scotland: 2017 Health Needs Assessment Update Report. NHS Health Scotland, Edinburgh					

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Ref	Name	Date	Type of Publication	Hierarchy of Evidence	Roles informed
Grey Literature					
ACPPLD	So your next patient has a learning disability	2016	Resource Guide	6	• Supporting access from mainstream health services
ACPPLD 2016. So your next patient has a learning disability. Available at: https://www.csp.org.uk/publications/so-your-next-patient-has-learning-disability-guide-physios-not-specialising-learning last accessed 01/08/19.					
Cole	Into the mainstream: physio access for those with learning disabilities	2016	Frontline Article	6	• Supporting access from mainstream health services
Cole A 2016. Into the mainstream: physio access for those with learning disabilities. Frontline; 22(11). Available at: http://www.csp.org.uk/frontline/article/mainstream-physio-access-those-learning-disabilities last accessed 01/08/19.					
Crooks	Adult learning disability physiotherapy service guidelines	2013	Service Spec	6	• Supporting access from mainstream health services • Respiratory Management • 24hr Postural Management • Falls Prevention and Intervention • Management of Mobility Problems • Health Promotion • Dysphagia Management • Training and Education
Crooks L 2017. Adult Learning Disability Physiotherapy Service Guidelines: NHS Shetland. Available at: http://www.shb.scot.nhs.uk/departments/physiotherapy/LDPGuidelines.pdf last accessed 01/08/19.					
Doukas et al.	Supporting people with profound and multiple learning disabilities	2017	Campaign	6	• 24hr Postural Management • Management of Mobility Problems • Falls Prevention and Intervention • Transition • Training and Education
Doukas T Fergusson A. Fullerton M. Grace J. 2017. Supporting people with profound and multiple learning disabilities: Core and lEssential Service Standards. Edition 1. Available at: http://www.pmldlink.org.uk/wp-content/uploads/2017/11/Standards-PMLD-h-web.pdf last accessed 01/08/19.					
Finlayson	Injury and Fall Prevention for People with Learning Disabilities	2016	Resource Guide	6	• Falls Prevention and Intervention
Finlayson J 2016. Injury and Fall Prevention for People with Learning Disabilities; A resource Guide for People who care for, or support people with learning disabilities. Available at: https://agile.csp.org.uk/system/files/?file=injury-and-fall-prevention-for-people-with-learning-disabilities-resource-guide.pdf last accessed 01/08/19.					
Hodges	Getting to grips with learning disabilities	2005	Frontline Article	6	• Supporting access from mainstream health services • Management of Mobility Problems • Health Promotion • Training and Education
Hodges C 2005. Getting to grips with learning disabilities. Frontline; 11(12).					

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Ref	Name	Date	Type of Publication	Hierarchy of Evidence	Roles informed
Grey Literature					
Hunt	Fit for purpose	2007	Frontline Article	6	• Health Promotion
Hunt L 2007. Fit for purpose. Frontline. 13 (4)					
Hunt	Home care: unbreakable bonds	2017	Frontline Article	6	• 24hr Postural Management • Respiratory Management • Dysphagia Management • Training and Education
Hunt L 2017. Home care: Unbreakable Bonds. Frontline. 23(10) Available at: http://www.csp.org.uk/frontline/article/home-care-unbreakable-bonds last accessed 01/08/19.					
Johnson	Physiotherapy intervention groups for people who fall and have a learning disability – A pilot study.	2007	ACPPLD newsletter	6	• Falls Prevention and Intervention
Johnson S 2007. Physiotherapy Intervention Groups for People who Fall and have a Learning Disability – A Pilot Study. FINAL NEWSLETTER March. 9-15.					
Lowes	An exploration of the attitudes and perceptions of NHS physiotherapists not specialised in learning disability towards treating adults with a learning disability in primary and secondary healthcare settings in Northumberland.	2006	ACPPLD newsletter	6	• Supporting access from mainstream health services
Lowes L 2006. An exploration of the attitudes and perceptions of NHS physiotherapists not specialised in learning disability towards treating adults with learning disabilities in primary and secondary healthcare settings in Northumberland. ACPPLD Newsletter.					
Lowes	Can tasks be delegated to non-qualified staff without consistency or effectiveness being affected?	2007	ACPPLD newsletter	6	• Training and Education
Lowes L 2007. Can tasks be delegated to non-qualified staff without consistency or effectiveness being affected? ACPPLD Newsletter.					
Mencap	Treat me well	2018	Campaign	6	• Training and Education
Mencap 2017. Treat me well: Simple adjustment make a big difference. Available at: https://www.mencap.org.uk/get-involved/campaign-mencap/current-campaigns/treat-me-well last accessed on 16.05.19.					
McMillan	Pedal Power	2013a	Frontline Article	6	• Health Promotion
McMillan I 2013. Pedal Power. Frontline. 19(1).					
McMillan	Physios could play crucial role following launch of learning disability strategy	2013b	Frontline Article	6	• Supporting access from mainstream health services
McMillan I 2013. Physios could play crucial role following launch of learning disability strategy. Frontline. 19(13).					

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Ref	Name	Date	Type of Publication	Hierarchy of Evidence	Roles informed
Grey Literature					
Miller	Rebound therapy – Where is the evidence?	2007	Frontline Article	6	• 24hr Postural Management • Respiratory Management • Falls Prevention and Intervention • Management of Mobility Problems
Miller A 2007. Rebound Therapy – Where is the Evidence? Available at: https://www.reboundtherapy.org/edu/ last accessed 01/08/19.					
Miller A 2015 Lanarkshire physios help people with learning disabilities get fit. Frontline.					
Millet	Body works: postural care for people with profound learning disabilities	2015b	Frontline Article	6	• 24hr Postural Management
Millet R 2015 Body works: postural care for people with profound learning disabilities. Frontline 2015; 21(12). Available at: http://www.csp.org.uk/frontline/article/body-work-postural-care-people-profound-learning-disabilities last accessed 01/08/19.					
Roberts	Bounce benefits	2006	Frontline Article	6	• 24hr Postural Management • Respiratory Management • Falls Prevention and Intervention • Management of Mobility Problems • Health Promotion • Spasticity Management
Robert D 2006. Bounce Benefits. Physiotherapy Frontline 12 (3), 12-14.					
Physiopedia contributors	The role of the physiotherapist in learning disabilities: Communication and health literacy	NK	Resource Guide	6	• Supporting access from mainstream health services • Falls Prevention and Intervention • 24hr Postural Management • Respiratory Management • Health Promotion • Training and Education
Physiopedia contributors 2017 The Role of the Physiotherapist in Learning Disabilities: Communication and Health Literacy, Physiopedia, Available at: https://www.physio-pedia.com/index.php?title=The_Role_of_the_Physiotherapist_in_Learning_Disabilities:_Communication_and_Health_Literacy&oldid=174440 Last accessed 01/08/19.					
Standley	Integrated respiratory pathway for people with complex physical and learning disabilities	2016	ACPPLD newsletter	6	• Respiratory Management • Dysphagia Management • Training and Education
Standley D 2016. Integrated Respiratory Pathway for People with Complex Physical and Learning Disabilities. ACPPLD Newsletter: Autumn Issue: 27-38					
Tinkler	Learning disabilities: help to build the right support	2015	Frontline Article	6	• Supporting access from mainstream health services
Tinkler J 2015. Learning disabilities: help to build the right support. Frontline. 21 (21).					

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Ref	Name	Date	Type of Publication	Hierarchy of Evidence	Roles informed
Grey Literature					
Tinkler	Twenty-four hour postural management for adults with a profound intellectual and multiple disability (PIMD) and body shape distortion: A Delphi consensus study exploring physiotherapists' perceptions of practice	2016	ACPPLD newsletter	6	• 24hr Postural Management • Training and Education
Tinkler J 2016. Twenty-four hour postural management for adults with a profound intellectual and multiple disability (PIMD) and body shape distortion: A Delphi consensus study exploring physiotherapists' perceptions of practice. ACPPLD Newsletter. Spring Edition. 14-19					
Tinkler	The physiotherapy role in the NHS England service model supporting people with a learning disability and /or autism who display behaviour that challenges, including those with a mental health condition.	2016	ACPPLD newsletter	6	• Behaviours that Challenge
Tinkler J 2016. The physiotherapy role in the NHS England service model supporting people with a learning disability and /or autism who display behaviour that challenges, including those with a mental health condition. ACPPLD Newsletter. Spring Edition.					
Tinkler	Twenty-four hour postural management for adults with profound intellectual and multiple disabilities (PIMD) and body shape distortion: A Delphi consensus study exploring physiotherapists' perceptions of practice.	2017	PHD	6	• 24hr Postural Management • Training and Education
Tinkler J 2017. PHD Thesis: Twenty-four hour postural management for adults with profound intellectual and multiple disabilities (PIMD) and body shape distortion: A Delphi consensus study exploring physiotherapists' perceptions of practice.					
Tinkler	STOMP it out	2018	Frontline Article	6	• Behaviours that Challenge
Tinkler J 2018. STOMP it out! Frontline 24 (2)					
Whyte	Improving mobility, balance and falls risk in adults with a learning disability: an analysis of two community-based exercise groups.	2016	ACPPLD newsletter	6	• Falls Prevention and Intervention
Whyte A 2016. Improving mobility, balance and falls risk in adults with learning disabilities: an analysis of two community-based exercise groups. ACPPLD Winter Newsletter. 33-42					
Wilde	Learning to keep fit	2006	Frontline Article	6	• Health Promotion
Wilde L 2006. Learning to Keep Fit. Frontline. 12 (17).					
Whitaker and Cooper	The role of the specialist physiotherapist in learning disabilities	2006	ACPPLD newsletter	6	• Supporting access from mainstream health services
Whitaker L 2006. The role of the specialist physiotherapist in learning disabilities. ACPPLD newsletter. 1(Mar). 16-21.					

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Barriers to adults with a learning disability accessing healthcare

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Intrinsic barriers

The main intrinsic factors that have been identified to cause barriers to adults with a learning disability accessing successful healthcare include:

Barrier	Description
Apprehension about accessing healthcare	Adults with a learning disability may have apprehensions about accessing healthcare thus avoid seeking help when required which leads to delay in assessment, diagnosis and treatments.
Behaviours that challenge	Some adults with a learning disability display behaviours that challenge. These can be a significant barrier to successful access to healthcare (Alborz et al. 2005; Emerson et al. 2010).
Capacity to consent	Adults with a learning disability may lack the capacity to make decisions about their own healthcare. They are therefore reliant on others to make decisions in their best interest. It is well evidenced that carers have difficulty identifying health needs and perceive the person they care for to be healthier than suggested by the results of medical examination (Heslop et al. 2013).
Challenges identifying and communicating health needs	Adults with a learning disability may have difficulty identifying and/or communicating needs to carers and health professionals due to poor body awareness and depressed pain responses. This can result in poor timely responses to physical symptoms (Alborz et al. 2005; Emerson et al. 2010). Adults with a learning disability are often unable to express when their needs change and do not proactively seek medical support to manage these changes. They are also less able to communicate side effects of drug changes and management plans. Limited communication skills reduces the capacity of people with a learning disability to convey health needs effectively to healthcare professionals, relatives, friends, paid support workers. This reduces their ability to advocate for themselves when accessing healthcare. This increases their reliance on others to interpret this limited communication, to diagnosis and treat presenting problems (Emerson et al. 2010).
Higher prevalence of health problems	Adults with a learning disability have a higher prevalence of cancer, coronary heart disease, respiratory disease, mental health problems, dementia, epilepsy, sensory and physical impairments, poor oral health, dysphagia, diabetes, gastro-oesophageal reflux, constipation, osteoporosis, endocrine disorders and injuries, accidents and falls (Emerson et al. 2010).

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Personal health risks and behaviours	Adults with a learning disability are less likely to have a healthy body mass index and weight. They are more likely to be over or underweight. Adults with a learning disability are less likely to eat a balanced diet, with sufficient intake of fruit and vegetables, especially if they live in supported accommodation. They are more likely to lead sedentary lifestyles and are less likely to engage in the minimum recommended level of physical activity as advised by the Department of Health. Thus, they have a higher incidence of obesity, which is likely to be associated with an increased risk of diabetes (Emerson et al. 2010).
Poor access to health promotion or screening	Adults with a learning disability are less likely to receive preventative healthcare due to the challenges in providing healthcare for a presenting condition. In addition, the uptake for health promotion and screening is lower than the general population (Robertson et al. 2010).
Poor health literacy	Adults with a learning disability often have poor health literacy which is the degree to which individuals have the capacity to obtain, process, and understand basic health information. This can result in poor understanding and compliance with healthcare (Alborz et al. 2005; Emerson et al. 2010).
Social determinants of health	Adults with a learning disability are more likely to be exposed to common 'social determinants' of poorer health such as poverty, poor housing conditions, unemployment, social disconnectedness and discrimination (Alborz et al. 2005; Emerson et al. 2010).
Specific genetic and biological causes of a learning disability	Associated conditions increase the risk of people with a learning disability having and developing specific health problems. For example: • People with Down's syndrome have congenital heart problems at a much higher rate than the general population and they have higher risk of developing Alzheimer's disease (Emerson et al. 2010). • Cerebral palsy increases risk of postural deformities, hip dislocation, chest infections, dysphagia, gastro-oesophageal reflux, constipation and incontinence (NICE 2017 and 2019).
Unmet health needs	A high proportion of adults with a learning disability have unmet health needs (Emerson et al. 2010). 72% to 94% of adults with a learning disability have one or more unmet health needs (Alborz et al. 2005).

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Extrinsic barriers

Network of care

Adults with a learning disability are often reliant and dependent on their network of care to identify, communicate and treat their health needs. This introduces potential external barriers to managing the health of adults with a learning disability. The network of care may have a poor understanding of the health needs of adults with a learning disability and where to access appropriate healthcare. The barriers posed by a person's network of care are increased significantly in multi-care environments and where there are complex social circumstances.

Barrier	Description
Difficulties identifying the health needs of adults with a learning disability	Carers regularly have difficulty recognising expressions of need, particularly if the person concerned does not communicate verbally. Identifying insidious and gradual deteriorations in health can be particularly challenging (Alborz et al. 2005; Emerson et al. 2010).
Not prioritising health care over activities	Carers may prioritise health management less than other activities of daily living which can result in high rates of non-compliance with health recommendations and appointments (Stewart et al. 2009)
Compliance with recommendations	Some carers have a poor understanding of and compliance with their own health recommendations. Thus, are not always the most appropriate person to advocate for the health needs of the person they support. They may make wrong assumptions about their health and be reluctant to seek help for what they consider 'trivial' issues or where they consider the person would not benefit from intervention (Emerson et al. 2010).

Healthcare professionals

Adults with a learning disability represent a small percentage of the general population. Therefore, healthcare professionals working in mainstream often not have the opportunity to develop the necessary knowledge, skills and experience required to provide effective healthcare. As a result, healthcare professionals can present as another extrinsic barrier. Mencap (2017) recognises this knowledge and skills gap and recommends the need to provide training that focused on learning disability for all healthcare professionals. Mencap's campaign has been supported by the Department of Health and Social Care (2019) who are proposing learning disability and autism training for all health and care staff. At the time of writing, the Department of Health and Social Care (2019) document was still in the consultation phase but recommends that training is mandatory and is based on the learning disabilities core skills education and training framework (Skills for Health 2019).

Barrier	Description
Challenges with Communication	Healthcare professionals working in mainstream healthcare settings lack the skills to communicate effectively with people with a learning disability. Thus, are reliant on the person's network of care which can be a barrier in itself (Alborz et al. 2005; Emerson et al. 2010).

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Negative attitudes of healthcare professionals.	There is evidence that some healthcare professionals and services have negative and disablist attitudes towards adults with a learning disability. This can result in assumptions about the appropriateness of performing tests and treatments and about quality of life. These views may deter people with a learning disability and their network of care from seeking healthcare because they perceive that their complaints are not taken seriously, or that staff are judgemental about their capabilities (Emerson et al. 2010).
Lack of involvement of network of care	A lack of engagement with the network of care is cited within the literature as one of the main contributing factors to poor access to healthcare for adults with a learning disability. There is often poor communication with the network of care about assessment and treatment options; and a lack of involvement in capacity assessment and best interest decisions (Alborz et al. 2005; Emerson et al. 2010).
Diagnostic overshadowing	Diagnostic overshadowing is the term used by the Disability Discrimination Act (1995) and others to describe the tendency to attribute symptoms and behaviour associated with illness to the learning disability. Thus, concerns are not taken seriously, and medical conditions are overlooked which leads to delays and failure to make the correct diagnosis (Mencap 2007; Michael and Richardson 2008; Department of Health 2009; Heslop et al. 2013).
Poor understating of Mental Capacity Act	Healthcare professionals working in a mainstream health setting may lack an understanding of the Mental Capacity Act and therefore do not apply the framework appropriately. It is common that consent is sought from the person's network of care rather than taking the time to gain consent or follow a best interest process (Emerson et al. 2010; Tuffrey-Wijne et al. 2014).
Poor understanding of the role of specialist learning disability services	Poor understanding of the role of specialist learning disability services reduces the appropriate use of the teams in supporting the healthcare of people with a learning disability.
Poor understanding of the health needs of people with a learning disability	Healthcare professionals often lack awareness of the specific health needs of adults with a learning disability which further leads to challenges in diagnosis and treatments (Tuffrey-Wijne et al. 2014).

Healthcare organisations and services

In addition to the barriers relating directly to the individual, their network of care, and healthcare professionals a range of organisational barriers to accessing successful healthcare have been well documented and evidenced.

Barrier	Description
Time constraints	Adults with a learning disability often require additional time to access healthcare including longer appointments and episodes of care. These are particularly challenging when accessing the GP or during hospital admissions.

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Lack of understanding about responsibilities to make reasonable adjustments	There is often a lack of understanding about the responsibility of health services to make reasonable adjustments to support adults with a learning disability to access quality healthcare (Tuffrey-Wijne et al. 2014).
Sparsity of specialist services	There is a lack of local specialist learning disability services to meet the needs of adults with a learning disability. Specialist services are critical to supporting people with a learning disability to access mainstream services and provide management where the person is unable to access services successfully (Department of Health 2009; RCGP 2013; Heslop et al. 2013).
Poor collaborative working	Collaboration between the network of care, GPs, primary health care teams and specialist services for adults with a learning disability is generally regarded as poor often resulting in disjointed care and management (Heslop et al. 2013).
Physical access barriers	There are several physical barriers to accessing healthcare including a lack of accessible transport links; changing facilities, hoisting equipment and quiet areas. There are also inaccessible signs and notices which are problematic for people with low literacy levels or sensory disabilities.
Identification of people with a learning disability	There is a lack of effective flagging systems to identify patients with learning disabilities therefore patients are not being identified and reasonable adjustments put in place whilst they access healthcare (Heslop et al. 2013; Tuffrey-Wijne et al. 2014).

Summary

There are a wide range of potential barriers to providing successful healthcare to people with a learning disability. In reality, there is usually a combination of barriers that are dependent on the person's learning, physical and sensory disabilities; their social circumstances; and the local healthcare services. In the same way, the adjustments required to overcome these barriers to provide successful healthcare to people with a learning disability need to be individually tailored. The more barriers an individual presents the more adjustments are required which increases the challenges for professionals and services. Under the Equality Act 2010, all disabled people have the right to reasonable adjustments when using public services, including healthcare. These adjustments aim to overcome the barriers that disabled people would otherwise face ensuring they have equal access to good quality healthcare (Mencap 2018).

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Reasonable adjustments to support adults with a learning disability to access successful physiotherapy outcomes.

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The adjustments that are reasonable for mainstream physiotherapists to make to provide successful physiotherapy to adults with a learning disability are well documented within the literature (Public Health England 2016; ACPPLD 2017; Mencap 2018). These are collated in the following tables. It is essential that adjustments are made both at an intrinsic and extrinsic level and mainstream physiotherapy and healthcare services should be expected to make these adjustments before signposting and referring to specialist learning disability services. However, they may require some advice or support to make these adjustments which is recognised as one of the core functions of the community learning disability team (Department of Health 2009; RCGP 2013; Learning Disability Professional Senate 2015; National Quality Board 2018).

Intrinsic adjustments	
1	Acknowledge that behaviours that challenge are usually a method of communication.
2	Adapt communication, for example using simple language; avoiding medical terms; using imitation and demonstration to minimise words; use visual aids such as pictures, symbols, videos.
3	Arrange appointments via telephone or using accessible letters.
4	Be flexible and relaxed during the appointment.
5	Develop person centred treatment plans that are meaningful to the adult with a learning disability.
6	Ensure that appointments are on time for adults with a learning disability who are unable to wait.
7	Offer a flexible treatment approach including keeping treatment simple with slow progressions.
8	Set rehabilitation goals that are person centred and relevant to the adult with a learning disability.
9	Focus the assessment and consider its format to improve engagement.
10	Make assessment and treatment functional and fun.
11	Offer flexible appointments in terms of the length, time and location.
12	Provide information and any treatment plans in an accessible format that are easy to follow and understand.
13	Recognise when an appointment is not effective, re-schedule to another time and consider another approach.
14	Talk directly to the person with a learning disability as well as the carer.
15	Triage appointments to ask about the adjustments required to provide successful physiotherapy to the adult with a learning disability.
16	Utilise specialist assessment tools to support communication such as the disability distress assessment tool (DisDAT).
17	Work within the Mental Capacity Act (2005) including performing capacity assessments and leading best interest decisions where required.

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Extrinsic reasonable adjustments

Service and organisation level adjustments

1	Understand the legal responsibility to provide services to adults with a learning disability and their duty to provide reasonable adjustments.
2	Develop a culture that encourages its employees to make reasonable adjustment to support people with a learning disability to have positive access to and responses from their services.
3	Ensure physiotherapists have time to prepare for appointments with adults with a learning disability. This includes time to contact the person or their network of care prior to the appointment to find out what adjustments are required; contacting the specialist learning disability team; and/or preparing the environment.
4	Have an appropriate environment to support the adult with a learning disability including hoisting equipment, changing facilities, quiet areas and additional space when required.
5	Develop an appropriate flagging system to highlight when adults with a learning disability are attending mainstream physiotherapy services.
6	Develop links with local specialist learning disability services to support collaborative working.
7	Offer a flexible did not attend (DNA) policy for adults with a learning disability who are reliant on their network of care to support them to appointments.
8	Ensure physiotherapists receive training to develop an awareness and understanding of the Mental Capacity Act (2005) and how it impacts on practice.
9	Support employees to attend learning disability awareness training in line with Department of Health and Social Care recommendations.

Engaging the person’s network of care

1	Request support from the carer that best knows the adult with a learning disability such as a key worker.
2	Allow carers to accompany the person with a learning disability on transport.
3	Consider accessibility of physiotherapy for the network of care including the time of the appointment and the physical environment.
4	Gather information about the person prior to the appointment in particular their communication needs, likes and dislikes.
5	Include the person’s network of care in physiotherapy assessment and management processes.
6	Provide the carer supporting the appointment with the information from them to hand back to the rest of the team if required.
7	Delegate physiotherapy programmes to the person’s network of care when required in line with Chartered Society of Physiotherapy (CSP) guidance.
8	Ensure physiotherapy treatment plans are easy for the network of care to follow.

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History of physiotherapy for adults with a learning disability

The emergence of the community learning disability team and the future

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Physiotherapy began as a profession in 1894 with the 'Society of Trained Masseuses'. Established by four nurses who wished to protect and legitimise their occupation. Examinations in anatomy, physiology and massage were held straight away. Initially for women only the society began to train men in 1920 and is granted a Royal Charter by King George V changing its name to the 'Chartered Society of Massage and Medical Gymnastics'. The Society adopted its current name 'The Chartered Society of Physiotherapy' (CSP) in 1944. The CSP has merged with many rival organisations over the years, the last one being in 1986 when they amalgamated with the Society of Remedial Gymnastics and Recreational Therapists. The term physiotherapy encompasses a range of interventions, services and advice aimed at maintaining, restoring and improving people's function and movement and thereby maximising the quality of their lives. As a profession physiotherapy has changed over the years from in the 1940's working with patients as prescribed by doctors, to the autonomous practitioners of today. However, whilst the establishment of physiotherapy as a profession and physiotherapy techniques may have changed over the years, human movement remains something of a constant.

It is believed that therapists began working in institutions for adults with a learning disability as early as the late 1800's, however, their role was not well documented. Physiotherapists were slow to enter the field of learning disability. At Larbut Hospital (Falkirk Scotland) formal physiotherapy was in place by the 1950's but this was unusual (Swain and French 1999). In 1960 in Northgate hospital in Morpeth Northumberland physiotherapists began working towards a multi-disciplinary approach. Physiotherapists visited for three sessions a week, handing on their skills to the nurses who carried out the treatment programmes (Auty 1991).

The National Health Service (NHS) was created in July 1948, based on three core principles 1. To meet the needs of everyone. 2. To be free at point of delivery and 3. Be based on clinical need, not on the ability to pay. At the beginning of the 1950s there were thought to be 55,000 adults with a learning disability living in hospitals/ institutions in England and Wales. The institutions became hospitals and inmates became patients, encouraging the belief that learning disability was an illness requiring doctors and psychiatrists. Thus the 'medical model' of care was established that was to continue until the 1959 Mental Health Act urged a move towards community-based services.

Although the Mental Health Act of 1959 required that more community care should be provided, the number of people being admitted into the long stay hospitals continued to rise, with more hospitals being built to meet demand. However, conditions in these hospitals continued to be poor, and in 1969 the Ely report exposed dreadful treatment of patients, care was described as old fashioned and 'custodial'.

The 1971 White Paper 'Better Services for the Mentally Handicapped' recognised that "not enough progress had been made in developing community services and getting people out of hospitals". The government outlined a desire to move away from caring for people with a 'mental handicap' in institutional hospital settings and to increase the provision of local and community care.

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In the 1970's specialist learning disability physiotherapists were working with adults who had 'severe and multiple handicaps and those with severe deformities' and their focus was on postural positioning, seating, promoting mobility and developing adapted equipment, including wheelchairs. Mostly they were working within a hospital setting within therapy departments in line with the medical model, treating patients, wearing a uniform and reporting to a medical doctor. In some areas physiotherapy was still prescribed by the doctor and was very specific. It was not until 1977 that physiotherapists gained autonomy and could take direct referrals. For many people their physical disability had not been managed since birth and they were either left in bed or on bean bags. Therefore, in the early years, physiotherapists were treating people with very severe and fixed postures. Specialist equipment for postural management was not available and adaptations to wheelchairs were very primitive. In the 1970's there is evidence of physiotherapists working in large institutions such as Fieldhead Hospital in Wakefield, which was built in 1972 for the treatment and care of the 'mentally handicapped'. A report written in 1978 'Helping Mentally Handicap People in Hospital' stated that there were only 80 full time physiotherapists in mental handicap hospitals in the whole country (Swain and French 1999).

There were several reports, papers and studies throughout the 1980's and 90's that supported the move from NHS care in institutions to community care. This coincided with a big shift in attitude. It was following the Jay Report in 1979 that the principles of 'normalisation' began to influence social policy discourse. 'Normalisation' as a concept was founded in Denmark 'letting the mentally retarded live as close to normal as possible'. Normalisation was a framework for understanding and influencing service values and practices, which later became known as Social Role Valorisation (SRV). SRV and specifically in 1981 research by' John and Connie O'Brien' led to the development of the 5 accomplishments:

1. **Community Presence** – ensuring that service users are present in the community by supporting their actual presence in the same neighbourhoods, schools, workplaces, shops, recreation facilities and churches as ordinary citizens.
2. **Choice** – ensuring that service users are supported in making choices about their lives by encouraging people to understand their situation; the options they face and to act in their own interest both in small everyday matters; and in such important issues as who to live with and what type of work to do.
3. **Competence** – developing the competence of service users by developing skills and attributes that are functional and meaningful in natural community environments and relationships, i.e. skills and attributes which significantly decrease a person's dependency or develop personal characteristics that other people value.
4. **Respect** – enhancing the respect afforded to service users by developing and maintaining a positive reputation for people who use the service by ensuring that the choice of activities, locations, and forms of dress and use of language promote perception of people with a learning disability as developing citizens.
5. **Community participation** – ensuring that service users participate in the life of the community by supporting people's natural relationships with their families, neighbours and co-workers and when necessary widening each individual's network of personal relationships to include an increasing number of people.

(O'Brien and Tyne's Five Service Accomplishments 1981)

Following the introduction of the O'Brien and Tyne's Five Service Accomplishments there was a steady stream of policy and legislative documents that influenced service provision for adults with a learning disability. By 1984 the long stay hospitals started to close, and people moved into residential care homes in the community. It was at this time that specialised community teams started to emerge. Health and social services for adults with a learning disability were commonly

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provided through specialised community teams. This model of health and social care has existed for nearly 20 years and has expanded since the closure of hospitals. It is responsible for direct services e.g. occupational therapy and physiotherapy (Swain and French 1999).

One example of the different models that districts took when planning for the return of their residents is from Darenth Park Hospital. In 1948 this was home to 2260 residents from across London and the south east. In 1977 it was sectorised and split into "mini-hospitals" each serving its own catchment area- thus paving a way towards community-based care. In 1987 Bromley borough moved their residents out of Darenth to 'Bassetts' which was a cluster of 9 houses for 72 people. In the neighbouring borough of Lewisham they had a staggered return to borough for their residents with 'not for profits' set up that developed bespoke homes within the community, each assessed and provided to meet an individual's needs, mostly in 1- 5 bedded homes. A few residents moved to the smaller hospital at Grove Park that already had a few residents, whilst appropriate accommodation was found. Grove Park finally closed its doors in 1994. In South Southwark they built a core and cluster (Bowley Close in Crystal Palace) which had flexible accommodation in a small housing estate next to a day centre that had a hydrotherapy pool, hairdressers etc. Across the country each district was developing its own local services. Alongside this the community multi-disciplinary teams were also developing. Again, documented accounts of these early community teams, how they were set up and how they functioned is very sketchy and therefore some of the accounts is from lived history, from staff who worked in teams in the 80's and early 90's. Although there is limited documentation, physiotherapists were very much a part of these early teams and as a result in 1985 'The Association of Chartered Physiotherapists in Mental Handicap', a special interest group was founded, having previously been a regional group in Trent. This group started with 26 members and enabled physiotherapists working in learning disability in the local area and wider afield to come together to facilitate learning, share ideas and support each other. Later, they changed their name to the Association of Physiotherapy for People with Learning Disabilities (ACPPLD). There are currently 9 regions with 333 members across the UK.

In 1985 Craft, Hollins and Bicknell wrote 'A multi-disciplinary approach to Mental Handicap'. This was a textbook of interest to a number of professional groups and those responsible for service planning and the allocation of funds. It was not a "hands on" book in the sense of telling a newly appointed professional how to begin. There was a short section on 'The role of the physiotherapist'. It covered topics such as mobility, postural management, additional support within wheelchairs, positioning for eating and drinking, respiratory function and management and discusses the assessment and treatment options for common medical conditions.

Services were developing at a very different pace across the UK and Scotland. In some areas there was a strong drive to close the institutions and support the residents to move into the community. One of the first large long-stay institutions for adults with a learning disability to close was the 'Royal Western Counties Hospital 'Starcross' in Exeter, which closed as early as 1986. The last long stay hospital to close was Orchard Hill Hospital in Sutton which only closed as recently as 2009.

Community based learning disability teams also developed at a different pace across the UK. In 1998 a key document that supported the development of these community teams was 'Signposts for Success'. The aim of this document was to promote good practice by clarifying the role of the NHS in providing services to adults with a learning disability. This became the standard by which community health teams benchmarked their service. Coming at a time when the impetus to close long stay institutions was gathering momentum, it acknowledged the need for specialist community learning disability services and set out basic best practice guidelines and checklists for action. The role of the specialist community health teams was considered vital. "A wide range of professional skills are required by people with learning disabilities to build and maintain their skill and abilities and to address particular difficulties or problems.

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Communication, mobility and daily living skills are important components of the enabling process and health services such as speech and language therapists, physiotherapists, occupational therapists and learning disability nurses all have relevant skills''. This good practice guidance laid out the expectation that specialist learning disability services needed to work with the service user, families and network of care to support access to health professionals in primary care or hospital. ''It is often necessary to work with or alongside staff from other and agencies, and skills in working across boundaries are also required. It is essential that community learning disability specialists place particular emphasis on working with other health professionals including the primary care team and other community and hospital services''. It also stated that most services are delivered in the community, offering various therapies to address a specific problem. ''The professional skills in the care of people with learning disabilities and the additional needs relating to mental health problems, epilepsy, sensory impairments and physical disabilities should be available''. The guidance stated community learning disability health services should:

- Offer a wide range of co-ordinated support and advice for people with a learning disability their families and carers
- Provide therapeutic services
- Offer training for people with a learning disability, their families, carers and staff of other organisations
- Work closely with other agencies
- Help the development of good practice in relation to health promotion and health care
- Facilitate access to general health services.

Considering this document was written in 1998 the principles within its guidance could just as easily apply to the core roles of the community learning disability team today.

There had been very little written specifically about the roles or standards of practice for the provision of physiotherapy for adults with a learning disability until in 1991 Patricia Auty, a specialist learning disability physiotherapist working in South London wrote 'Physiotherapy for People with Learning Difficulties'. This was the first book specifically for physiotherapists working with adults with a learning disability. It provided a historical background to services for people with a learning disability and outlined specific roles and ways of working for the specialist learning disability physiotherapist including assessment, individual programme plans, treatment methods, teaching guidelines and multi-disciplinary working. Later in 2001 Jeanette Rennie wrote 'Learning Disability, Physical Therapy, Treatment and Management, A Collaborative Approach,' which was updated in 2007. This book provided a comprehensive overview of the diverse approaches to treatment and management issues, as well as methods to help physiotherapists achieve the rehabilitation aims. Split into three sections, the book covers 1 Underlying theory; 2 Assessment; 3 Practical methods of physical treatment and management.

The five accomplishments initially development by O'Brien and Tyne's (1981) were a foundation stone for Valuing People: A New Strategy for Learning Disability for the 21st century (Department of Health 2001). This was the first white paper about adults with a learning disability for 30 years and was the first policy that signalled a new approach to the delivery of care, and a new relationship between the state and the citizen. It provided a vision for the lives of adults with a learning disability and their families based on the four principles of rights, independence, choice and inclusion. It sought new ways to give people and families a voice, to be at the centre of their own plans, and to have some control over how resources were spent on them through Direct Payments.

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The key elements were:

- An end to the last long-stay hospitals.
- A five-year programme to modernise local council day services.
- A new national learning disability information centre and helpline in conjunction with the charity Mencap.
- A national forum for adults with a learning disability.
- A learning disability task force.
- Specialist local services for people with severe and challenging behaviour and integrated facilities for children with severe disabilities and complex needs.
- An extension of eligibility to "directs payments", a scheme which allows service users to choose and purchase their own care.

As time went on and the move from long stay hospital to the community was completed, community teams needed to review and adjust their core roles. Whereas much of their work initially was supporting the relocation, they now needed to develop how they were going to support people in the future. Legislation also continued to develop and shape the direction of services. Albeit initially the thought was that all health services for adults with a learning disability should and would be provided by mainstream services (Valuing people 2001). There was an awareness from the therapists within community learning disability teams that mainstream services were not able to provide all the health support and that some people needed specialist support. This was especially true of people who had complex postural health needs; those who had mobility difficulties or at risk of falls; or where someone's learning disability impacted on the level of care they were able to receive from mainstream services. Therefore, community teams continued to develop and change over the years in both structure and role.

In 'Commissioning Specialist Adult Learning Disability Health Services Good Practice Guidance' (Department of Health 2007). Rob Grieg stated that there is growing concern that some areas of the country found it difficult to develop commissioning strategies for specialist adult learning disability health services, which reflect both current policy and best practice. This led to, in places, inappropriately funded services, outdated service models, poor development of community infrastructures and the lack of appropriately funded and skilled specialist learning disability health services.

Three major factors were creating change in the demand for specialist learning disability services:

1. Significantly increased numbers of adults with a learning disability, partly caused by people living substantially longer as a result of medical and technological advances. Therefore people needed additional support around illnesses linked to old age, in particular dementia and people with Down's syndrome.
2. Significant changes in the demographic profile with increased numbers of people with complex needs requiring input from specialist health professionals. This particularly applies to young people with multiple disabilities and, together with the above point, will require commissioners to consider levels of investment in both mainstream and specialist health services.
3. The increasing empowerment of adults with a learning disability and their families, resulting in them expecting and demanding better quality services located nearer to their home and communities.

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Rob Grieg acknowledged that the most critical component of specialist learning disability health services is the commissioning and employment of a range of staff with the skills to support adults with a learning disability in all settings, providing specific and additional input as required to respond to their health care needs. There will need to be a range of staff skills commissioned and recruited as part of these community health infrastructures. This will include, but not necessarily be limited to, physiotherapists, occupational therapists, speech and language therapists, psychiatrists, clinical psychologists and learning disability nurses.

Debra Moore Associates, wrote 'the role of specialist health services in supporting the health needs of people with a learning disability' in 2011 (Moore and Thorley 2011). The authors make recommendation about the future role and function of community learning disabilities teams. They stated that 'specialist learning disability health professionals continue to have an important role to play in supporting the health and wellbeing of people with learning disabilities and their families. They are required to both support mainstream practice and directly serve those with the most complex needs.' Political and demographic changes provide the back drop in which we have to consider role and function of specialist health professionals in community teams. Specifically, how we can make best use of this valuable resource now and in the future. Evidence suggested that the capability of mainstream services to appropriately support people with learning disabilities was still problematic. At the time, a raft of documents, guidance and inquiry papers were published that described the failings of the mainstream NHS to meet the needs of this group. A common theme within all these reports is a requirement to provide training for mainstream health professionals and to provide expert support and advice as required. The source of this expertise is often identified as the local community-based learning disability teams.

The evolution of community teams continued but not in a structured or uniform way and not always guided by National policy. As a result, it is possible to visit ten different community learning disability teams and each one will have a very different configuration. Some of this is determined by the host provider and whether it was a NHS Health Trust, Mental Health Trust, Private Enterprise or Integrated Social Care Teams. Some will have been influenced by Government led agenda's and the national awareness of the needs of adults with a learning disability.

One of the most significant events that has happened in the last 8 years that has influenced the delivery of services to adults with a learning disability is the Winterbourne View scandal. In May 2011 the BBC broadcast a documentary that shocked the country and raised the alarm over the care of patients in a private hospital, Winterbourne View that provided assessment and treatment for adults with a learning disability and challenging behaviour. Panorama sent in an undercover journalist using hidden cameras that showed residents were being bullied and physically and emotionally abused by staff. In 2012, 11 members of staff were convicted of over 40 offences. There was an immediate response that all services that provide care and treatment to adults with a learning disability were inspected, some were issued with improvement notices and some were closed. The Government made a commitment to close long-stay institutions such as Winterbourne View, and for all adults with a learning disability and/or autism who were inappropriately placed in hospital to be moved to community-based support by June 2014. This commitment was known as Concordat.

Winterbourne View was truly shocking and there is no doubt that significant change in the provision of services and support to adults with a learning disability and challenging behaviour had to happen. However, this client group are not those that specialist learning disability physiotherapists routinely see. They would make up only a very small percent of a specialist physiotherapist's caseload. A recent audit found that under 5% of the referrals received by Guy's and St Thomas' NHS Foundation Trust Specialist learning disability physiotherapy team were related to people with a learning disability and behaviours that challenge. This trend may vary across UK.

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The implementation of the Health and Care Act in 2012 was another significant change that impacted on the delivery of services. This was an extensive reorganisation of the NHS which abolished Primary Care Trusts and Strategic Health Authorities transferring commissioning to Clinical Commissioning Groups (CCG's), removing day to day management from central government and passing this on to NHS England.

In 2012 the 'Learning Disability Professional Senate' (LD senate) was established. The aim of the 'LD senate' is to provide a single voice through which professionals can lead and inform NHS England, the Department of Health, and other strategy leads about the needs of children and adults with a learning disability. It brings together professional leaders from across the UK to provide cross-professional collaboration; strategic advice and innovation; and to develop both mainstream and specialist services.

A member of the national executive committee of the ACPPLD sits on the 'LD Senate'. Their role is to act as a conduit to promote the importance of the role of the specialist learning disability physiotherapist. Championing the needs of people with a learning disability that have physiotherapy needs. The ACPPLD representative also feeds back to the NEC and wider ACPPLD membership on national directives and strategies.

In 2013 the Confidential Inquiry into deaths of people with learning disabilities (CIPOLD) published its' final report following an independent inquiry into the premature deaths of people with learning disabilities. The report presented 18 key recommendations. Much of the impact of CIPOLD 'came from arming practitioners, family carers, people with learning disabilities and policy makers with the research findings and encouraging them to take on the mantle of change. For example, by increasing the provision of training or reviewing their current practice (Heslop et al. 2013). Specialist learning disability physiotherapists should review these 18 key recommendations and relate them back to their own service delivery and use them to provide evidence to support practice. Recommendation nine is of particular importance and directly relates to the population of adults with a learning disability that specialist physiotherapists take the lead in providing health support. It states that adults with a learning disability should be considered a high-risk group for deaths from respiratory problems. It recommends that CCGs must ensure they are commissioning sufficient, and sufficiently expert, preventative services for people with learning disabilities regarding their high risk of respiratory illness. This would include expert, proactive postural care support (Heslop et al. 2013).

In 2015 the Learning Disability Senate produced 'Delivering Effective Specialist Community Learning Disabilities Health Team Support to People with Learning Disabilities and their Families or Carers: a briefing paper on Service Specifications and Best Practice for Professionals, NHS Commissioners, CQC and Providers of Community Learning Disability Health Teams'. This is a significant document that highlights that "there remain particular groups at risk of unnecessarily restrictive lifestyles, poor access to services and opportunities, and serious health inequalities" and that "locally commissioned effective specialist Community Learning Disabilities Health Teams are critical to providing the essential support needed by people with learning disabilities and their families. And their success can only be judged if this group of vulnerable people live full lives with more opportunities and less exposure to harm, as well as experience health outcomes in line with the wider general population". Physiotherapy was outlined as one of the lead areas for health activity. The LD senate described the role of the physiotherapist as:

> *"To prevent and reduce the incidence/impact of complex health issues and profound or multiple physical/sensory disabilities, including clinical case management for the delivery of packages of care through collaborative working with colleagues within primary and secondary care"*

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> *"Providing support to individuals with health facilitation/access issues for people with learning disabilities and their carers across health and social care communities, including issues in relation to primary/secondary health care access, and the provision of specialist moving and handling assessments, respiratory/dysphagia/postural care, mobility assessments, specialist equipment/access issues, systematic skills teaching/rehabilitation and complex support needs."*

The learning disabilities mortality review (LeDeR) programme commenced in June 2015, initially for 3 years, but since has been extended until May 2020. The programme is the first national programme of its kind in the world. Its overall aims are to:

1. Support improvements in the quality of health and social care service delivery for people with learning disabilities.
2. Help reduce premature mortality and health inequalities for people with learning disabilities.

It was being implemented at the time of considerable spotlight on the deaths of patients in the NHS. The first LeDeR annual report was published in 2018 and covered reported deaths from July 2016 to November 2017. Of the 103 completed reviews there were 189 learning points or recommendations identified. The most commonly reported learning and recommendations were made in relation to the need for a) inter-agency collaboration and communication b) awareness of the needs of people with learning disabilities c) the understanding and application of the Mental Capacity Act (2005). LeDeR data identified that almost a third of deaths (31%) had an underlying cause related to disease of the respiratory system. Public Health England (2018b) report that respiratory problems are the main reason people with profound and multiple learning disabilities need primary or secondary medical care, and pneumonia is the most common cause of death in this group. They recognise that some of the risk factors for respiratory problems that can be reduced by good postural management are airway clearance dysfunction, saliva management difficulties, immobility, reflux, sleep disordered breathing and thoracic deformity.

In 2018 the National Quality Board wrote 'Safe and sustainable staffing. An improvement resource for learning disability services'. The authors reviewed the available literature to outline the roles of the specialist learning disability multidisciplinary team. They reviewed one document that outlined the role of the specialist learning disability physiotherapist to continue to the development of the 'right staff' section. This was provided by the learning disability senate (2015) titled 'The role of physiotherapy in the NHS England service model supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition'. Unfortunately, this document did not describe the main roles of the specialist learning disability physiotherapist or include the cohort of people with a learning disability who have physiotherapy needs. For example, people with postural needs, mobility problems, fallers or at risk of falls, and respiratory complications.

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NICE published guidelines on cerebral palsy in adults in 2019. NICE recognise learning disability services are a key part of the local network of care for people with cerebral palsy. They acknowledge that the presence of a learning disability in addition to cerebral palsy increases the complex needs of the person and impacts on their health outcomes and their access to health and social care. They recommend that all adults with severe cerebral palsy (GMFCS level 4 and 5) and a learning disability should have an annual review by a healthcare professional with expertise in neuro-disability. The other key recommendations from the guidelines that are particularly relevant to specialist learning disability physiotherapy services include:

1. Supporting adults with cerebral palsy to engage with physical activities (including sport) and tasks of daily living.
2. Being aware that, because of abnormal musculoskeletal development, adults with cerebral palsy are more likely to have bone and joint disorders.
3. Adults with cerebral palsy at high risk of lower respiratory tract infections should be considered for a prophylactic review of their chest care including the assessment of the person's postural management. NICE recognise that adults with severe cerebral palsy and aspiration pneumonia, chronic cardiorespiratory disorders, chronic suppurative lung disease, kyphoscoliosis, poor saliva control, and/or recurrent chest infections are at high risk of developing respiratory complications. This describes a large population of the people specialist learning disability physiotherapists manage under their postural management pathways.
4. Adults with cerebral palsy and persistent or multiple signs and symptoms of respiratory impairment, or risk factors for respiratory impairment should be referred to specialist services.

Although not solely applicable for adults with a learning disability, a high prevalence of people with cerebral palsy have a learning disability, especially those with more severe manifestations of the condition. People with cerebral palsy and a learning disability make up a large percentage of the specialist learning disability physiotherapy caseload therefore the guidance is very relevant to the profession and can be used to evaluate and develop services.

Specialist physiotherapy services for adults with a learning disability continue to evolve.

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20th century timeline

The key legislation; publications; national developments; policies; guidelines and labelling related to the health needs of adults with a learning disability

➡ Go Back

This is not an exhaustive list, but gives a flavor of the change in attitudes and approaches to supporting adults with a learning disability.

LABELLING 1900 - c.1950.'Mental defective' and 'mental deficiency' most common terms.

1904 Royal Commission on the Care and Control of the Feeble-Minded. Set up by Winston Churchill who was a strong supporter of eugenics.

1907 Formation of the Science of Eugenics Education Society. Only the fit and healthy should have children. 'Mental defectives' were seen as genetically tainted; they should be both separated from society and prevented from reproducing.

1908 Radnor Report Royal Commission on the care of the feeble minded. This was the main influence on the 1913 The Mental Deficiency Act. It recommended one central authority for the general protection and supervision of mentally defective persons, and for the regulation of the provision for their accommodation and maintenance, care, treatment, education, training, and control. Under the heading" Mentally Defective Persons" (Radnor Commission 1908).

1913 The Mental Deficiency Act (Replaces the 1886 Idiots Act). This act adds two new categories of 'feeble minded persons' and 'moral imbeciles' to the older laws two categories of 'idiot' and 'imbecile'. This Act initiated institutionalisation. It meant that people with a learning disability could be forced to live in asylums, many never returning to their families. In particular this influential Act made it possible to institutionalise women with illegitimate children who were receiving poor relief. At the height of the Mental Deficiency Act 65,000 individuals were institutionalised.

1914 Elementary Education (defective and epileptic) Act extended the right for an education to children who were 'mentally defective and epileptic'.

1918 The Education Act made schooling for all disabled children compulsory. It was a very significant piece of legislation. By 1921, there were more than 300 institutions for blind, deaf, 'crippled', tubercular and epileptic children. It was often thought that children with disabilities were better off away from their families, so even though a small number of them stayed in mainstream education, many left home to go off to residential schools.

1927 Mental Deficiency (Amendment) Act replaced the term 'moral defective' with 'moral imbecile'; crucially allowed for mental deficiency resulting from illness or accident. Previously it had to have been there from birth.

1929 The Wood report on Mental Deficiency published. The report was important because it argued that 'mentally deficient' children should not be isolated from the mainstream of education. Its view of special education as a variant of ordinary education advanced a principle which would later be extended to all forms and degrees of disability (Wood Report 1929).

1930 The eugenics movement was at its height. Some 60,000 people were subjected to sterilisation in Sweden between 1935 and 1976. Most were women and the majority were labelled as mentally defective, although most probably had only minor physical or social disability.

1933 Forced sterilisation of 360,000 disabled people in Germany.

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1934 The Brock Report of the Departmental Committee on Sterilisation chaired by Lord Brock recommended legislation to ensure the ‹voluntary› sterilisation of ‹mentally defective women›. Brocks report listed 10 western nations which had either introduced or were in process of introducing sterilisation laws. The eugenics movement was powerfully supported within the social establishment, and Britain seemed to be on the brink of introducing one of the most wide-ranging sterilisation laws. Although the Report had great support from Churchill and the government, British legislation never adopted sterilization laws. However, both institutionalization and segregation were employed to help prevent “multiplication of the unfit” (Brock 1934).

During World War 2 between 75,000 and 250,000 learning disabled and physical impaired people were murdered by the Nazis. Following World War 2 the Eugenics movement had been discredited.

1944 Education Act involved a thorough recasting of the educational system. That it was a requirement of secondary education for all, a requirement that meant that no school fees could be charged in any school maintained by public authority; and the replacement of the former distinction between elementary and higher education by a new classification of three progressive stages to be known as primary education, secondary education, and further education.

LABELLING c 1940’s ‘Uneducable’ label, introduced by 1944 Education Act, used with regard to people with a learning disability.

1944 Disabled Person Employment Act. ‘An Act to make further and better provision for enabling persons handicapped by disablement to secure employment, or work on their own account, and for purposes connected therewith’.

1946 Judy Fryd, a mother of a child with a learning disability formed the National Association of Parents of Backward Children founded (later Mencap).

1948 Birth of the NHS. The NHS took over the responsibility for the care of people with a learning disability living in the large institutions.

1948 Darenth Park Hospital was an example of the type of institution the NHS took control over. It had 2260 beds. A special ward was opened in 1949 for maladjusted patients whose behaviour was undisciplined and irresponsible. A Social Adjustment Centre was established, and patients were employed by outside companies. In this way, contracts were procured for box and carton-making, finishing plastic products, wiring electronic organs and fitting plugs. In 1951 over 3000 books had been bound and over 500,000 forms printed. There was a mattress making shop, upholsterers, mat making, brush making, and basketwork. The tailors’ shop made and repaired the patients’ clothes and the women made all their own dresses. The shoemakers made six pairs of orthopaedic boots needed for patients and repaired over 8000 pairs of shoes. Patients were paid 5 to 10 shillings (25-50p) weekly pocket money (the exact amount depended on performance). They were able to buy clothes and sundry items with this and the remainder of their wages was banked for them. In the 1960’s, it was decided to close large institutions for mental illness. Darenth Park was too big, too old, too run down and too isolated to meet modern standards of care. There was only one lift in the entire complex and the blocks were 3 storeys high. The central heating system was too old and not powerful enough to heat the hospital properly in winter. The decoration was poor, and it needed re-wiring. The hospital was isolated and difficult to reach. Its catchment area was huge which meant that relatives had a long and difficult journey. The hospital was closed slowly as four out of ten

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patients had spent more than 25 years there. In 1977 the hospital was sectorised – split into "mini-hospitals" each serving its own catchment area- thus paving a way towards community-based care. The Darenth Park Hospital finally closed in 1988 – One the first NHS institutions of its kind to close as a result of government policy to move mental health care out of hospitals and into 'the community'.

1948 United Nations Universal Declaration of Human Rights. Article 3 states everyone has the rights of life; liberty and security of person.

1948 National Assistance Act. ''An Act to terminate the existing poor law (The Act for the Relief of the Poor 1601, popularly known as the Elizabethan Poor Law,) which directed via the National Assistance Board , local authorities; to make further provision for the welfare of disabled, sick, aged and other persons and for regulating homes for disabled and aged persons and charities for disabled persons'. Established a social safety net for those who did not pay National insurance contributions (such as the homeless, the physically handicapped, and unmarried mothers) and were therefore left uncovered by the National Insurance Act 1946.

1951 National Council for Civil Liberties (NNCL) and advocacy group led the campaign to reform the mental health system. The NNCL Published '50,000 Outside the Law', a ground-breaking report on those unjustly incarcerated under the 1913 Mental Deficiency Act. This publication was pivotal in the repeal in 1959 of the 1913 Mental Deficiency Act.

1953 Nearly half the National Health Service›s hospital beds were for ‹mental illness or mental defect›. Concerns about the level of spending were likely to be a factor in shifting government thinking towards Community Care policies.

1954-7 Royal Commission on the Law Relating to Mental Illness and Mental Deficiency (under Lord Percy); National Association of Parents of Backward Children gave evidence to Royal Commission.

1957 The Report of the Royal Commission on the law relating to 'Mental Illness and Mental Deficiency (the Percy Commission) was published in June 1957. The commission concluded that: 'the law should be altered so that whenever possible suitable care may be provided for mentally disordered patients with no more restriction of liberty or legal formality than is applied to people who need care because of other types of illness, disability or social difficulty'. One of its recommendations was 'where possible, people with mental disorders should be treated in the community and not in large psychiatric institutions – this required an expansion of community services' (Percy 1957).

1958 The Brooklands experiment by Professor Jack Tizard at the Maudsley Hospital. Showed that children who lived in small houses in the community developed better than those who l ived in hospitals.

1959 'The 1913 **Mental Deficiency Act** is abolished'.

1959 Extra 21st Chromosome identified as a cause for Downs Syndrome by Jerome Lejeune

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1959 Mental Health Act. This repealed the 1913 Mental Deficiency Acts: espoused 'community care' but little funding; and said that patients should only be admitted on a voluntary basis unless seen as a danger to themselves or others (subsequently know as being 'sectioned'). Ended the compulsory certification enabling the discharge of many people with a learning disability from long stay institutions.

1960 The Brooklands experiment by Professor Jack Tizard at the Maudsley Hospital showed that children who lived in small houses in the community developed better than those who lived in hospitals (Tizard 1960).

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LABELLING c1960 ‘Subnormal’ ‘and ‘severely subnormal’ terms used in 1959 Mental Health Act. ‘Backward’ came into vogue as a descriptive term.

1961 Enoch Powell, Minister of Health, says mental hospitals to close in 15 years.

1962 Ministry of Health Report: A Hospital Plan for England and Wales – a 10-year report that included the development of hostels (Ministry of Health 1962).

1964 Tizard›s Community Services for the Mentally Handicapped argues for small residential units.

1967 A long-stay hospital for people with a learning disability hit the headlines in a way which had rarely happened before. Ely Hospital, built in 1862 as a Poor Law institution and converted to a long-stay NHS hospital in 1948, was hit with allegations of endemic maltreatment of its patients, including cruelty, verbal abuse, beatings, stealing of food, clothes and other items, indifference to complaints, lack of medical care and medication used to sedate patients.

1969 Independent inquiry following the whistle blowing to the news of the world by a nursing staff assistant at Ely Hospital, Cardiff of allegations of abuse and ill treatment of vulnerable long stay patients and other irregularities. It is seen as the first modern inquiry into the NHS. It confirmed the truth of the allegations and described problems of poor clinical leadership, an isolative and inward-looking culture, inadequate management structures and systems and inadequate resources.

Ely Hospital men’s ward

1970 Education (Handicapped Children) Act made education universal.

1970 Chronically Sick and Disabled Persons Act required local authorities to provide welfare services. Welfare services are those services that involve the provision of benefits and assistance to those in need. To disabled people who fell within section 29 of the National Assistance Act 1948 (those who were blind, deaf, people with a learning disability or mental illness and disabled people).

1971 Department of Health and Social Security White paper ‘Better Services for the Mentally Handicapped’. Advocated 50% reduction in hospital places by 1991 and an increase in provision of local authority based residential day care. Multi professional teams encouraged to support (Department of Health and Social Security 1971).

1971 Professor Gerry Simon set up British Institute of Learning Disabilities (BILD) because he was convinced there could be better support in the community for people with disabilities.

1972 Wolfensberger introduced the principle of normalisation in human management services.

‘Utilisation of means which are as culturally normative as possible, in order to establish and maintain personal behaviours and characteristics which are as culturally normal as possible’ (Wolfensberger et al. 1972).

1975 The United Nations proclaimed the “Declaration on the Rights of Disabled Persons.” In doing so, they reaffirmed that disabled individuals have the same rights as all other persons, including rights to medical, psychological; functional treatments, economic and social security, protection against exploitation; and a right to respect of their inherent human dignity.

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1979 Jay Report published that called for a ‘normal life’ and investment in an appropriate workforce. The Jay Report said that the lives of people with a learning disability should be normal and they should be part of their communities and re-emphasised the need for local authority led care, this was based on an idea called ‘Normalisation’ that had been followed in Denmark since the late 1950s (Jay 1979).

1980 ‘An Ordinary Life‘. David Towell and his colleagues at The Kings Fund worked to alert society to the rights of each person to live an ordinary life alongside other citizens. They included the rights to live in the mainstream of life, in ordinary houses, to have the same range of choices as other citizens and to mix equally as members of the community. Since the 1980’s this philosophy has been kept alive by John O’Brien’s Five Accomplishments, and it was at the core of Valuing People later published in 2001 (Towell 1980).

LABELLING c.1980 ‘People with Mental Handicap’ became the preferred term.

1981 Education Act laid down that children should be educated in mainstream schools or classes wherever possible.

1981 O’Brien’s ‘The principle of normalisation’: a foundation for effective services. Five essential accomplishments for quality of life (O’Brien and Tyne 1981).

1981 Three residents of Calderstones Hospital (for people with learning difficulties) successfully campaign for the right to vote in General Elections.

1983 Wolfensberger redefined normalisation as Social Role Valorisation (SRV) (Wolfensburg 1983).

1983 Mental Health Act. Law that sets out the criteria for admission, treatment (and if appropriate) the detention of patients with mental health issues in a hospital setting.

1984 People First group founded in England. In 1984 Gary Bourlet, a campaigner for people with a learning disability, created the self-advocacy group People First groups are often known as self-advocacy groups. They are groups of people with learning difficulties, people with intellectual disabilities, people with developmental disabilities and/or people with disabilities who speak up for themselves and work to improve the lives of their members.

LABELLING 1985 ‘People with learning difficulties’ adopted by self-advocacy groups.

Having previously been a regional group in Trent, ‘The Association of Chartered Physiotherapists in Mental Handicap’ was founded in 1985 with 26 members. This enabled physiotherapists in learning disabilities from across their local area and wider afield could join together to facilitate learning, share idea and a support each other. Later changed their name to the Association of Chartered Physiotherapist for People with Learning Disabilities (ACCPLD) there are now 9 regions with 333 members across the UK.

1986 The first closure of a large long-stay institution for people with learning difficulties – Starcross, Exeter. The Royal Western Counties Hospital Starcross was built in 1874-1877 in Starcross in Kenton, Devon. The building was originally known as the Western Counties Idiot Asylum. This institution was founded in 1864 and housed 40 patients by 1870 and a larger building was needed which opened in 1877 and was able to house 60 boys and 40 girls. Additions to the building were added in 1886 and 1909 and a total of 1,451 patients were admitted by 1913. A national policy of transferring people with psychiatric problems and learning difficulties back into the community in 1986 marked the Royal Western Counties Hospital for closure. The building was demolished in 1990.

1988 Griffin Review. Commissioned by the secretary of state to undertake a review of community care policy (Griffin et al. 1988).

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1989 Caring For People. White paper confirmed the government's commitment to the development of locally based health and social care services. Many group homes were developed as long stay institutions were closed.

1990 NHS and Community Care Act provided the necessary support structures to enable, where possible, people to remain in their own homes thereby reducing the demand for long term care. These structures included an increase in the range of domiciliary, respite and day services including the promotion of independent care options and a greater emphasis on supporting informal carers.

LABELLING c1990 Department of Health official term: 'people with learning disabilities'.

1991 Book published by Patricia Auty called Physiotherapy for People with Learning Difficulties (Auty 1991).

1995 Disability Discrimination Act published which made it unlawful to discriminate against disabled persons in connection with employment, the provision of goods, facilities and services, or the disposal or management of premises. The act also made provision about the employment of disabled persons; and established the National Disability Council.

1996 Mencap›s 50th anniversary Judy Fryd 1909 – 2000 Campaigner and founder member.

1998 Human Rights Act. Contains 15 basic rights including

The right not to be tortured or treated in an inhumane or degrading way* e.g. an older person from being subject to abuse, exploitation or violence by those supposed to care for them or others.

1. The right to liberty and security. e.g. to support a person's right to choose to move from one local authority area to another while maintaining their package of care and support.
2. The right to a fair trial e.g. in relation to detention under the Mental Health Act (1983) and complaints processes
3. The right to respect for private and family life, home and correspondence e.g. ensuring that lesbian, gay or bisexual people living in residential care do not face discrimination in maintaining their relationships and friendships
4. The right to freedom of thought, conscience and religion* e.g. to support people with religious observance such as prayer, diet or the opportunity to participate in religious festivals
5. The right to freedom of expression* e.g. accessing communication support or independent advocacy

Human rights belong to everyone and cover aspects of everyday life such as rights to food, shelter, education and health, freedoms of thought, religion and expression. Rights are underpinned by core values or principles, including fairness, respect, equality, dignity, autonomy, universality and participation.

1998 Signposts for Success. An NHS Executive good practice guide in the commissioning and provision of health service for people with a learning disability. The aim of this document was to promote good practice by clarifying the role of the NHS in providing services to people with a learning disability. People with learning disabilities are known to have much greater health needs than the general population. They have high rates of general health problems, sensory impairments, mental health problems (including challenging behaviour), epilepsy, cerebral palsy and other physical disabilities. It stated that there was a risk that people with a learning disability and that carers may not recognise health needs and ensure appropriate help is obtained. There is evidence that they do not use primary care as much as would be expected from their needs. People with a learning disability need to have equal access to primary care, community and hospital services and in addition will also require specialised services to meet some of their mental and physical health needs (NHS Executive 1998).

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2000 The first Scottish white paper 'The Same as You' detailed a comprehensive review of services for people with a learning disability in Scotland and included a series of recommendations for future development (Scottish Executive 2000).

2001 Valuing people: A new strategy for learning disability for the 21st century published emphasis on consultation with parents and the principles of rights, independence, choice and inclusion (Department of Health 2001).

2001 Special Educational Needs and Disability Act (SENDA): removed two of three caveats for mainstream education; made educational discrimination unlawful.

2001 Book published. Learning Disability, Physical therapy, treatment and management, a collaborative approach by Jeanette Rennie (Rennie 2001).

2004 Mencap 'Treat me Right!' report and campaign exposed the unequal healthcare that people with a learning disability often receive from healthcare professionals. The report made clear that much work needs to be done within the NHS to ensure that people with a learning disability are treated decently and equally (Mencap 2004).

2005 Mental Capacity Act. People with a learning disability have the right to make their own decisions if they have the capacity to do so.

2006 White Paper, Our Health, Our Care, Our Say, sought greater integration of health and social care, and to manage performance against shared outcome target (Department of Health 2006).

2007 Mencap published Death by indifference, reported the appalling deaths of six people with a learning disability – deaths that the six families involved and Mencap believe were the result of failings in the NHS. The report highlights that mainstream service cannot meet the need of adults with a learning disability alone and exposes the fatal consequences of inequalities in NHS healthcare (Mencap 2007).

2007 Putting People First: Department of Health›s commitment to making individual budgets a choice for anyone receiving social care (Department of Health 2007).

2007 UN Convention on Rights of Persons with Disabilities: UK a signatory to this Convention which commits states to uphold human rights for disabled people.

2007 Updated version of the book 'Physical therapy, treatment and management, a collaborative approach 'Jeanette Rennie (Rennie 2007).

2007 Several organisations came together to form the Learning Disability Coalition to campaign against cuts and for better funding for social care for people with a learning disability.

2008 Healthcare for All: An independent inquiry into access to healthcare for people with a learning disability following the publication of the Mencap report Death by Indifference, The Disability Rights Commission Formal Investigation into equal treatment had also raised questions about the quality of healthcare for people with a learning disability who were physically ill. The Independent Inquiry into Access to Healthcare for People with a learning disability emphasises the need for urgent change to improve grossly inadequate NHS healthcare. Community learning disabilities teams highlighted (Michael and Richardson 2008).

2008 Transition: Moving on well. A good practice guide for health professionals and their partners on transition planning for young people with complex health needs for a disability. Provides guidance in relation to planning transition, multi-agency working, and the planning and commissioning of services (Department of Health 2008).

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2009 Estimating Future Need for Adult Social Care Services for People with Learning Disabilities published by the Centre for Disability Research. The aim of the project was to estimate changes in the needs of adults with a learning disability in England for social care services from 2009 to 2026 (Emerson 2009).

2009 Valuing People Now' reviewed progress from Valuing People in 2001 and set new goals to support more people with a learning disability to get homes and jobs and lead fulfilled lives. Recognition of the importance of the specialist learning disabilities team and physiotherapy as part of this team (Department of Health 2009).

2009 Orchard Hill Hospital Sutton closes. The last NHS learning disabilities hospital to close. Most learning disability institutions in England were closed by 2004 but Orchard Hill remained because of delays in finding alternative accommodation.

2010 Raising our Sights was released which was a review of services for adults with profound intellectual and multiple disabilities by Jim Mansell (Mansell 2010).

2010 Mencap and the PMLD Network produced a series of how to guides and films to help local areas meet the needs of people with PMLD based on the key recommendations from the Mansell report 'Raising our Sights' in 2010 funded by the Department of Health (Mencap 2016).

2010 Equality Act was released. The Three aims of the equality act are:

1. eliminate unlawful discrimination, harassment and victimisation;
2. advance equality of opportunity between different groups; and
3. foster good relations between different groups

The Equality Act recognised nine protected characteristics. Age; disability; gender(sex); gender reassignment marriage and civil partnership; pregnancy and maternity; race; religion and belief; and sexual orientation (Parliament of the UK 2010).

2011 Health inequalities and people with a learning disability in the UK was published by Emerson and Baines. This is the third in a series of annual reports from the Learning Disabilities Public Health Observatory. In this series they summarise the most recent evidence from the UK on the health status of people with a learning disability and the determinants of the health inequalities they face. The series builds on a previous review of the UK research literature on the health needs of people with a learning disability and the response of health services (Emerson and Baines 2011).

2010 Improving Health and Lives (IHAL) of people with learning disabilities published information on characteristics of people with learning disabilities in England, the services and supports they use, and their carers is collected by several government departments and made publicly available through a number of diverse channels. The aim of this report is, within a single publication, to provide a concise summary of this information and to provide links to key data collections (Emerson et al. 2010).

2011 Winterbourne View Hospital scandal. BBC Panorama programme in revealed widespread abuse by staff of people with a learning disability. Six members of staff were prosecuted and sentenced to service time in prison.

2011 The role of the specialist health services in supporting the health needs of people with learning disabilities was published by the Debra Moore associates. Report on the future role and function of community learning disabilities teams. The authors recognised that specialist learning disability health professionals continue to have an important role to play in supporting the health and wellbeing of people with learning disabilities and their families. They are required to both support mainstream practice and directly serve those with the most complex needs. A key message from the document was that community learning disability teams should be

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delivering person centred services, within the community that respect and promote the rights of people with a learning disability as full citizens. To do this, there needs to be in place, good commissioning, a competent workforce and a robust system to check quality and outcomes. Community learning disability teams provide assessment, care management, care co-ordination, therapeutic intervention and health professional training and support for people with a learning disability (Moore and Thorley 2011).

2012 Mencap›s Death by Indifference: 74 Deaths and counting a progress report 5 years on highlights continuing critical inequalities in NHS health care for people with learning difficulties (Mencap 2012).

2012 Health and Care Act. Extensive reorganisation of the NHS. Abolished Primary Care Trusts and strategic Health authorities transferring commissioning to Clinical Commissioning groups (CCG's). Removed day to day management from central government and passed it to NHS England.

2012 Transforming care: A national response to Winterbourne view. Department of Health paper outlining the steps that needed to be taken in response to the findings of the investigation into Winterbourne View hospital (Department of Health 2012).

2012 Learning Disability Professional Senate was established with the aim to provide a single voice through which we can lead and inform NHS England, Department of Health and other strategy leads about the needs of children and adults with a learning disability. Brings together professional leaders from across the UK to provide cross-professional collaboration; strategic advice and innovation; and to develop both mainstream and specialist services for children and adults with a learning disability. The senate recognises and works with the range of professionals working with children and adults with a learning disability to champion inter-agency, multi-disciplinary, holistic approaches.

2012 Improving health and lives: The Learning Disabilities Public Health Observatory published which highlights the significant health inequalities people with intellectual disabilities experience. This paper describes an innovative approach to helping local agencies make the best use of available information in order to commission services that may reduce these inequalities (Emerson et al. 2012).

2012 NHS England produced 'Learning Disabilities Guidance for CCGs' in collaboration with improving health and lives learning disability public health observatory (iHAL). This guide was written to help Clinical Commissioning Groups to:

- commission high quality cost effective general and specialist health services for people with a learning disability;
- jointly commission services for people who challenge services and those with complex needs; and
- work with health and wellbeing boards, local authorities and others to address the social factors which affect the health of people with a learning disability.

(NHS England 2012)

2013 The Confidential Inquiry into premature deaths of people with learning disabilities in England (CIPOLD) was commissioned to provide evidence about contributory factors to avoidable and premature deaths in this population. The Confidential Inquiry reviewed the deaths of 247 people with intellectual disabilities. Nearly a quarter (22%, 54) of people with intellectual disabilities were younger than 50 years when they died, and the median age at death was 64 years (range 52-75). The median age at death of male individuals with intellectual disabilities was 65 years (range 54-76), 13 years younger than the median age at death of male individuals in the general population of England and Wales (78 years). The median age at death of female individuals with intellectual disabilities was 63 years (range 54-75), 20 years younger than the

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median age at death for female individuals in the general population (83 years). Avoidable deaths from causes amenable to change by good quality health care were more common in people with intellectual disabilities (37%, 90 of 244) than in the general population of England and Wales (13%). CIPOLD made eighteen key recommendations from their findings to improve the health outcome of people with learning disabilities (Heslop et al. 2013).

2013 Government response to the Confidential Inquiry into premature deaths of people with learning disabilities was published (Department of Health 2013).

2013 Connor Sparrowhawk (known as Laughing Boy, or LB) drowned in the bath in an NHS Assessment and Treatment Unit (Slade House) in Oxford. He was 18 and diagnosed with epilepsy and autism. Two months after LB's death, an unannounced Care Quality Commission inspection of Slade House found the unit to be inadequate in all 10 measures of assessment.

2013 Guidance developed by the Royal College of Nursing Learning Disability Nursing Forum, 'Dignity in health care for people with learning disabilities, 2nd edition. This guidance aims to improve dignity in health care for people with learning disabilities (Hardy 2013).

2013 Royal College of Nursing guidance for nursing staff. 'Meeting the health needs of people with learning disabilities' an updated guide that has been developed to support registered nurses and nursing students across the range of health services, who are trained in fields other than learning disabilities, to deliver high-quality health care to people with a learning disability. It highlights the specific health needs of people with learning disabilities and supports staff in making their services more accessible (Royal College of Nursing 2013).

2013 The Royal College of General Practitioners publish Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups. A practical guide designed to support Clinical Commissioning Groups, with Local Authorities and Learning Disability Partnership Boards, to commission health services in ways that achieve better health outcomes for people with a learning disability in a challenging financial climate (RCGP 2013).

2014 Southern Health NHS Foundation Trust published an independent report into the death of 18-year-old Connor Sparrowhawk that found his death was the outcome of a combination of poor leadership and poor care in the unit. The results indicated:

1. That Connor's death was preventable
2. That there were significant failings in his care and treatment
3. That the failure of staff to respond to and appropriately risk assess Connor's epilepsy ed to a series of poor decisions around his care
4. That the level of observations in place at bath time was unsafe and failed to safeguard Connor
5. That if a safe observation process had been put in place and Connor had been appropriately supervised in the bath, he would not have died on 4 July 2013
6. That the STATT unit lacked effective clinical leadership
7. That there had been no comprehensive care plan in place for the management of Connor's epilepsy and his epilepsy was not considered as part of Connor's risk assessment, in breach of NICE epilepsy guidance.

2015 NICE Guideline (NG11) Challenging behaviour and learning disabilities: prevention and interventions for people with a learning disability whose behaviour challenges. This guideline covers interventions and support for children, young people and adults with a learning disability and behaviour that challenges. It highlights the importance of understanding the cause of behaviour that challenges and performing thorough assessments so that steps can be taken to

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help people change their behaviour and improve their quality of life. The guideline also covers support and intervention for family members or carers (NICE 2015).

2015 Transforming care for people with learning disabilities – Next steps published which set out an ambitious programme of system wide change, to drive forward improvements, at pace, for people with a learning disability. The work aimed to ensure

- a substantial reduction in the number of people placed in inpatient (hospital) settings;
- a better quality of care for people who are in inpatient and community settings;
- a reduction in the length of stay for all people in inpatient settings; and
- a better quality of life for people who are in inpatient and community settings.

The publication highlighted five key priority areas:

1. **Empowering individuals.** Giving people with a learning disability and/or autism, and their families, more choice and say in their care. This area is led by the Department of Health (DH) and the Local Government Authority (LGA).
2. **Getting the right care in the right place.** Ensuring that we deliver the best care now, whilst re-designing services for the future. This area is led by NHS England, the LGA and Assistant Directors of Adult Social Services (ADASS).
3. **Workforce.** Improving care quality and safety by developing the skills and capability of the workforce to ensure we provide high quality care. This area is led by Health Education England (HEE).
4. **Regulation and inspection.** Tightening regulation and the inspection of providers, strengthening providers' corporate accountability and responsibility, to drive up the quality of care. This area is led by the Clinical Quality Commission (CQC).
5. **Data and information.** Making sure the right information is available at the right time for the people that need it. This area led by the Department of Health, working closely with NHS England and the LGA.

(ADASS, CQC, DH, HEE, LGA and NHS England 2015)

2015 Public Health England and Learning Disabilities Observatory publish People with Learning Disabilities in England 2015. This report, the fifth in a series, and reports the most recent data available at the time of writing (typically for 2014/15) for people with a learning disability in England. The authors also publish the data table from which the population estimates are derived (Hatton et al. 2015).

2015 Learning Disability Professional Senate published Delivering Effective Specialist Community Learning Disabilities Health Team Support to People with Learning Disabilities and their Families or Carers. The briefing paper on service specifications and best practice for professionals, NHS commissioners, CQC and providers of community learning disabilities health teams (Learning Disability Professional Senate 2015).

2015 The establishment of national mortality review based on CIPOLD's eighteenth recommendation. On 18 June 2015 NHS England, the Healthcare Quality Improvement Partnership (HQIP) and the University of Bristol announced the world's first national review of deaths of people with a learning disability. Known as the Learning Disability Mortality Review Programme (LeDeR), the three-year review aims to "get to the bottom of why people with learning disabilities typically die much earlier than average, and to inform a strategy to reduce this inequality".

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2016 The first national annual review report for the LeDeR Programme was produced and details the progress made in establishing the programme in its first year during the 11 months from 01 June 2015 to 01 May 2016. The LeDeR programme was established to support local areas to establish steering groups to review the deaths of people with a learning disability; identify learning from those deaths; and take forward the learning into service improvement initiatives. The programme has developed a review process for the deaths of people with a learning disability. All deaths receive an initial review. And those where there are any areas of concern in relation to the care of the person who has died; or if it is felt that further learning could be gained receive a full multi-agency review of the death (NHS England 2016).

2016 NICE Guideline (NG54) Mental health problems in people with learning disabilities: prevention, assessment and management and NICE pathway Mental health problems in people with learning disabilities published (NICE 2016b).

2016 Care Quality Commission (CQC) report 'Learning Candour and Accountability'. The report describes what the CQC found when it reviewed how NHS Trusts identify, investigate and learn from the deaths of people under their care. The report authors indicated that there was a 'common' level of acceptance and sense of inevitability when people with a learning disability or mental illness died, and that the lack of a single framework for NHS Trusts that sets out what they need to do to maximise the learning from deaths that may be the result of problems in care was problematic (CQC 2016).

2017 NICE Guidance in Spasticity in under 19s: management. This guideline covers managing spasticity and co-existing motor disorders and their early musculoskeletal complications in children and young people (from birth up to their 19th birthday) with non-progressive brain disorders. It aims to reduce variation in practice and help healthcare professionals to select and use appropriate treatments (NICE 2017).

2017 National Guidance on Learning from Deaths was published by the National Quality Board. It provides a framework for NHS Trusts and NHS Foundation Trusts in England for identifying, reporting, investigating and learning from deaths of people in their care. The guidance emphasises the importance of learning from reviews of the care provided to patients who die, and that this should be integral to a provider's clinical governance and quality improvement work. It requires providers to have a clear policy for engagement with bereaved families and carers, and an updated policy on how they respond to, and learn from, deaths of patients who die. From April 2017, Trusts have been required to collect and publish on a quarterly basis specified information on deaths (National Quality Board 2017).

2017 NICE Guidance (NG62) Cerebral palsy in under 25s: assessment and management. This guideline covers diagnosing, assessing and managing cerebral palsy in children and young people from birth up to their 25th birthday. It aims to make sure they get the care and treatment they need for the developmental and clinical comorbidities associated with cerebral palsy, so that they can be as active and independent as possible (NICE 2017).

2017 A National Project stop over-medicating people with a learning disability, autism or both (STOMP) with psychotropic medicines. The project involves many different organisations which are helping to stop the over use of these medicines. STOMP aims to help people to stay well and have a good quality of life (NHS England 2018).

2017 NICE Quality Standard (QS142) Learning disabilities: identifying and managing mental health problems. This quality standard covers the prevention, assessment and management of mental health problems in people with learning disabilities in all settings (including health, social care, education, and forensic and criminal justice). It also covers family members, carers and care workers (NICE 2017b).

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2017 NICE Quality standards (QS162) Cerebral palsy in children and young people. This quality standard covers diagnosing, assessing and managing cerebral palsy in children and young people under 25. It describes high-quality care in priority areas for improvement (NICE 2017c).

2018 LeDeR annual report published for 1st July 2016 to 30th November 2017. 1,311 deaths were notified to the LeDeR programme. The report highlights that the average age at death of people with a learning disability was 59 for males and 56 for females. More than a quarter (28%) of deaths were of people aged under 50 years (NHS England 2018).

2018 MENCAP 'Treat me well' campaign launched that advocated for improved treatment of people with a learning disability in hospital (MENCAP 2018).

2018 NICE Guideline (NG93) Learning disabilities and behaviour that challenges: service design and delivery. This guideline covers services for children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges. It aims to promote a lifelong approach to supporting people and their families and carers, focusing on prevention and early intervention and minimising inpatient admissions (NICE 2018).

2018 National Quality Board publish Safe, sustainable and productive staffing: An improvement resource for community and inpatient learning disability services developed in the context of reducing health inequalities and increasing the life-expectancy of people with a learning disability, as well as enabling sustainability and transformation plans in the NHS (National Quality Board 2018).

2019 NHS Long Term Plan published which present the five ways that they will improve the care of people with a learning disability and autism:

1. Tackle preventable deaths: stopping overmedication and improving health checks;
2. Improve understanding of learning disabilities and autism within the NHS;
3. Reduce waiting times for specialist services;
4. Increase investment in community support: reducing inpatient admissions; and
5. Improve quality of inpatient care across NHS and independent sector.

(NHS England 2019)

2019 NICE guidance (NG119) Cerebral palsy in adults. This guideline covers care and support for adults with cerebral palsy. It aims to improve health and wellbeing, promote access to services and support participation and independent living (NICE 2019).

2019 (May) MENCAP. Profound impact Day. Focussing on the issues facing people with profound and multiple learning disabilities in hospital.

2019 (July) UPDATED NICE guidance. Service model for people with learning disabilities and behaviour that challenges [QS101] (NICE 2019a).

2019 (July) UPDATED NICE guidance. Care and support of people growing older with a learning disability. [QS187] (NICE 2019b).

Publications to look out for:-

2020 (January) NICE Quality Standards for Cerebral Palsy in Adults (GID-QS10080).

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Physiotherapy needs of adults with a learning disability

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Adults with a learning disability have are a number of factors and associated conditions that increase the prevalence of developing physiotherapy related problems either from an early age or within their lifetime. Some common conditions that increase the need for adults with a learning disability to access physiotherapy include:

Cerebral palsy

Cerebral palsy is the name for a group of lifelong conditions that affect movement and co-ordination, caused by a problem with the brain that occurs before, during or soon after birth (NHS 2017). The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, learning, cognition, communication, behaviour, epilepsy and secondary musculoskeletal problems' (Rosenbaum et al. 2006).

Palisano et al. (2007) developed the Gross Motor Functioning Classification System (GMFCS) to classify children with cerebral palsy into categories depending on their physical level and functional presentation (Table 1). The GMFCS has been validated for children and adolescence with Cerebral Palsy up to the age of 19 years old (Palisano et al. 2007). Recently, NICE (NICE 2019) recognised the classification system as an accurate tool for adults with cerebral palsy in the absence of an alternative descriptive system.

Table 1: Gross Motor Function Classification System (Palisano et al. 2007)

Level	Descriptor of Disability	Illustration
I	Walks without assistance	
II	Walks without assistive devices, limitations outdoors and in the community	
III	Walks with assistive devices, limitations outdoors and in the community, requiring wheelchair use in these settings	
IV	Self-mobility in wheelchair with limitations, transported or uses power mobility in a community	
V	Very limited self-mobility, even with assistive tech	

NICE (2017) state that 50% of people with cerebral palsy will have a learning disability (IQ below 70) and 25% will have a severe learning disability (IQ below 50). The presence of a learning disability can be associated with any functional level, but prevalence increases with severity of motor impairment. 33.3% of people with cerebral palsy (GMFCS level 1 or 2) have a learning disability. This increases to 66.6% in people with more severe cerebral palsy (GMFCS level 3, 4 and 5). As a result, people with cerebral palsy are one of the most common cohorts to require access to specialist learning disability physiotherapy services. The researchers conducted a cohort study of the people with complex physical disability (GMFCS level 4 and 5) accessing the local postural management pathway (Standley 2019b). The results indicated that 78% (115/147) of people had cerebral palsy.

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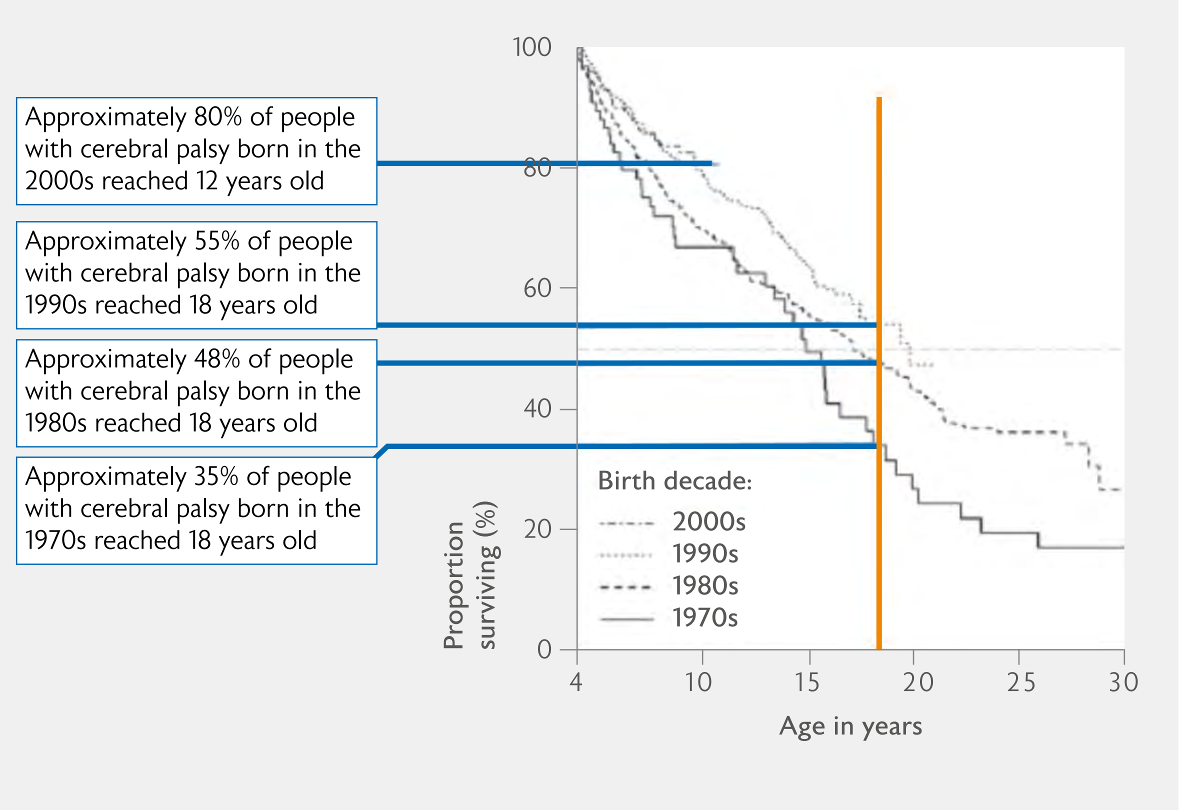
Cerebral palsy is thought to occur in 2 to 2.5 per 1000 live births and is the most common severe physical disability affecting children (Hutton and Paroah 2006). Developments in modern medicine, in particular improvements in neonatal care, enteral feeding and spinal surgery have had an impact of the number of people with severe cerebral palsy surviving birth. They have also had a profound effect on the number of individuals reaching adolescence and adulthood.

Research indicates that life expectancy for people with cerebral palsy is similar to the general population unless the person has no ability to change their position, are unable to feed by mouth, and have severe learning disabilities (Hutton and Phoroah 2006; Westbom et al. 2011; Young et al. 2011; NICE 2016). Westbom et al. (2011) report that 60% of people with cerebral palsy GMFCS level 5 survive to the age of 19. Hatton and Phoroah (2006) reported that the survival rate of wheelchair users to 35 years of age was reduced from individuals who walked, with or without an aid. Interestingly they found that life expectancy markedly reduced in people who required a carer-operated wheelchair in comparison to those who self-propelled.

Brookes et al. (2014) performed an observational cohort study of 51,134 people with cerebral palsy aged 4 years and older registered with the California Department of Developmental Services between 1983 and 2010. 6% of this cohort of people had severe cerebral palsy defined as not being able to lift their head in prone. The authors developed survival curves for 4 year olds born in the 1970s, 1980s, 1990s and 2000s categorised by level of disability. They found that there was no significant difference in the survival rates of those with mild to moderate disability but found a significant increase in the cohort with severe disability (figure 10). The results of Brookes et al. study are particularly important and relevant to adult services because it provides evidence of an increasingly complex group of people reaching adulthood whom are likely to require access to specialist services.

Figure 10: Survival curves of 4-year-old children with cerebral palsy who do not lift their heads when lying in the prone position born in the 1970s, 1980s, 1990s, and 2000s (n=1147) born (Adapted from Brooke et al. 2014).



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People with complex physical and learning disabilities

Complex physical disability is an umbrella term used to describe people who typically, but not exclusively, have non-progressive neurological conditions which significantly affects their physical presentation and functional abilities (Table 2). This population have severe physical disabilities which affects all four limbs and their trunk, resulting in postural abnormalities and movement disorders. Individuals require wheelchairs and assistive devices to mobilise and maintain themselves upright against gravity (GMFCS level 4 and 5). Morbidity and mortality are, in general, attributed to the development of secondary complications such as osteoporosis, contractures, joint dislocations, urinary infections, pressure sores and respiratory infections (Pope 2007; Department of Health 2009; Tosi 2009; Mansell 2010; Young et al. 2011). People with complex physical disability can present with a learning disability anywhere on the continuum from mild to profound.

Table 2: Potential causes of complex physical disability

	Common conditions	Morbidity and mortality
Non – progressive neurological conditions	Cerebral palsy Spinal bifida Chromosomal abnormalities Traumatic brain Injury in childhood	Associated with the development of secondary complications, and are not, in the main, the direct manifestation of the pathological impairment
progressive neurological conditions	Duchene muscular dystrophy Leukodystrophies	Associated with the trajectory of the neurological condition and the development of secondary complication

Adults with a learning disability and dementia

Adults with a learning disability are living longer thanks to improvements in healthcare. As a result, age related problems and conditions such as dementia are becoming more prevalent. Public Health England (2018a) recently published reasonable adjustment guidance for people with a learning disability and dementia. They state that estimates of the prevalence of dementia in people with a learning disability vary, in part because there has not always been good recognition, assessment and diagnosis. Research suggests that age-related dementia of all types is more common at earlier ages in people with a learning disability than in the rest of the population (about 13% in the 60 to 65 year old age group compared with 1% in the general population). Prevalence is estimated at 2 to 3 times greater in people with a learning disability than the general population in all over-60 age groups. People with Down’s syndrome are at particular risk of early onset Alzheimer’s disease. Approximately 30% of people will have Alzheimer’s in their 50s and 50% by their 60s.

Adults with a learning disability and dementia, especially those with Down’s syndrome and Alzheimer’s disease are at high risk of developing physiotherapy related secondary complications as their dementia progresses. This includes mobility problems and falls in the early to mid-stages of dementia; and postural, swallowing and respiratory problems towards the later stages.

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Epilepsy

About 1 in 3 people (33.3%) who have a mild to moderate learning disability also have epilepsy (Epilepsy Society 2016). Over 60% of people with profound and multiple learning disabilities have epilepsy and it is one of the most common and persistent health problems. In general, the more severe the developmental delay, the higher the risk of epilepsy (Mencap 2016). Seizure activity or side effects of medication can further compromise cognitive ability and have a significant effect on mobility and movement. People can also present with wide fluctuations in functional abilities in line with seizure patterns.

Profound and Multiple Learning Disability

Jim Mansell (2010) uses the term profound intellectual and multiple disabilities to describe a group of people who have a profound learning and multiple disabilities, which may include impairments of vision, hearing and movement as well as other problems like epilepsy and autism. Most people in this group are unable to walk unaided and many people have complex health needs requiring extensive help. People with profound intellectual and multiple disabilities need high levels of support from others with most aspects of daily living, including help to eat, to wash, to dress, to use the toilet, to move about and to participate in any aspect of everyday life. They have great difficulty communicating; they typically have very limited understanding and express themselves through non-verbal means, or at most through using a few words or symbols. They often show limited evidence of intention. Some people have, in addition, problems of challenging behaviour such as self-injury.

Bellemy et al. (2010) conducted a study to define the term profound and multiple learning disabilities. They reviewed the available literature to determine the different definitions available within the literature. They then explored these definitions with different stakeholders through interviews and group work. The study agreed the on following definition:

> *"People with profound and multiple learning disability (PMLD) have extremely delayed intellectual and social functioning; may have limited ability to engage verbally, but respond to cues within their environment (e.g. familiar voice, touch, gestures); often require those who are familiar with them to interpret their communication intent; and frequently have an associated medical condition which may include neurological problems, and physical or sensory impairments. They have the chance to engage and to achieve their optimum potential in a highly structured environment with constant support and an individualised relationship with a carer."*

Research conducted by the Centre for Disability Research suggests there will be a sustained and accelerating growth in the numbers of adults with profound intellectual and multiple disabilities receiving health and social care services in England. There will be an average annual increase of 1.8 per cent from 78 in 2009 to 105 in 2026 (per 250,000 population) (Figure 11). And the number of young people with profound intellectual and multiple disabilities becoming adults in any given year will rise from 3 in 2009 to 5 in 2026 (per 250,000 population) (Mansell 2010).

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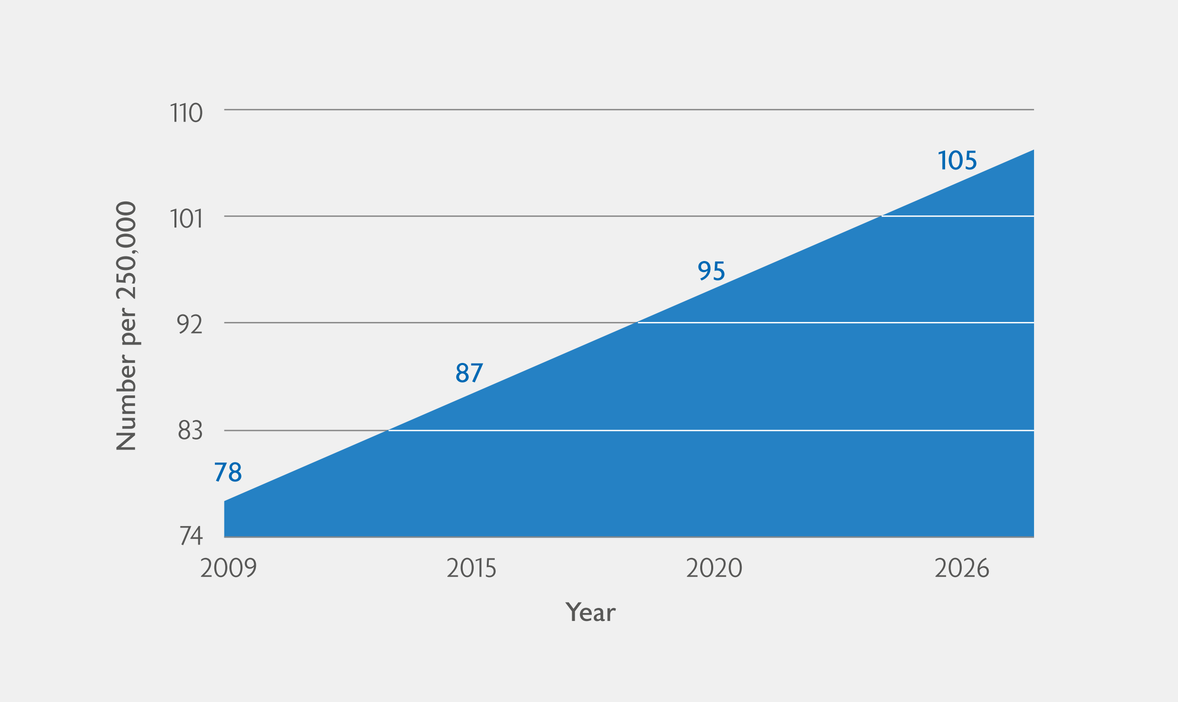
Figure 11: The projected increase in the number of people with PMLD between 2009 to 2026 (Mansell 2010)



People with profound and multiple learning disabilities are among the most disabled individuals in our community (Mansell 2010). They are likely to require life long and regular access to health care services. They often present with physiotherapy related problems because of the physical disability and associated conditions. Therefore, they will require access to specialist physiotherapy services throughout their lives.

Behaviours that challenge

It is relatively common for people with a learning disability to develop behaviours that challenge, and more common for people with more severe disability. People with a learning disability who also have communication difficulties, autism, sensory impairments, sensory processing difficulties and physical or mental health problems (including dementia) may be more likely to develop behaviour that challenges (NICE 2015).

People with a learning disability who display behaviours that challenge are predisposed to developing physiotherapy issues due to the long term use of particular antipsychotic medications, and problems caused by repetitive or ritualistic movement. In addition, people may display an exacerbation in their behaviour because of a physiotherapy related problem such as musculoskeletal pain or deterioration in mobility. Behaviours that challenge can be a significant barrier to accessing healthcare. Thus, people require support to positively access mainstream healthcare and frequently require specialist learning disability services.

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Supporting Evidence

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Definition

Supporting evidence:
Valuing people recognised that professional staff employed in local community learning disability team provide a vital role as health facilitators to support for people with a learning disability gain full access to the health care they need, whether from primary or secondary NHS services (Department of Health 2001).
In 2007 the Department of Health published good practice guidance on commissioning specialist adult learning disability health services. The Department of Health recognised that the focus of specialist community health staff commissioned by the Primary Care Trust Care Trust should be on supporting mainstream health services to ensure the delivery of good quality general health care to people with a learning disability. They state that specialist learning disability health services have an essential clinical and therapeutic role, which will include providing support to people and their families when their needs cannot be met by mainstream services alone (Department of Health 2007).
Valuing People Now (Department of Health 2009) reported that some people with a learning disability and additional complex or profound physical disabilities will require health professionals from mainstream and specialist learning disability services to work in partnership in order to access essential therapeutic assessments and interventions. Similar partnership arrangements are also needed to ensure that people with more complex needs gain access to the best care and treatment in the full range of health services, from maternity services through to end of life care.
Royal College of General Practitioners reports that one of the main functions the community learning disability team is to offer specialist provision and direct support to people and their families when their needs cannot be met by mainstream services alone. The second is enabling adults with a learning disability to access other services through health facilitation and providing support to primary and secondary care to ensure reasonable adjustments are in place to allow people to access services (RCGP 2013).
CIPOLD recommended that the barriers to people with a learning disability accessing healthcare should be addressed by proactive referral to specialist learning disability services. The authors recommend that commissioners and other agencies, review their eligibility criteria for access to specialist learning disability services to ensure they are based on vulnerability and need, not on an assumed level of a person's learning disability. CIPOLD also reported that where specialist expertise is required, the community learning disability team should be involved in working with the individual, their family and carers to create a bridge to primary and secondary health services to facilitate familiarisation and desensitisation (Heslop et al. 2013).
The learning disability professional senate states that supporting positive access to and responses from mainstream services should be seen as a non-negotiable component of a community learning disabilities health team's service specification. This is because their understanding of learning disability will be critical to achieving high quality health and social care outcomes. To achieve this, community learning disability services must engage in work that supports better universal access to mainstream services and positive outcomes to reduce the known health inequalities. They should also provide on-going support, supervision and advice to mainstream services to support them in the provision of 'reasonable adjustments' and positive support plans (Learning Disability Professional Senate 2015).
The National Quality Board report that commissioned community learning disabilities health teams must be available to all people with learning disabilities in the commissioning clinical commissioning groups (CCG) locality and in all locations where CCG registered patients reside (National Quality Board 2018).

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24-hour postural management

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Supporting Evidence:
Mansell (2010) reports that people with profound intellectual and multiple disabilities face several specific health problems including in postural care. The report recognises that postural management services for adults are often not sufficiently well-developed to recognise and intervene effectively. This can lead to discomfort, pain and premature death. The author recommends that NHS bodies should ensure they provide health services to adults with profound intellectual and multiple disabilities which focus on protection of body shape and the resolution of pain and distress (Recommendation 12).
NICE (2012) recommend that young people with spasticity have timely access to equipment necessary for their management programme (for example, postural management equipment such as sleeping, sitting or standing systems).
The Royal College of General Practitioners reports that clinical commissioning groups (CCGs) should consider investing in postural care interventions to improve quality of life and save money. They recognise that postural care challenges the assumption that changes in body shape are inevitable for people who have movement difficulties. They acknowledge that changes in body shape, particularly chest distortion, result in secondary problems such as chest infections and aspiration, which result in a poor quality of life and can lead to premature death. The authors state that body distortion is costly in terms of equipment and increasingly complicated medical intervention. They recommend that adults with a learning disability and postural care needs have access to services, equipment and training to support the long-term management of their body shape (RCGP 2013).
CIPOLD established the link between a failure to protect body shape and resultant premature death. It recommended that CCGs should ensure they commission expert, preventative services including proactive postural care support (Heslop et al. 2013).
NICE (2014) acknowledge that people who have a neurological condition; impaired mobility; impaired nutrition; and/or poor posture or a deformity are potentially at risk of developing a pressure ulcer. NICE recommend that adults who have been assessed as being at high risk of developing a pressure ulcer should change their position frequently and at least every 4 hours. If they are unable to reposition themselves, professionals should ensure that repositioning equipment is available and ensure that patients, parents and carers understand the reasons for repositioning.
Poor postural care can have severe and life-threatening complications for people who have a limited ability to change position (Crawford and Stinson 2015). Body shape distortion is associated with physical health problems including: • Respiratory problems; • Problems with the musculoskeletal system, such as hip dislocation, contractures, curvature of the spine and reduced movement; • Impairments of the neurological system, including problems with spasticity/ muscle tone, reflexes, altered sensation and joint position sense, pain and weakness. • Difficulties in swallowing and risk of choking; • Constipation; • Pressure on internal organs; and • Recurrent pressure sores. Additional areas where problems may arise include respiratory function, kidney/renal function, personal hygiene, personal care; functional ability (e.g. weight bearing, transfer and hand function); environment interaction (sensory perception, body aesthetics, learning, communication); sleep pattern; and irritability. Complications will cause discomfort and possibly severe pain. They will certainly have a negative impact on the person's quality of life and can lead to emotional and psychological problems (NHS Purchasing and Supply Agency 2009; Crawford and Stinson 2015; Public Health England 2018b).

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The learning disability professional senate recognise that specialist learning disability physiotherapists support people with a learning disability in the provision of postural care (Learning Disability Professional Senate 2015).

NICE (2017a) recognise that people with cerebral palsy are at risk of having low bone mineral density especially those who are non-ambulant (GMFCS level IV or V); have the presence of eating, drinking and swallowing difficulties; concerns about nutritional status; are low weight for age; have a history of low-impact fracture; and/or use of anticonvulsant medication. NICE recommend that professionals consider an active movement programme, active weight bearing, and minimising risks associated with movement and handling as possible interventions to reduce the risk of reduced bone mineral density and low-impact fractures.

NICE (2017) recognise that common condition-specific causes of pain, discomfort and distress in young people with cerebral palsy include musculoskeletal problems (for example, scoliosis, hip subluxation and dislocation), increased muscle tone (including dystonia and spasticity), and muscle fatigue and immobility.

Public Health England recognise that the provision of 24-hour postural care reduces health risks and improves quality of life for individuals. It can also benefit those caring for the person. Although postural care can be an expensive service it does reduce the need for invasive and costly interventions including surgical procedures; complex equipment for mobility; adaptation to the home; enteral feeding; pain management; and increased need for medications such as Botox or Baclofen (Public Health England 2018b).

NICE (2019) recommend that adults with cerebral palsy at high risk of lower respiratory tract infections should be considered for a prophylactic review of their chest care including the assessment of the person's postural management. NICE define a review of 24-hour postural needs as an assessment that considers all the relevant postures that an individual has the ability to adopt over the 24 hours of any given day, including postures to allow for participation in daily activities. The panel who developed the guidance report that postural care is likely to prevent respiratory infections and their associated costs which offsets the investment required to resource postural management services.

NICE (2019) recommend an annual review for people with cerebral palsy who have complex needs such as GMFCS levels IV and V, communication difficulties, learning disabilities, living in long-term care settings, living in the community without sufficient practical and social support, or multiple comorbidities. NICE define a review as a planned clinical appointment between an adult with cerebral palsy and a healthcare professional or multidisciplinary team. They may explore common concerns, physical symptoms, mental health, pain, nutrition and communication to ensure an individualised approach to care. The healthcare professional may be a GP, specialist nurse, rehabilitation specialist or therapist. This also allows the opportunity to address general health issues that affect people as they grow older. NICE report that annual review is likely to prevent an emergency department visit per year for this group and thus would be cost effective.

A number of reports have noted gaps in postural management services for people with a learning disability (Michael and Richardson 2008; Mansell 2010; Murphy et al. 2010; RCGP 2013; Heslop et al. 2013; Public Health England 2018b). Murphy et al. (2010) report that the provision of physical management is ad hoc in nature, and patchy in effectiveness.

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Community level respiratory management

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Supporting Evidence:
National Quality Board recognise that a role of the specialist learning disability physiotherapist is to support individuals with respiratory care (National Quality Board 2017).
CIPOLD found that respiratory disease (usually pneumonia) was reported as the final illness from which adults with a learning disability included in the study died, and the immediate cause of their death in over a third of people (Heslop et al. 2013). This finding is supported by a number of authors (Truesdale and Brown 2017; Public Health England 2018b). In response, Heslop et al. (2013) recommends that adults with a learning disability are considered a high-risk group for deaths from respiratory problems. They recommend that CCGs must ensure they are commissioning expert, preventative services to manage people with a learning disability at high risk of respiratory illness which includes expert and proactive postural management.
NICE (2019) acknowledge that adults with cerebral palsy, many of who have a learning disability, are at increased risk of respiratory failure. NICE recognise that risk factors for respiratory impairment are more common in adults with severe cerebral palsy (GMFCS level IV or V). These include aspiration pneumonia, chronic cardiorespiratory disorders (for example, cor pulmonale or pulmonary, circulation hypertension), chronic suppurative lung disease, kyphoscoliosis, poor saliva control and recurrent chest infections. NICE (2019) recommend that if an adult with cerebral palsy is at high risk of lower respiratory tract infection, they should be receive a prophylactic physiotherapy chest care review. This should include postural management; advice on exercise and opportunities to move; positional changes; and interventions to assist ventilation and secretion control management. In addition, the person's network of care should receive adequate advice and training to help with ongoing chest care. NICE predict that there may be a small increase in the number of referrals for chest reviews but state that this demand is likely to be balanced by improved ongoing chest care, which would reduce respiratory infections and the costs associated with them.
Wolff et al. (2015) found that a community based respiratory service reduced hospital admissions from 36 to 24 and emergency department attendances from 48 to 33 in a 12 month period in 34 children and young people (aged 1 to 19) with neurological disability. Community respiratory physiotherapy included: 1. The development of a daily tailored chest physiotherapy programme involving manual techniques, suction airway management, and use of equipment to increase lung volumes and instigate cough; 2. Delegation of the specific chest physiotherapy programme to the person's network of care including training and education to ensure the programme is delivered competently; and 3. A rapid response respiratory physiotherapy service, between 8:30 am to 4:30 pm Monday to Friday. The authors conclude that a community respiratory physiotherapy service can lead to reduced hospital admissions and reduced hospital bed days for children and young people with severe disability and can pay for itself in reduced admission costs.
Public Health England (2018b) report that respiratory problems are the main reason people with profound and multiple learning disabilities need primary or secondary medical care, and pneumonia is the most common cause of death in this group. Some of the risk factors for respiratory problems that can be reduced by good postural management are airway clearance dysfunction, saliva management difficulties, immobility, reflux, sleep disordered breathing and thoracic deformity.

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Falls prevention and intervention

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Supporting Evidence:
Finlayson et al. (2010) conducted a longitudinal cohort study to determine the incidence and types of injuries experienced by a community-based cohort of 511 adults with a learning disability in a 12-month period. The results found that 40% of people with a learning disability experience at least one fall (with or without injury) and 22.5% more than once in a 12-month period. 30% of people who fell injured themselves as a result. The results also found that adults with a learning disability are more likely than an aged matched population to fracture as a result of an injury.
Petropoulou et al. (2017) completed an observational cohort study of 593 adults with a learning disability living with paid support to determine the incidence, causes and types of injuries experienced over a 12 month period of time. The results found that adults with a learning disability are twice as likely to experience injury as the aged matched population. Falls were the most common cause of injury (16.2%). The author defined an injury as those which required medical, nursing or certificated first-aider support worker attention or treatment.
Falls in the elderly population costs the NHS an estimated £2.3 billion per year (NICE 2013) with 1.5billion spent on A&E admissions (CSP 2015). Evidence suggest that adults with a learning disability experience similar rates of falls as older adults in the wider population, but at a younger age (Sherrard et al. 2001; Finlayson et al. 2010; Finlayson et al. 2016).
The factors that increase the risk of falls in people with a learning disability are abnormal patterns of walking; greater instability during standing and walking; more variable body sway; decreased motor responses to balance perturbances; concurrent medical problems; poly pharmacy; issues with impulsiveness and distractibility; visual deficits; and epilepsy (Finlayson et al. 2010; Enkelaar et al. 2012; Hsieh et al. 2015; Hale et al. 2016;). Providing training in falls prevention for adults with a learning disability can minimise the potential for and reduce severity of falls (Enkelaar et al. 2012).
Crockett et al. (2014) implemented a tailored 12 week home-based tailored strength, balance and aerobic exercise programme designed by a physiotherapist on 27 adults with a learning disability who reported having experienced one or more falls (age range 28-81; mean 58). Intervention included an assessment and development of falls programme; a training session for the network of care; follow up visit at 4, 8 and 12 weeks; review at 16 weeks; and development and issuing information leaflets to prevent future falls. Crockett et al. found that the programme significantly reduced the number of reported falls from 3.2 (range 1 to 14) to 1 (range 0 to 3) over the 16 week programme. The authors conclude that physiotherapists have a key role to play in promoting exercise to prevent falls within multidisciplinary falls services for adults with a learning disability. In addition, exercise which improves mobility/balance, increases physical activity and reduces falls is important for the overall health and well-being for adults with a learning disability.
Hale et al. (2016) conducted a mixed method study on 27 adults with a learning disability at risk of falls or active fallers to evaluate the clinical benefit; and acceptability, utility and feasibility of a 6 month falls prevention intervention (PROFAID). PROFAID included a training workshop for network of care; a tailored community accessible exercise programme; and weekly or biweekly telephone follow up. Intervention was completed over 3 visits by a physiotherapist and followed up at 6 months. Results indicated a statistically significant improvement in balance scale for adults with intellectual disability and a trend to improvement in other outcome measures. Semi-structured interviews of the network of care demonstrated that the intervention is realistic and feasible to complete within daily routines and activities. The authors conclude that targeting physiotherapy to improve balance capabilities can help to prevent falls.

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Public Health England published guidance in preventing falls in people with learning disabilities as part of the making reasonable adjustments series in August 2019. They recognise that people with learning disabilities are at risk of falls throughout their lives with 25-40% experiencing at least one fall per year. This is similar to the rate reported for older people in the general population (30%). Falls are the leading cause of injury, including fractures, in people with a learning disability. Around one-third of falls are reported to result in injury; the rate of fractures is higher than in the general population and fractures can occur in younger people. They acknowledge that the growing evidence relating to falls in people with a learning disability suggests that much of the policy and guidance for preventing and responding to falls in older people is equally relevant. Therefore they recommend that policy developed from work with the general population can be applied, with consideration of the factors specific to people with a learning disability. These include:

- Providing accessible information for individuals and information for family members and paid support staff;
- Ensuring that risk assessments cover those to be associated with having a learning disability;
- Making reasonable adjustments to enable full assessment of bone density;
- Tailoring interventions to the individual, their lifestyle and the support available to them; and
- Providing adapted interventions such as strength and balance exercise programmes.

The document links readers to the Public Health England's consensus statement that sets out a collaborative, whole system approach to prevention, responses and treatment of falls in older people for further guidance on delivering falls services to people with a learning disability (Public Health England 2017).

Public Health England acknowledges that falls and injuries are avoidable causes of frailty and reduced wellbeing, in addition to causing significant cost to health and social care. The authors review the available evidence regarding falls in people with a learning disability and use the results to develop the document. Some of the key findings that are relevant to the specialist learning disability physiotherapist include:

1. Sedentary lifestyle and problems with gait and balance are risk factors for falls.
2. Given the high risk of falls in people with learning disabilities, and the associated risk of injury, proactive primary prevention will be useful as part of person-centred health action planning. This involves promotion of healthy lifestyles with encouraging physical activity (accompanied by individual risk assessment and management where appropriate).
3. Following a fall or a 'near miss', a structured approach to prevention is required involving an individually tailored risk assessment and management plan. This focuses on (amongst other factors):
    - general health and fitness, including levels of physical activity;
    - balance and gait problems; and
    - mobility aids and adaptations.
4. There is some evidence from studies with people with a learning disability to support the finding from the general population that promotion of physical activity can help to improve general health and wellbeing. However, more structured strength and balance exercise programmes are required to make a difference to falls risk.
5. A formal assessment of environmental hazards (both at home and out and about) and of the ways the individual interacts with their environment may be appropriate based on the individual's falls risks.

The publication provides an evidence based guide to preventing falls in people with a learning disability including examples of good practice from around the UK, and resources for people with a learning disability; family and paid carers; and health and social care professionals. The guidance can be used to support current practice as well as provide evidence for developing and commissioning specialist learning disability falls services.

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Management of mobility problems

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Supporting Evidence:
National Quality Board recognise that the specialist learning disability physiotherapist support individuals with mobility assessments (National Quality Board 2017).
CIPOLD reviewed the deaths of 247 people with a learning disability over the 2-year period in 2010–2012. Two-thirds lacked independent mobility which was most prevalent health and social care needs of the population reviewed (Heslop et al. 2013).
Adults with a learning disability who are immobile are at a sevenfold increase risk of early death then those who are fully mobile. And adults with a learning disability who are partially mobile are at twofold increased risk of early death (Emerson and Baines 2011).
Mobility problems are common in people with a learning disability. The prevalence increases in people with severe learning disabilities and those with cerebral palsy. Balance and gait issues are apparent from an early age and have been found to continue across the lifespan, with an age-related decline (Truesdale and Brown 2017).
People with a learning disability have been found to have slower walking speed, abnormal walking patterns, slower motor responses to postural perturbations, shorter step lengths, and increased knee flexion angles at heel contact which increases the likelihood of slips and falls (Hale et al. 2007; Haynes and Lockhart 2012).
People with a learning disability can gain positive benefits from exercise therapy interventions, including increased muscle strength, improvement in gross motor skills and functional independence. Some people with a learning disability have difficulty accessing and engaging with mainstream physiotherapy and modified or alternative programmes may be required (Hocking et al. 2013).

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Rehabilitation from acute injuries and/or conditions

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Supporting Evidence:
People with a learning disability are 14 times more likely to have musculoskeletal impairments than the general population (Emerson et al. 2010).
Finlayson et al. (2010) report that people with a learning disability are 1.78% more likely to have at least one injury more than the general population that requires medical or nursing attention or treatment in a 12-month period. The high prevalence of injuries is likely to increase the need for people with a learning disability to access mainstream physiotherapy and services to received rehabilitation from their injuries.
People with a learning disability are at increased risk of low bone mineral density (BMD), for example, osteopenia, osteoporosis and fractures, compared with those in the non-disabled population (Emerson et al. 2010; Burke et al. 2016; Hess et al. 2017; Truesdale and Brown 2017). Contributory factors include lack of weight-bearing exercise, delayed puberty, earlier-than-average age at menopause for women, poor nutrition and being underweight. In addition, people with cerebral palsy are at high risk of low bone mineral density and fragility fracture due to being non-ambulant (GMFCS level IV and V); having vitamin D deficiency; the presence of eating, drinking and swallowing difficulties; concerns about nutritional status; low weight; a history of low-impact fractures; and using of anticonvulsant medication. Low bone density increases the risk of sustaining fragility fractures from low impact injuries. This is likely to increases need to access mainstream services for rehabilitation post fractures and soft tissue injuries.
The ACPPLD (2016) recognise that the majority of people with a learning disability can successfully access mainstream physiotherapy services when reasonable adjustments are made. However, some will require access to specialist services to receive effective rehabilitation.

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Multidisciplinary management of dysphagia

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Supporting Evidence:
The Royal College of General Practitioners report that organisations providing services for people with a learning disability and dysphagia should have a lead clinician (probably a speech and language therapist) with overall responsibility for dysphagia services. Care and support from trained practitioners should also be available (RCGP 2013).
National Quality Board recognise that the specialist learning disability physiotherapist support individuals with dysphagia (National Quality Board 2017).
People with a learning disability are more likely to have dysphagia than the general population, and even more so if they have severe cognitive impairment (Robertson et al. 2018). Over 60% of people with a profound and multiple learning disability have been found to have problems with swallowing, either difficulties with dealing with food and drink in the mouth or the process of swallowing. There can be serious consequences of having dysphagia including coughing and distress when eating or drinking, choking, recurrent chest infections, aspiration pneumonia, weight loss, dehydration, malnutrition, and social isolation. In the worst cases it can contribute to an individuals' death (Mencap 2016b).
Public Health England (2017) acknowledge that there are no reliable data on the prevalence of dysphagia in people with a learning disability. Historically, estimates have ranged from 36% (based on speech and language therapy caseloads) to over 70% (based on inpatient populations). More recent studies have shown that about 15% of adults with a learning disability require support with eating and drinking and 8% of those known to learning disability services will have dysphagia.
Research has found that 99% of the people with severe cerebral palsy are affected by dysphagia (Marks 2008; Summerville et al. 2008; Kim et al. 2013). 50-80% of people with severe cerebral palsy aspirate with 60-97% doing so silently (Kim et al. 2013).
Emerson et al. (2010) report that 40% of people with a learning disability and dysphagia experience recurrent respiratory tract infections.
Mansell (2010) reports that people with profound intellectual and multiple disabilities face several specific problems with their health including dysphagia. The report recognises that dysphagia services for adults are often not sufficiently well-developed to recognise and intervene effectively. This can lead to discomfort, pain and premature death. The author recommends that NHS bodies should ensure they provide health services to adults with profound intellectual and multiple disabilities which focus on protection of dysphagia (Recommendation 12).
NICE (2017) recognise that people with cerebral palsy under the age of 25 are at high risk of swallow problems. To manage dysphagia NICE recommends that healthcare professionals create an individualised plan for managing eating, drinking and swallowing difficulties taking into account the understanding, knowledge and skills of the network of care. Management plans should consider the role of postural management and positioning in reducing the risk of aspiration.
NHS England (2018) recognise the integral role of the specialist learning disability physiotherapist in the multidisciplinary management of dysphagia in the soon to be pushed national Dysphagia pathway for people with a learning disability. The document is in draft form at the time of writing but states that physiotherapy is a core health professional in a dysphagia pathway. NHS England report that physiotherapy services should be adequately commissioned to maximise the postural care of people with a learning disability; to assess for the optimal position for safe swallow; and actively monitor and review postural care plans to reduce the risks associated with eating, drinking and swallowing problems. NHS England also acknowledge physiotherapists role in the respiratory management of people with a learning disability with dysphagia.

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CIPOLD found that people with a learning disability experience respiratory disorders, which are the leading cause of death for this population. There is an increased risk of chest infections in people with a learning disability and dysphagia, with an estimated prevalence of about 8.15% (Heslop et al. 2013). Analysis of information from death certificates has shown that people with a learning disability are much more likely to die of the consequences of solids or liquids in their lungs or windpipe than those in the general population (Public Health England 2017).
There is an increased prevalence of swallowing and eating problems in people with severe learning disabilities, which if untreated result in aspiration, chest infections, pneumonia and can result in death. Pathogenic microorganisms in the oral cavity and poor oral health contribute to respiratory infections in people with a learning disability (Binkley et al. 2009).
Public Health England (2016) report that dysphagia has been linked to avoidable hospital admissions from problems such as dehydration, constipation and aspiration pneumonia. Eating and drinking is a fundamental aspect of a person's and their network of cares' lives. Therefore, successful management of dysphagia has the potential to improve physical health, psychological wellbeing and to reduce hospital admissions. Public Health England support the inter-professional dysphagia framework which stresses a holistic approach to the assessment and management of dysphagia. The model highlights issues beyond a physical assessment of the swallow such as environment, levels of alertness, behavioural issues, psychological issues, cultural issues and posture. Public Health England recognises that posture is an important factor to consider because poor posture can negatively affect breathing and swallowing. Thus recommend careful consideration of positioning during dysphagia assessment and management to help improve swallow efficacy and safety; and decrease the risk of aspiration and choking.

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Health promotion

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Supporting Evidence:
Research indicated that 92-50% of people with a learning disability have low physical activity levels (Emerson 2005; Hawkins and Look 2006; Finlayson et al. 2009; Emerson et al. 2010; Finlayson et al. 2011; McKeon 2013; Dairo et al. 2016) compared to 38% of the general population (NHS Digital 2017). Thus, they have a higher incidence of obesity, which is associated with an increased risk of diabetes, and predispose the person to other health problems (Emerson et al. 2010).
People with a learning disability are less likely to seek or make use of health screening services and are more likely to have poor diets (Malik et al. 2006; Rosenheck 2008).
The predictors of low levels of physical activity in adults with a learning disability includes older age, severity of learning disability, being female, having epilepsy, immobility, no day opportunities, faecal incontinence, and living in supported/residential care (Finlayson et al. 2009). The main barriers to adults with a learning disability participating in physical activity include a lack of understanding of the benefits of physical activity; the client's mood; client's lack of awareness of the available options for physical activity; risk assessment issues; and financial constraints (Hawkins and Look 2006).
The Royal College of General Practitioners recognise that one of the main roles of the community learning disability teams is to enable adults with a learning access to other services. This includes supporting people to access health promotion and screening services to promote healthy eating, weight loss and physical exercise (RCGP 2013).
Learning disability professional senate (2015) acknowledge that an increase and change in intensity of needs for people with a learning disability can affect the community learning disability team's public health role and its capacity to prevent ill health; improve health outcomes; and support people with the less demanding and urgent needs of maintaining good health.
Valuing People (2001) recognised that specialist learning disability teams and professionals have a health promotion role.
Valuing people now (2009) acknowledges that good health and well-being begins with healthy active lifestyles and this is the same for people with a learning disability.
NICE (2019) recognise that physical activity can help people with cerebral palsy to improve strength and range of movement, as well as maintain their general fitness and a healthy weight. NICE recommend that physical activity should be promoted by providing information and discussing the benefits with the adult with cerebral palsy. Some adults with cerebral palsy may need extra support to overcome barriers to participation in physical activities. In these cases, NICE recommend referring people with cerebral palsy to services with experience and expertise in neurological impairments, such as physiotherapy, that can provide support with physical activities (including sport) and tasks of daily living.
Co-morbid health problems such as cerebral palsy, spina bifida or other conditions that limit mobility may lead to people with a learning disability being overweight and obesity (Rimmer et al. 2010). Other determinants of obesity include age (Flegal et al. 2010; Stancliffe et al. 2011); female gender (Emerson 2005; Bhaumik et al. 2008; Melville et al. 2008; Moran et al. 2009; Stancliffe et al. 2011; de Winter et al. 2012; Hsieh et al. 2014); living in less restrictive environments (Melville et al. 2008); severity of learning disability (Emerson 2005; Melville et al. 2008; Stancliffe et al. 2011; de Winter et al. 2012); and taking medications that cause weight gain (Hsieh et al. 2014).
Finlayson et al. (2011) conducted a cohort study measuring the activity levels and pattern of activity and inactivity in adults with a learning disability. The results conclude that the population in this study were significantly less likely to participate in sufficient physical activities of at least moderate intensity than men and women in the general population.

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Finlayson et al. (2009) recommend that to increase adults with a learning disability participation in physical activity healthcare professionals need to engage more with the network of care to instil an active support ethos. They also found that walking was the most common form of regular physical activity undertaken by adults with a learning disability across all levels of disabilities. However individuals are not walking at a sufficient intensity or duration. In response, the authors recommend that healthcare professionals develop walking interventions to build on these findings.
Stewart et al. (2009) explored the perceptions of physiotherapy by carers working with adult with a learning Disability living in residential homes; and the priority given to completing daily physiotherapy programmes. The results indicated that the average priority rating was higher for leisure activities than physiotherapy programmes. Carers also perceived therapeutic activities such as rebound therapy and hydrotherapy as fun and enjoyable which increase priority. This indicated that physiotherapists working with adults with a learning disability need to be creative in the way they develop physiotherapy programmes and plans.

Specialist level respiratory management

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Supporting Evidence:
NICE (2019) recommend referring adults with cerebral palsy and persistent or multiple signs and symptoms of respiratory impairment; or have risk factors for respiratory impairment to specialist services. NICE agreed that referral for specialist assessment would enable prevention or treatment of respiratory complications in people at high risk. NICE recognise that risk factors for respiratory impairment are more common in adults with severe cerebral palsy (GMFCS level IV or V). These include aspiration pneumonia, chronic cardiorespiratory disorders (for example, cor pulmonale or pulmonary, circulation hypertension), chronic suppurative lung disease, kyphoscoliosis, poor saliva control and recurrent chest infections. NICE recognise that there are relatively few respiratory specialists with a special interest in adults with cerebral palsy available. They report that better survival of children with cerebral palsy into adulthood means that specialist adult respiratory services is an emerging area of practice. NICE admit that the recommendation might affect practice by an increase in referrals to and pressure on limited specialist services. However, earlier recognition and treatment will lead to improved outcomes. Respiratory conditions can often lead to hospital admission and reducing the need for this would potentially lead to cost savings.
A service evaluation of Guy's and St Thomas' NHS Foundation Trust's Integrated Respiratory Pathway for People with Complex Physical and Learning Disabilities concluded that specialist multi-disciplinary services are critical to managing the respiratory health of this cohort of people. The author reported that 30% of the population required access to specialist assessment and management completed via respiratory consultants. The respiratory health of the remaining 70% could be managed successfully by the community multidisciplinary team. People were escalated to specialist level respiratory management when they required regular access to primary and secondary healthcare despite community level respiratory management (Standley 2019a).

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Management of hypertonia and spasticity

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Supporting Evidence:
NICE (2016) report that all young people with spasticity should be promptly assessed by a physiotherapist and offered a physical therapy programme tailored to their individual needs. This should take into account the balance between possible benefits and difficulties of completing the programme; the view of the person and their network of care; and who will be delivering the programme. Programme should be integrated into daily routines where possible. Physiotherapists should consider 24-hour postural management strategies to prevent or delay the development of contractures or skeletal deformities; and to enable the person to take part in activities appropriate to their stage of development.

Contribute to multidisciplinary manual handling assessments for adults with a learning disability with complex manual or therapeutic handling needs.

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Supporting Evidence:
The Learning disability professional senate recognise that Specialist physiotherapists provide support to people with a learning disability with the provision of specialist moving and handling assessments (Learning Disability Professional Senate 2015).

Assessment and provision of specialist equipment

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Supporting Evidence:
National Quality Board recognise that specialist learning disability physiotherapists support the provision of specialist equipment (National Quality Board 2017).
The Royal College of General Practitioners recognise that in order for people with a learning disability to have good postural care they require access to services, equipment and training to support the long term management of their body shape (RCGP 2013).
Public health England (2018b) acknowledge that a barrier to the provision of good postural care services is the lack of provision of specialist equipment. They report that the range of equipment an individual needs is often provided by different departments or statutory bodies with different commissioning and assessment arrangements. This makes securing funding for essential equipment challenging with wide variations across the UK.

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Training and education: Adults with a learning disability and their network of care; health and social care professionals; and local community services

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Supporting Evidence:
Learning Disability professional Senate (2016) state that community learning disabilities health teams have a key role in providing targeted teaching and accessible materials to people with a learning disability and family carers about healthy living and specific health topics. The learning disability professional senate also report that professionals have a role in providing and supporting local multi-agency and multi-professional training programmes.
National Quality Board (2017) report that staff in NHS-commissioned learning disability services have a role in ensuring the wider workforce is skilled in provide healthcare to adults with a learning disability. This should be accomplished through teaching and role modelling the delivery of person-centred healthcare and interventions.
The Royal College of General Practitioners report that CCG's should commission community learning disability services to provide teaching, advice and support to both mainstream and specialist services to enable people with a learning disability to access other services (RCGP 2013).
Valuing People (2001) recognised that specialist learning disability professionals should recognise the importance of enhancing the competence of local services.
CIPOLD identified that gaps in the knowledge and skills level of non-specialist health and social care providers makes the person more vulnerable to a premature death. The authors found that the most common training and education needs for health and social care staff related to: • Learning disability awareness. • The Mental Capacity Act. • Decisions not to attempt CPR. • End-of-life care and the use of end-of-life care pathways. • Communication skills. • Commonly used medications. • Dementia. • Risk assessments. • The prevention and management of pressure sores. • The prevention and management of falls. • The prevention and management of venous thromboembolism. (Heslop et al. 2013)

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Transition of young people with a learning disability from paediatric to adult services

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Supporting Evidence:
The Royal College of General Practitioners recommend a well-planned, person centred transition for young people with a learning disability to reduce the risk of serious health outcomes following disengagement with health services (RCGP 2013).
Mansell (2010) acknowledges that despite very substantial attention over many years, transition from children's to adult services is still typically a very difficult and poor experience for people with a learning disability who have complex needs and their families. In response, the author recommends that the government continue to lead the development of more effective transition arrangements for people with a learning disability so that there is proper planning and timely provision of appropriate services as people move into adulthood.
The learning disability professional senate (2015) reports that specialist community learning disabilities health teams should be available for joint working with young people with complex health support needs from 14 years.
NICE (2017) recognise that challenges for young people with cerebral palsy continue into adulthood and that functional challenges (including those involving eating, drinking and swallowing, communication and mobility) and physical problems (including pain and discomfort) may change over time. NICE states that this should be taken into account in transition planning and that as a minimum standard of care, young people should have access to adults' services both locally and regionally that include healthcare professionals with an understanding of managing cerebral palsy.

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Co-ordinated approach to care and multi-disciplinary and multi-agency working

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Supporting Evidence:
The learning disability professional senate (2015) reports that one of the key functions of the community learning disability team is to enabling others to provide effective person-centred support to people with a learning disability through short-term care coordination.
CIPOLD found that many of the deaths reviewed had complex needs which necessitated multi-agency input. The inquiry found that the care of people with the most complex health needs can seem poorly coordinated which contributed to vulnerability and premature death of the people studied. They recognise that a key issue was the lack of coordination of care across and between the different disease pathways and service providers, and the episodic nature of care provision. The authors recognise the importance of good communication and of having a named coordinator when many agencies are involved. Thus, recommends a named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions. In addition, commissioners should ensure that the coordination of care role is enshrined and monitored in contracts across health and social care, with named lead professionals to coordinate care across and beyond episodic reviews (Heslop et al. 2013).
NICE (2016) acknowledge that people with multi-morbidities are at particular risk of deterioration in their health through uncoordinated care. NICE defined multi-morbidity as the presence of 2 or more long-term health conditions, which can include defined physical and mental health conditions such as diabetes or schizophrenia; ongoing conditions such as learning disability; symptom complexes such as frailty or chronic pain; sensory impairment such as sight or hearing loss; and alcohol and substance misuse. NICE recommend that these individuals receive an approach to care that takes account of multi-morbidity. This involves personalised assessment and the development of an individualised management plan that aims to improve quality of life by reducing treatment burden, adverse events, and unplanned or uncoordinated care. The approach takes account of a person's individual needs, preferences for treatments, health priorities and lifestyle. It aims to improve coordination of care across services, particularly if this has become fragmented. NICE states that healthcare professionals should consider an approach to care that takes account of multi-morbidity if the person requests it; if they find it difficult to manage their treatments or day-to-day activities; they receive care and support from multiple services and need additional support; they have both long-term physical and mental health conditions; they have frailty or falls; they frequently seek unplanned or emergency care; and/or they are prescribed multiple regular medicines.

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Hydrotherapy/Aquatic therapy

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Specialist learning disability physiotherapy services may use hydrotherapy/aquatic therapy as a treatment modality to manage the physiotherapy problems of adults with a learning disability especially where they are non-compliant with; are unable to engage successfully in land-based treatment; or to supplement their management programmes.

Standard of Practice Statements

Where hydrotherapy/aquatic therapy is indicated specialist learning disability physiotherapists:

1. Complete a person centred hydrotherapy/aquatic therapy assessment to develop a treatment plan utilising the properties of warm water.
2. Develop a person centred hydrotherapy/aquatic therapy treatment plan based on the person's individual physiotherapy needs and goals.
3. Complete relevant risk assessments to support the provision of safe and effective hydrotherapy/aquatic therapy.
4. Document an accessible hydrotherapy/aquatic therapy treatment plan and delegate to the person's support team following the CSP guidance on the delegation of tasks to support workers where clinically indicated and appropriate.
5. Develop pathways for hydrotherapy/aquatic therapy provision in the community using local resources and trained staff where appropriate.

Knowledge and Skills

Specialist learning disability physiotherapists will need to develop competence in the delivery of hydrotherapy/aquatic therapy to adults with a learning disability especially those with neurological dysfunction. This will also include knowledge and skills in delegating hydrotherapy/aquatic therapy programme to support workers. Physiotherapists should consult the guidance on good practice in Aquatic Physiotherapy available via the Aquatic Therapy Association of Chartered Physiotherapists.

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Supporting Evidence:
Aquatic therapy is defined as “a therapy program utilising the properties of water, specifically designed by a suitably qualified physiotherapist for an individual to maximise their level of function whether physical, physiological or psychological. Treatments ideally should be carried out in a purpose built and suitably heated hydrotherapy pool by appropriately trained personnel” (Aquatic Therapy Association of Chartered Physiotherapist 2007).
Geytenbeek (2002) conducted a systematic literature search to appraise the quality of evidence supporting clinical effectiveness of Aquatic therapy. The author found that most clinical trials were conducted in populations with rheumatic conditions, chronic low back pain and older adults. Neurological populations are under-investigated, and there was a dearth of studies for people with complex disability. The study concluded that the body of evidence supporting the effectiveness of Aquatic therapy is incomplete. However, they acknowledge that there are a number of perceived advantages to water based over land based exercises.
Becker (2002) conducted a narrative review of the research base supporting aquatic therapy, both within the basic science and clinical literature. The article describes the many physiological changes that occur during immersion applied to a range of common rehabilitative issues and problems. The reported benefits of aquatic therapy include reduced pain due to hormonal, thermal, circulatory and neural effects; improved circulation; reduced muscle tone; enhanced sensory stimulation; reduced mechanical stress on the joint and soft tissue due to the reduced effect of gravity; reduced weight bearing; increased motivation and empowerment due to increased independent movement which is not possible on land; and enhance cardio-vascular response to exercise to maintain fitness despite physical disabilities. The author reviews the evidence base finding literature that support aquatic therapy in the areas of cardiovascular and cardiopulmonary rehabilitation; applications in respiratory and athletic rehabilitation; musculoskeletal rehabilitation; applications in athletic training; geriatrics and osteoporosis; pain and psychiatric; and obesity. The author concludes that aquatic exercise and rehabilitation remains vastly underused and that there is potential public health benefits to be achieved through programs targeted at the most costly chronic diseases.
Novak et al. (2013) in their systematic review exploring treatments for spasticity in children with cerebral palsy found low level evidence to support hydrotherapy in improving motor function in the population of people.
Lambeth PMLD project (Mencap 2010) conducted survey of families and carers of people with profound and multiple learning disabilities. The aim of the paper was to scope the local scene in relation to the national picture and recommendations set out in Raising our Sights (Mansell 2010). The results highlighted that parents valued hydrotherapy to help maintain health and as a meaningful activity.
Pope (2007) dedicates a chapter of her book on the Management of the Physical Condition of people with Severe and Complex Neurological Disability to hydrotherapy as a therapeutic activity for this population of people. The chapter is written by Babara Cook who concludes that therapists who are skilled in the use of hydrotherapy as a therapeutic tool are convinced of the benefits to people who enjoy the medium, but there is little robust evidence or scientific research to prove the benefits of hydrotherapy.

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Physiotherapy on a trampoline/ rebound therapy

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Specialist learning disability physiotherapy services may use physiotherapy on a trampoline/rebound therapy as a treatment modality to manage the physiotherapy problems of adults with a learning disability especially where they are non-compliant with; are unable to engage successfully in land-based treatment; or to supplement their management programmes.

Standard of Practice Statements

Where Rebound therapy/physiotherapy on a trampoline is indicated specialist learning disability physiotherapists:

1. Complete a person-centred physiotherapy on a trampoline/rebound therapy on a trampoline assessment to develop a treatment plan utilising the properties of the trampoline.
2. Develop a person-centred physiotherapy on a trampoline/rebound therapy treatment plan based on the person's individual physiotherapy needs and goals.
3. Complete relevant risk assessments to support the provision of safe and effective physiotherapy on a trampoline/rebound therapy.
4. Document an accessible physiotherapy on a trampoline/rebound therapy treatment plan and delegate to the person's support team following the CSP guidance on the delegation of tasks to support workers where clinically indicated and appropriate.
5. Develop pathways for Physiotherapy on a trampoline/rebound therapy provision in the community using local resources and trained staff.

Knowledge and Skills

Specialist learning disability physiotherapists will need to develop competence in the delivery of physiotherapy on a trampoline/rebound therapy to adults with a learning disability safely and effectively. Physiotherapists should consult the Safe Practice in Rebound Therapy paper developed by the Rebound Therapy Association for Chartered Physiotherapists.

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Supporting Evidence:

Rebound therapy is the therapeutic use of the trampoline. Rebound therapy is currently used with people with a wide range of abilities from mild to profound physical and learning disability, sensory needs, mental health needs and some neurological and other medical conditions. In addition to providing a physical therapy, rebound therapy provides many people with a valuable opportunity to enjoy movement and interaction (Rebound Therapy Association for Chartered Physiotherapists 2016).

Miller (2007) conducted a narrative review of the available research which is published on the rebound therapy official website. The author reports that there are a wide range of benefits reported for Rebound therapy but there has been minimal research conducted into its effectiveness to confirm these benefits. Miller reports that there is some evidence to support the use of the properties of a trampoline for physical, psychological, learning and social benefit (Carr and Shepherd 1998; Roberts 2006; Smith and Cook 2007). Rebound therapy has been observed to:

- Reduce hypertonia and increase hypertonia with the correct application of bounce;
- Work the cardio-respiratory system increasing exercise tolerance and fitness;
- Provide a good source of cardiovascular exercise for children with profound and multiple learning disabilities who may have limited access to exercise activities;
- Stimulate postural mechanisms through utilising the unstable surface of the trampoline bed;
- Improve balance and develop protective and saving reactions;
- Facilitate movement;
- Stimulate gaseous movement and improve bowel function particularly in non-ambulatory people who can often suffer with constipation;
- Assist chest clearance through the combination of shaking of the lungs, increasing respiratory rate and stimulating of the cough reflex;
- Induce relaxation;
- Provides the sense of freedom and independence in people who are dependent on their network of care; and
- Increase vocalisation, eye contact and concentration, confidence and self-esteem.

The author concludes that Rebound therapy is a useful adjunct to therapy similar to that of hydrotherapy and therapeutic horse riding, providing an enjoyable method of exercise with therapeutic effects and some time for independence and free movement.

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Therapeutic riding or hippotherapy

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Specialist learning disability physiotherapy services may deliver or recommend the use of therapeutic riding or hippotherapy as a treatment modality to manage the physiotherapy problems of adults with a learning disability, especially where they are non-compliant with; are unable to engage successfully in land-based treatment, or to supplement their management programmes.

Standard of Practice Statements

Where therapeutic riding or hippotherapy are indicated and available specialist learning disability physiotherapy services:

1. Consider the use of therapeutic riding and hippotherapy as a specialist intervention in the physiotherapy management of adults with a learning disability where clinically indicated.
2. Contribute to the development of a person-centred treatment plan based on the person's individual physiotherapy needs and goals.
3. Contribute to the development of relevant risk assessments to support the provision of safe and effective therapeutic riding and hippotherapy.
4. Advise on moving and handling issues in relation to mounting and dismounting the horse.
5. Provide advice and educate on specific conditions as per guidance from Chartered Society of Physiotherapy Special Interest Section, Riding for the Disabled.

Knowledge and Skills

Where appropriate specialist learning disability physiotherapists will need to develop competence in the delivery of therapeutic riding or hippotherapy to adults with a learning disability safely and effectively. Physiotherapists should consult advice by the Chartered Society of Physiotherapy Special Interest Section, Riding for the Disabled.

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Supporting Evidence:

Therapeutic riding is an equine-assisted activity for the purpose of contributing positively to the cognitive, physical, emotional and social well-being. Therapeutic riding provides benefits in the areas of health, education, sport and recreation and leisure. All sessions are conducted by a certified instructor and periodically reassessed by a licensed therapist.

Hippotherapy literally means" treatment with help of the horse". It's a treatment strategy that utilises equine movement in a therapeutic way for patients with movement dysfunction. Hippotherapy is done by a therapist who has been specially trained to use the movement of the horse to facilitate improvements. Therapists use traditional techniques such as neurodevelopmental treatment and sensory integration along with the movement of the horse as part of their treatment strategy. All goals are therapy directed such as improving balance, coordination, posture, fine motor control, articulation and increasing cognitive skills.

The evidence to support the use of therapeutic riding or hippotherapy as a therapeutic modality for adults with a learning disability is lacking. The chartered physiotherapists in therapeutic riding and hippotherapy have a number of resources on their website that outline up to date guidance on the area. Christine Bowes writes chapter 9 of the Management of the Physical Condition of people with Severe and Complex Neurological Disability (Pope 2007) on the value of horse riding in the management of severe and complex physical disability. Bowes outlines the range of physical, psychological and social benefits to riding. The physical benefits include:

- facilitating the optimal sitting position and postural alignment;
- stimulates normal movement;
- balance and righting reactions;
- mobilisation of joints;
- normalisation of muscle tone;
- improves general fitness;
- provides a multi-sensory experience; and
- develops spatial awareness.

Bowes also reports that riding provides psychological and social benefits because it:

- provides an enjoyable, normal, recreational activity;
- is motivating;
- empowers the rider to make choices and gives control;
- teaches new skills;
- improves self-confidence and social image;
- counters social stigmatism;
- encourages communication and social skills; and
- provides an opportunity to bond with animals and people.

The author concludes that horse riding is a useful way of providing continuity of therapy to people with severe and complex physical disability across their lifetime in a more acceptable way than convention therapies.

(Pope 2007)

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Abdominal Massage for Constipation

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Specialist learning disability physiotherapists may use abdominal massage as a treatment modality for constipation in people with a learning disability as part of a holistic constipation care plan.

Standard of Practice Statements

Where abdominal massage for constipation is indicated, specialist learning disability physiotherapists:

1. Complete an assessment of the person's bowel elimination to identify signs of constipation. This includes a subjective and objective assessment of elimination patterns supplemented by bowel charts and the Bristol stool charts.
2. Work in collaboration with the multidisciplinary team to support the person and their network of care to develop a person-centred constipation care plan. This includes non-pharmacological interventions such as a healthy diet, fluid intake, mobility and exercise, toileting positioning and routine, social and psychological factors and abdominal massage. Make onward referrals to the GP and specialist services for further advice on the pharmacological management of constipation.
3. Gain relevant medical clearance and complete appropriate risk assessments to support the safe provision of abdominal massage for constipation.
4. Complete abdominal massage with the person, taking into consideration the person's learning, sensory and physical disability to evaluate the effectiveness of the technique.
5. Document an accessible abdominal massage treatment plan and delegate to the person's network of care in line with CSP guidance on the delegation of tasks to support workers.
6. Monitor the effectiveness of abdominal massage after delegation of the technique using subjective feedback and bowel and Bristol stool charts.
7. Work in collaboration with the GP to reduce dependency on laxatives where appropriate.
8. Develop local multidisciplinary pathways and networks to support constipation management and abdominal massage.

Knowledge and Skills

Specialist learning disability physiotherapists will need to develop knowledge, skills and competence in the delivery and delegation of abdominal massage for constipation. This includes:

- The causes, incidence, risk factors and impact of constipation.
- Anatomy and physiology of the intestinal tract.
- Assessment of bowel elimination and identification of constipation.
- Non-pharmacological and pharmacological treatments for constipation.
- Indications, benefits and contraindications for abdominal massage.
- Abdominal massage technique.
- Teaching and delegation of the abdominal massage technique to the person's network of care.

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Supporting Evidence:
Constipation is a symptom-based disorder which describes defecation that is unsatisfactory because of infrequent stools, difficulty passing stools, or the sensation of incomplete emptying. Constipation is characterised by not having a poo for 3 or more days; not having a poo at least 3 times in a week; having poo that is sometimes difficult to push out without straining; having poo that is larger than usual, dry, hard, like pellets; and/or after a long time between poos passing lots of soft, smelly poo (LeDeR 2019; NICE 2019c).
Robertson et al. (2018a) conducted a systematic literature review as part of the Centre of Disability Research supported by Public Health England to explore the prevalence of constipation in people with intellectual disability. 31 studies published between 1990 to January 2016 were included into the study. The results indicated that constipation rates of 33% to 50% or more were reported. Over 25% of people received a repeat prescription for laxatives in one year, compared to 0.1% of the general population. Constipation was more common in those with cerebral palsy and profound intellectual disability and was associated with immobility but not age. The researchers conclude that constipation is a significant issue for people with intellectual disability across the life course and should be actively considered as a diagnosis in this population.
NICE guidelines on constipation in children and young people acknowledge that some children and young people with physical disabilities, such as cerebral palsy, are more prone to idiopathic constipation as a result of impaired mobility. Children and young people with Down's Syndrome or autism are also more prone to the condition (NICE 2010c).
The Learning Disability Mortality Review (LeDeR) programme released a learning into action bulletin in 2019 on constipation called 'Dying for a poo'. LeDeR found that constipation can affect up to half of all people with a learning disability and that unrecognised, untreated constipation has been known to cause death. They report that this is rare, but is an entirely avoidable and unnecessary, thus it can be stopped from happening. In addition, LeDeR report that constipation can cause pain and distress, hence the effective monitoring and management of constipation in people with a learning disability is essential to maintain their safety and well-being. They state that unplanned hospital admissions which could be prevented by effective interventions in the community and the bill for laxative prescription a year could be reduced (LeDeR 2019a). In response the Learning Disability Programme, have developed Poo Matters information booklets for families and carers to raise awareness of the problem of constipation in people with a learning disability. This includes a tool to develop a care plan to improve the management of constipation and bowel habits. There is also an information leaflet for healthcare professionals which outlines the assessment of constipation and the treatment options available (NHS England 2019a).

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Public Health England published guidance on constipation in people with a learning disability as part of their making reasonable adjustments series in 2016. They recommend that anybody supporting people with a learning disability should be aware that they are at a high risk of having constipation; know how to recognise the signs and symptoms; and who to approach for advice on management.

Public Health England report that people with a learning disability mainly get constipation because of inadequate diet and fluid intake; reduced mobility and lack of exercise; side effects of certain medications; and anxiety or depression. People with Down's Syndrome or cerebral palsy have an increased risk of constipation and people with more severe learning disabilities are at an even higher risk. Immobility and environmental factors can also increase the likelihood of constipation.

The report highlights the impact of constipation for people with a learning disability. In addition to the physical consequences, there is a body of research demonstrating the link between chronic constipation and behavioural problems, including self-harm.

Public Health England recommend a holistic and personalised approach to bowel management including both pharmacological and non-pharmacological treatments delivered by the multidisciplinary team and the person's network of care. This includes:

- family or paid carers;
- learning disability nurse;
- GP;
- Physiotherapist;
- occupational therapist; and
- dietician.

The guidance makes recommendation for the different treatment options available including diet and exercise, toileting position and routine, physical health, medication, abdominal massage, and laxatives. Public Health England recognises that abdominal massage can be as effective as laxatives in the treatment of constipation. They recognise that holistic bowel management can be time consuming but can help to improve the bowel habits of people with a learning disability and can lead to a reduction or cessation of laxatives.

Public Health England identify that constipation is a significant problem for people with a learning disability that impact on their health and quality of life. They recommend the need for a total bowel management approach which includes abdominal massage delivered by a multi-disciplinary team with physiotherapy as an integral part. This can improve the health outcomes for people with a learning disability as well as having potential cost savings for the NHS.

(Public Health England 2016c)

In a follow up to the systematic review exploring the prevalence of constipation in people with intellectual disability, Robertson et al. (2018b) summarised the international research pertaining to the management of constipation. The authors reviewed 18 studies published from 1990 to 2017.

The results found that the main management response to constipation in people with intellectual disability is laxative use, but this is not effective for all people. Studies also reported positive results for dietary fibre and abdominal massage although study quality was limited.

In relation to abdominal massage, the authors reported that whilst the effectiveness of abdominal massage was found not to be demonstrably different to that of laxatives, a number of other positive outcomes have been attributed to the technique. Such as improved sleep (in children), pain, mood and behaviour; and enhanced therapeutic relationships between those implementing and receiving the abdominal massage across a range of settings. However, it was not clear to what extent positive results can be attributed solely to abdominal massage, with implementation being confounded by the introduction of toileting plans or by additional components of a total bowel management programme.

The authors conclude that further robust research is required to better understand what works well in managing constipation in people with intellectual disability. But in the meantime, services should consider adopting the guidelines for the management of chronic constipation of adults within the community outlined by Emly and Marriott (2017).

Management of chronic constipation of adults within community (Emly and Marriott 2017).

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Conor et al. (2014) completed an audit of the benefits of abdominal massage as part of a total bowel management programme for people with a learning disability living within the locality. Total bowel management is a multidisciplinary approach to constipation management which was introduced in 2006 by community learning disability physiotherapists and nurses. The authors describe the approach as a systematic regime including:

- A baseline assessment of elimination habits over a two week period. Including completion of the Bristol Stool chart and attention to diet, fluid intake, mobility, toilet regime and positioning.
- Assessment for the suitability for abdominal massage including GP medical clearance and a risk assessment.
- If agreement is reached, the professional (either a physiotherapist or nurse) completes the initial abdominal massages and evaluates the effectiveness of the technique. The service adopts the abdominal massage technique described by Marian Emly (Emly 2008).
- If effective, classroom based and one to one training is provided for the person's network of care and their competence assessed before the task is delegated.
- The performance of network of care is reviewed after six months, and they can contact the team for updates or reviews as required.

The authors outline the evidence base for abdominal massage in people with a learning disability and acknowledge it is limited. They report that abdominal massage can:

1. Increase peristalsis in the gut and reduce colonic transit time.
2. Make stools easier to pass by softening their consistency.
3. Resolve constipation in some patients where diet and laxatives have failed.
4. Reduce cost of pharmaceutical treatments of constipation.

The authors report that other advantages include a lack of known side effects; limited number of contraindications; and the non-invasive nature of the technique making it preferable to more invasive treatments such as suppositories and enemas.

To evaluate abdominal massage as part of total bowel management the authors sent questionnaires to families and carers to identify positive and negative aspects of abdominal massage. The results found that all feedback was positive. They indicated that abdominal massage improved bowel elimination; reduced pain and associated behaviours that challenge; and lessened reliance on laxatives. The findings are supported with four case studies.

The results of the study indicate that abdominal massage could be used by an appropriate trained professional as part of a total bowel management programme to improve pain, discomfort and laxative use in people with a learning disability who have constipation.

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Specialists, generalists and generalising specialists

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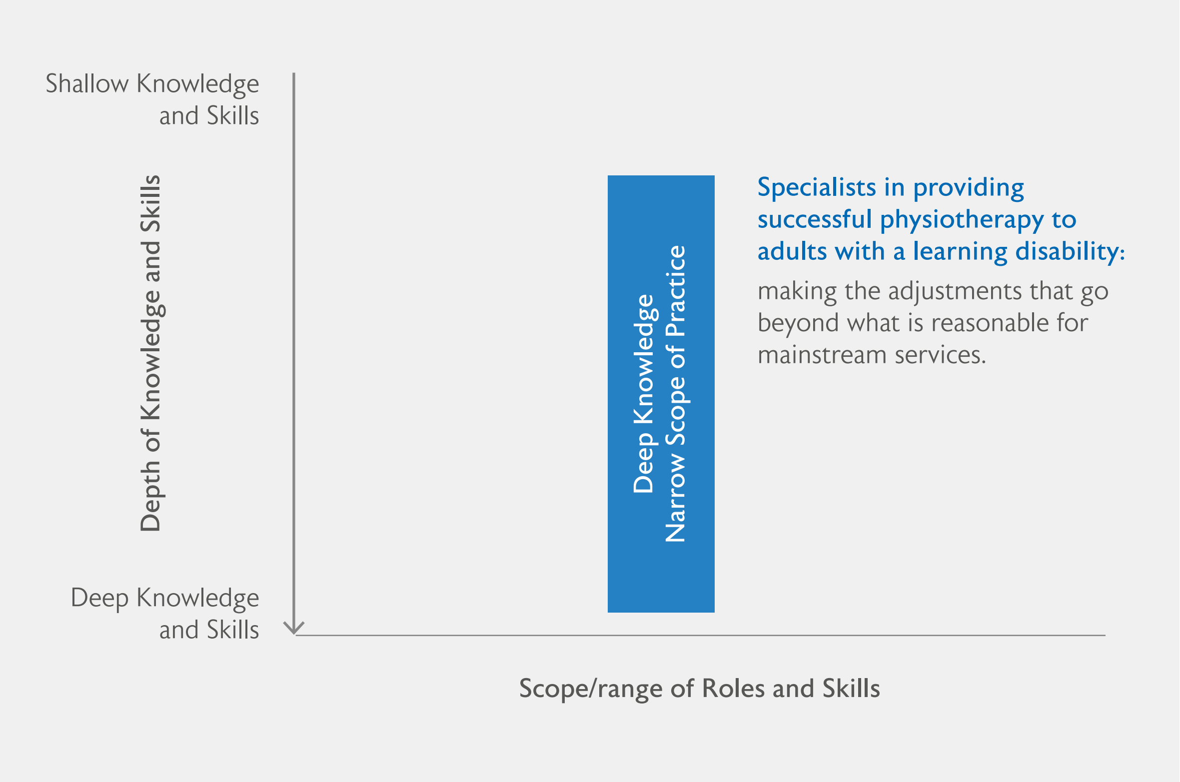
The Specialist

Specialists are defined as people who have deep knowledge and skills relating to a particular role or area of study. Specialists can be described as the letter 'I', they are 'Master of one', and are experts in their specific field (Figure 12). Specialists are valued within organisations because they have deep knowledge and skills within their chosen area and thus become the 'go to' for specific problems. The disadvantage of being a specialist is they can only work within a specific field and their opinion and input on other issues is less valid and important.

Figure 12: Specialist knowledge and skills of the learning disabilities physiotherapist



The Generalist

The simple definition of a generalist is a person who knows something about a lot of subjects. They are employees with broad knowledge across different disciplines and fields of experience, but they do not possess a deep level of knowledge or expertise in one area (Figure 13). There are a number of advantages having generalist knowledge and skills, especially when working in an area where a broader more holistic view is required. A broader approach and wider understanding can help the professional see the bigger picture and think outside the box.

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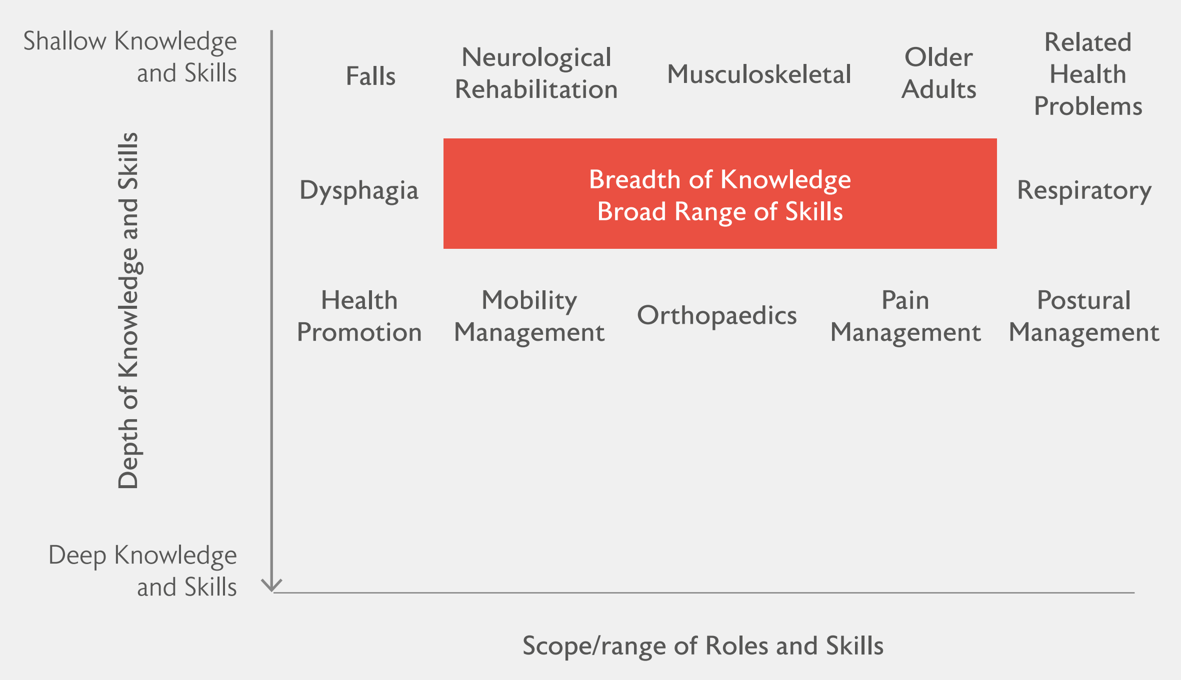
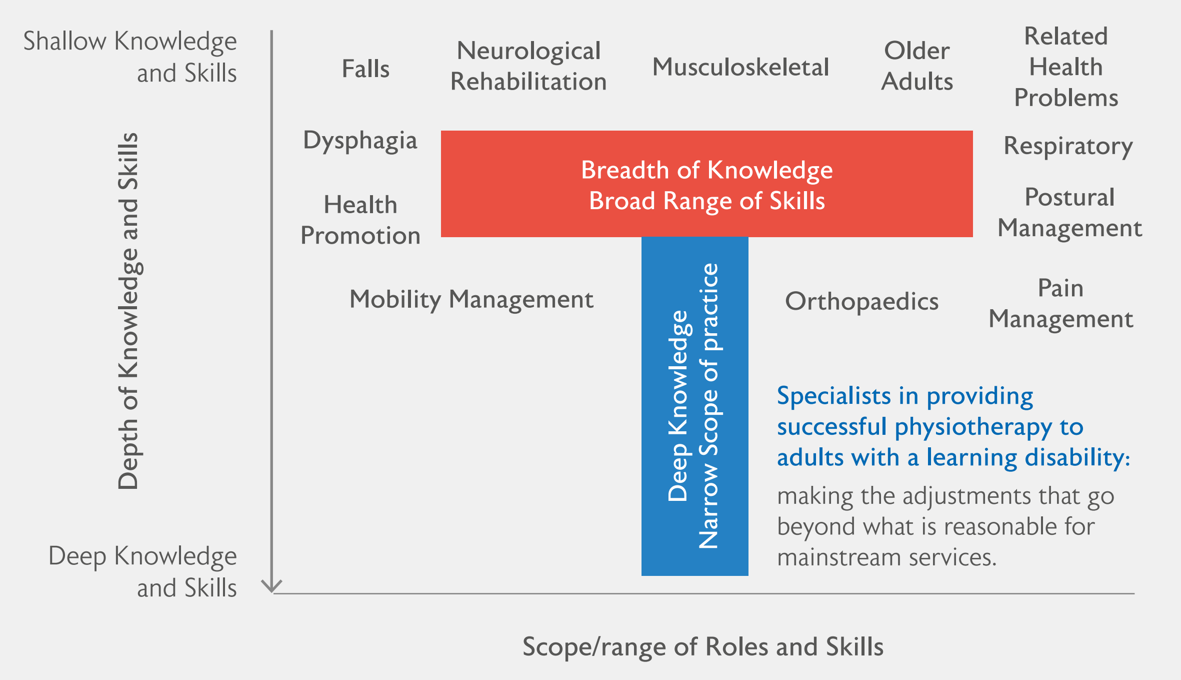
Figure 13: Generalist knowledge and skills of the learning disabilities physiotherapist



Generalising Specialists

The generalist and specialist elements of the role of the physiotherapist working with adults with a learning disability results in them becoming a generalising specialist. There are a number of advantages to becoming a generalising specialist both for the person and the organisation that they work for. They not only have specialist knowledge in one or more specific areas, they also are able to take a holistic view and contribute to a range of areas. The generalising specialist is common within the healthcare setting where many professionals are trained as generalists before specialising in certain area of clinical practice. A generalising specialist can be represented as the letter "T". The horizontal bar illustrates the broad range of knowledge, and the vertical bar or bars demonstrates the deep knowledge in their specialist area (Figure 14).

Figure 14: T-shaped generalising specialist



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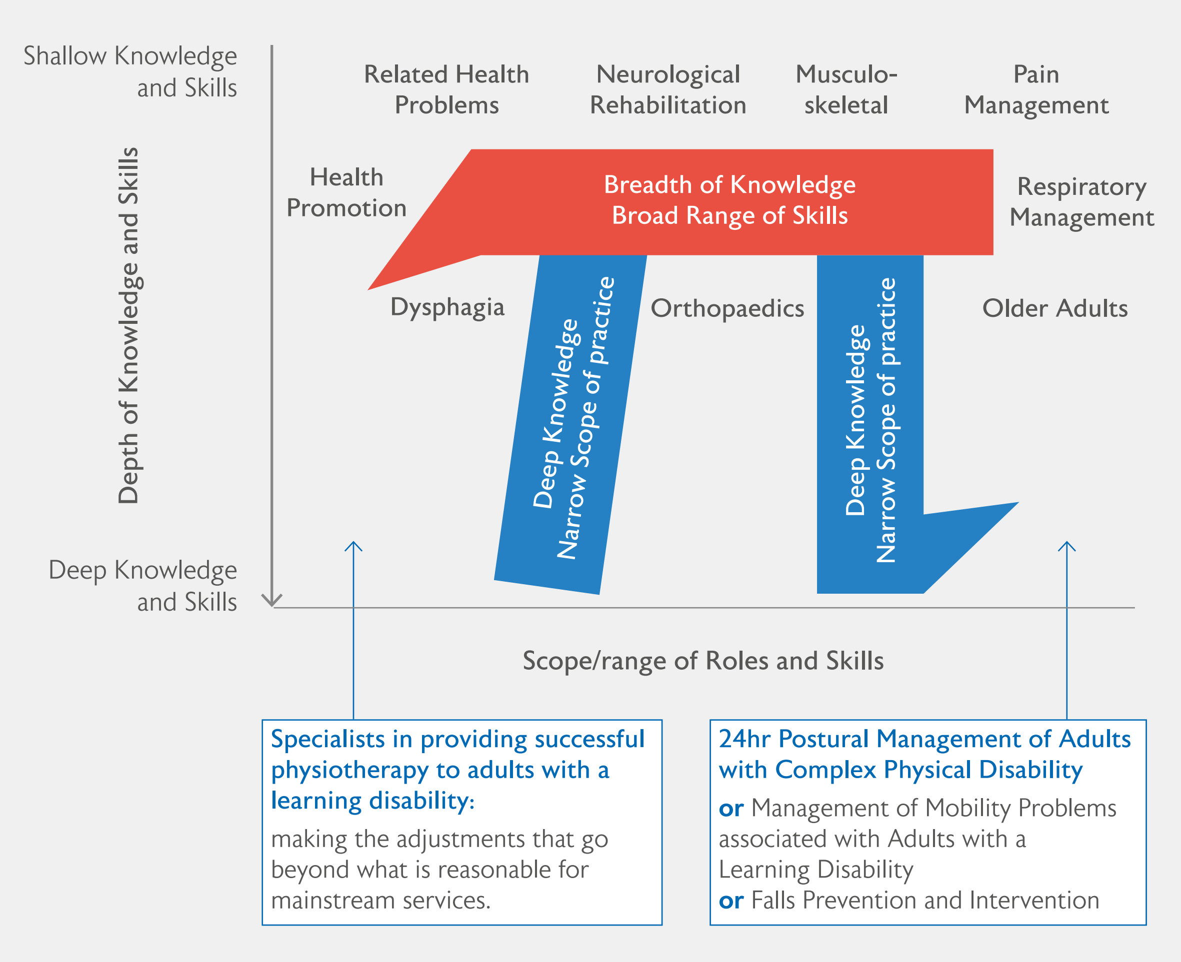
It is essential that learning disability physiotherapists develop specialist knowledge in the specific aspects of physiotherapy that are critical to managing the physical needs of adults with a learning disability and where there are gaps in service provision. As a result, specialist learning disability physiotherapists will often develop into Pi shaped generalising specialist with specialism in two areas of practice (Figure 15). Although this shape is preferable to T-shaped people, maintained specialist knowledge in two domains as well as their general knowledge can be challenging and takes dedication.

Figure 15: Pi shaped generalising specialist



Specialists in providing successful physiotherapy to adults with a learning disability:
making the adjustments that go beyond what is reasonable for mainstream services.

24hr Postural Management of Adults with Complex Physical Disability
or Management of Mobility Problems associated with Adults with a Learning Disability
or Falls Prevention and Intervention

For services where there is one physiotherapist per team this significantly restricts the ability of the professional to develop into a Pi shaped practitioner. Instead they remain as a T shaped generalising specialist due to a lack of time, resources, supervision and support in developing specialist knowledge and skills in another domain.

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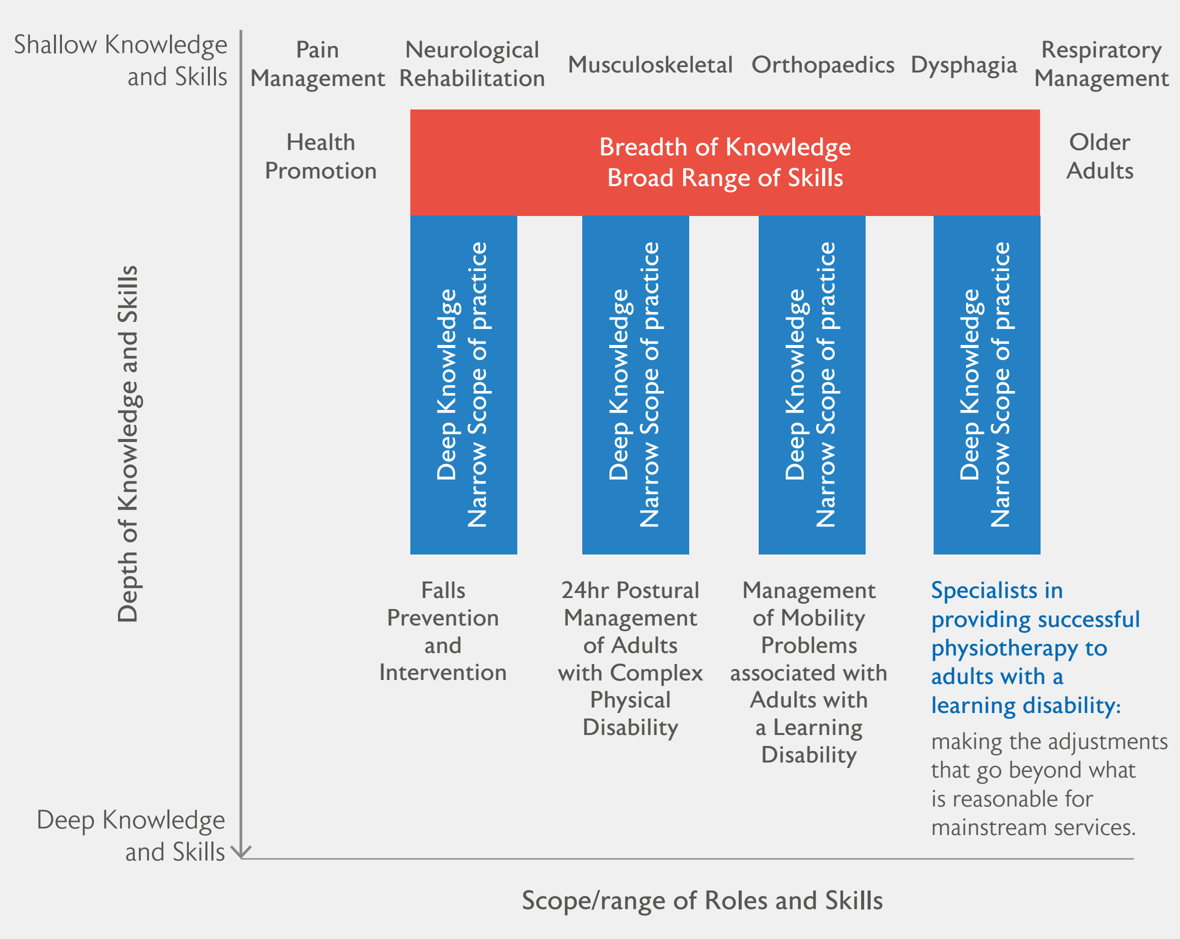
Ideally, community learning disability physiotherapy teams employ a number of physiotherapists that each develop specialist knowledge and skills in the different aspects of physiotherapy critical to meeting the physical needs of adults with a learning disability. This creates a service with a comb shaped set of knowledge and skills (figure 16). This unfortunately is not the reality for many services across the UK. This can impact on the team's ability to successfully meet the physiotherapy needs of adults with a learning disability locally. Therefore, services need to be commissioned and resourced appropriately to enable the right knowledge and skills mix.

Figure 16: Comb spaced generalising specialist learning disability service



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Training, education and development responsibilities

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Individual

1. Active in supervision and peer supervision
2. Actively participate in special interest groups and professional networks
3. Actively sharing own practice and experience via the ACPPLD newsletter and website
4. Attend relevant training and education course
5. Be actively involved in professional, multi-disciplinary and/or multi-agency in-service training sessions
6. Complete relevant post graduate training opportunities e.g. Oxford Postural Management course.
7. Complete yearly appraisals including personal development plan
8. Critically appraise and synthesise the outcome of relevant research, evaluation and audit
9. Critically engage in research activity
10. Engage in continued professional development
11. Engage in self-directed learning
12. Engage on Social Media including Twitter and iCSP
13. Keep abreast of relevant research, NICE guidelines, and publications
14. Present case studies to support clinical reasoning and reflection
15. Reflection and Learning through Action
16. Support student placement

Regional

1. Develop and run specialist training and education events to update skills to keep abreast of developments in current practice
2. Provide a platform for peer support, shared learning and practices
3. Run regular learning events on relevant topics
4. Support opportunities for research

Organisational

1. Develop a culture that encourages service development, audit and research
2. Develop and run in-service training programmes including professional, multi-disciplinary and/or multi-agency sessions
3. Develop opportunities for multidisciplinary and peer group supervision
4. Facilitate a culture of learning through action and reflection through adverse incidents
5. Offer mentoring opportunities
6. Offer yearly appraisals
7. Provide a platform to implement knowledge and skills into practice
8. Provide opportunities to implement any training and education into practice
9. Provide regular supervision with a suitably qualified and experienced clinician
10. Provide time and resources to support continue professional development
11. Seek opportunities to bench mark service against local teams and national guidelines such as NICE
12. Support multidisciplinary working, training and education
13. Support opportunities for employee's continued professional development

National

1. CPPLD yearly objective – improve membership engagement and participation
2. Development and endorsement of standards of practice
3. Development of competence framework
4. Development of standardised assessment tools and measures
5. Publish professional newsletter which supports research, shared learning and practices
6. Run regular learning events on relevant topics
7. Support opportunities for research

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Resource to develop an understanding of the local population of adults with a learning disability

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Population statistics

There are a range of resources available to develop an understanding of the number of people with a learning disability living locally. Some resources provide exact numbers of people whereas others rely on applying estimated population statistics for adults with a learning disability to population demographics available through the Observatory of National Statistics or equivalent in Northern Ireland, Scotland and Wales.

England

- ➜ Public Health England: Learning Disability Profiles (2019).
- ➜ Public Health England: Learning disabilities Observatory (2016).

Northern Ireland

- ➜ Northern Ireland Assembly: Statistics on people with a learning disability in Northern Ireland (2014).

Scotland

- ➜ Scotland Commission for Learning Disability: Learning Disability Statistics Scotland (2017).

Wales

- ➜ Welsh Government: Learning Disability Improving Lives Programme (2018).

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Evidence based local estimates

There are a number of resources and cohort studies available that state the percentage or incidence of people with a learning disability with specific health problems. For example:

- Percentage of people with cerebral palsy with a learning disability.
- Prevalence of falls and rates of fracture.
- Percentage of people with a learning disability and dysphagia.
- Number of people with profound and multiple learning disabilities.
- The percentage of the leading causes of death in people with a learning disability.

The statistics can be applied to the number of people with a learning disability to develop evidence-based estimates of the number of people with specific health problems. This provides a baseline to compare local data and to develop an understanding of needs and gaps in service provision.

Local databases

Once the population estimates have been developed it is critical to assess how accurately the statistics represent the local population. This can be a challenging task due to the reliance on the accessibility and quality of local data. The methods of collecting data will vary locally therefore their data will need to be harvested from different sources. For example:

- GP data for people with a learning disability.
- Data from A&E admissions for learning disabilities and falls, fractures, respiratory infections, etc.
- Number of referrals received for falls in a calendar year.
- Local database of people with complex physical disability.
- Number of people who have received postural assessment in a year.
- Caseload trends and numbers.

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Recommendations of further research

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Introduction

The researchers conducted a systematic literature search of available evidence and uncovered limited robust research exploring the role of the specialist learning disability physiotherapist. The research that is available is mainly cohort studies describing the characteristics and needs of the population of people with a learning disability especially the incidence of accidents, falls and sedentary lifestyles. There is also very few studies examining the clinical outcomes of physiotherapy assessment and interventions.

The lack of robust research into people with a learning disability is well acknowledged within the literature and government publications (Public Health England 2018b; Robertson et al. 2018; NICE 2019). There are additional challenges when conducting research which includes people with a learning disability (Robertson et al. 2018). Firstly, there are challenging ethical and logistical problems when conducting randomised controlled trials with people with a learning disability. Secondly, the population of people with a learning disability who are likely to require a specific treatment or intervention, such as postural management, is relatively small and scattered across services where geographically there is a lack of consistency in the provision of services. Thirdly, behavioural issues may influence the participation of people with a learning disability. Finally, people may be unable to cooperate or tolerate the study protocol.

The inclusion of people with a learning disability who may lack capacity to consent is governed by law. The applicable legislation depends on the country where the research is to be conducted.

England and Wales: Section 30-33 of the Mental Capacity Act (2005)

Scotland: Adult with Incapacity Act (2000)

Northern Ireland: Part 8 of the Mental Capacity Act Northern Ireland (2016)

There is a wealth of further information on completing health research available on-line. The following websites can be a good starting place:

England and Wales: Health Research Authority

Scotland: NHS research Scotland

Northern Ireland: Health and Social Care Research and Development Department

If readers are interested in conducting research, local research and development departments of employers and universities are an important way of accessing support and supervision. These can support the development of research ideas, protocols and ethical considerations. There are also a number of potential funding bodies who fund health and social care research. Local research and development offices should provide the relevant information and advice on costing research appropriately.

Recommendations for further research

A number of researchers have made recommendations and suggestions for further research into specific aspects of physiotherapy for people with a learning disability (Finlayson et al. 2010; Crockett et al. 2014; Dairo et al. 2016; Public Health England 2018b; Robertson et al. 2018; NICE 2019).

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24 hour postural management: Public Health England (2018b) acknowledge that there is a lack of evidence to support postural management in people with a learning disability and that the existing research does not provide the evidence required by commissioners. The authors state that there is an urgent need for evidence about the clinical and cost effectiveness of 24-hour postural care programmes and services. This could support the calls for improved specialist services and better funding for equipment, such as night time positioning systems.

Robertson et al. (2018) conducted a systematic review of the relevant research literature on the postural management of people with a learning disability. They identified a number of gaps in the evidence base. The authors make recommendations for further research priorities which they propose would begin to ascertain how best postural care interventions can be employed to help improve the health and quality of life of people with a learning disability. These include:

- Large-scale survey work could identify the potential needs that exist for postural care and map the current picture of service provision relating to postural care for people with a learning disability.
- Evaluation work investigating the impact on people and families of living in an area with a comprehensive postural care service versus areas without such a service.
- Health economic modelling could consider the costs and effectiveness of postural care as a whole, and also particular components of postural care.

Respiratory: NICE (2019) in the guidelines on cerebral palsy in adults recommend that one of the key priorities for research is to determine the most effective methods of detecting and managing respiratory disorders in primary and community care.

Falls prevention and intervention: There is a body of evidence that explores falls in people with a learning disability. Finlayson et al. (2010) make recommendations for further study on fractures/osteoporosis with this population; and the development and piloting of balance, safety, and staff training interventions for high-risk groups of people with a learning disability for fall injuries. Crockett et al. (2014) report that further work is needed to address issues related to non-participation or non-compliance with prescribed exercise and to learn more about clinical benefit outcomes of falls prevention pathways.

Health promotion: Dairo et al. (2016) conducted a systematic review of physical activity levels in adults with a learning disability. The findings highlighted a crucial need to increase physical activity in this population. To inform measurement and intervention design for improved physical activity the authors recommend that there is an urgent need for future studies. This includes people with severe and profound learning disability who have the lowest levels of physical activity.

In addition to the areas for further research identified in the evidence a number of priority areas where identified by the participants and researchers. These include:

1. Analysis of the current provision of specialist learning disability physiotherapy around the UK in comparison to the standards of practice.
2. Assessment of the appropriate time between reviews and the factors that influence these decisions.
3. Case studies published in peer review journals.
4. Clinical effectiveness of treatment and management approaches.
5. Cohort studies of the adults with a learning disability accessing specialist learning disability physiotherapy services especially people with complex physical disability.

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6. Cost effectiveness of specialist learning disability physiotherapy management.
7. Development and validation of standardised assessment tools.
8. Impact of specialist learning disability physiotherapy on access to primary and secondary healthcare.
9. The adjustments specialist learning disability physiotherapists make to provide successful physiotherapy to adults with a learning disability.
10. The experiences of people with a learning disability and their network of care with specialist learning disability physiotherapy.

Evidencing the impact of specialist learning disability physiotherapy

It is the responsibility of all specialist learning disability physiotherapists and services to contribute to the literature pool and to evidence the impact of the profession. This does not mean that all physiotherapists need to conduct research, but it would beneficial if they evidence, publish and share how their current practice improves clinical outcomes; the experiences of people with a learning disability and their network of care; and/or the potential cost effectiveness of their interventions.

Clinical Outcomes: Clinical outcomes are broadly agreed, measurable changes in health or quality of life that result from care. Clinical outcomes can be measured through a range of tools including validated outcome measures, an individualised measure, or specific outcome.

For example:

- Improved Tinnetti assessment score post exercise programme.
- Achieved goal evidenced through Goal Attainment Scale (GAS) following intervention.
- Reduced number of falls through implementation of a falls pathway.
- Reduced number of chest infections per year through implementing prophylactic postural management.
- Reduced number of A&E admission through implementing annual reviews of people with severe cerebral palsy and a learning disability.
- Reduced number of chest infections through multidisciplinary dysphagia assessment and management.

Experience of Care: Experience is one of the three key components of quality and needs to be given equal emphasis along with safety and effectiveness. There is a link between experience and health outcomes i.e. people who have a better experience of care generally have better health outcomes. There is also a link between experience and cost of care i.e. poor experiences generally lead to higher costs as people may have poorer outcomes and require longer and multiple episodes of care (NHS England 2013).

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Assessing the experiences of people with a learning disability can be challenging due to the impact of their communication impairments therefore, assessment of the experiences of the network of care may be more achievable and realistic. Table 3 outlines examples of methods to gain feedback of service user experiences.

Table 3: Methods to gain feedback of service user experiences

	Less descriptive	More descriptive
More generalisable	Surveys Comment cards Kiosk questions	In-depth interviews Focus groups Patient panels
Less generalisable	Online ratings Public meetings	Patient stories Patient feedback Complaints and compliments

Cost Effectiveness: For managers and commissioners who invest money into services it is important to see the return on their investment. Not only from the improved outcomes but also how services can save money in the long term. In addition, evidencing potential cost saving is an essential part of developing a business case for service development especially where increased investment is required. Cost effectiveness and saving can be demonstrated through evidencing or projecting the impact of an intervention or service has on clinical outcomes that are attributable to a unit cost of health or social care. For example:

- Number of bed days saved.
- Discharge from hospital or services.
- Delay/avoidance of admissions to hospital.
- Reducing a person's package of care through maintenance of standing transfers.
- Reduction in the number of care visits involved in delivering care e.g. reduction in the need for double handed care.
- Reduced hospital length of stay through hospital in-reach.
- Reduction in use of emergency and crisis response services.
- Reduced access to mainstream health services.
- Reduction in GP visits and medication prescriptions.

The Royal College of Occupational Therapy has launched the Improving Lives, Saving Money campaign which has a range of resources that demonstrate how occupational therapists improve lives and save money for the health and social care services on a daily basis. In line with this campaign, the researchers have developed resources to help services and professionals demonstrate the financial impact of specialist learning disability physiotherapy. This includes a case study outline including a summary of the relevant unit costs of health and social care to specialist learning disability physiotherapy.

Toolkit: **Evidencing the cost effectiveness of physiotherapy**

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Shared learning and disseminating results

Sharing the results of any service developments, case studies, audits and research projects is essential. Communicating the findings with the wider audience ensures that others working in the same field are able to learn from the results to improve care and knowledge; and influence policy or service planning. It also adds to the literature and evidence pool supporting the role of the specialist learning disabilities physiotherapist. Ideally, results would be published in a peer review journal because these have the biggest impact factor and widest audience. It is important to remember that there are a range of journals available all with different criteria for publication which give authors a number of options for publishing their results (Table 4). All journals will have specific aims and scope; as well as guidelines and instructions for authors which details the style and format of the manuscript.

Table 4: Examples of relevant research journals

Physiotherapy Related Journals	• Clinical Rehabilitation • Physiotherapy • Physiotherapy Research International • Physiotherapy Theory and Practice: An International Journal of Physical Therapy
Learning Disability Journals	• British Journal of Learning Disabilities • Focus on Autism and Other Developmental Disabilities • Journal of Applied Research in Intellectual Disabilities • Journal of Intellectual Disabilities • Journal of Intellectual Disability Research • Journal of Learning Disabilities • Learning Disabilities • Learning Disabilities Research and Practice • Learning Disability Practice • Research in Developmental Disabilities
Disability Journals	• Disability and Rehabilitation • Research and Practice for person with Severe Disabilities • Disability and Society • British Journal of Therapy and Rehabilitation • International Journal of Therapy and Rehabilitation

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If disseminating the results in a peer reviewed journal is not feasible there are a range of other options which may be interested in publishing work. These platforms are often retrievable by other researchers and contribute to the pool of grey literature which can contribute to narrative and literature reviews. These include:

- Newsletters from different special interest groups.
- NICE, Public Health England, NHS England, and other government and charitable organisations regularly request examples of good practice to support policy and recommendations.
- The ACPPLD website has a document sharing section in which case studies and examples of good practice can be posted and attributed to the author.

Presenting at conferences may involve poster or oral presentations and the opportunity to discuss or debate the findings with peers. These can be extremely valuable, but information presented at conferences may not be so easily retrievable by other researchers.

CONCLUSION

The evidence for the role of the specialist learning disability physiotherapist will not increase on its own. Therefore, it is the responsibility of all professionals with an interest and a passion for working in the area to promote the role and contribute to the literature pool. Professionals are all guilty of completing service developments; a quality improvement project, an audit, presenting a case study; or local research but not disseminating the results beyond the local team. The researchers recognise that finding the time to complete this task and prioritise it over clinical work is challenging. Including objectives relating to research and sharing learning could be a way to dedicate and ring fence time to commit to this important aspect of the role, CPD and development of the profession. Sharing the outcomes and impact of specialist learning disability physiotherapists on the lives of adults with a learning disability and their network of care, as well as demonstrating how we can save money at the same time is critical to developing and safeguarding the profession moving forwards.

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Standards of Practice for Physiotherapists

Working with adults with a learning disability

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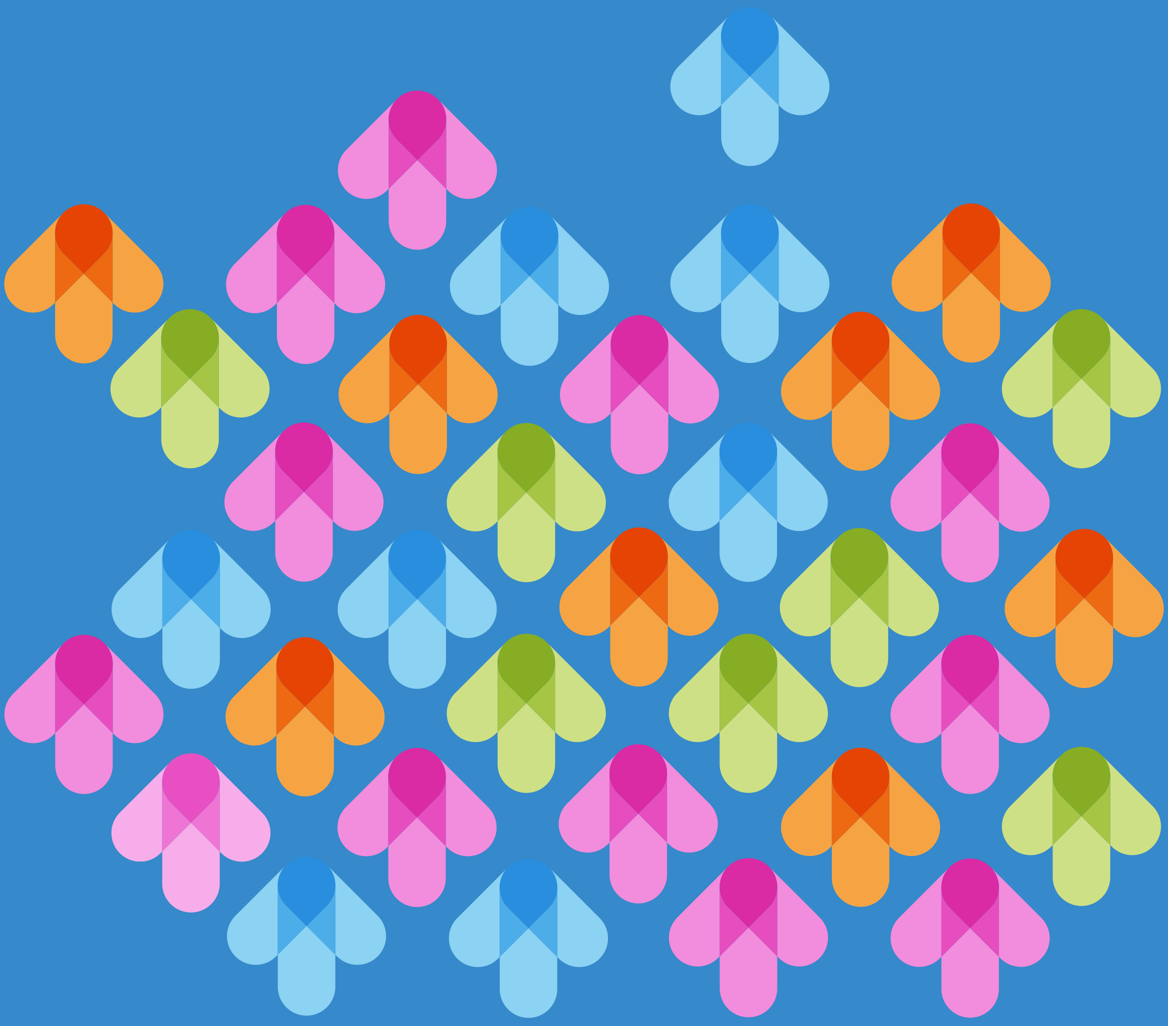

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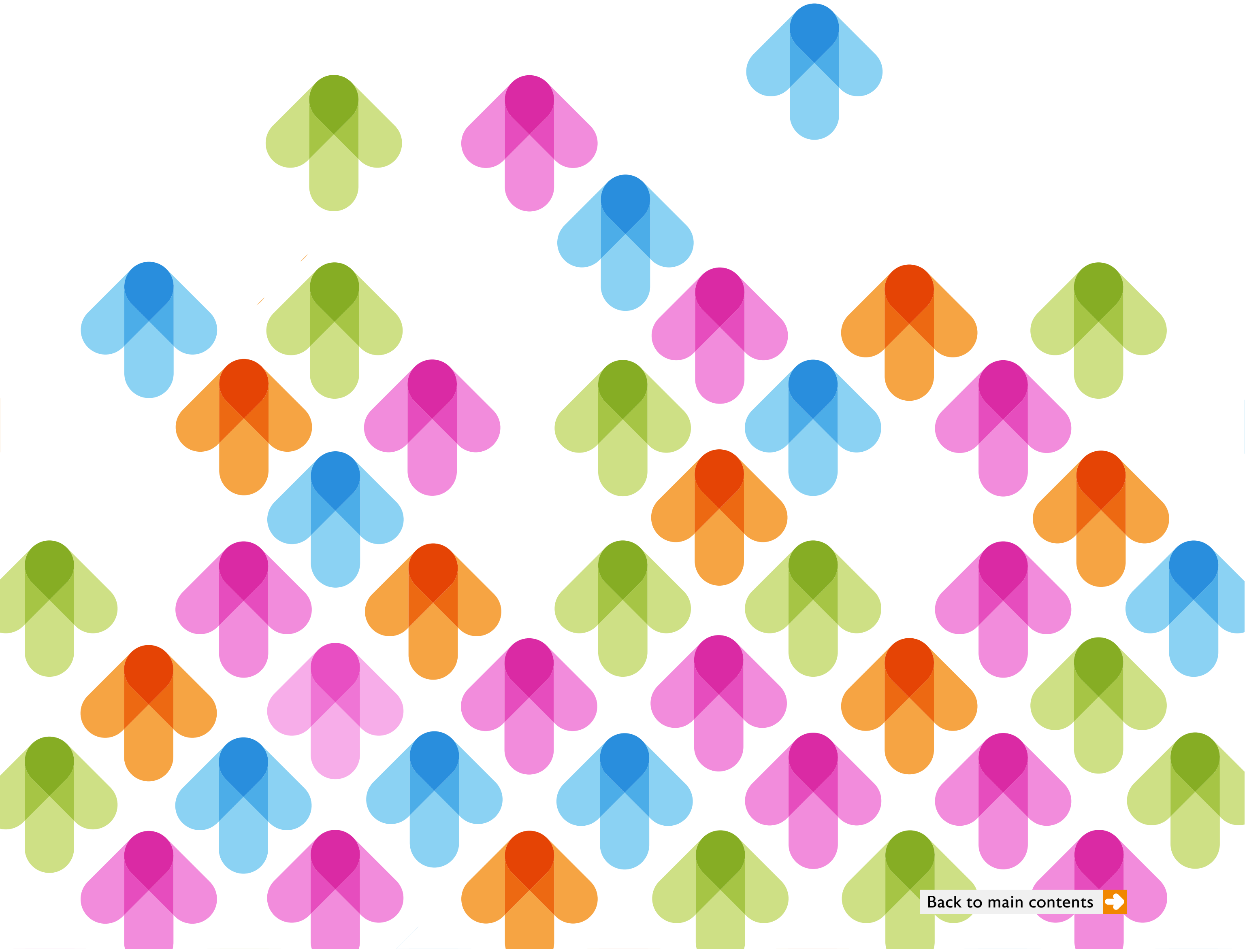

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SO YOUR NEXT PATIENT HAS A LEARNING DISABILITY?

A GUIDE FOR PHYSIOS NOT SPECIALISING IN LEARNING DISABILITIES

A learning disability is a significant, lifelong condition that started before adulthood, that affected the person’s development and which means they need help to understand new or complex information, learn new skills and cope independently.*

*The Same as You, 2000; Valuing People, 2001

The majority of people with a learning disability can successfully access mainstream physiotherapy services when reasonable adjustments are made.

Planning and preparation for your appointment

A person with a learning disability has individual needs like everyone else, however, the following suggestions may be helpful when preparing for your appointment.

Try to find out in advance

- Relevant medical history - they might not be able to remember or explain all the details you need
- Information relating to the particular condition or syndrome they may have
- If the person has a Health Action Plan, Health Passport or communication passport and request a copy
- If the person has specific likes or dislikes, which may affect the appointment

Appointment planning

- If possible consider the location of the appointment, and where the person is most likely to be relaxed and comfortable. For community visits try to choose a location which limits disruption to the person's routine. In a clinic setting choose a separate quiet room to reduce distractions; curtained cubicles are not ideal.
- Provide longer appointments so that you can take your time with the person and avoid rushing them. Alternatively, if you are aware that someone has a short attention span, it may be better to offer several short appointments.
- Some people with learning disabilities may be unable to read. Consider arranging appointments via telephone and back this up with a letter, using an accessible format.
- Where appropriate ask for a carer who knows the person well to attend with them.
- Check whether the person needs specialist equipment for the appointment (e.g. hoist).
- If your location is difficult to find offer to meet them at front door.

Don't forget about consent!

Many people with learning disabilities are able to give consent to treatment, however, some may not. Assume a person has capacity to give consent until an assessment indicates otherwise.

Remember

- A capacity assessment is not a blanket decision, it relates to a specified task/activity.
- A person can have capacity for one decision and not for another.
- Capacity can fluctuate – it may be necessary to review the decision or wait until capacity returns.

Where someone is unable to give informed consent, you will need to adhere to the Mental Capacity Act 2005 or the Adults with Incapacity (Scotland) Act 2000, depending on your location. You should also refer to your own organisational policies for further guidance.

How to get the best outcome from your appointment

Time Start your appointment on time. Many people with a Learning Disability don't understand the concept of waiting and may find waiting areas stressful.

Environment Consider the environment. Minimise sensory stimulation, limit the likelihood of interruption and remove unnecessary equipment. Enclosed and noisy waiting rooms, and the smell of clinical environments may be unsettling for some people. A number of short pre-visits might help them relax.

Communication

- Think about how you will speak to the person. Use short sentences, avoiding using abstract ideas and jargon. Using words the person is familiar with can help to get ideas across more effectively.
- Always talk directly to the person using their chosen name, even if they are unable to answer. Include the carer in the discussion to confirm information and advice. A good balance of involving both is needed.

Flexibility Be prepared to work from the person's perspective. A flexible and relaxed approach is essential. Encourage the person to look at and touch equipment, as appropriate.

Assessment Think about your assessment from a practical point of view. Plan the order of your assessment to minimise frequent positional changes.

Functional and fun

- If you want to observe their movement ask the person to perform functional activities that make sense, or make the task fun and relevant to their interests. Be creative! Dance, music, iPads, puzzles are just a few examples that could be effective.
- Use imitation and role modelling; asking them to copy you or including their carer in demonstrations can be a good strategy.

Making communication work Use visual aids to explain what you want the person to do and what will happen. Pictures, photographs, symbols and video can be helpful. If you need to give them information to take home try to make it accessible, and refer to their communication passport if available.

Difficult behaviour Difficult behaviour is not part of having a learning disability. It can often be someone's way of communicating information. Use your assessment, carers advice and specialist tools, such as DisDAT, to rule out potential physical causes before assuming these are behavioural issues.

Lack of success If your appointment doesn't go to plan don't despair, just stop the session and schedule a follow up. Continuing with a negative experience may make future sessions more difficult. Discuss this with the carer and think about alternative approaches you could use next time.

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The professional, educational and trade union body for the United Kingdom's 59,000 chartered physiotherapists, physiotherapy students and support workers.

Who can help?

Your local Community Learning Disability Team (CLDT) should have a specialist physiotherapist who provides specialist support to people with a learning disability who are unable to access mainstream physiotherapy services even with reasonable adjustments. They will be happy to discuss any concerns you may have and will be able to give you further advice on working with people with learning disabilities.

Further advice and information

For more information about Physiotherapy for adults with a Learning Disability please see the 'Standards of Practice for Physiotherapists Working with Adults with a Learning Disability'
acppld.csp.org.uk/standards-of-practice

acppld.csp.org.uk
www.enable.org.uk
www.mencap.org.uk
www.pamis.org.uk
www.choiceforum.org
www.pcpld.org
www.downs-syndrome.org.uk
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www.scld.org.uk

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and updated January 2020

ASSOCIATION
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PHYSIOTHERAPISTS
FOR PEOPLE
WITH LEARNING
DISABILITIES
ACPPLD

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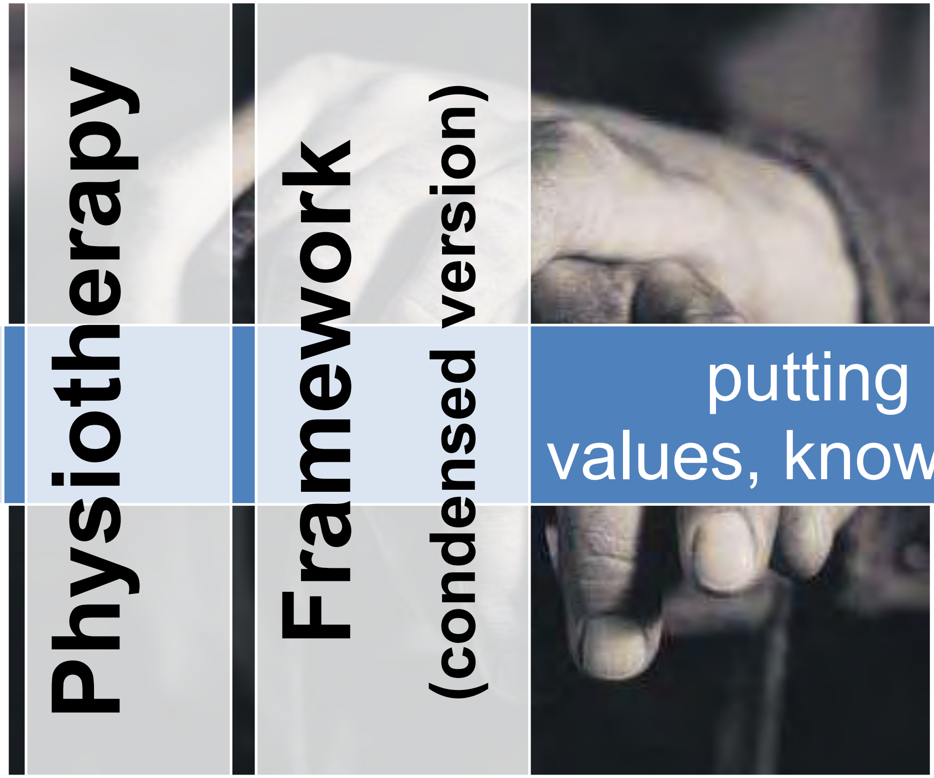
Chartered Society of Physiotherapy

Physiotherapy Framework

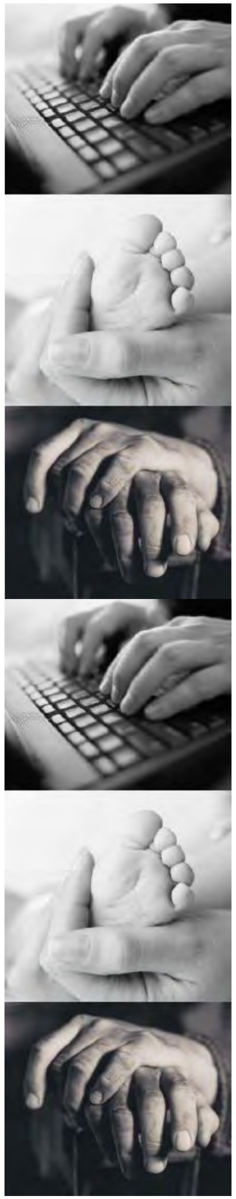
(condensed version)



putting physiotherapy behaviours, values, knowledge & skills into practice

A resource to promote & develop physiotherapy practice

CSP (2011) Physiotherapy Framework: putting physiotherapy behaviours, values, knowledge & skills into practice [updated May 2020]



Welcome to the CSP's Physiotherapy Framework.

The CSP's Physiotherapy Framework is a resource designed to promote & develop physiotherapy practice. The Physiotherapy Framework defines & describes the behaviours (& underpinning values), knowledge & skills required for contemporary physiotherapy practice:

- at all levels - from a new support worker through to a senior level registered physiotherapist;
- across a variety of occupational roles – clinical, educational, leadership, managerial, research, & support;
- in a variety of settings – in health & social care, in industry & workplaces, in education & development, & in research environments;
- across all 4 nations of the UK.

The Physiotherapy Framework is based on the idea of physiotherapy being a complex intervention. It therefore goes beyond the task-based focus of existing generic competency frameworks & defines the unique blend of behaviours, knowledge & skills used by the physiotherapy workforce. The framework's content is based on an analysis of policy drivers across the UK & sources describing the behaviours, knowledge & skills used in physiotherapy practice. The content was refined with feedback from the CSP's Charting the Future Steering Group, Standing Committees, & Council, & consultation with the wider CSP membership during 2008-10.

Please note that this is a condensed version of the CSP's Physiotherapy Framework. The document is divided into 3 sections:

1. Definition of physiotherapy

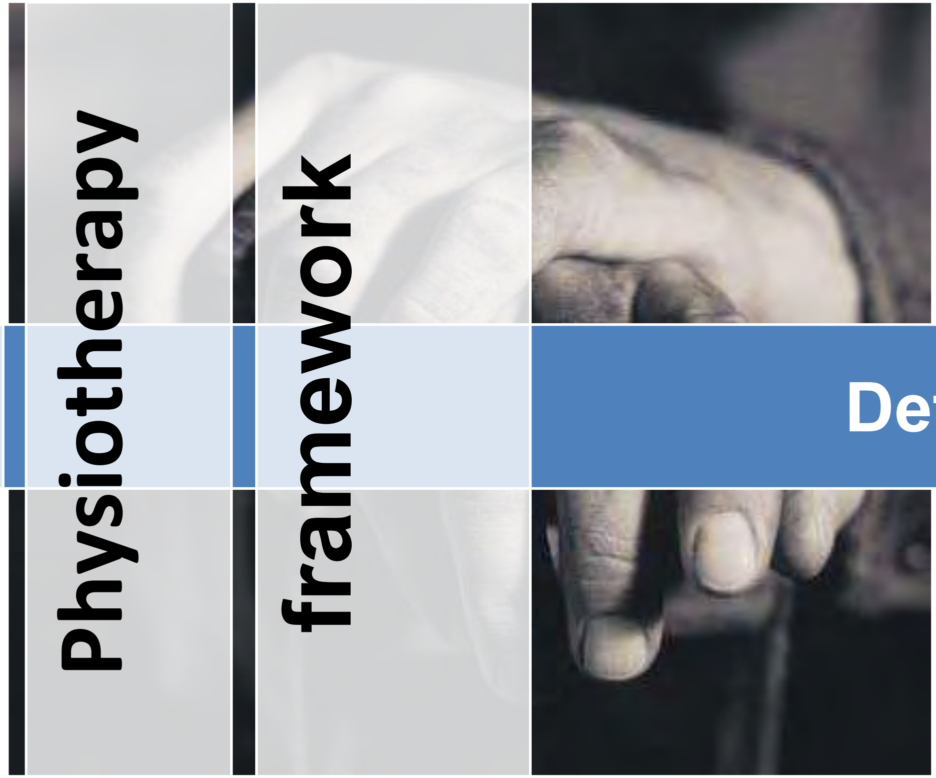
2. Structure of the framework:
This section explains how the domains & descriptors within the framework work together to describe physiotherapy practice

3. Physiotherapy values, behaviours, knowledge & skills
Tables that describe the behaviours, knowledge & skills used by the physiotherapy workforce at 6 different levels of practice

The full version of the framework is available for members to use in the CPD Resources workspace of the CSP's ePortfolio system (http://www.csp.org.uk/professional-union/careers-development/cpd/csp-eportfolio/my-eportfolio/cpd-resources). This full interactive version of the Physiotherapy Framework contains detailed information about the domains/ descriptors & signposts to specific CPD resources & tools.

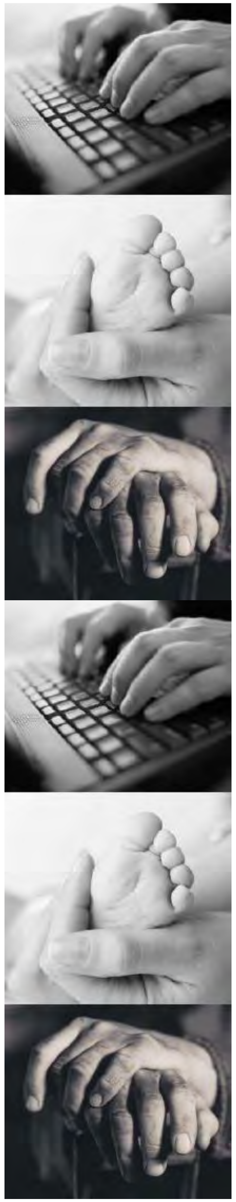
Chartered Society of Physiotherapy

Physiotherapy framework



Definition of physiotherapy

CSP(2011) Physiotherapy Framework: putting physiotherapy behaviours, values, knowledge & skills into practice [updated May 2020]



Definition of physiotherapy

This definition is based on sources that present a picture of contemporary physiotherapy practice. This definition presents a picture of what the behaviours, knowledge & skills described by the framework look like in practice.

Physiotherapy is a healthcare profession that works with people to identify & maximise their ability to move & function. Functional movement is a key part of what it means to be healthy. This means that physiotherapy plays an important role in enabling people to improve their health, wellbeing & quality of life.

Physiotherapists use their professional knowledge & practical skills, together with thinking skills & skills for interaction in their day-to-day practice. This combination of knowledge & skills means that practitioners can work in partnership with the individual & other people involved with that person. Physiotherapists recognise that physical, psychological, social & environmental factors can limit movement & function. They use their knowledge & skills to identify what is limiting an individual’s movement & function, & to help individuals decide how to address their needs.

Physiotherapy's values means that practice is person-centred, ethical & effective. The evidence-base underpinning physiotherapy is constantly evolving as practitioners develop new knowledge & understanding through critical reflection, evaluation & research. This evolving evidence base supports the use & development of physiotherapy's scope of practice. The Royal Charter gives physiotherapy a broad scope of practice that includes manual therapy, exercise & movement, electrotherapy & other physical approaches.

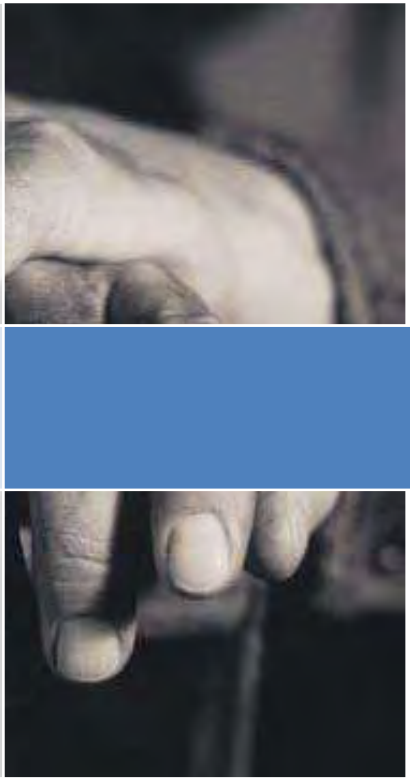
Physiotherapy is an autonomous profession. This means that physiotherapists can accept referrals for assessment from a range of sources: from an individual themselves (self-referral) or from other people involved with that individual. Physiotherapy can offer a range of interventions, services & advice to improve individuals' health & wellbeing. Physiotherapy works to maximise an individual’s movement capability at three different levels. It can help maintain & improve the body’s movement & function by offering treatment when someone is acutely ill in hospital. It can also improve someone’s function & independence (at home, at work) by offering rehabilitation & advice. It can also enhance their performance & participation (in their community & wider society) by offering advice & by challenging the environmental or social barriers that limit participation.

Physiotherapy's strong clinical leadership & adaptable workforce means that it can deliver high quality innovative services that are accessible, effective & efficient. Physiotherapy maintains strong links between clinical & academic settings. This means that the profession responds to developments in practice, education or research, & actively ensures its workforce continues to be fit for purpose.

CSP (2011) Physiotherapy Framework: putting physiotherapy behaviours, values, knowledge & skills into practice [updated May 2020]

Chartered Society of Physiotherapy

Physiotherapy framework



Framework structure

Structure of the framework

Physiotherapy is made up of many different elements (or sets of behaviours, knowledge & skills) - all essential to practice. No one element can be defined as *the* 'active ingredient' which makes practice effective. The individual elements that make up practice ultimately influence one another - a real example of the whole being greater than the sum of its component parts. This idea has informed the structure & content of the physiotherapy framework.

Figure 1: structure of physiotherapy framework showing how individual elements work together to produce physiotherapy practice

CSP (2011) Physiotherapy Framework: putting physiotherapy behaviours, values, knowledge & skills into practice [updated May 2020]

A review of the literature & reflection on contemporary physiotherapy practice suggests that physiotherapy practice is made up of four elements that become integrated in practice.

1. Physiotherapy values
At the heart of physiotherapy practice is a set of values that are shared by all CSP members - regardless of their occupational role, practice setting, or level of practice. These values inform the behaviour of CSP members, & the knowledge (theoretical & applied) & skills that the physiotherapy workforce uses & develops.

2. Physiotherapy knowledge
The theoretical knowledge required for physiotherapy practice. Physiotherapy knowledge shapes, & is shaped by the profession's constantly evolving scope of practice. Although an individual's knowledge base will be shaped by the demands & context of their practice, physiotherapists must demonstrate how their knowledge & understanding relates to physiotherapy & their individual scope of practice.

3. Physiotherapy practice skills
The practical (psycho-motor) skills used by the physiotherapy workforce. In order to apply physiotherapy-specific practice skills, physiotherapy values & knowledge are required. Without physiotherapy values & knowledge, physiotherapy-specific practice skills of exercise & movement, manual therapy, electro-physical modalities & other physical approaches become nothing more than a physical technique. The physiotherapy workforce also uses practical skills/techniques such as First Aid or Manual Handling that are shared with other groups of staff that work in the health & wellbeing economy. As with physiotherapy knowledge, an individual's skill-base will evolve according to their experiences & context of practice, but practitioners must demonstrate how their skills relate to physiotherapy & their personal scope of practice.

4. Generic behaviours, knowledge & skills
As well as its physiotherapy values, knowledge & practice skills, the physiotherapy workforce also requires generic knowledge & skills. These are behaviours, knowledge & skills used by all practitioners working in the health & wellbeing economy. The physiotherapy workforce uses these sets of generic behaviours, knowledge & skills to apply its physiotherapy values, knowledge & practice skills to maximise individuals' potential – through its clinical, educational, leadership & research practice. This element is subdivided: behaviours, knowledge & skills for interaction; & behaviours, knowledge & skills for problem-solving & decision-making.

CSP(2011) Physiotherapy Framework: putting physiotherapy behaviours, values, knowledge & skills into practice [updated May 2020]

Each element of the framework contains a number of inter-related domains (specific sets of behaviours, knowledge & skills) as Table 1 shows.

Element	Framework domain
1. Physiotherapy values [1 domain]	Values
2. Physiotherapy knowledge [3 domains]	Knowledge & understanding of physiotherapy Political awareness Self-awareness
3. Physiotherapy practice skills [1 domain]	Physiotherapy practice skills
4. Generic behaviours, knowledge & skills: - for interacting [6 domains]	Communicating Helping others learn & develop Managing self & others Promoting integration & teamwork Putting the person at the centre of practice Respecting & promoting diversity
- for problem-solving & decision-making [6 domains]	Ensuring quality Improving & developing services Lifelong learning Practice decision making Researching & evaluating practice Using evidence to lead practice

Table 1: summary of physiotherapy framework elements/domains

Describing roles in practice

The structure of the Physiotherapy Framework is designed to help individuals recognise/describe the behaviours/knowledge/skills they use as part of their day-to-day physiotherapy practice. Although the behaviours/knowledge/skills presented in the framework are shared across the physiotherapy workforce, how they are used in practice will vary depending on what an individual's practice is at any given time.

Table 2 shows how 3 different roles that are part of physiotherapy practice draw on different sets of behaviours/knowledge/skills. Mapping practice in this way is useful to show how different aspects of an individual's role draw on specific sets of behaviours/knowledge/skills.

Framework domain	Conducting a physiotherapy assessment	Supporting someone else's development as a mentor	Leading a team to evaluate & redesign a service
Physiotherapy values	✓	✓	✓
Knowledge & understanding of physiotherapy	✓	✓	✓
Political awareness		✓	✓
Self-awareness	✓	✓	✓
Physiotherapy practice skills	✓		
Communicating	✓	✓	✓
Helping others learn & develop		✓	
Managing self & others	✓	✓	✓
Promoting integration & teamwork			✓
Putting the person at the centre of practice	✓	✓	
Respecting & promoting diversity	✓	✓	✓
Ensuring quality	✓	✓	✓
Improving & developing services			✓
Lifelong learning	✓	✓	✓
Practice decision making	✓	✓	✓
Researching & evaluating practice			✓
Using evidence to lead practice			✓

Table 2: using the Physiotherapy Framework domains to describe roles in practice

CSP(2011) Physiotherapy Framework: putting physiotherapy behaviours, values, knowledge & skills into practice [updated May 2020]

As these examples illustrate, the Physiotherapy Framework can be used to highlight how a particular set of behaviours, knowledge & skills transfer from one role to another, & what elements make one role distinct from another. This function of the framework enables it to move beyond the task-based focus of existing competency frameworks.

The Physiotherapy Framework can therefore be used to:

- deconstruct practice to recognise & celebrate personal strengths & highlight potential learning/development needs.
- recognise how specific sets of behaviours, knowledge & skills transfer from one area of practice to another.
- build a picture of individual/departmental/organisational profile of the physiotherapy workforce.

Levels of practice

Although all the elements/domains within the framework are shared by the physiotherapy workforce, across all levels of practice, in different occupational roles & practice settings, some domains are more highly developed in some contexts of practice than in others. A review of the literature & descriptors used to design programmes of education suggests that progression from one level of practice to the next reflects a change in 3 different dimensions: complexity; predictability; sphere of influence; which together inform the extent of an individual's personal autonomy. The relationship between these dimensions is presented in Figure 2.

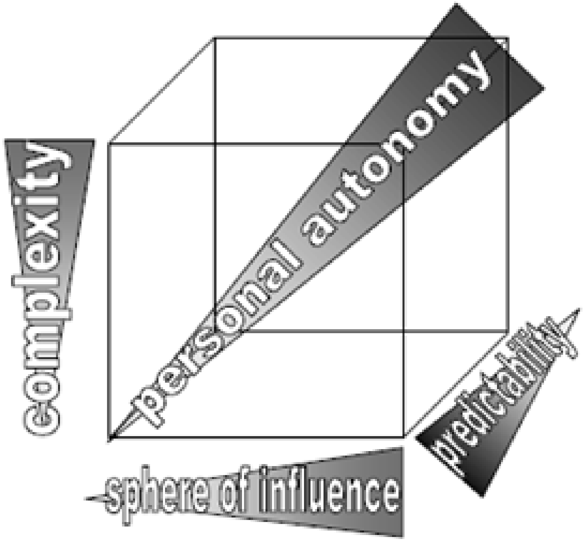


Figure 2: relationship between practice dimensions

The framework domains are described at 6 levels on a continuum from support to expert (summarised in Table 3). An individual's progression through & across the levels will depend on their access to & engagement with personalised learning & development opportunities.

Support level practice is generally predictable, the practitioner has a very local sphere of influence (e.g. self, client and physiotherapy team) and works with a relatively straightforward caseload. Personnel practising at this level have their work delegated by others who take responsibility for ensuring the individual has the necessary knowledge, skills and behaviours to undertake the delegated task.

Graduate level practice is sub-divided into 2 levels to show how a newly qualified physiotherapist's practice evolves during the early years of their career. The early experiences of new graduates will have a lasting effect on their future professional practice & commitment to physiotherapy. Evidence also highlights the emotional rollercoaster ride experienced by new entrants as they work to consolidate their existing behaviours/knowledge/skills & develop a deeper understanding of physiotherapy's ways of working. The key factors differentiating the 'entry-level' & 'experienced' graduate is a growth in the individual's confidence & competencies which is gained from applying their knowledge & skills in a supported clinical environment. The divisions within graduate level demonstrate the added value of providing a supportive working environment, processes & resources to support an individual's transition from student to qualified staff.

Expert level practice works within complex, unpredictable & normally specialised contexts that demand innovative work that may involve extending the current limits of knowledge. Practice at this level therefore provides opportunities to have a broader sphere of influence (e.g. through professional leadership or consultancy roles), & the complex/unpredictable nature of the practice carries high levels of personal autonomy.

The level descriptors within the physiotherapy framework were developed using descriptors used to design programmes of education. 'Support' & 'Advanced support' practice reflects the descriptors associated with vocational qualifications (e.g. S/NVQ; HNC/D; Foundation degrees). 'Entry-level graduate' practice reflects the descriptors associated with a Bachelor degree, while 'advanced' & 'expert' practice reflect the descriptors associated with Masters & Doctoral level study respectively.

CSP(2011) Physiotherapy Framework: putting physiotherapy behaviours, values, knowledge & skills into practice [updated May 2020]

Framework level	complexity (examples)	predictability	sphere of influence (examples)	personal autonomy
support	Delegated caseload of clients requiring rehabilitation	Practice within predictable contexts	Clients on caseload & delegating physiotherapist(s)	Responsible to delegating physiotherapist(s) Practice according to treatment protocols & Trust policies/procedures
advanced support	Delegated caseload - some presenting with complex needs	Practice within predictable & normally specialised contexts	Clients on caseload; MDT	Responsible to delegating physiotherapist(s) Practice according to set treatment protocols & Trust policies/procedures
entry-level graduate	Own caseload of clients with complex needs	Practice within complex & generally predictable contexts	Clients on caseload; MDT; support workers (delegation)	Responsible for own actions. Practice according to professional codes & Trust policies/procedures
experienced graduate	Own caseload of clients with complex needs	Practice within complex & increasingly unpredictable contexts	Clients on caseload; MDT; support workers (delegation & supervision)& students	Responsible for own actions. Practice according to professional codes & Trust policies/procedures
advanced	Specialised caseload of clients with complex needs	Practice within complex & unpredictable contexts which demands innovation	Clients; MDT; staff in primary & secondary care; professional networks at local & national level; students	Professionally & legally accountable for own actions
expert	Highly specialised caseload of clients with complex needs	Practice within complex, unpredictable and normally specialised contexts demanding innovative work	Clients/carers on caseload; AHPs (clinical, professional & education leadership); public/ other professions/policy makers at regional/national level.	Accountable for own actions. Practice characterised by an element of risk taking - guided by own knowledge & relevant professional codes/standards /guidelines.

Table 3: summary of support to expert continuum

How are the definitions and descriptors presented?

In this version of the framework, each of the 17 domains, except for the values domain, is presented as a set of tables.
The main table is structured and colour-coded to make it easier to follow. The left hand column defines the domain, with the rest of the table describing what the domain looks like at the 6 different levels of practice.

FRAMEWORK ELEMENT

						DOMAIN TITLE
Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
Definition of the domain Description of the specific behaviours, knowledge & skills	Individual level descriptors that describe what the behaviours, knowledge & skills look like at a particular level of practice					

The domains have been mapped to a set of 6 other competency frameworks relevant to the practices of the physiotherapy workforce:

- Department of Health (2004) Knowledge & Skills Framework
- Skills for Health (2008) Career Framework
- NHS Leadership Academy (2011) Leadership Framework
- Public Health Resource Unit/Skills for Health (2008) Public Health Skills & Career Framework
- Joint Negotiating Committee for Higher Education Staff (2004 – amended Jan 2005) Academic role profiles
- VITAE (2011) Researcher Development Framework

Table 4 presents a summary of how each domain from the CSP's Physiotherapy Framework maps across to these other competency frameworks. A more detailed breakdown of that mapping is available in the full version of the Physiotherapy Framework which is available to CSP members in the CPD Resources workspace in the CSP ePortfolio system.

Mapping physiotherapy framework domains against other competency frameworks relevant to physiotherapy practice (summary).

	DoH (2004) NHS KSF	Healthcare careers (SfH 2008)	Clinical Leadership (NHSLA 2011)	Public health (PHRU, 2008)	JNCHES (academic)	VITAE (research)
Physiotherapy Framework						
Physiotherapy values						
Knowledge & understanding of physiotherapy		✓		✓	✓	✓
Political awareness	✓	✓	✓	✓	✓	✓
Self-awareness			✓	✓	✓	✓
Physiotherapy practice skills	✓	✓				
Communicating	✓	✓	✓	✓	✓	✓
Helping others learn & develop	✓	✓	✓	✓	✓	
Managing self & others	✓	✓	✓	✓	✓	✓
Promoting integration & teamwork	✓	✓	✓	✓	✓	✓
Putting the person at the centre of practice	✓	✓	✓	✓	✓	
Respecting & promoting diversity	✓	✓	✓	✓	✓	✓
Ensuring quality	✓	✓	✓	✓	✓	✓
Improving & developing services	✓	✓	✓	✓	✓	✓
Lifelong learning	✓	✓	✓	✓	✓	✓
Practice decision making	✓	✓	✓	✓	✓	✓
Researching & evaluating practice	✓	✓	✓	✓	✓	✓
Using evidence to lead practice	✓	✓	✓	✓	✓	✓

CSP(2011) Physiotherapy Framework: putting physiotherapy behaviours, values, knowledge & skills into practice [updated May 2020]

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Physiotherapy framework

Physiotherapy behaviours, knowledge & skills

CSP(2011) Physiotherapy Framework: putting physiotherapy behaviours, values, knowledge & skills into practice [updated May 2020]

Values

Values are defined as a set of ideals that motivates & informs an individual's behaviour & actions. The nature of values means that, unlike the other domains in the framework, they cannot be described at different levels.

The values at the heart of the Physiotherapy Framework are shared by all CSP members; regardless of their occupational role, practice setting or level of practice. They are fundamental to the CSP's expectation of members' professionalism (www.csp.org.uk/code).

As the figure shows, these values underpin the behaviours, knowledge & skills used by the physiotherapy workforce in their day-to-day professional practice.

2. Physiotherapy knowledge

KNOWLEDGE & UNDERSTANDING OF PHYSIOTHERAPY						
Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
Demonstrate knowledge & understanding that is relevant to their area of practice & that underpins their individual scope of practice The core knowledge of physiotherapy addresses: • the role of other professions in health & social care • the principles & applications of scientific enquiry • concept of leadership • structure & function of the human body • the theories underpinning the approaches used in physiotherapy practice • understanding of scientific bases of physiotherapy - biological science - physical science - clinical science - behavioural science • the ethical principles underpinning physiotherapy practice • the legal & policy frameworks governing physiotherapy practice HCPC (2013)	practice within predictable & straightforward contexts which requires the application of basic knowledge & facts relevant to their area of practice.	practice within predictable & normally specialised contexts which requires the application & understanding of basic knowledge, ideas & principles relevant to their area of practice.	practice within complex & generally predictable contexts which requires the application of current physiotherapy knowledge	practice within complex & increasingly unpredictable contexts which requires the application of current physiotherapy knowledge	practice within complex & unpredictable contexts which demands innovative work which may involve exploring current limits of knowledge	practice within complex, unpredictable & normally specialised contexts demanding innovative work which may involve extending the current limits of knowledge
			working to consolidate the knowledge gained from qualifying physiotherapy programme	continuing to consolidate the knowledge gained from qualifying physiotherapy programme, & learning how that knowledge transfers from one area of practice to another	a systematic understanding of knowledge, much of which is at, or informed by, the forefront of professional practice	a systematic acquisition & understanding of a substantial body of knowledge which is at the forefront of professional practice
					demonstrate a critical awareness of current problems & /or new insights through application of research or advanced scholarship techniques relevant to their area of practice	create & interpret new knowledge, through original research or other advanced scholarship, of a quality to satisfy peer review, extend the forefront of the discipline, & merit publication

2. Physiotherapy knowledge

POLITICAL AWARENESS

Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
Knowledge & understanding of the political, social, economic & institutional factors shaping the health & wellbeing economy & how they inform the design/delivery of physiotherapy. *Political awareness* describes the behaviour, knowledge & skills required to: • identify the political, social, economic & institutional factors influencing the delivery & organisation of health & social care & the design, delivery & development of physiotherapy • engage with the implementation & development of policy.	basic knowledge of the political, social, economic & institutional factors that inform their practice	knowledge of the political, social, economic & institutional factors that inform the delivery of physiotherapy services locally	knowledge of the political, social, economic & institutional factors shaping the health & wellbeing economy & how they inform the delivery of physiotherapy across the UK	knowledge & understanding of the political, social, economic & institutional factors shaping the health & wellbeing economy & how they inform the design & delivery of physiotherapy across the UK	critical awareness of the political, social, economic & institutional factors shaping the health & wellbeing economy & how they inform the current & future design, delivery & professional development of physiotherapy at a local & regional level	critical awareness of the political, social, economic & institutional factors shaping the health & wellbeing economy & how they inform the design, delivery & professional development of physiotherapy across the UK
	participate in professional networks & relevant discussions to inform the implementation of policies specific to their area of practice	contribute to the work of professional networks, relevant discussions & provide feedback to inform the implementation of policies relevant to their area of practice	participate in professional networks & relevant discussions to inform the implementation & development of policies specific to physiotherapy practice	contribute to the work of professional or policy networks, relevant discussions & provide feedback to inform the implementation & development of policies relevant to professional practice	play an active role in a variety of professional & policy networks that inform the implementation & development of policies relevant to professional practice	play an active role in a wide variety of professional & policy networks that inform the development of policies that influence the shape the future of professional practice

CSP(2011) Physiotherapy Framework: putting physiotherapy behaviours, values, knowledge & skills into practice [updated May 2020]

2. Physiotherapy knowledge

SELF-AWARENESS						
Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
A conscious knowledge & understanding of one's self which is developed through reflective practice. *Self-awareness* describes the behaviour, knowledge & skills required to: • identify personal values, preferences & ways of working (e.g. likes & dislikes; strengths & weaknesses; emotions & prejudices; personal scope of practice), & understand how these can affect the individual's behaviour, judgement, & practice.	demonstrate a growing self-awareness by using the guidance of others to identify & articulate their personal values, preferences, & with support, acknowledge how these may influence behaviour, judgement & practice.	demonstrate self-awareness by using reflection on personal practice & feedback from others to identify & articulate their personal values, preferences & ways of working, & with guidance, understand how these may influence behaviour, judgement & practice.	demonstrate self-awareness by using reflection on personal practice & feedback from others to identify & articulate their personal values, preferences & ways of working, & with guidance, analyse how these may influence behaviour, judgement & practice.	demonstrate self-awareness by using reflection on personal practice & feedback from others to identify & articulate their personal values, preferences & ways of working, & with guidance, evaluate how these may influence behaviour, judgement & practice.	demonstrate strong self-awareness by using critical reflection on personal practice & feedback from others to identify & articulate their personal values, preferences & ways of working, & critically evaluate how these may influence behaviour, judgement & practice.	demonstrate strong self-awareness by using critical reflection on personal practice & feedback from others to identify & articulate their personal values, preferences & ways of working, & critically evaluate how these may influence behaviour, judgement & practice.

3. Physiotherapy practice skills

PHYSIOTHERAPY PRACTICE SKILLS						
Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
Profession-specific practice skills These relate to physiotherapy's scope of practice & primary aim of maximising individuals' movement potential. Approaches that fall within the scope of physiotherapy practice include: • manual therapy • exercise & movement • electrophysical modalities • kindred physical approaches	perform a range of routine skills safely & effectively with guidance & support	perform a range of routine skills consistently with confidence & a degree of co-ordination & fluidity within relatively predictable contexts	working to consolidate & refine the performance of complex skills gained from qualifying physiotherapy programme	perform complex skills consistently with confidence & a degree of co-ordination & fluidity, learning how those skills transfer from one area of practice to another	demonstrate technical mastery of complex skills within unpredictable contexts	demonstrate technical mastery of complex skills within unpredictable & normally specialised contexts
	modify routine skills with guidance	modify routine skills within accepted standards	modify a technique in response to feedback (e.g. from a client, peer, supervisor)	becoming increasingly self-aware of when/how to modify a technique & less dependent on feedback from others	modify a technique in-action	subconsciously modify a technique in-action
Generic practical & technical skills: These practical & technical skills are shared with other workers in health, social care & education e.g. First Aid, Manual handling.	evaluate own performance with guidance & support from others	evaluate own performance with guidance from others	evaluate own performance	evaluate own & others' performance	evaluate own & others' performance in unpredictable contexts	evaluate own & others' performance in unpredictable & normally specialised contexts

4. Generic behaviours, knowledge & skills for interacting

						COMMUNICATING
Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
The interactive process of constructing & sharing information, ideas & meaning through the use of a common system of symbols, signs & behaviours. *Communicating* describes the behaviour, knowledge & skills required to: • facilitate the sharing of information, advice & ideas with a range of people, using a variety of media (including spoken, non-verbal, written & e-based) • modify communication to meet individuals' preferences & needs • engage with technology, particularly the effective & efficient use of Information & Communication Technology	use a range of routine communication skills to share information & ideas with both specialist & non-specialist audiences	use a wide range of routine communication skills to share information, ideas, problems & solutions with both specialist & non-specialist audiences	use a wide range of routine & some advanced communication skills to share information, ideas, problems & solutions, with both specialist & non-specialist audiences	use a wide range of routine & advanced communication skills to share specialised information, ideas, problems & solutions with both specialist & non-specialist audiences	use a range of advanced & specialised communication skills to share specialised information & ideas/engage in critical dialogue with a range of audiences with different levels of knowledge & expertise	use a broad range of advanced & specialised communication skills to share complex information & ideas/engage in critical dialogue with a wide range of audiences with different levels of knowledge & expertise
	with guidance, modify communication in response to feedback to meet the needs of different audiences	with guidance, modify communication in response to feedback to meet the needs of different audiences & to enhance user involvement	modify communication in response to feedback (e.g. from a client, peer, supervisor) to meet the needs of different audiences & to enhance user involvement	becoming increasingly self-aware & able to modify communication to meet the needs of different audiences & to enhance user involvement & collaboration	modify communication to take account of the needs of different audiences & demonstrate a commitment to user involvement & collaboration	modify communication in-action to take account of the needs of different audiences & demonstrate a commitment to user involvement & collaboration
	use standard ICT applications to obtain, process & combine information & data	use a range of standard ICT applications to obtain & process a variety of information & data	use a range of ICT to support & enhance practice	use a range of ICT to support & enhance the effectiveness of practice	use a wide range of ICT to support & enhance the effectiveness of practice	use a wide range of ICT to support & enhance the effectiveness of practice & specify software requirements to enhance work

4. Generic behaviours, knowledge & skills for interacting

HELPING OTHERS LEARN & DEVELOP						
Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
The process of working with individuals &/or groups to create activities & opportunities to promote learning & development. *Helping others learn & develop* describes the behaviour, knowledge & skills required to: • assess the learner's needs & preferences • design materials/ experiences that facilitate learning & development • deliver materials/ experiences that facilitate learning • evaluate the effectiveness of the learning & development experience [continued overleaf]	with guidance, deliver pre-planned learning activities to specified individuals/groups	with guidance & support, plan & deliver learning activities to a specified range of individuals/groups	with guidance, plan & deliver learning activities to a specified range of individuals/groups	with guidance, design, plan & deliver learning sessions of activities & opportunities to a range of audiences with similar levels of knowledge & expertise	design, plan & deliver learning activities & opportunities to a range of audiences with different levels of knowledge & expertise	design, plan & deliver learning activities & opportunities to a wide range of audiences with different levels of knowledge & expertise
	with guidance, apply standard approaches to learning & teaching (techniques & material) to meet specific learning outcomes	with guidance, apply a range of standard approaches to learning & teaching (techniques & material) to meet specific learning outcomes	apply appropriate approaches to learning & teaching (techniques & material) to meet learners' needs	select & apply appropriate approaches to learning & teaching (techniques & material) to meet learners' needs	select & apply appropriate approaches to learning & teaching (techniques & material) to meet learners' needs & promote a change in practice	develop & apply innovative approaches to learning & teaching (techniques & material) to meet learners' needs & promote a change in practice
	with guidance, use a basic evaluation tool to assess a learner's performance	with guidance, use a standardised evaluation tool to assess a learner's performance & provide them with appropriate feedback.	with guidance, predetermined criteria to assess a learner's performance & progress & provide them with appropriate feedback	use predetermined criteria to assess a learner's performance & progress, & provide them with constructive feedback	select & apply appropriate assessment tools to evaluate a learner's performance & progress, & provide them with constructive feedback	develop & apply innovative approaches to assess a learner's performance & progress, & provide them with constructive feedback

HELPING OTHERS LEARN & DEVELOP continued						
Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
• reflect on the learning & development process	with guidance & support, identify strengths & weaknesses of learning & teaching performance, & use this information to inform future practice.	with guidance & support, reflect on learning & teaching performance & use this evaluation to inform future practice	with guidance, reflect on learning & teaching performance & use this evaluation to inform future practice.	reflect on learning & teaching performance & use this evaluation to inform future practice.	critically reflect on learning & teaching performance & use this evaluation to inform future practice.	critically reflect on learning & teaching performance & use this evaluation to inform future practice (self & others)

4. Generic behaviours, knowledge & skills for interacting

						MANAGING SELF & OTHERS
Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
The process of planning, prioritising, organising, directing/facilitating action & evaluating performance. This process may involve the organisation of financial, human, physical & technological resources. *Managing self & others* describes the behaviour, knowledge & skills required to: • plan, prioritise & organise personal workload/activities & use of resources to fulfil work requirements & commitments • adapt personal behaviour & actions in response to the demands of the situation [continued overleaf]	take responsibility for carrying out tasks delegated by others	take responsibility for carrying out a range of delegated activities with in-direct supervision	exercise autonomy & initiative in accordance with current professional codes & practices seeking guidance where appropriate	exercise autonomy & initiative in accordance with current professional codes & practices	exercise substantial autonomy & initiative in complex & unpredictable situations at the limits of current professional codes & practices	exercise a high level of autonomy & initiative in complex & unpredictable situations not addressed by current professional codes & practices
	work alone or with others on tasks with supervision & manage limited resources within delegated areas of work	take some supervisory responsibility for the work of others & manage limited resources within delegated areas of work	take some responsibility for the work of others (e.g. delegation of tasks to support workers) & for a range of resources	take significant responsibility for the work of others (e.g. support workers, students) & for a range of resources	take managerial responsibility for the work of others & for a significant range of resources	take significant managerial responsibility for the work of others & /or for a significant range of resources
	with guidance, modify personal behaviour & actions in response to feedback to meet the demands of the situation	with guidance, modify personal behaviour & actions in response to feedback to meet the demands of the situation & to enhance own performance	modify personal behaviour & actions in response to feedback to meet the demands of the situation & to enhance own performance	becoming increasingly self-aware & able to modify personal behaviour & actions to meet the demands of the situation & to enhance own performance	modify personal behaviour & actions to meet the demands of the situation & to enhance own & others' performance	modify personal behaviour & actions 'in-action' to meet the demands of the situation & to maximise the impact of own & others' performance

MANAGING SELF & OTHERS continued

Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
• evaluate the effectiveness of performance (own & others) • lead & inspire others	with guidance & support, identify strengths & weaknesses of personal performance, & use this information to inform future practice	with guidance & support, reflect on personal performance & use this evaluation to inform future practice	with guidance, reflect on personal performance & use this evaluation to inform future practice	reflect on personal performance & use this evaluation to inform future practice	critically reflect on own & others' performance & use this evaluation to inform future practice	critically reflect on own & others' performance & use this evaluation to inform future practice (own & others)
	take the lead in implementing specified tasks in familiar or defined contexts	take the lead in implementing agreed plans in familiar or defined contexts	take the lead in implementing agreed plans designed to bring about change, development & /or new thinking in complex but predictable contexts	exercise leadership & /or initiative to bring about change, development & /or new thinking in complex & increasingly unpredictable contexts	exercise leadership with responsibility for decision making designed to bring about change & development within complex & unpredictable contexts	exercise leadership with accountability for decision making & development across a range of contexts, including those within which there is a high degree of uncertainty & a need to take innovative approaches to service delivery & development

4. Generic behaviours, knowledge & skills for interacting

PROMOTING INTEGRATION & TEAMWORK

Domain descriptors	Support	advanced support	entry-level graduate	experienced graduate	advanced	expert
The process of working with others to achieve shared goals. *Promoting integration & teamwork* describes the behaviour, knowledge & skills required to: • build, maintain & promote effective interpersonal relationships • work collaboratively with others to achieve shared goals • work with others to maintain & develop the effective performance of teams/networks	join appropriate professional networks to foster collaboration, share information & ideas to enhance practice	participate in & promote professional networks to foster collaboration, share information & ideas to enhance practice	participate in & develop professional networks to foster collaboration, share information & ideas to enhance practice	support & develop professional/ policy networks to foster collaboration, share information & ideas to enhance practice	support, lead & develop local/ regional professional & policy networks to foster collaboration, share information & ideas to enhance practice	support, lead & develop regional/ national professional & policy networks to foster collaboration, share information & ideas to enhance practice
	work effectively with others to complete specific delegated tasks	work effectively with others to meet the requirements of their delegated areas of work	work effectively with others to meet the responsibilities of professional practice	work effectively with others to meet the responsibilities of professional practice, & to identify situations where collaborative approaches could add value to practice	work effectively with others to meet the responsibilities of professional practice, & to develop collaborative approaches that add value to practice	work effectively with others to meet the responsibilities of professional practice, & use innovative collaborative approaches that add value to & develop practice
	with guidance & support, identify enablers of & barriers to collaborative working, & use this information to support the effective performance of teams/networks	with guidance, identify enablers of & barriers to collaborative working, & use this information to identify solutions to support & maintain the effective performance of teams/networks	reflect on experiences of collaborative working, & with guidance, use this information to identify solutions to maintain & develop the effective performance of teams/networks	reflect on experiences of collaborative working, & use this information to identify & implement solutions to maintain & develop the effective performance of teams/networks	critically reflect on experiences of collaborative working & use this information to identify & implement creative solutions to maintain & develop the effective & efficient performance of teams/networks	critically reflect on experiences of collaborative working & use this information to identify & implement innovative solutions to maintain & develop the effective & efficient performance of teams/networks

4. Generic behaviours, knowledge & skills for interacting

PUTTING THE PERSON AT THE CENTRE OF PRACTICE						
Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
The process of developing an understanding of an individual & their lived experience, & using that understanding to tailor practice to the needs of that person *Putting the person at the centre of practice* describes the behaviour, knowledge & skills required to: • demonstrate respect for the individual • provide information & support that enables an individual to make informed choices • involve individuals in shaping the design & delivery of their service	demonstrate respect for the individual by acknowledging their unique needs, preferences, & values, autonomy & independence in accordance with legislation, policies, procedures & best practice	demonstrate respect for the individual by acknowledging their unique needs, preferences & values, autonomy & independence in accordance with legislation, policies, procedures & best practice	demonstrate respect for the individual by acknowledging their unique needs, preferences & values, autonomy & independence in accordance with legislation, policies, procedures & best practice	demonstrate respect for the individual by acknowledging their unique needs, preferences & values, autonomy & independence in accordance with legislation, policies, & procedures, & by working to promote best practice	demonstrate respect for the individual by acknowledging their unique needs, preferences & values, autonomy & independence in accordance with legislation, policies, procedures, & by working to inform & promote legislation, policies, procedures & best practice	demonstrate respect for the individual by acknowledging their unique needs, preferences & values, autonomy & independence in accordance with legislation, policies, procedures, & by working to inform, develop & promote legislation, policies, procedures & best practice

PUTTING THE PERSON AT THE CENTRE OF PRACTICE continued						
Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
	provide information that empowers an individual to make an informed choice & to exercise their autonomy in accordance with legislation, policies, procedures & best practice	provide information that empowers an individual to make an informed choice & to exercise their autonomy in accordance with legislation, policies, procedures & best practice	provide information & support that empowers an individual to make an informed choice & to exercise their autonomy in accordance with legislation, policies, procedures & best practice	provide information & support that empowers an individual to make an informed choice & to exercise their autonomy in accordance with legislation, policies & procedures, & work to promote best practice	provide info. & support that empowers an individual to make an informed choice & to exercise their autonomy in accordance with legislation, policies, procedures, & work to inform & promote legislation, policies, procedures & best practice	provide info. & support that empowers an individual to make an informed choice & to exercise their autonomy in accordance with legislation, policies, procedures, & work to inform, develop & promote legislation, policies, procedures & best practice
	with guidance & support, involve individuals in shaping the design & delivery of their service by working in accordance with policies & processes that promote a culture of service user involvement	with guidance, involve individuals in shaping the design & delivery of their service by working in accordance with policies & processes that promote a culture of service user involvement	involve individuals in shaping the design & delivery of their service by working in accordance with policies & processes that promote a culture of service user involvement	involve individuals in shaping the design & delivery of their service, & work with others to implement & support policies & processes that promote a culture of service user involvement	involve individuals in shaping the design & delivery of their service, & work with others to critically appraise user involvement, & to develop & implement policies, & processes that promote a culture of service user involvement	actively involve individuals in shaping the design & delivery of their service, & work with others to critically appraise user involvement, & to develop policies & processes that promote a culture of service user involvement that contribute to the development of best practice

4. Generic behaviours, knowledge & skills for interacting

RESPECTING & PROMOTING DIVERSITY						
Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
The process of recognising, respecting & valuing people's differences (e.g. age, disability, gender, race, religion & belief, sexuality) & applying this to daily work & decision making *Respecting & promoting diversity* describes the behaviour, knowledge & skills required to: • respect & value diversity • examine own values & principles to avoid discriminatory behaviour & to minimise the potential negative effects of individual differences • work constructively with people of all backgrounds & orientations [continued overleaf]	respect & value diversity by working in accordance with legislation, policies, procedures & best practice	respect & value diversity by working in accordance with legislation, policies, procedures & best practice	respect & value diversity by working in accordance with legislation, policies, procedures & best practice	respect & value diversity by working in accordance with legislation, policies, procedures, & to promote best practice	respect & value diversity by working to inform & promote legislation, policies, procedures & best practice	respect & value diversity by working to inform, develop & promote legislation, policies, procedures & best practice
	with guidance & support, identify & articulate their own values & principles, acknowledge how these may differ from other individuals/groups & with guidance, use this knowledge to maintain standards of practice even in situations of personal incompatibility	with guidance, identify & articulate their own values & principles & recognise how these may differ from other individuals/groups & with guidance use this understanding to maintain standards of practice even in situations of personal incompatibility	identify & articulate their own values & principles, & with guidance, evaluate how these may differ from other individuals/groups & use this understanding to maintain high standards of practice even in situations of personal incompatibility	identify & articulate their own values & principles, evaluate how these may differ from other individuals/groups & use this understanding to maintain high standards of practice even in situations of personal incompatibility	identify & articulate their own values & principles, critically evaluate how these may differ from other individuals/groups & use this understanding to maintain high standards of practice even in situations of personal incompatibility	identify & articulate their own values & principles, critically evaluate how these may differ from other individuals/groups & use this understanding to maintain excellent standards of practice even in situations of personal incompatibility

RESPECTING & PROMOTING DIVERSITY continued

Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
	work constructively with people of all backgrounds & orientations by treating individuals with dignity & respect	work constructively with people of all backgrounds & orientations by recognising & respecting individuals' expressed beliefs, preferences & choices	work constructively with people of all backgrounds & orientations by recognising & responding to individuals' expressed beliefs, preferences & choices.	work constructively with people of all backgrounds & orientations by recognising & responding to individuals' expressed beliefs, preferences & choices, & with guidance, support individuals who need assistance in exercising their rights	work constructively with people of all backgrounds & orientations by recognising & responding to individuals' expressed beliefs, preferences & choices, & support individuals who need assistance in exercising their rights	work constructively with people of all backgrounds & orientations by recognising & responding to individuals' expressed beliefs, preferences & choices, & support individuals whose rights have been compromised
	identify & report practice that discriminates against an individual or group of people	identify discriminatory behaviour & with guidance, take appropriate action to challenge this behaviour	identify discriminatory behaviour & take appropriate action to challenge this behaviour	identify & challenge discriminatory practices & work with others to implement & promote policies & processes that promote a non-discriminatory culture	identify & challenge discriminatory practices & work with others to critically appraise current practice, & to develop & implement policies & processes that promote a non-discriminatory culture	identify & actively challenge discriminatory practices & work with others to critically appraise current practice, & to develop policies & processes that promote a non-discriminatory culture that contribute to the development of best practice

4. Generic behaviours, knowledge & skills for problem-solving & decision making

ENSURING QUALITY						
Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
The process of maintaining the effectiveness, efficiency & quality of a service provided. *Ensuring quality* describes the behaviour, knowledge & skills required to: • fulfil the requirements of the legal & policy frameworks governing practice • recognise situations where the effectiveness, efficiency & quality of a service are compromised, & take appropriate action • critically reflect on practice	with guidance, fulfil the requirements of the legal & policy frameworks governing their practice	fulfil the requirements of the legal & policy frameworks governing their practice	fulfil the requirements of the legal & policy frameworks governing professional practice	fulfil the requirements of the legal & policy frameworks governing professional practice, & work to promote best practice	fulfil the requirements of the legal & policy frameworks governing professional practice, & work to inform & promote legislation, policies, procedures & best practice	fulfil the requirements of the legal & policy frameworks governing professional practice, & work to inform, develop & promote legislation, policies, procedures & best practice
	with guidance & support, recognise & report situations where the effectiveness, efficiency & quality of a service are compromised	with guidance, recognise & report situations where the effectiveness, efficiency & quality of a service are compromised	with guidance, recognise situations where the effectiveness, efficiency & quality of a service are compromised, & with support, take appropriate action to challenge the situation	recognise situations where the effectiveness, efficiency & quality of a service are compromised, & with guidance, take appropriate action to challenge the situation	recognise & critically appraise situations where the effectiveness, efficiency & quality of a service are compromised, & take appropriate action to resolve the situation	recognise & critically appraise situations where the effectiveness, efficiency & quality of a service are compromised, & take appropriate action to resolve the situation & contribute to best practice
	with guidance, identify strengths & weaknesses of personal performance, & with support, use this information to enhance the effectiveness, efficiency & quality of future practice.	with guidance, reflect on personal performance & with support, use this evaluation to enhance the effectiveness, efficiency & quality of future practice.	with guidance, reflect on personal performance & use this evaluation to enhance the effectiveness, efficiency & quality of future practice.	reflect on personal performance & with guidance, use this evaluation to enhance the effectiveness, efficiency & quality of future practice.	critically reflect on own & others' performance & use this evaluation to enhance the effectiveness, efficiency & quality of future practice.	critically reflect on own & others' performance & use this evaluation to enhance the effectiveness, efficiency & quality of future practice (own & others).

CHARTERED SOCIETY OF PHYSIOTHERAPY

4. Generic behaviours, knowledge & skills for problem-solving & decision making

IMPROVING & DEVELOPING SERVICES

Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
The process of improving the effectiveness, efficiency & quality of the service provided. *Improving & developing services* describes the behaviour, knowledge & skills required to: • critically evaluate practice & use this appraisal to inform service improvement, development & redesign • develop innovative & sustainable recommendations to improve the quality of service • plan, facilitate & manage change • critically evaluate the process & outcome [continued overleaf]	with guidance & support, use a basic tool to evaluate practice & share the outcome of this appraisal with relevant personnel	with guidance, use a standardised tool to evaluate practice & share the outcome of this appraisal with relevant personnel	with guidance, critically evaluate practice, & share the outcome of this appraisal with relevant personnel	critically evaluate practice, & with guidance, use this appraisal in combination with knowledge of best practice & political awareness to inform service improvement	critically evaluate practice & use this appraisal in combination with knowledge of best practice & political awareness to identify opportunities for service improvement & development	critically evaluate practice & use this appraisal in combination with knowledge of best practice & political awareness to identify opportunities for service improvement, development & redesign
	with guidance & support use a problem-solving approach to develop safe & effective recommendations for improving the quality of an area of routine practice in a predictable context	with guidance, use a problem-solving approach to develop safe, effective & efficient recommendations for improving the quality of an area of routine but normally specialised practice in predictable contexts	use a problem-solving approach to develop safe & effective recommendations for improving the quality of professional practice in predictable contexts	use problem-solving approaches to develop safe, effective & efficient recommendations for improving the quality of professional practice in increasingly unpredictable contexts	use problem-solving approaches to develop original, safe, effective & efficient recommendations for improving the quality of professional practice in unpredictable contexts	use problem-solving approaches to develop original, effective & efficient recommendations that demonstrate evidence of positive risk taking, for improving the quality of professional practice in unpredictable & normally specialised contexts

CSP(2011) Physiotherapy Framework: putting physiotherapy behaviours, values, knowledge & skills into practice [updated May 2020]

IMPROVING & DEVELOPING SERVICES continued

Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
	support change & development within their specific area of practice	support change & development within the profession or service at a local level	contribute to change & development within the profession or service at a local level	contribute to change & development within the profession or service at a local or regional level	make an identifiable contribution to change & development within the profession or service at a regional or national level	make an identifiable contribution to change & development within the profession or service & beyond – at a national or international level
	with guidance & support, identify strengths & weaknesses of the change process & use this information to appraise the outcome & inform future practice	with guidance & support, reflect on the change process & use this information to appraise the outcome & inform future practice	with guidance, reflect on the change process, & use this information to appraise the outcome & inform future practice	reflect on the change process, & use this information to appraise the outcome & inform future practice	critically reflect on the change process, & use this information to appraise the outcome & inform future practice	critically reflect on the change process, & use this information to appraise the outcome & inform future practice

4. Generic behaviours, knowledge & skills for problem-solving & decision making

LIFELONG LEARNING

Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
The process of learning & development directed towards maintenance & enhancement of professional competence *Lifelong learning* describes the behaviour, knowledge & skills required to: • assess personal learning & development needs & preferences • develop & engage in a personalised plan designed to meet those needs • reflect on the learning process • document process	developing self-awareness of learning preferences, & with guidance & support can identify personal learning & development needs	demonstrate self-awareness of learning preferences, & with guidance & support can identify personal learning & development needs	demonstrate self-awareness of learning preferences, & with guidance can identify personal learning & development needs.	demonstrate increasing self-awareness of learning preferences, & with guidance can identify personal learning & development needs	demonstrate strong self-awareness of learning preferences, & with minimal guidance can identify personal learning & development needs	demonstrate strong self-awareness of learning preferences, & can independently identify personal learning & development needs
	with guidance & support, advance personal knowledge & skills in line with identified learning needs, by making use of a variety of learning & development resources & opportunities	with guidance, advance personal knowledge, understanding & skills in line with identified learning needs, by making use of a variety of learning & development resources & opportunities	independently advance personal knowledge, understanding & skills in line with identified learning needs, & with guidance & support, can use a variety of learning & development resources & opportunities	independently advance personal knowledge, understanding & skills in line with identified learning needs, & with guidance, can use a variety of learning & development resources & opportunities	independently advance personal knowledge, understanding & skills in line with identified learning needs by making appropriate use of a variety of learning & development resources & opportunities	independently advance personal knowledge, understanding & skills in line with identified learning needs by making appropriate use of a wide variety of learning & development resources & opportunities

LIFELONG LEARNING continued

Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
	with guidance & support, identify enablers of & barriers to personal learning & development, & use this information to inform the planning & management of future learning & development experiences	with guidance, identify enablers of & barriers to personal learning & development, & use this information to inform the planning & management of future learning & development experiences.	reflect on personal learning & development, & with guidance & support, use this information to inform the planning & management of future learning & development experiences	reflect on personal learning & development, & with guidance, use this information to inform the planning & management of future learning & development experiences	critically reflect on personal learning & development, & with guidance, use this information to inform the planning & management of future learning & development experiences	critically reflect on personal learning & development & use this information to inform the planning & management of future learning & development experiences
	with guidance & support, record the outcome of personal learning & development in a format that meets personal preferences & organisational requirements	with guidance & support, record the outcome of personal learning & development in a format that meets personal preferences & organisational requirements	with guidance, record the outcome of personal learning & development in a format that meets personal preferences & professional requirements	record the outcome of personal learning & development in a format that meets personal preferences & professional requirements	select & apply appropriate approaches to record the outcome of personal learning & development in a format that meets personal preferences & professional requirements	develop & apply innovative approaches to record the outcome of personal learning & development in a format that meets personal preferences & professional requirements

4. Generic behaviours, knowledge & skills for problem-solving & decision making

						PRACTICE DECISION MAKING
Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
The context-dependent thinking & decision making processes used in professional practice to guide practice actions *Practice decision making* describes the behaviour, knowledge & skills required to: • collect information from a variety of sources relevant to the decision making situation • process & analyse the information collected • draw reasoned conclusions & make informed judgements to address issues/resolve problems in practice • critically evaluate the decision making process.	efficient & effective use of a range of routine approaches & techniques to systematically collect information from a specified set of sources	efficient & effective use of a wide range of routine approaches & techniques to systematically collect information from a specified set of sources	efficient & effective use of a wide range of routine & some specialised approaches & techniques to systematically collect information from a variety of sources relevant to the situation	efficient & effective use of a wide range of routine & advanced approaches & techniques to systematically collect information from a variety of sources relevant to the situation	efficient & effective use of a range of advanced & specialised approaches & techniques to systematically collect information from a variety of sources relevant to the situation	efficient & effective use of a broad range of advanced & specialised approaches & techniques to systematically collect information from a wide variety of sources relevant to the situation
	process & interpret information in predictable & straightforward situations where data/information comes from a specified set of sources	process & analyse information in predictable & normally specialised situations where data/information comes from a specified set of sources	process & critically analyse information in complex & predictable situations where data/information comes from a range of sources or is incomplete	process & critically analyse information in complex & unpredictable situations where data/information comes from a range of sources or is incomplete	process & critically analyse information in complex & unpredictable situations where data/information is incomplete or consistent	process & critically analyse information in complex, unpredictable & normally specialised situations where data/information is incomplete or inconsistent

PRACTICE DECISION MAKING continued

Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
	draw reasoned conclusions & make informed judgements supported by factual information to address issues arising in practice in predictable & straightforward situations	draw reasoned conclusions & make informed judgements supported by factual & theoretical information to address issues arising in practice in predictable & normally specialised situations	draw reasoned conclusions, supported by current policy & evidence-based thinking, & make informed judgements to address ethical & professional issues in complex & predictable situations	draw reasoned conclusions, supported by current policy & evidence-based thinking, & make informed judgements to address ethical & professional issues in complex & unpredictable situations	draw reasoned conclusions, supported by current policy & evidence-based thinking, & make informed judgements to address ethical & professional issues in complex & unpredictable situations at the limits of current professional codes & practices	draw reasoned conclusions, supported by current policy & evidence-based thinking, & make informed judgements to address ethical & professional issues in complex & unpredictable situations not addressed by current professional codes & practice
	with guidance & support, identify strengths & weaknesses of the decision making process, & use this information to appraise the outcome	with guidance & support, reflect on their decision making process & use this evaluation to appraise the outcome & to inform future practice	with guidance, reflect on their decision making process & use this evaluation to appraise the outcome & to inform future practice	reflect on their decision making process & use this evaluation to appraise the outcome & to inform future practice	critically reflect on their decision making process & use this evaluation to appraise the outcome & to inform future practice	critically reflect on their decision making process & use this evaluation to appraise the outcome & to inform future practice

4. Generic behaviours, knowledge & skills for problem-solving & decision making

RESEARCHING & EVALUATING PRACTICE						
Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
Systematic processes of collecting, analysing, & synthesising information to evaluate current practice & generate new understandings about practice	with guidance & support, plan, conduct & manage a project to evaluate a specific aspect of practice	with guidance, plan, conduct & manage a project to evaluate specific aspects of practice	with guidance, plan, conduct & manage evaluation & research projects to address a specific issue arising from practice	plan, conduct & manage evaluation & research projects to address specific issues arising from practice	design, plan, conduct & manage evaluation & research projects to address problems & issues arising from practice	design, plan, conduct & manage evaluation & research projects to address new problems & issues arising from practice.
Researching & evaluating practice describes the behaviour, knowledge & skills required to: • design, plan, conduct & manage the research/ evaluation process • use methods of enquiry to collect & interpret data in order to address problems or issues arising from practice [descriptors cont overleaf]	with guidance, apply a range of standard tools of enquiry showing an awareness of related ethical considerations	apply a range of standard tools of enquiry showing an awareness of related ethical considerations	with guidance, apply a range of standard research methods/tools of enquiry showing an appreciation of related ethical considerations	becoming increasingly confident to apply a range of standard research methods/tools of enquiry showing an appreciation of related ethical considerations.	apply a range of standard & specialised research methods/tools of enquiry showing a detailed understanding of related ethical considerations	apply a range of standard & specialised research methods/tools of enquiry, contributing to the development of new techniques or approaches, & showing a detailed understanding of related ethical considerations

RESEARCHING & EVALUATING PRACTICE continued

Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
• critically evaluate the research/ evaluation process • communicate the outcome of the research/evaluation process *Research* is defined as a study or investigation undertaken based on a systematic understanding & critical awareness of knowledge which generates new knowledge. *Evaluation* is defined as the systematic process of using specific standards/criteria to make reasoned judgements about the quality of something/someone.	with guidance & support, identify strengths & weaknesses of the research process & use this information to appraise the project	with guidance & support, reflect on the research process & use this information to appraise the project & inform future practice.	with guidance, reflect on the research process, & use this information to appraise the project & inform future practice	reflect on the research process, & use this information to appraise the project & inform future practice	critically reflect on the research process, & use this information to appraise the project & inform future practice.	critically reflect on the research process, & use this information to appraise the project & inform future practice.
	with guidance & support, identify the practical & professional applications of completed work.	with guidance, identify & promote the practical & professional applications of completed work.	identify, & with support, promote the practical & professional applications of completed work, & seek opportunities to share & disseminate findings to both specialist & non-specialist audiences.	identify & promote the practical & professional applications of completed work, & seek opportunities to share & disseminate findings to both specialist & non-specialist audiences.	identify & promote the practical & professional applications of completed work, & actively seek opportunities to share & disseminate findings to a range of audiences with different levels of knowledge & expertise.	identify & promote the practical & professional applications of completed work, & actively create opportunities to share & disseminate findings to a wide range of audiences with different levels of knowledge & expertise.

4. Generic behaviours, knowledge & skills for problem-solving & decision making

USING EVIDENCE TO LEAD PRACTICE						
Domain descriptors	support	advanced support	entry-level graduate	experienced graduate	advanced	expert
The process of analysing, synthesising & evaluating the best-available evidence, & integrating it with individual expertise & service users' needs & preferences to inform practice *Using evidence to lead practice* describes the behaviour, knowledge & skills required to: • systematically search for evidence • critically appraise evidence & use the information to address problems & issues arising in practice	with guidance & support, use of a range of routine approaches & techniques to systematically search for information from a specified set of sources	with guidance, use a range of routine approaches & techniques to systematically search for information from a specified set of sources	with guidance, use a range of approaches & techniques to systematically search for evidence from a variety of sources relevant to the situation	use a range of approaches & techniques to systematically search for evidence from a variety of sources relevant to the situation	efficient & effective use of a range of approaches & techniques to systematically collect information from a variety of sources relevant to the situation	efficient & effective use of a broad range of approaches & techniques to systematically search for information from a wide variety of sources relevant to the situation
	with guidance, use a basic tool to evaluate information collected, & with guidance & support, use the appraisal to address a specific issue arising from practice	with guidance, use a standardised tool to evaluate information collected, & with guidance, use the appraisal to address a specific issue arising in practice	critically evaluate current research & scholarship & with guidance, use the appraisal to address specific issues arising in professional practice	critically evaluate current research & scholarship & use the appraisal to address specific issues arising in professional practice	critically evaluate current research & scholarship & use the appraisal to address issues which are at the forefront or informed by developments at the forefront of professional practice	critically evaluate current research & scholarship & use the appraisal to address new problems & issues arising in professional practice

Implementation of GAIN Guidelines in BHSCT Physiotherapy Service 2014

Background: The Guidelines and Audit Implementation Network GAIN have published guidelines to ensure that people with Learning Disability are cared for in the appropriate manner in hospital settings. The following information lays out a framework to demonstrate how this will be delivered within the BHSCT Physiotherapy Service. **The Learning Disability Team** provides a hospital based service in Muckamore Abbey Hospital and a Trust wide community service which provides a domiciliary service and an in reach service to Day Centres and other residential Facilities across the Trust. The Learning Disability Team at all times act in an advocacy role for people with a Learning Disability. The Senior Staff on the team are:

- **Gillian Bingham, Clinical Specialist, Telephone: 02890638933**
- **work mobile 07557208163**
- **Alison Buchanan, Band 6 North and West Belfast, based in Carlisle HWBC Telephone 02895042376, work mobile: 07788694402**
- **Claire Wilson, Band 6 South and East Belfast based in Finaghy Health Centre, Telephone: 02895042693 work mobile 07917614131**
- **The service is also composed of 1 rotational Band 5 Physiotherapist, 2.0 Band 4 PT Assistants,1.0 Band 3 PT Assistant.**

- **The Specialist Aids and Appliances Service based In Muckamore is also part of the Physiotherapy LD Team, the number for this service is 90638932**

ATTITUDES and VALUES **Best practice means that: Physiotherapy staff should make sure that they offer people with a learning disability the same range and level of care and treatment as they would offer anyone else. staff should:**	
• see the person not their disability • make sure that they communicate with the person in a way that is appropriate and sensitive to what the person needs and prefers • involve people with learning disabilities in decisions, and understand the law around capacity and consent	**• involve carers and advocates (people who can speak for the person) when appropriate • deliver care that focuses on the needs of the person • get training on learning disability • deliver dignified, respectful and compassionate Care • not make judgements about people.**

Gain Recommendation	Service Implementation	Gain Recommendation	Service Implementation
Outpatients		**Inpatient**	
The hospital should invite the person with a learning disability or their carer to contact the outpatient department staff before the first outpatient appointment in order to find out • how well the person can communicate • what physical care needs they have • how they can help if the person becomes distressed. The service should provide clear information. This should include contact details of staff who can help • Physiotherapy staff should explain to the person in plain language what will happen during the appointment. • Physiotherapy staff should monitor the person’s level of comfort, anxiety and understanding of what	1. All Physiotherapy referrals are allocated to the most appropriate service to meet patient/client clinical needs 2. Appointment notification letter to a person with a Learning Disability should include a request that the person brings their Health Passport to the first appointment 3. Information sent to a person with a Learning Disability should be bespoke information leaflets about the service they are due to attend 4. A double slot should be allocated to a person with a Learning Disability at their first appointment where at all possible with consideration given to the requirement for optimal environmental conditions	• Carers should be given the opportunity to inform inpatient staff about the person’s needs • Staff in the local Physiotherapy Learning Disability Team should also help inpatient staff to understand the needs of the person • Inpatient staff should adapt behaviours and attitudes that facilitate this • Inpatient staff should always care for the patient in a way that respects their dignity and privacy. • The offer of support from the person’s carer should be facilitated where this could improve quality of life	1. Inpatient staff should avail of every opportunity to acquire information regarding a person with a Learning Disability in a relevant and timely manner 2. Inpatient staff should request and avail of the information contained in the patient Health passport 3. In patient staff should contact the Physiotherapy Learning Disability Team in order to seek clarity about any clinical management 4. Ongoing communication between acute and LD teams should be maintained during hospital stay regarding intervention and progress 5. Inpatient Staff should ensure that onward timely referral is undertaken for a person with a Learning Disability 6. On discharge Inpatient staff should liaise with LD Team regarding discharge care and arrangements. 7. Consideration should be given to the expert knowledge of the carer

is happening. • At the end of the appointment hospital staff should clearly explain what will happen next. • They should also contact the local Physiotherapy Learning Disability • Do not assume that the person is refusing to cooperate; this may be due to a number of factors e.g. pain, lack of familiarisation • All staff should be aware of their training requirement in respect to Learning Disability awareness, Disability Discrimination and Seeking consent ,	5. The Physiotherapy LD Team should be contacted for advice regarding intervention and management if required 6. A leaflet with details of Physiotherapy LD service should be available in all departments 7. Staff should liaise and avail of the expertise of the Physiotherapy Learning Disability Team 8. Staff should access available training		

Standards of proficiency

Dietitians

health professions council

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038/SOP/DT/A5 July 2003

health professions council

contents

foreword

> **“...to become the best organised, best managed and strongest health professional regulatory body in the United Kingdom, the Council must work together with its stakeholders.**

I am delighted to present the Health Professions Council's Standards of Proficiency to you. The standards in this document are a vital tool for the Council as it seeks to protect the public by ensuring that its registrants are safe and effective in their practice.

I have often said that to become the best organised, best managed and strongest health professional regulatory body in the United Kingdom, the Council must work together with its stakeholders. This document is an example of why this approach is so important: several rounds of consultation with experts from across the health professions went into the detailed and lengthy process of development of these standards. The consultation produced extremely valuable feedback that has undoubtedly improved the standards greatly. Of course, the standards remain the responsibility of the Health Professions Council, and if you have any questions, concerns or comments about what you read here, you should contact the Council.

As with other documents that the Council has produced, the standards are written in clear, modern English, so that registrants and prospective registrants can easily find out what is expected of them.

Professor Norma Brook
President, The Health Professions Council

introduction

This document sets out the **standards of proficiency** for safe and effective practice that we expect registrants to meet. We also expect registrants to keep to our **standards of conduct, performance and ethics**, which are published in a separate document.

The standards of proficiency in this document include both generic elements, which all our registrants must meet, and profession-specific elements, which are relevant to registrants belonging to one of the 12 professions we currently regulate. There is no other difference between the generic and profession-specific elements of the standards, and we will treat any breach of the standards seriously. The generic standards are written in black, and the profession-specific standards are written in blue italics, to help you distinguish between them. The summary standards are all generic and are therefore all written in black.

The generic standards explain the key obligations that we expect of you. Occasionally, we have pointed out specific elements of those key obligations. We have **not** attempted to create exhaustive lists of all the areas that each generic standard covers; we have simply highlighted specific elements where we think this will help you to understand what we require of you.

For instance, we have highlighted the fact that the key obligation of maintaining your fitness to practise also includes a specific obligation about taking care of yourself.

If you are a student, you may only have practised under supervision and not independently. Nonetheless, you must be confident that you will be able to meet these standards when you begin to practise without supervision. Sometimes the standards relate to ongoing practice and normally your clinical placements will have given you the opportunity to demonstrate that you are capable of meeting these.

A note about our expectations of you

The standards of proficiency play a central role in how you can gain admission to, and remain on, the Register and thereby gain the right to use the protected title(s) of your profession. Therefore we expect you to be able to meet these standards.

We do recognise, though, that your practice will develop over time and that the practice of experienced registrants frequently becomes more focused and specialised than that of newly registered colleagues, because it relates to a particular client group, practice environment, employment sector or occupational role. Your particular scope of practice may mean that you are unable to demonstrate that you continue to meet each of the standards that apply for your profession. For instance, if you work with adults alone, then any standards that relate to how you must work with children will not apply to your day-to-day work. So long as you stay within your scope of practice and make reasonable efforts to stay up to date with the whole of these standards, this will not be problematic. However, if you want to move outside your scope of practice, you must be certain that you are capable of working safely and effectively, including undertaking any necessary training and experience. We can and will investigate if we have good reasons for believing that you might not meet the standards.

These standards may change in the future (but not for the next two years)

We keep these standards under continual review, and we will update them to take into account changes in practice in the professions we regulate. So the version that you have now may not be the same as future versions that you may see. We will highlight all the changes we make to the standards, so you will be able to see what has changed. However, we will try not to make any changes to the standards during the transitional period during which grandparenting can take place. The transitional period lasts for two years from the date that the register opens. We will always publicise any changes to the standards that we make by, for instance, publishing notices on our website and informing professional bodies.

summary of standards

Expectations of a health professional

1a: Professional autonomy and accountability

Registrants must:

1a.1 be able to practise within the legal and ethical boundaries of their profession

1a.2 be able to practise in a non-discriminatory manner

1a.3 be able to maintain confidentiality and obtain informed consent

1a.4 be able to exercise a professional duty of care

1a.5 know the limits of their practice and when to seek advice

1a.6 recognise the need for effective self-management of workload and be able to practise accordingly

1a.7 understand the obligation to maintain fitness to practise

1a.8 understand the need for career-long self-directed learning

1b: Professional relationships

Registrants must:

1b.1 know the professional and personal scope of their practice and be able to make referrals

1b.2 be able to work, where appropriate, in partnership with other professionals, support staff, patients, clients and users, and their relatives and carers

1b.3 be able to contribute effectively to work undertaken as part of a multi-disciplinary team

1b.4 be able to demonstrate effective and appropriate skills in communicating information, advice, instruction and professional opinion to colleagues, patients, clients, users, their relatives and carers

1b.5 understand the need for effective communication throughout the care of the patient, client or user

The skills required for the application of practice

2a: Identification and assessment of health and social care needs

Registrants must:

2a.1 be able to gather appropriate information

2a.2 be able to use appropriate assessment techniques

2a.3 be able to undertake or arrange clinical investigations as appropriate

2a.4 be able to analyse and evaluate the information collected

2b: Formulation and delivery of plans and strategies for meeting health and social care needs

Registrants must:

2b.1 be able to use research, reasoning and problem solving skills (and, in the case of clinical scientists, conduct fundamental research)

2b.2 be able to draw on appropriate knowledge and skills in order to make professional judgements

2b.3 be able to formulate specific and appropriate management plans including the setting of timescales

2b.4 be able to conduct appropriate diagnostic or monitoring procedures, treatment, therapy or other actions safely and skilfully

2b.5 be able to maintain records appropriately

2c: Critical evaluation of the impact of, or response to, the registrant's actions

Registrants must:

2c.1 be able to monitor and review the ongoing effectiveness of planned activity and modify it accordingly

2c.2 be able to audit, reflect on and review practice

Knowledge, understanding and skills

3a:

Registrants must:

3a.1 know the key concepts of the biological, physical, social, psychological and clinical sciences which are relevant to their profession-specific practice

3a.2 know how professional principles are expressed and translated into action through a number of different approaches to practice, and how to select or modify approaches to meet the needs of an individual

3a.3 understand the need to establish and maintain a safe practice environment

dietitians

Expectations of a health professional

1a: Professional autonomy and accountability

Registrant dietitians must:

1a.1 be able to practise within the legal and ethical boundaries of their profession
- understand what is required of them by the Health Professions Council
- understand the need to respect, and so far as possible uphold, the rights, dignity and autonomy of every patient including their role in the diagnostic and therapeutic process
- *understand the ethical and legal implications of withholding or withdrawing feeding*

1a.2 be able to practise in a non-discriminatory manner

1a.3 be able to maintain confidentiality and obtain informed consent

1a.4 be able to exercise a professional duty of care

1a.5 know the limits of their practice and when to seek advice
- be able to assess a situation, determine the nature and severity of the problem and call upon the required knowledge and experience to deal with the problem
- be able to initiate resolution of problems and be able to exercise personal initiative

1a.6 recognise the need for effective self-management of workload and be able to practise accordingly

1a.7 understand the obligation to maintain fitness to practise
- understand the importance of caring for themselves, including maintaining their health

1a.8 understand the need for career-long self-directed learning

1b: Professional relationships

Registrant dietitians must:

1b.1 know the professional and personal scope of their practice and be able to make referrals

1b.2 be able to work, where appropriate, with other professionals, support staff, patients, clients and users, and their relatives and carers

- understand the need to build and sustain professional relationships as both an independent practitioner and collaboratively as a member of a team
- understand the need to engage patients, clients, users and carers in planning and evaluating diagnostics, treatments and interventions to meet their needs and goals

1b.3 be able to contribute effectively to work undertaken as part of a multi-disciplinary team

1b.4 be able to demonstrate effective and appropriate skills in communicating information, advice, instruction and professional opinion to colleagues, patients, clients, users, their relatives and carers

- be able to communicate in English to the standard equivalent to level 7 of the International English Language Testing System, with no element below 6.5
- understand how communications skills affect the assessment of patients, clients and users, and how the means of communication should be modified to address potential barriers such as age, physical and learning disability
- be able to select, move between and use appropriate forms of verbal and non-verbal communication with patients, clients, users and others
- be aware of the characteristics and consequences of non-verbal communication and how this can be affected by culture, age, ethnicity, gender, religious beliefs and socio-economic status
- understand the need to provide patients, clients and users (or people acting on their behalf) with the information necessary to enable them to make informed decisions
- recognise that relationships with patients, clients and users should be based on mutual respect and trust, and be able to maintain high standards of care even in situations of personal incompatibility

1b.5 understand the need for effective communication throughout the care of the patient, client or user

- recognise the need to use interpersonal skills to encourage the active participation of patients, clients and users

The skills required for the application of practice

2a: Identification and assessment of health and social care needs

Registrant dietitians must:

2a.1 be able to gather appropriate information

2a.2 be able to use appropriate assessment techniques

- be able to undertake and record a thorough, sensitive and detailed assessment, using appropriate techniques and equipment
- *be able to choose, undertake and record the most appropriate method of dietary and nutritional assessment, using appropriate techniques and equipment*

2a.3 be able to undertake or arrange clinical investigations as appropriate

2a.4 be able to analyse and evaluate the information collected

- *be able to use nutritional analysis programmes to analyse food intake, records and recipes*

2b: Formulation and delivery of plans and strategies for meeting health and social care needs

Registrant dietitians must:

2b.1 be able to use research, reasoning and problem solving skills to determine appropriate actions

- recognise the value of research to the systematic evaluation of practice
- be able to conduct evidence-based practice, evaluate practice systematically, and participate in audit procedures
- be aware of methods commonly used in health care research
- be able to demonstrate a logical and systematic approach to problem solving
- be able to evaluate research and other evidence to inform their own practice
- *be able to use statistical, epidemiological and research skills to gather and interpret evidence in order to make reasoned conclusions and judgements with respect to dietetic practice*

2b.2 be able to draw on appropriate knowledge and skills in order to make professional judgements

- be able to change their practice as needed to take account of new developments
- demonstrate a level of skill in the use of information technology appropriate to their profession
- *be able to choose the most appropriate strategy to influence nutritional behaviour and choice*
- *be able to undertake and explain dietetic treatment, having regard to current knowledge and evidence-based practice*
- *be able to advise on safe procedures for food preparation, menu planning, manufacture and handling and be able to interpret food labels which may have nutritional or clinical implications*

2b.3 be able to formulate specific and appropriate management plans including the setting of timescales

- understand the requirement to adapt practice to meet the needs of different client groups distinguished by, for example, physical, psychological, environmental, cultural or socio-economic factors
- *understand the need to be sensitive to social, economic and cultural factors that affect diet, lifestyle and health*
- *understand the significance and potential impact of non-dietary factors when helping individuals to make informed choices about their dietary treatment and health care.*
- *be able to assist individuals and groups to undertake and to become committed to self-care activities including diet, exercise and other lifestyle adjustments*
- *understand the need to demonstrate sensitivity to the factors which shape individual food choice and lifestyle which may impact on the individual's health and affect the interaction between client and dietitian*

2b.4 be able to conduct appropriate diagnostic or monitoring procedures, treatment, therapy or other actions safely and skilfully

- understand the need to maintain the safety of both patients, clients and users, and those involved in their care

2b.5 be able to maintain records appropriately

- be able to keep accurate, legible records and recognise the need to handle these records and all other clinical information in accordance with applicable legislation, protocols and guidelines
- understand the need to use only accepted terminology (which includes abbreviations) in making clinical records

2c: Critical evaluation of the impact of, or response to, the registrant's actions

Registrant dietitians must:

2c.1 be able to monitor and review the ongoing effectiveness of planned activity and modify it accordingly

- be able to gather information, including qualitative and quantitative data, that helps to evaluate the responses of patients, clients and users to their care
- be able to evaluate management plans against treatment milestones using recognised health outcome measures and revise the plans as necessary in conjunction with the patient, client or user
- recognise the need to monitor and evaluate the quality of practice and the value of contributing to the generation of data for quality assurance and improvement programmes
- be able to make reasoned decisions to initiate, continue, modify or cease treatment or the use of techniques or procedures, and record the decisions and reasoning appropriately
- understand that outcomes may not always conform to expectations but may still meet the needs of patients, clients or users

2c.2 be able to audit, reflect on and review practice

- understand the principles of quality control and quality assurance
- be aware of the role of audit and review in quality management, including quality control, quality assurance and the use of appropriate outcome measures
- be able to maintain an effective audit trail and work towards continual improvement
- participate in quality assurance programmes, where appropriate
- understand the value of reflection on clinical practice and the need to record the outcome of such reflection
- recognise the value of case conferences and other methods of review
- *be able to evaluate nutritional and dietetic information critically, and to engage in the process of reflection in order to inform dietetic practice*
- *be able to adapt dietetic practice as a result of unexpected outcomes or further information gained during the dietetic interview*

Knowledge, understanding and skills

3a:

Registrant dietitians must:

3a.1 know the key concepts of the biological, physical, social, psychological and clinical sciences which are relevant to their profession-specific practice

- understand the structure and function of the human body, relevant to their practice, together with a knowledge of health, disease, disorder and dysfunction
- be aware of the principles and applications of scientific enquiry, including the evaluation of treatment efficacy and the research process
- recognise the role of other professions in health and social care
- understand the theoretical basis of, and the variety of approaches to, assessment and intervention
- *understand, in the context of dietetics, biochemistry, clinical medicine, diet therapy, food hygiene, food science, genetics, immunology, microbiology, nutrition, pathophysiology, pharmacology and physiology*
- *be aware of catering and administration*
- *understand sociology, social policy, psychology, public health and educational methods relevant to the dietetic management of individual clients or groups*
- *understand the methods commonly used in nutrition research and be able to evaluate research papers critically*

3a.2 know how professional principles are expressed and translated into action through a number of different assessment, treatment and management approaches and how to select or modify approaches to meet the needs of an individual

3a.3 understand the need for, and be able to establish and maintain, a safe practice environment

- be aware of applicable health and safety legislation, and any relevant safety policies and procedures in force at the workplace, such as incident reporting, and be able to act in accordance with these
- be able to work safely, including being able to select appropriate hazard control and risk management, reduction or elimination techniques in a safe manner in accordance with health and safety legislation
- be able to select appropriate personal protective equipment and use it correctly
- be able to establish safe environments for clinical practice, which minimise risks to patients, clients and users, those treating them, and others, including the use of hazard control and particularly infection control
- *be able to advise on safe procedures for food preparation*

hpc health professions council

Standards of proficiency

Dietitians

Contents

Foreword

I am pleased to present the Health Professions Council's standards of proficiency.

We first published the standards of proficiency when our Register opened in July 2003. We began to review them in October 2005 to look at how they were working and to check whether they continued to reflect current practice as experienced by registrants, employers, educators and others. The review was led by a professional liaison group (PLG), which included members of our Council, as well as representatives from professional bodies and patient groups. We also held a formal consultation on the draft proposed standards. The review process and consultation produced extremely valuable feedback and we are grateful to all those who gave their time to help us in shaping the standards that follow.

We made a small number of changes to the previous standards, mainly to reflect developments in education, to clarify our intentions and to correct any errors or omissions. We also revised the introduction to explain more clearly the purpose behind the standards, especially in relation to registrants who specialise or move into non-clinical areas of practice.

I am confident that the standards are both fit for purpose and reflect current thinking in relation to safe professional practice across the professions.

These standards are effective from 1 November 2007.

Anna Van der Gaag

Anna van der Gaag
President

Introduction

This document sets out the **standards of proficiency**. These are the standards we have produced for the safe and effective practice of the professions we regulate. They are the minimum standards we consider necessary to protect members of the public.

You must meet these standards when you first become registered. After that, every time you renew your registration you will be asked to sign a declaration that you continue to meet the standards of proficiency that apply to your scope of practice.

We also expect you to keep to our **standards of conduct, performance and ethics**, which are published in a separate document.

The standards of proficiency in this document include both generic elements, which apply to all our registrants, and profession-specific elements that are relevant to registrants belonging to one of the professions we currently regulate. The **generic standards are written in black**, and the **profession-specific standards are written in blue** to help you distinguish between them.

The generic standards explain the key obligations that we expect of you. Occasionally, we have pointed out specific elements of those key obligations. We have not attempted to create exhaustive lists of all the areas that each generic standard covers; we have simply highlighted specific elements where we consider this to be helpful.

A note about our expectations of you

The standards of proficiency play a central role in how you can gain admission to, and remain on, the Register and thereby gain the right to use the protected title(s) of your profession.

It is important that you read and understand this document. If your practice is called into question we will consider these standards (and our **standards of conduct, performance and ethics**) in deciding what action, if any, we need to take.

The standards set out in this document complement information and guidance issued by other organisations, such as your professional body or your employer.

Your scope of practice

Your scope of practice is the area or areas of your profession in which you have the knowledge, skills and experience to practise lawfully, safely and effectively, in a way that meets our standards and does not pose any danger to the public or to yourself.

We recognise that a registrant's scope of practice will change over time and that the practice of experienced registrants often becomes more focused and specialised than that of newly registered colleagues. This might be because of specialisation in a certain clinical area or with a particular client group, or a movement into roles in management, education or research.

Your particular scope of practice may mean that you are unable to continue to demonstrate that you meet all of the standards that apply for the whole of your profession. As long as you make sure that you are practising safely and effectively within your given scope of practice and do not practise in the areas where you are not proficient to do so, this will not be a problem. If you want to move outside of your scope of practice you should be certain that you are capable of working lawfully, safely and effectively. This means that you need to exercise personal judgement by undertaking any necessary training and experience.

Meeting the standards

It is important that our registrants meet our standards and are able to practise lawfully, safely and effectively. However, we don't dictate how you should meet our standards. There is normally more than one way in which each standard can be met and the way in which you meet our standards might change over time because of improvements in technology or changes in your practice. As an autonomous professional you need to make informed, reasoned decisions about your practice to ensure that you meet the standards that apply to you. This includes seeking advice and support from education providers, employers, colleagues and others to ensure that the wellbeing of service users is safeguarded at all times.

In particular, we recognise the valuable role played by professional bodies in representing and promoting the interests of their members. This often includes guidance and advice about good practice which can help you meet the standards laid out in this document.

Service users

We recognise that our registrants work in a range of different settings, which include clinical practice, education, research and roles in industry. We recognise that different professions sometimes use different terms to refer to those who use or who are affected by their practice and that the use of terminology can be an emotive issue.

We have tried to use a term in the generic standards which is as inclusive as possible. Throughout the generic standards we have used the term ‘service users’ to refer to anyone who uses or is affected by the services of registrants. Who your service users are will depend on how and where you work. For example, if you work in clinical practice, your service users might be your patients or your staff if you manage a team. The term also includes other people who might be affected by your practice, such as carers and relatives. In the profession-specific standards, we have retained the terminology which is relevant to each individual profession.

These standards may change in the future

We have produced this new version of our standards after speaking to our stakeholders about how the standards were working and how relevant they were to registrants’ practice.

We will continue to listen to our stakeholders and will keep our standards under continual review. So we may make further changes in the future to take into account changes in practice.

We will always publicise any changes to the standards that we make by, for instance, publishing notices on our website and informing professional bodies.

Expectations of a health professional

1a Professional autonomy and accountability

Registrant dietitians must:

1a.1 be able to practise within the legal and ethical boundaries of their profession

- understand the need to act in the best interests of service users at all times
- understand what is required of them by the Health Professions Council
- understand the need to respect, and so far as possible uphold, the rights, dignity, values and autonomy of every service user including their role in the diagnostic and therapeutic process and in maintaining health and wellbeing
- be aware of current UK legislation applicable to the work of their profession
- understand the ethical and legal implications of withholding or withdrawing nutrition

1a.2 be able to practise in a non-discriminatory manner

1a.3 understand the importance of and be able to maintain confidentiality

1a.4 understand the importance of and be able to obtain informed consent

1a.5 be able to exercise a professional duty of care

1a.6 be able to practise as an autonomous professional, exercising their own professional judgement

- be able to assess a situation, determine the nature and severity of the problem and call upon the required knowledge and experience to deal with the problem
- be able to initiate resolution of problems and be able to exercise personal initiative

- know the limits of their practice and when to seek advice or refer to another professional
- recognise that they are personally responsible for and must be able to justify their decisions

1a.7 recognise the need for effective self-management of workload and resources and be able to practise accordingly

1a.8 understand the obligation to maintain fitness to practise

- understand the need to practise safely and effectively within their scope of practice
- understand the need to maintain high standards of personal conduct
- understand the importance of maintaining their own health
- understand both the need to keep skills and knowledge up to date and the importance of career-long learning

1b Professional relationships

Registrant dietitians must:

1b.1 be able to work, where appropriate, in partnership with other professionals, support staff, service users and their relatives and carers

- understand the need to build and sustain professional relationships as both an independent practitioner and collaboratively as a member of a team
- understand the need to engage service users and carers in planning and evaluating diagnostics, treatments and interventions to meet their needs and goals
- be able to make appropriate referrals

1b.2 be able to contribute effectively to work undertaken as part of a multi-disciplinary team

1b.3 be able to demonstrate effective and appropriate skills in communicating information, advice, instruction and professional opinion to colleagues, service users, their relatives and carers

- be able to communicate in English to the standard equivalent to level 7 of the International English Language Testing System, with no element below 6.5[1]
- understand how communication skills affect the assessment of service users and how the means of communication should be modified to address and take account of factors such as age, physical ability and learning ability
- be able to select, move between and use appropriate forms of verbal and non-verbal communication with service users and others
- be aware of the characteristics and consequences of non-verbal communication and how this can be affected by culture, age, ethnicity, gender, religious beliefs and socio-economic status
- understand the need to provide service users (or people acting on their behalf) with the information necessary to enable them to make informed decisions
- understand the need to use an appropriate interpreter to assist service users whose first language is not English, wherever possible
- recognise that relationships with service users should be based on mutual respect and trust, and be able to maintain high standards of care even in situations of personal incompatibility

1b.4 understand the need for effective communication throughout the care of the service user

- recognise the need to use interpersonal skills to encourage the active participation of service users

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[1] The International English Language Testing System (IELTS) tests competence in spoken and written English. Applicants who have qualified outside of the UK, whose first language is not English and who are not nationals of a country within the European Economic Area (EEA), have to provide evidence that they have reached the necessary standard. We accept a number of other tests as equivalent to the IELTS examination. Please visit our website for more information.

The skills required for the application of practice

2a Identification and assessment of health and social care needs

Registrant dietitians must:

2a.1 be able to gather appropriate information

2a.2 be able to select and use appropriate assessment techniques

– be able to undertake and record a thorough, sensitive and detailed assessment, using appropriate techniques and equipment

– be able to choose, undertake and record the most appropriate method of dietary and nutritional assessment, using appropriate techniques and equipment

2a.3 be able to undertake or arrange investigations as appropriate

2a.4 be able to analyse and critically evaluate the information collected

– be able to use nutritional analysis programs to analyse food intake, records and recipes and interpret the results

2b Formulation and delivery of plans and strategies for meeting health and social care needs

Registrant dietitians must:

2b.1 be able to use research, reasoning and problem-solving skills to determine appropriate actions

– recognise the value of research to the critical evaluation of practice

– be able to engage in evidence-based practice, evaluate practice systematically and participate in audit procedures

– be aware of a range of research methodologies

– be able to demonstrate a logical and systematic approach to problem solving

- be able to evaluate research and other evidence to inform their own practice
- be able to use statistical, epidemiological and research skills to gather and interpret evidence in order to make reasoned conclusions and judgements with respect to dietetic practice in disease prevention and management

2b.2 be able to draw on appropriate knowledge and skills in order to make professional judgements

- be able to change their practice as needed to take account of new developments
- be able to demonstrate a level of skill in the use of information technology appropriate to their practice
- be able to choose the most appropriate strategy to influence nutritional behaviour and choice
- be able to undertake and explain dietetic treatment, having regard to current knowledge and evidence-based practice
- be able to advise on safe procedures for food preparation and handling, food processing and menu planning, and the resulting impact on nutritional quality and menu planning
- be able to interpret nutritional information including food labels which may have nutritional or clinical implications

2b.3 be able to formulate specific and appropriate management plans including the setting of timescales

- understand the requirement to adapt practice to meet the needs of different groups distinguished by, for example, physical, psychological, environmental, cultural or socio-economic factors
- understand the need to be sensitive to social, economic and cultural factors that affect diet, lifestyle and health
- understand the significance and potential impact of non-dietary factors when helping individuals, groups and communities to make informed choices about their dietary treatment and health care

- be able to assist individuals, groups and communities to undertake and to become committed to self-care activities including diet, physical activity and other lifestyle adjustments
- understand the need to demonstrate sensitivity to the factors which shape individual food choice and lifestyle which may impact on the individual's health and affect the interaction between client and dietitian

2b.4 be able to conduct appropriate diagnostic or monitoring procedures, treatment, therapy or other actions safely and skilfully

- understand the need to maintain the safety of both service users and those involved in their care

2b.5 be able to maintain records appropriately

- be able to keep accurate, legible records and recognise the need to handle these records and all other information in accordance with applicable legislation, protocols and guidelines
- understand the need to use only accepted terminology in making records

2c Critical evaluation of the impact of, or response to, the registrant's actions

Registrant dietitians must:

2c.1 be able to monitor and review the ongoing effectiveness of planned activity and modify it accordingly

- be able to gather information, including qualitative and quantitative data, that helps to evaluate the responses of service users to their care
- be able to evaluate intervention plans using recognised outcome measures and revise the plans as necessary in conjunction with the service user
- recognise the need to monitor and evaluate the quality of practice and the value of contributing to the generation of data for quality assurance and improvement programmes

- be able to make reasoned decisions to initiate, continue, modify or cease treatment or the use of techniques or procedures, and record the decisions and reasoning appropriately

2c.2 be able to audit, reflect on and review practice

- understand the principles of quality control and quality assurance
- be aware of the role of audit and review in quality management, including quality control, quality assurance and the use of appropriate outcome measures
- be able to maintain an effective audit trail and work towards continual improvement
- participate in quality assurance programmes, where appropriate
- understand the value of reflection on practice and the need to record the outcome of such reflection
- recognise the value of case conferences and other methods of review
- be able to evaluate nutritional and dietetic information critically, and to engage in the process of reflection in order to inform dietetic practice
- be able to adapt dietetic practice as a result of unexpected outcomes or further information gained during the dietetic intervention

Knowledge, understanding and skills

3a Knowledge, understanding and skills

Registrant dietitians must:

3a.1 know and understand the key concepts of the bodies of knowledge which are relevant to their profession-specific practice

- understand the structure and function of the human body, relevant to their practice, together with knowledge of health, disease, disorder and dysfunction
- be aware of the principles and applications of scientific enquiry, including the evaluation of treatment efficacy and the research process
- recognise the role of other professions in health and social care
- understand the theoretical basis of, and the variety of approaches to, assessment and intervention
- understand, in the context of dietetics, biochemistry, clinical medicine, diet therapy, food hygiene, food science, genetics, immunology, microbiology, nutrition, pathophysiology, pharmacology and physiology
- be aware of catering and administration
- understand sociology, social policy, psychology, public health and educational methods relevant to the dietetic management of individuals, groups or communities
- understand the methods commonly used in nutrition research and be able to evaluate research papers critically

3a.2 know how professional principles are expressed and translated into action through a number of different approaches to practice, and how to select or modify approaches to meet the needs of an individual, groups or communities

3a.3 understand the need to establish and maintain a safe practice environment

- be aware of applicable health and safety legislation, and any relevant safety policies and procedures in force at the workplace, such as incident reporting, and be able to act in accordance with these
- be able to work safely, including being able to select appropriate hazard control and risk management, reduction or elimination techniques in a safe manner in accordance with health and safety legislation
- be able to select appropriate personal protective equipment and use it correctly
- be able to establish safe environments for practice, which minimise risks to service users, those treating them, and others, including the use of hazard control and particularly infection control
- be able to advise on safe procedures for food preparation

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health & care professions council

Standards of proficiency

Dietitians

Contents

Foreword

We are pleased to present the Health and Care Professions Council's standards of proficiency for dietitians.

We first published standards of proficiency for dietitians when our Register opened in July 2003. We published revised standards in 2007. We review the standards regularly to look at how they are working and to check whether they continue to reflect current practice in the professions we regulate.

These new revised standards are a result of our most recent review of the standards of proficiency. As a result of the first stage of the review, and the results of a public consultation, we have revised our generic standards which apply to all the professions we regulate. The revised standards are now based around 15 generic statements. This new structure means that we can retain the standards which are shared across all the professions we regulate, whilst allowing us more flexibility in describing the detailed standards which are specific to individual professions.

The profession-specific standards for dietitians included in this document were developed with the input of the relevant professional bodies and the views of all stakeholders during a further public consultation. The review process and consultation produced valuable feedback and we are grateful to all those who gave their time to help us in shaping the new standards.

We have made a small number of changes to the standards overall, mainly to reflect developments in education and practice, to clarify our intentions and to correct any errors or omissions. We have also made some minor changes to the introduction, in particular, to explain the language we use in the standards.

We are confident that the standards are fit for purpose and reflect safe and effective professional practice in dietetics.

These standards are effective from 1 March 2013.

Introduction

This document sets out the standards of proficiency. These standards set out safe and effective practice in the professions we regulate. They are the threshold standards we consider necessary to protect members of the public. They set out what a student must know, understand and be able to do by the time they have completed their training, so that they are able to apply to register with us. Once on our Register you must meet those standards of proficiency which relate to the areas in which you work.

We also expect you to keep to our standards of conduct, performance and ethics and standards for continuing professional development. We publish these in separate documents, which you can find on our website.

The standards of proficiency in this document include both generic elements, which apply to all our registrants, and profession-specific elements which are relevant to registrants belonging to one of the professions we currently regulate. The generic standards are written in **bold**, and the profession-specific standards are written in plain text.

We have numbered the standards so that you can refer to them more easily. The standards are not hierarchical and are all equally important for practice.

A note about our expectations of you

You must meet all the standards of proficiency to register with us and meet the standards relevant to your scope of practice to stay registered with us.

It is important that you read and understand this document. If your practice is called into question we will consider these standards (and our standards of conduct, performance and ethics) in deciding what action, if any, we need to take.

The standards set out in this document complement information and guidance issued by other organisations, such as your professional body or your employer. We recognise the valuable role played by professional bodies in providing guidance and advice about good practice which can help you to meet the standards in this document.

Your scope of practice

Your scope of practice is the area or areas of your profession in which you have the knowledge, skills and experience to practise lawfully, safely and effectively, in a way that meets our standards and does not pose any danger to the public or to yourself.

We recognise that a registrant's scope of practice will change over time and that the practice of experienced registrants often becomes more focused and specialised than that of newly registered colleagues. This might be because of specialisation in a certain area or with a particular client group, or a movement into roles in management, education or research. Every time you renew your registration, you will be asked to sign a declaration that you continue to meet the standards of proficiency that apply to your scope of practice.

Your particular scope of practice may mean that you are unable to continue to demonstrate that you meet all of the standards that apply for the whole of your profession. As long as you make sure that you are practising safely and effectively within your given scope of practice and do not practise in the areas where you are not proficient to do so, this will not be a problem. If you want to move outside of your scope of practice, you should be certain that you are capable of working lawfully, safely and effectively. This means that you need to exercise personal judgement by undertaking any necessary training or gaining experience, before moving into a new area of practice.

Meeting the standards

It is important that you meet our standards and are able to practise lawfully, safely and effectively. However, we do not dictate how you should meet our standards. There is normally more than one way in which each standard can be met and the way in which you meet our standards might change over time because of improvements in technology or changes in your practice.

We often receive questions from registrants who are concerned that something they have been asked to do, a policy, or the way in which they work might mean they cannot meet our standards. They are often worried that this might have an effect on their registration.

As an autonomous professional, you need to make informed, reasoned decisions about your practice to ensure that you meet the standards that apply to you. This includes seeking advice and support from education providers, employers, colleagues, professional bodies, unions and others to ensure that the wellbeing of service users is safeguarded at all times. So long as you do this and can justify your decisions if asked to, it is very unlikely that you will not meet our standards.

Language

We recognise that our registrants work in a range of different settings, which include direct practice, management, education, research and roles in industry. We also recognise that the use of terminology can be an emotive issue.

Our registrants work with very different people and use different terms to describe the groups that use, or are affected by, their services. Some of our registrants work with patients, others with clients and others with service users. The terms that you use will depend on how and where you work. We have used terms in these standards which we believe best reflect the groups that you work with.

In the standards of proficiency, we use phrases such as ‘understand’, ‘know’, and ‘be able to’. This is so the standards remain applicable to current registrants in maintaining their fitness to practise, as well as prospective registrants who have not yet started practising and are applying for registration for the first time.

These standards may change in the future

We have produced these standards after speaking to our stakeholders and holding a formal public consultation.

We will continue to listen to our stakeholders and will keep our standards under continual review. Therefore, we may make further changes in the future to take into account changes in practice.

We will always publicise any changes to the standards that we make by, for instance, publishing notices on our website and informing professional bodies.

Standards of proficiency

Registrant dietitians must:

1 be able to practise safely and effectively within their scope of practice

1.1 know the limits of their practice and when to seek advice or refer to another professional

1.2 recognise the need to manage their own workload and resources effectively and be able to practise accordingly

2 be able to practise within the legal and ethical boundaries of their profession

2.1 understand the need to act in the best interests of service users at all times

2.2 understand what is required of them by the Health and Care Professions Council

2.3 understand the need to respect and uphold the rights, dignity, values, and autonomy of service users and their central role in decisions about their health

2.4 recognise that relationships with service users should be based on mutual respect and trust, and be able to maintain high standards of care even in situations of personal incompatibility

2.5 know about current legislation applicable to the work of their profession

2.6 know about policy, ethical and research frameworks that underpin, inform, and influence the practice of dietetics

2.7 understand the importance of and be able to obtain informed consent

2.8 be able to exercise a professional duty of care

2.9 understand the ethical and legal implications of withholding and withdrawing feeding including nutrition

3 be able to maintain fitness to practise

3.1 understand the need to maintain high standards of personal and professional conduct

3.2 understand the importance of maintaining their own health

3.3 understand both the need to keep skills and knowledge up to date and the importance of career-long learning

4 be able to practise as an autonomous professional, exercising their own professional judgement

4.1 be able to assess a professional situation, determine the nature and severity of the problem and call upon the required knowledge and experience to deal with the problem

4.2 be able to make reasoned decisions to initiate, continue, modify or cease interventions or the use of techniques or procedures, and record the decisions and reasoning appropriately

4.3 be able to initiate resolution of problems and be able to exercise personal initiative

4.4 recognise that they are personally responsible for and must be able to justify their decisions

4.5 be able to make reasoned decisions to accept or decline requests for intervention

4.6 be able to make appropriate referrals and requests for interventions from other services

4.7 understand the importance of participation in training, supervision and mentoring

5 be aware of the impact of culture, equality and diversity on practice

5.1 understand the requirement to adapt practice and resources to meet the needs of different groups and individuals

5.2 understand the significance and potential effect of non-dietary factors when helping individuals, groups and communities to make informed choices about interventions and lifestyle

6 be able to practise in a non-discriminatory manner

6.1 be able to demonstrate sensitivity to factors that affect diet, lifestyle and health and that may affect the interaction between service user and dietitian

7 understand the importance of and be able to maintain confidentiality

7.1 be aware of the limits of the concept of confidentiality

7.2 understand the principles of information governance and be aware of the safe and effective use of health and social care information

7.3 be able to recognise and respond appropriately to situations where it is necessary to share information to safeguard service users or the wider public

8 be able to communicate effectively

8.1 be able to demonstrate effective and appropriate verbal and non-verbal communication skills when interacting with a diverse range of individuals, groups and communities

8.2 be able to communicate in English to the standard equivalent to level 7 of the International English Language Testing System, with no element below 6.5[1]

8.3 understand how verbal and non-verbal communication skills affect assessment and engagement of service users and how the means of communication should be modified to address and take account of factors such as the characteristics of the individual, group or community

8.4 be able to select, move between and use appropriate forms of verbal and non-verbal communication with service users and others

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[1] The International English Language Testing System (IELTS) tests competence in the English language. Applicants who have qualified outside of the UK, whose first language is not English and who are not nationals of a country within the European Economic Area (EEA) or Switzerland, must provide evidence that they have reached the necessary standard. Please visit our website for more information.

8.5 be aware of the characteristics and consequences of verbal and non-verbal communication and how this can be affected by factors such as age, culture, ethnicity, gender, socio-economic status and spiritual or religious beliefs

8.6 understand the need to provide service users or people acting on their behalf with the information necessary to enable them to make informed decisions

8.7 understand the need to assist the communication needs of service users such as through the use of an appropriate interpreter, wherever possible

8.8 recognise the need to use interpersonal skills to encourage the active participation of service users

9 be able to work appropriately with others

9.1 be able to work, where appropriate, in partnership with service users, other professionals, support staff, communities and others

9.2 understand the need to build and sustain professional relationships as both an independent practitioner and collaboratively as a member of a team

9.3 understand the need to empower and engage individuals, groups, and communities in planning and evaluating interventions to meet their needs and goals

9.4 be able to contribute effectively to work undertaken as part of a multi-disciplinary team

9.5 be able to empower individuals, groups and communities to make informed choices including diet, physical activity and other lifestyle adjustments

9.6 be able to work with service users to implement changes in interventions in line with new developments

10 be able to maintain records appropriately

10.1 be able to keep accurate, comprehensive and comprehensible records in accordance with applicable legislation, protocols and guidelines

10.2 recognise the need to manage records and all other information in accordance with applicable legislation, protocols and guidelines

11 be able to reflect on and review practice

11.1 understand the value of reflection on practice and the need to record the outcome of such reflection

11.2 recognise the value of multi-disciplinary team review and other methods of review

12 be able to assure the quality of their practice

12.1 be able to engage in evidence-based practice, evaluate practice systematically and participate in audit procedures

12.2 recognise the need to monitor and evaluate the quality of practice and the value of contributing to the generation of accurate data for quality assurance, governance, clinical audit, research and improvement programmes

12.3 be able to gather and share information, including qualitative and quantitative data, that evaluates outcomes

12.4 be aware of, and be able to participate in, quality improvement processes to assure the quality of their practice

12.5 be able to evaluate intervention plans using recognised outcome measures and revise the plans as necessary in partnership with individuals, groups and communities

13 understand the key concepts of the knowledge base relevant to their profession

13.1 understand the structure and function of the human body, together with knowledge of health, disease, disorder and dysfunction relevant to their profession

13.2 be aware of the principles and applications of scientific enquiry, including the evaluation of interventions and the research process

13.3 understand the concept of leadership and its application to practice

13.4 recognise the role of other professions in health and social care

13.5 understand the structure and function of health and social care services in the UK

13.6 understand the wider determinants of health and wellbeing

13.7 understand the theoretical basis of, and the variety of approaches to, assessment, diagnosis, intervention and evaluation

13.8 understand, in the context of nutrition and dietetic practice:

- biochemistry
- clinical dietetics
- clinical medicine
- epidemiology
- genetics
- immunology
- microbiology
- nutritional sciences
- pathophysiology
- pharmacology
- physiology
- public health nutrition

13.9 understand, in the context of nutrition and dietetic practice:

- food hygiene
- food science
- food skills
- food systems management
- menu planning
- the factors that influence food choice

13.10 understand the principles behind the use of nutritional analysis programs to analyse food intake records and recipes and interpret the results

13.11 understand in the context of nutrition and dietetic practice legislation relating to food labelling and health claims

13.12 understand, in the context of nutrition and dietetic practice, the use of appropriate educational strategies, communication, and models of empowerment, behaviour change and health promotion

13.13 understand, in the context of nutrition and dietetic practice:

- management of health and social care
- psychology
- public health relevant to the dietetic management of individuals, groups or communities
- social policy
- sociology

13.14 understand the methods commonly used in nutrition research and be able to evaluate research papers critically

14 be able to draw on appropriate knowledge and skills to inform practice

14.1 be able to accurately assess nutritional needs of individuals, groups and populations, in a sensitive and detailed way using appropriate techniques and resources

14.2 be able to change their practice as needed to take account of new developments or changing contexts

14.3 be able to gather appropriate information

14.4 be able to select and use appropriate assessment techniques

14.5 be able to undertake or arrange investigations as appropriate

14.6 be able to analyse and critically evaluate the information collected in order to identify nutritional needs and develop a diagnosis

14.7 be able to analyse and critically evaluate assessment information to develop intervention plans including the setting of timescales, goals and outcomes

14.8 be able to conduct appropriate diagnostic or monitoring procedures, treatment, therapy, interventions or other actions safely and effectively

14.9 be able to monitor the progress of nutrition and dietetic interventions using appropriate information, techniques and measures

14.10 be able to critically evaluate the information gained in monitoring to review and revise the intervention

14.11 be able to use nutritional analysis programs to analyse food intake, records and recipes and interpret the results

14.12 be able to use research, reasoning, and a logical and systematic approach to problem solving skills to determine appropriate actions

14.13 recognise the value of research to the critical evaluation of practice

14.14 be able to use statistical, epidemiological, and research skills to gather and interpret evidence to make reasoned conclusions and judgements to enhance dietetic practice

14.15 be aware of a range of research methodologies and be able to critically evaluate research in order to inform practice

14.16 be able to use information and communication technologies appropriate to their practice

14.17 be able to choose the most appropriate strategy to influence nutritional behaviour and choice

14.18 be able to undertake and explain dietetic interventions, having regard to current knowledge and evidence-based practice

14.19 be able to advise on safe procedures for food preparation and handling and any effect on nutritional quality

14.20 be able to advise on the effect of food processing on nutritional quality

14.21 be able to advise on menu planning, taking account of food preparation and processing, nutritional standards and requirements of service users

14.22 be able to interpret nutritional information including food labels which may have nutritional or clinical implications

15 understand the need to establish and maintain a safe practice environment

15.1 understand the need to maintain the safety of both service users and those involved in their care

15.2 be aware of applicable health and safety legislation, and any relevant safety policies and procedures in force at the workplace, such as incident reporting, and be able to act in accordance with these

15.3 be able to work safely, including being able to select appropriate hazard control and risk management, reduction or elimination techniques in a safe manner and in accordance with health and safety legislation

15.4 be able to select appropriate personal protective equipment and use it correctly

15.5 be able to establish safe environments for practice, which minimise risks to service users, those treating them and others, including the use of hazard control and particularly infection control

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Code of Professional Conduct

May 2004

Foreword

As dietitians one of our key aims is to promote and communicate accurate evidence-based knowledge to the public in a practical manner. In undertaking this role we must ensure that we are meeting the standards which the public have the right to expect from a registered health professional.

This Code of Professional Conduct has been developed to support BDA members by providing clear guidance on what are considered to be the minimum standards of professional conduct for Dietitians who are members of the professional association.

The Code of Conduct forms part of the association's governance framework and links closely with the BDA's *Professional Standards for Dietitians* and other professional development guidance papers e.g. *Good Practice in Consent: A Guide for Dietitians*. Together these documents are complementary to and underpin the Health Professions Council's *Standards of Conduct, Performance and Ethics* and the *Standards of Proficiency: Dietitians.*

I am pleased to commend to you the Code of Professional Conduct and trust that it will help to ensure a consistent, high level of best practice by dietitians across the UK.

I would like to extend my thanks and congratulations to all those involved with its production

SE.

Susan E. Jones
Honorary Chairman

CONTENTS

SECTION ONE

Introduction

The Health Act 1999[1] bestows the status of a profession on dietetics, which automatically carries the statutory requirement to regulate professional conduct for the protection of the patient/client/user. The title "Dietitian" is protected by law and can only be used by persons who are registered with the Health Professions Council (HPC).

This means that as a registered dietitian, you must:

- Protect and support the health of individual patients and clients
- Protect and support the health of the wider community
- Act in such a way that justifies the trust and confidence the public has in you
- Uphold and enhance the good reputation of the profession.

As an independent practitioner, who practises autonomously:

- You are personally accountable for your practice. This means that you are answerable for your actions and omissions, **regardless** of advice or directions from another professional.
- You have a duty of care to your patients and clients, who are entitled to receive safe and competent care.
- You must adhere to the laws of the country in which you are practising.

There are five guiding principles which underpin professional conduct. These are:

- ☐ *Beneficence* – that the actions taken should do good
- ☐ *Non maleficence* – taking steps to prevent harm to others
- ☐ *Justice* – ensuring that people are treated fairly
- ☐ *Fidelity* – being faithful to promises made (this includes the need to be explicit and realistic about what service can be provided)
- ☐ *Autonomy* – each individual has the right to freely choose their own course of action and to choose what happens to them

The purpose of this *Code of Professional Conduct for Dietitians* is to provide a **set of principles** that apply to all dietitians. It requires dietetic practitioners to discharge their duties and responsibilities in a professional, ethical and moral manner.

The Code is necessarily broad and cannot provide definitive answers to the many dilemmas that dietitians may experience within their professional practice. For this reason, it is obviously open to different interpretations, depending on the circumstances to which it is applied. However, if used as a **guidance** document, this Code should support all dietetic practitioners to ensure that their practice is safe, effective and of high quality.

This Code is a public document which supplements the HPC *Standards of Conduct, Performance and Ethics[2], and Standards of Proficiency[3]*. It should be used in conjunction with *Professional Standards for Dietitians* (BDA 2003)[4] and other documents for guidance, such as *Good Practice in Consent: A Guide for Dietitians* (BDA 2002)[5]. The British Dietetic Association (BDA) strongly recommends recognition of the Code by all other individuals, organisations and institutions involved with the profession.

Any action which conflicts with the word or spirit of this Code should be considered unethical. This Code may be used by others to determine the standards of professional conduct which can be expected from dietitians. This will change with time. It confers no rights, and offers no protection against any sanction imposed by the laws of the United Kingdom.

Uncertainty or dispute as to the interpretation or application of this Code should be referred, in the first instance, to the Ethical and Professional Advisory Panel of the BDA c/o the BDA office.

SECTION TWO

Patient / Client / User Autonomy and Welfare

Respecting the autonomy of the patient/client/user

2.1 Dietitians will at all times recognise, respect and uphold the autonomy of patients/clients/users: i.e. their right to make choices and to work in partnership with dietitians. Dietitians will promote the dignity, privacy and safety of all patients/clients/users.

2.1.1 Dietitians will respect the decisions of their patients/clients/users concerning their own health and independence, even when such decisions conflict with professional opinion.

2.1.2 Patients/clients/users should be given sufficient information and time to enable them to make informed decisions about their health and social care.

2.1.3 Dietitians will take care to present information in a way that patients/clients/users can understand.[3,6]

2.1.4 Reasonable steps should be taken to ensure that the patient/client/user understands the nature, purpose and likely effect of the proposed intervention.[5,7]

2.1.5 Patients/clients/users have a right to refuse intervention, and should be offered the opportunity to refuse it. Any such refusal should be respected and recorded in writing.

2.1.6 Discussions with or about patients/clients/users should be confidential and be conducted in such a place and manner as to protect their privacy.

NOTE: Exceptional circumstances may, however, prevail, for example where the patient/client/user is deemed to lack competence in relation to consent to treatment (mental health legislation and current case law). [8,9,10,11,12,13]

Patient / Client / User Well-being

2.2 Dietitians must not engage in or condone behaviour that causes mental distress or physical harm. Such behaviour includes neglect, intentional acts, indifference to the pain or misery of others and other malpractice.

2.2.1 Any intervention that may cause pain or distress should first be explained to the patient/client/user, who should also understand its nature, purpose and likely outcome, before it begins.

2.2.2 A dietitian should make every reasonable effort to avoid leaving a patient/client/user in pain or distress after any intervention. If distress continues, relevant parties should be informed as soon as is reasonably practical.

2.2.3 Any dietitian who witnesses, or has evidence of behaviour which appears to cause unnecessary or avoidable pain or distress (including unreasonable restraint), has a duty to make this known confidentially to his/her line manager or other appropriate agency.[14,15]

2.2.4 Dietitians should act to prevent such action from continuing, providing their action is within their professional competence and does not conflict with local policies and procedures. If the dietitian is unable to intervene they should withdraw from the action.

2.2.5 Dietitians should take all reasonable steps to prevent patients/clients/users following action or advice which they know to be harmful to health.

Duty of Care to the Patient / Client / User

2.3 Dietitians have a duty to take reasonable care of patients/clients/users.

2.3.1 Dietitians' legal and professional 'duty of care' is established at the moment when a patient/client/user is accepted for assessment and intervention. They have a duty to ensure that any intervention is likely to be of benefit to the patient/client/user.

2.3.2 Dietitians should be aware that they have a common law duty of care to their patients/clients/users[2] and that a breach of this duty may lead to a civil claim for damages for negligence by the patient/client/user.

2.3.3 Dietitians must obtain adequate insurance or professional indemnity cover for any part of their practice not covered by an employer's indemnity scheme.

2.3.4 Dietitians must not refuse to treat someone just because the patient has an infection.[2]

2.3.5 Dietitians must take appropriate precautions to protect patients/clients/users, their carers and families, and themselves from infection. In particular they should protect their patients/clients/users from infecting one another.[2]

SECTION THREE

Services to Patients / Clients / Users

Referral of patients/clients/users

3.1 Dietitians shall only accept referrals which they deem to be appropriate and for which they have the resources.[16]

3.1.1 It is the duty of the dietitian to determine the appropriateness of the referral, which may be made verbally or in writing by a medical practitioner, another health professional, or by individual patients/clients/users.

3.1.2 It is not a requirement of professional dietetic practice for dietitians to accept only medical referrals. Dietetics is an autonomous profession and the responsibility for assessment and subsequent treatment remains with the individual dietetic practitioner.

3.1.3 Dietitians are legally liable for their intervention, teaching and advice carried out following assessment. This applies regardless of whether the intervention requested by the referrer is found to be appropriate or not.

3.1.4 Responsibility lies with the dietitian to identify whether or not dietetic intervention is indicated. Criteria must be established to ensure that clear objectives are agreed for any intervention.

Dietitians have a threefold responsibility to ensure that the intervention is necessary and appropriate:

- The patient/client/user; to make sure that expectations are not raised that cannot be fulfilled, and not to waste time or treat patients/clients/users to whom the treatment will not be beneficial or has ceased to be beneficial.
- Themselves as dietitians; by treating a patient/client/user who does not require such treatment. It is morally wrong to give treatment when it is not required or when referral to another agency is necessary or more appropriate.
- Their employer; whether self employed or employed through a Health Trust, private hospital or industrial concern, it is ethically wrong to waste time and money by treating patients/clients/users unnecessarily.

If the dietitian decides that dietetic advice is not appropriate, the referrer should be informed so as to increase awareness of the role and limitations of dietetic practice.

3.1.5 Prescriptive referrals

Some dietetic referrals are contentious. Usually, these are 'prescriptive' referrals and tend to fall into three categories:

- Requests for dietetic intervention that would be actively harmful to the patient/client/user.
- Requests for interventions that are unnecessary.
- Requests for intervention that would be of doubtful benefit.

3.1.5.1 Actively harmful

Health Circular HC(77)33[17] *Relationships between the Medical and Remedial Professions* includes comments by the Joint Consultants' Committee. Para. 2(ii) states:

*"In asking for treatment by a therapist (dietitian) the doctor is clearly asking for the help of another trained professional, and the profession of medicine and the various therapies differ. It follows from this that the therapist (dietitian) has a duty and a consequential right to **decline** to perform any therapy (intervention) which his professional training and expertise suggests is **actively harmful** to the patient. Equally, the doctor who is responsible for the patient has the right to instruct the therapist (dietitian) not to carry out certain forms of treatment which he believes harmful to the patient".*

Medical colleagues have, therefore, clearly acknowledged that dietitians have the right to refuse to treat a patient/client/user when the treatment requested is considered to be actively harmful. It would be courteous in these circumstances and beneficial to the patient/client/user to discuss the matter with the medical practitioner and suggest an alternative course of management based on the dietetic assessment.

3.1.5.2 Unnecessary treatment

If it is clear that a request is inappropriate or cannot be justified in terms of possible benefits or available resources, the referring practitioner must be approached and the responsibilities of the dietitian explained as set out above. If the practitioner persists in making such inappropriate requests, it may be necessary for a more formal approach to be made by a dietetic service manager. Prescription by the referrer of the number of sessions required to fulfil a therapeutic intervention should also be challenged.

It is not considered good practice to let the medical practitioner assume that their "prescription" is being carried out, when the dietetic intervention considered appropriate is substantially different.

3.1.5.3 **Treatment of dubious benefit**

Many areas of health-care, although appearing to have a beneficial effect, have not been evaluated or researched. It is the responsibility of each individual dietitian to keep up to date in respect of the research, evaluation of dietetic practice and approaches to the care of various conditions. If such a request is made, the dietitian has a duty of care to discuss the implications of the intervention and negotiate the way forward.

Equity of service provision

3.2 Dietitians will provide an equitable service to all patients/clients/users.

3.2.1 Dietitians should provide services that are sensitive to, and which value and respect diversity of culture and lifestyle.

3.2.2 Resources will never be infinite and therefore choices will have to be made. Priorities should always be based on sound ethical principles and current best practice in relation to the reasonableness, availability and suitability of services to meet the needs of patients/clients/users.

Provision of services to patients/clients/users

3.3 Services should be patient/client/user centred and needs led.

3.3.1 Dietitians should act to uphold and promote patients'/clients'/users' autonomy.

3.3.2 Dietitians should report to employers any deficiencies of provision for patients/clients/users, and should substantiate their concerns.

3.3.3 If they feel unable to practise safely and effectively, dietitians have a duty to raise their concerns with their employers. This dialogue must be recorded.[16]

Recording of information

3.4 Dietitians should keep accurate records

3.4.1 Dietitians should keep a written (and/or electronic) record of the intervention, advice given and the outcome of decisions taken.

3.4.1.1 Every patient/client/user should have a clearly recorded assessment of need and objectives of intervention.

3.4.2 Records should be accurate, legible, factual, in sequence, promptly made, and signed by the person who made them. In the case of students or assistants, records should be countersigned.[18,19]

3.4.3 Subjective opinion should always be identified as such and should be clinical and relevant.

3.4.4 Records should be stored securely so as to be confidential.[18,29]

Confidentiality

3.5 Dietitians are ethically, morally and legally obliged to safeguard confidential information relating to patients/client/users.[20,32]

3.5.1 The disclosure of confidential information is normally only permissible where the patient/client/user gives consent (expressed or implied); or when there is legal justification (by statute or court order); or it is thought to be in the public interest to prevent serious harm to anyone.[2]

3.5.2 Disclosure of the patients'/clients'/users' diagnosis, treatment, prognosis or future requirement should only be made when there is valid consent or legal justification.

3.5.3 Records should be kept secure from all but those who have a legitimate right/need to see them.[21]

3.5.4 Local and national policies on the confidentiality of electronic notes (including faxes and e-mails) should always be followed.

3.5.5 Access to records by patients/clients/users must be granted in accordance with current statutory provision. Reference should be made to current codes of practice and other guidance (both local and national) on access to personal health information, particularly in relation to:

Access to Personal Files Act 1987[22]
Data Protection Act 1998[23]
Human Rights Act 1998[24]
Access to Medical Reports Act 1988[25]
Access to Health Records Act 1990[26]
Citizen's Charter 1991[27]
Patient's Charter 1994[28]
Caldicott Guidance 1999[29]
The Children Act 1989[30]
The Freedom of Information Act 2000[31]
Confidentiality: NHS Code of Practice 2003[32]

NOTE: Exceptional circumstances may, however, prevail where the rights of access to information may be curtailed in certain circumstances such as the Data Protection Act 1998 and the Children Act 1989.

SECTION FOUR

Personal / Professional Integrity

Personal integrity

4.1 The highest standards of personal integrity are expected of dietitians.

4.1.1 Dietitians have a duty to refrain from bullying and other forms of harassment, and to be aware of how their behaviour affects others.[33]

Personal relationships with patients/clients/users

4.2 Dietitians will not enter into relationships that exploit or abuse patients/clients/users sexually, physically, emotionally, financially, socially or in any other manner.

4.2.1 It is considered unethical for dietitians to indulge in relationships which may impair their professional judgement and objectivity and/or may give rise to advantageous/disadvantageous treatment of the patient/client/user.

Professional integrity

4.3 Dietitians should not criticise any colleague in public.

4.3.1 Dietitians may give expert evidence in court about the alleged negligence of a colleague, though such evidence should be objective and capable of substantiation. **Under no circumstances must a dietitian who witnesses malpractice by any other professional, remain silent about it.**

4.3.2 If a dietitian has reasonable grounds to believe that the behaviour or professional performance of a colleague, of whatever discipline, is below the expected standards of professional competence, this should be notified confidentially to the line manager or other appropriate person in accordance with the recommendations of the NHS Executive following the *Public Interest Disclosure Act* 1998[34] (HSC 1991/198).[35]

4.3.3 Care should be taken, when giving a second opinion, to confine it to the issue and not the competence of the first professional.

Whistle-blowing

4.4 All dietitians should be aware of the available mechanisms for 'whistle-blowing'.[34,35,36]

4.4.1 Dietitians employed in the NHS should be aware of the nominated officer in their Trust, whom they should consult when appropriate. **All staff are protected in these circumstances.** Dietitians who are not employed by the NHS should seek advice from the BDA.

4.4.2 Whistle-blowing should not be used to resolve personal, partnership or business disputes. In these cases, any areas of concern must be raised with the individual first.

Professional demeanour

4.5 Dietitians must conduct themselves in a professional manner appropriate to the setting.

4.5.1 At all times when carrying out professional duties, dietitians must act and dress in such a way as to maintain the confidence of the patient/client/user.

4.5.2 Personal appearance, clothing, jewellery and footwear must be appropriate to the setting and in accordance with health and safety provisions and any local policies and guidelines.

Personal health and substance misuse

4.6 Dietitians must not be under the influence of any substance which is likely to impair the performance of their duties.

4.6.1 Dietitians must not misuse, nor encourage others to misuse alcohol, drugs or other substances.

4.6.2 Dietitians must take action if they become aware that their physical and/or mental health could affect their fitness to practise.[2]

Personal profit / gain

4.7 Dietitians must not accept favours, gifts, or hospitality from patients/clients/users, their families or commercial organisations when the offer might be construed as an attempt to gain preferential treatment.[37,38]

4.7.1 Dietitians have a prime duty to the patient/client/user and should not let this duty be influenced by any commercial or other interest that conflicts with it.

4.7.2 A bequest in a will to a dietitian should be declared to the employer, where appropriate.

4.7.3 Local policies concerning gifts should be observed.

NOTE: In certain cases, the property and affairs of a patient/client/user may be subject to the authority of the Court of Protection.

Advertising

4.8 Dietitians may make direct contact with potential referring agencies to promote their services.

4.8.1 Dietitians should be guided by the *HPC Standards of Conduct, Performance and Ethics*[2] and the *Standards of Proficiency: Dietitians*.[3]

4.8.2 Dietitians must take care not to make or support unjustifiable statements relating to particular products.

Representation of information

4.9 Dietitians must give a true account of their qualifications, education, experience, training and competence and the services they can provide.

4.9.1 Dietitians shall not convey any information they know, or have reasonable grounds to know, to be false, fraudulent, deceptive or untrue.

4.9.2 Dietitians who become aware that information which they have given is false should notify the appropriate authority.

SECTION FIVE

Professional Competence and Standards

Professional competence

5.1 Dietitians shall achieve and maintain high standards of competence.

5.1.1 All dietitians are responsible for the maintenance of their own professional competence and knowledge of the laws affecting their practice.[2]

5.1.2 Dietitians will only provide services for which they are qualified by education, training and/or experience, and which are within their professional competence.[2,4,39]

5.1.3 Any dietitian who is asked to act up or cover for an absent colleague must identify and decline to undertake any aspect of work which he/she knows or believes to be outside the scope of his/her clinical competence. Such duties should not be undertaken in the absence of adequate supervision and training. [2,4]

5.1.4 Dietitians seeking work for which their training or experience is insufficient or out of date, have a responsibility to ensure that adequate self-directed learning, training and supervision takes place.[39]

Delegation

5.2 Dietitians who delegate treatment or other procedures must be satisfied that the person to whom these are delegated is competent to carry them out. Such persons may include students, support workers or volunteers. In these circumstances the dietitian will retain ultimate responsibility for the patient/client/user.[2]

5.2.1 Dietitians must provide supervision appropriate to the level of competence of the individuals for whom they have responsibility.

Collaborative practice

5.3 Dietitians will respect the needs, working practices, skills and responsibilities of others with whom they work.

5.3.1 Dietitians should acknowledge the need for multi-professional collaboration to ensure the provision of well-coordinated services delivered in the most effective way. In so doing the unique contribution of each profession should be acknowledged.

5.3.2 Dietitians must refer patients/clients/users to, or consult with, other service providers when additional knowledge and expertise is required.

5.3.3 With the exception of the seeking of a second opinion, it is in the interests of good patient/client/user care and best practice that there should be one dietitian taking overall responsibility for the assessment and treatment of a patient/client/user for any one episode of care.

5.3.4 When more than one dietitian is involved in the treatment of the same patient/client/user, they must liaise with each other and agree explicit areas of responsibility.

Continuing Professional Development

5.4 It is the responsibility of individual dietitians to develop their knowledge and skills and keep themselves up to date.[2,3]

5.4.1 Dietitians must continue to develop and maintain their professional knowledge and skills.

5.4.2 Dietitians should keep a record of their professional development.

5.4.3 Dietitians should set themselves annual objectives as part of the appraisal process.

5.4.4 It is the duty of dietitians to ensure that their practice is evidence based, whererever possible.

Dietetic student education

5.5 Dietitians have a professional responsibility to participate in the education of dietetic students.

5.5.1 Dietitians should ensure they have adequate training and skills to be a competent trainer before training dietetic students.

5.5.2 Dietitians should treat all students with fairness and respect.

5.5.3 Dietitians should ensure that they promote student-centred learning and that the training they offer is appropriate to the student’s level of education and training.

5.5.4 Dietitians accepting a student for placement should have a clear understanding of their role and responsibility and those of the student and the educational institution.

5.5.5 Dietitians should regularly evaluate the quality of their training and strive for continuous improvement.

Development of the profession

5.6 Dietitians shall promote an understanding of, and contribute to, the development of dietetics.

5.6.1 Dietitians have a responsibility to contribute to the continuing development of the profession by critical evaluation, audit and research.

5.6.2 Dietitians undertaking research and audit must always address the ethical implications and refer to local protocols.

5.6.3 Dietitians undertaking research or audit have a responsibility to share their findings in order to inform or change practice.

This document has been based on the Code of Ethics and Professional Conduct for Occupational Therapists 2000, the Chartered Society of Physiotherapy Rules of Professional Conduct 2002 and the Nursing and Midwifery Council Code of Professional Conduct 2002.

Produced by: Shirena Counter, Jane Eaton, Lorna Hill and Najia Qureshi on behalf of the Professional Development Committee of The British Dietetic Association.

Thanks must also be given for the input from the BDA Ethical, Professional and Advisory Panel, and Fiona Scott, Chair of the BDA Trade Union Committee.

Please direct any enquiries on this document to the Professional Affairs Section of the Association.

May 2004

SECTION SIX

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THE BRITISH DIETETIC ASSOCIATION

Code of Professional Conduct

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Contents

Foreword

In the assessment, diagnosis and treatment of diet and nutrition problems, dietitians have a responsibility to act in a professional and ethical manner. The *Code of Professional Conduct* provides a governance framework to ensure the accountability of dietitians who work in the interest of public safety at all times.

In addition to this, the code provides a set of professional principles that apply to the wider dietetic workforce, which will provide support and help to make informed choices when faced with ethical and professional dilemmas.

The Code of Conduct forms part of the Association's governance framework and links closely with the BDA's *Professional Standards for Dietitians* and other professional practice guidance papers, e.g. *Records and Record Keeping*. Together, these documents are complementary to and underpin the Health Professions Council's *Standards of Conduct*, *Performance and Ethics* and the *Standards of Proficiency: Dietitians.*

I am pleased to present to you the *Code of Professional Conduct* and trust that it will help to ensure a consistent and high level of best practice by the dietetic workforce across the UK.

I would like to extend my thanks and congratulations to all those involved with its production.

Pauline Douglas
Honorary Chairman

Introduction

The Health Act 1999[1] bestows the status of a profession on dietetics, which automatically carries the statutory requirement to regulate professional conduct for the protection of the service user. The title "Dietitian" is protected by law and can only be used by persons who are registered with the Health Professions Council (HPC).

This means that as registered practitioners, dietitians must:

- protect and support the health of individual service users;
- protect and support the health of the wider community;
- act in such a way that justifies the trust and confidence of the public;
- uphold and enhance the good reputation of the profession.

As independent practitioners, who practise autonomously, dietitians:

- are personally accountable for their practice. This means that dietitians are answerable for their actions and omissions, regardless of advice or directions from another professional;
- have a duty of care to their service users, who are entitled to receive safe and competent care;
- must adhere to the laws of the country in which they are practising.

Whilst this document addresses the profession of dietetics and dietitians, most aspects contained within it are pertinent to members of the wider dietetic workforce. This includes dietetic support workers and pre-registration student dietitians.

It is an obligation of this wider workforce to ensure that they apply these same principles and precepts within their own scope of practice to ensure the public's trust in the dietetic service provision and thus also in the profession of dietetics.

Although dietetic support workers are not currently regulated by statute, like dietitians, they are accountable for their actions in four ways:

- **To the patient/client – civil law (duty of care)**
  The support worker is accountable for their actions and omissions when they can reasonably foresee that they would be likely to injure service users, or cause further discomfort or harm, e.g. if a support worker failed to report that a patient had fallen out of bed.
- **To the public – criminal law**
  For example, if a support worker were to physically assault a patient, then they would be held accountable and could be prosecuted under criminal law, as well as being in breach of their contract of employment.
- **To the employer – employment law**
  Working outside their job description would breach the employment contract
- **To professional codes of conduct (e.g. The BDA Code of Professional Conduct)**
  A code of conduct exists for some professions. Ethical, moral and legal issues form these codes in conjunction with standards of practice.

Purpose

The purpose of the BDA *Code of Professional Conduct* is to provide a **set of principles** that applies to all dietitians. It requires the dietetic workforce to discharge their duties and responsibilities in a professional, ethical and moral manner.

Producing and promoting a code cannot alter the behaviour of an individual who is determined to act unethically. However, a major function of this code of conduct is to enable professionals to make an informed choice when faced with an ethical dilemma so that they do not behave unethically by error rather than by design.

There are five guiding principles which underpin professional conduct. These are:

- *Beneficence* – that the actions taken should do good;
- *Non maleficence* – taking steps to prevent harm to others;
- *Justice* – ensuring that people are treated fairly;
- *Fidelity* – being faithful to promises made (this includes the need to be explicit and realistic about what service can be provided);
- *Autonomy* – each individual has the right to freely choose their own course of action and to choose what happens to them.

This code may be used by others to determine the standards of professional conduct which can be expected from dietitians.

The code is necessarily broad and cannot provide definitive answers to the many dilemmas that dietitians may experience within their professional practice. For this reason, it is obviously open to different interpretations, depending upon the circumstances to which it is applied. However, if used as a **guidance** document, the Code should support all dietetic practitioners to ensure that their practice is safe, effective and of high quality.

This code is a public document which supplements the HPC *Standards of Conduct, Performance and Ethics*[2] and *Standards of Proficiency*[3]. It should be used in conjunction with *Professional Standards for Dietitians* (BDA 2003)[4] and other documents for guidance, such as *BDA Guidance on Records and Record Keeping* (BDA 2008)[16]*.* The British Dietetic Association (BDA) strongly recommends recognition of the Code by all other individuals, organisations and institutions involved with the profession.

It is the personal duty of every dietitian to ensure that their HPC registration is kept up to date.

Any action which conflicts with the word or spirit of this code should be considered unethical. It confers no rights, and offers no protection against any sanction imposed by the laws of the United Kingdom.

Uncertainty or dispute as to the interpretation or application of this code should be referred, in the first instance, to the Education and Professional Development section of the BDA office.

There are aspects of the code which will only be relevant for HPC registered professionals, and for these elements the protected title *Dietitian* is used.

Note

In this document the following terms are used:

"'You must" is used as an overriding principle or duty.

"You should" is used where the principle or duty may not apply in all circumstances or where there are factors outside your control affecting your ability to comply.

This document replaces *Code of Professional Conduct* which was issued by The British Dietetic Association in January 2004.

Section One

Service Users Autonomy and Welfare

Respecting the autonomy of the service user

1.1 You will at all times recognise, respect and uphold the autonomy of service users: i.e. their right to make choices and to work in partnership with dietetic practitioners. You will promote the dignity, privacy and safety of all service users.

1.1.1 You will respect the decisions of service users concerning their own health and independence, even when such decisions conflict with professional opinion.

1.1.2 Service users should be given sufficient information and time to enable them to make informed decisions, about their health and social care.

1.1.3 You will take care to present information in a way that service users can understand[3,6].

1.1.4 Reasonable steps should be taken to ensure that the service user understands the nature, purpose and likely effect of the proposed intervention[5,7].

1.1.5 Service users have a right to refuse intervention, and should be offered the opportunity to refuse it. Any such refusal should be respected and recorded in writing.

1.1.6 Discussions with, or about, service users should be confidential and be conducted in such a place and manner as to protect their privacy.

NOTE: Exceptional circumstances may, however, prevail, for example where the service user is deemed to lack competence in relation to consent to treatment (mental health legislation and current case law)[8,9,10,11,12,13].

Mental Capacity Act (2005) England and Wales[8] governs decision-making on behalf of adults, where they lose mental capacity at some point in their lives or where the incapacitating condition has been present since birth. The Act received Royal Assent on 7 April 2005 and came into force during 2007.

The *Adults with Incapacity Act (2000) Scotland* sets out in law a range of options to help people aged 16 or over who lack the capacity to make some or all decisions for themselves. It allows other people to make decisions on their behalf.

There is currently no equivalent law on mental capacity in Northern Ireland. The Bamford Review of Mental Health and Learning Disability is looking at how current law affects people with mental health needs or a learning disability in Northern Ireland.

Service User Well-being

1.2 You must not engage in or condone behaviour that causes mental distress or physical harm. Such behaviour includes neglect, intentional acts, indifference to the pain or misery of others and other malpractice.

1.2.1 Any intervention that may cause pain or distress should first be explained to the service user, who should also understand its nature, purpose and likely outcome, before it begins.

1.2.2 You should make every reasonable effort to avoid leaving a service user in pain or distress after any intervention. If distress continues, relevant parties should be informed as soon as is reasonably practical.

1.2.3 If you witness, or have evidence of, behaviour which appears to cause unnecessary or avoidable pain or distress (including unreasonable restraint), you have a duty to make this known confidentially to your line manager or other appropriate agency[12,13].

1.2.4 You should act to prevent such action from continuing, providing this action is within your professional competence and does not conflict with local policies and procedures. If you are unable to intervene you should withdraw from the action.

1.2.5 You should take all reasonable steps to prevent service users following action or advice which you know to be harmful to their health.

Duty of Care to the Service User

1.3 You have a duty to take reasonable care of service users.

1.3.1 Professional “duty of care” is established at the moment when you accept a service user for assessment and intervention. You have a duty to ensure that any intervention is likely to be of benefit to the service user.

1.3.2 You should be aware that you have a common law duty of care to your service users[2] and that a breach of this duty may lead to a civil claim for damages for negligence by the service user.

1.3.3 You must obtain adequate public liability insurance or professional indemnity cover for any part of your practice not covered by an employer’s indemnity scheme.

1.3.4 You must not refuse to treat someone just because the patient has an infection[2].

1.3.5 You must take appropriate precautions to protect service users, their carers and families, and yourself from infection. In particular you should protect your service users from infecting one another[2].

1.3.6 You must take precautions against the risks that you may infect someone else. This is especially important if you suspect or know that you have an infection that could harm others[2].

1.3.7 If you believe or know that you may have such an infection, you must get medical advice and act on it[2].

Section Two

Services to Service Users

Referral of service users

2.1 Dietitians shall only accept referrals which they deem to be appropriate and for which they have the resources[14].

2.1.1 It is the duty of the dietitian to determine whether the referral is appropriate. The referral may be made verbally or in writing by a medical practitioner, another health professional, or by individual service users.

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Dietitians have a threefold responsibility to ensure that the intervention is necessary and appropriate to:

a. the service user; to make sure that expectations are not raised that cannot be fulfilled, and to not waste time and resources treating service users for whom the treatment will not be or has ceased to be beneficial.

b. themselves as dietitians; by treating a service user who does not require such treatment. It is morally wrong to give treatment when it is not required, or when referral to another agency is necessary, or more appropriate.

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2.1.6.1 Actively harmful

Health Circular HC(77)33[15], *Relationships between the Medical and Remedial Professions,* includes comments by the Joint Consultants’ Committee. Para. 2(ii) states:

> *“In asking for treatment by a therapist (dietitian) the doctor is clearly asking for the help of another trained professional, and the profession of medicine and the various therapies differ. It follows from this that the therapist (dietitian) has a duty and a consequential right to* ***decline*** *to perform any therapy (intervention) which his professional training and expertise suggests is* ***actively harmful*** *to the patient. Equally, the doctor who is responsible for the patient has the right to instruct the therapist (dietitian) not to carry out certain forms of treatment which he believes harmful to the patient.”*

Medical colleagues have, therefore, clearly acknowledged that dietitians have the right to refuse to treat a patient/client/user when the treatment requested is considered to be actively harmful. It would be courteous in these circumstances and beneficial to the service user to discuss the matter with the medical practitioner and suggest an alternative course of management based on the dietetic assessment.

2.1.6.2 Unnecessary treatment

If it is clear that a request is inappropriate or cannot be justified in terms of possible benefits or available resources, the referring practitioner must be approached and the responsibilities of the dietitian explained as set out above. If the practitioner persists in making such inappropriate requests, it may be necessary for a more formal approach to be made by a dietetic service manager. Requests by the referrer for the number of sessions required to fulfill a therapeutic intervention should also be challenged. It is not considered good practice to let the medical practitioner assume that their request is being carried out, when the dietetic intervention considered appropriate is substantially different.

2.1.6.3 Treatment of dubious benefit

Many areas of healthcare, although appearing to have a beneficial effect, have not been evaluated or researched. It is the responsibility of each individual dietitian to keep up to date in respect of the research, evaluation of dietetic practice and approaches to the care of various conditions. If such a request is made, the dietitian has a duty of care to discuss, with both the service user and the referrer, the implications of the intervention and negotiate the way forward.

Equity of service provision

2.2 You will provide an equitable service to all service users.

2.2.1 You should provide services that are sensitive to, and which value and respect, the diversity of culture and lifestyle.

2.2.2 You must not allow your views about a service user's sex, age, colour, race, disability, sexuality, social or economic status, lifestyle, culture, religion or beliefs to affect the way you treat them or the professional advice you give[2]. You should strive for consistency of care at all times and in all situations.

2.2.3 You must not judge service users and you should ensure that children and other vulnerable individuals are protected.

2.2.4 Resources will never be infinite and therefore choices about their use will have to be made. Priorities should always be based on sound ethical principles and current best practice in relation to the reasonableness, availability and suitability of services to meet the needs of patients/clients/users.

Provision of services to service users

2.3 Services should be centered on the needs of the service users.

2.3.1 You should act to uphold and promote service users' autonomy.

2.3.2 You should report to employers any deficiencies of provision for service users, and should substantiate your concerns.

2.3.3 If you feel unable to practise safely and effectively, you have a duty to raise your concerns with your employers. This dialogue must be recorded[14].

Recording of information

2.4 You should keep accurate records

2.4.1 You should keep a written (and/or electronic) record of the intervention, advice given and the outcome of decisions taken.

2.4.1.1 Every service user should have a clearly recorded assessment of need and objectives of intervention.

2.4.2 Records should be accurate, legible, factual, in sequence, made promptly, and signed by the person who made them.

2.4.3 If you are delegating care activities to another member of staff appropriately (e.g. students, support workers) there must be a system in place to ensure the accuracy of the record, i.e. that what has been done has been accurately recorded. This may, but not necessarily, include countersigning their entries. Until there is UK-wide national guidance on the countersigning of records by support workers and students the decision is one for individual departmental interpretation. Further information and guidance on this can be found in the *BDA Guidance on Records and Record Keeping Document 2008*[16].

2.4.4 Subjective opinion should always be identified as such and should be clinical and relevant.

2.4.5 Records should be stored securely so as to be confidential[16,27].

Confidentiality

2.5 You are ethically, morally and legally obliged to safeguard confidential information relating to service users[2,18,31].

2.5.1 The disclosure of confidential information to a third party is normally only permissible where the service user gives consent (expressed or implied); or when there is legal justification (by statute or court order); or it is thought to be in the public interest to prevent serious harm to anyone[2].

2.5.2 Disclosure of the service user's diagnosis, treatment, prognosis or future requirements should only be made when there is valid consent or legal justification.

2.5.3 Records should be kept secure from all but those who have a legitimate right/need to see them[19].

2.5.4 Local and national policies on the confidentiality and storage of electronic notes (including faxes and e-mails) should always be followed.

2.5.5 Access to records by service users must only be granted in accordance with current statutory provision. Reference should be made to current codes of practice and other guidance (both local and national) on access to personal health information, particularly in relation to:

Policies and Procedures

Access to Personal Files Act 1987[20]
Data Protection Act 1998[21]
Human Rights Act 1998[22]
Access to Medical Reports Act 1988[23]
Access to Health Records Act 1990[24]
Caldicott Guidance 1999[27]
The Children Act 1989[28]
The Freedom of Information Act 2000[29]
Confidentiality: NHS Code of Practice 2003[30]

NOTE: Exceptional circumstances may, however, prevail where the rights of access to information may be curtailed in certain circumstances such as the Children Act 1989 and Data Protection Act 1998.

Section Three

Personal/Professional Integrity

Personal integrity

3.1 The highest standards of personal integrity are expected of you.

3.1.1 You have a duty to refrain from bullying and other forms of harassment, and to be aware of how your behaviour affects others[32].

3.1.2 You have a duty to behave safely, responsibly and legally online, particularly in relation to the use of social networking sites. You must not:

- breach confidentiality and data protection laws;
- engage in potentially libellous gossip;
- bring your profession into disrepute.

Personal relationships with service users

3.2 You will not enter into relationships that exploit or abuse service users sexually, physically, emotionally, financially, socially or in any other manner.

3.2.1 It is considered unethical for you to enter into relationships which may impair your professional judgment and objectivity and/or may give rise to advantageous/disadvantageous treatment of the service user.

Professional integrity

3.3 You should not criticise any colleague in public.

3.3.1 You may give expert evidence in court about the alleged negligence of a colleague, though such evidence should be objective and capable of substantiation. **If you should witness malpractice by any other professional, under no circumstance should you remain silent about it.**

3.3.2 If you have reasonable grounds to believe that the behaviour or professional performance of a colleague, of whatever discipline, is below the expected standards of professionalism, this should be notified confidentially to your line manager or other appropriate person in accordance with the recommendations of the NHS Executive following the *Public Interest Disclosure Act* 1998[33] (HSC1991/198)[34]. For those working outside the NHS setting, advice should be sought from the BDA or the HPC registrar[2].

3.3.3 Care should be taken, when giving a second opinion, to confine it to the issue and not the competence of the first professional.

Whistle-blowing

3.4 You should be aware of the available mechanisms for "whistle-blowing"[33,34,35].

3.4.1 If you are employed within the NHS you should be aware of the nominated officer in your Trust/Board, with whom you should consult when appropriate. **All staff are protected in these circumstances.** If you are not employed by the NHS you should seek advice from the BDA.

3.4.2 Whistle-blowing should not be used to resolve personal, partnership or business disputes. In these cases, any areas of concern must be raised with the individual first.

Professional demeanour

3.5 You must conduct yourself in a professional manner appropriate to the setting.

3.5.1 At all times when carrying out professional duties, you must act in such a way as to maintain the confidence of the service user.

3.5.2 You should wear appropriate uniform or work-based clothing which meets the need to inspire confidence in your patients and to afford protection against cross infection risks and other health and safety considerations. Your employing authority will determine the nature of your work-based clothing which must also take into account the cultural and religious requirements of members of staff.

Personal health and substance misuse

3.6 You must not work whilst under the influence of any substance which is likely to impair the performance of your duties.

3.6.1 You must not misuse, nor encourage others to misuse, alcohol, drugs or other substances.

3.6.2 You must seek advice and take action if you become aware that your physical and/or mental health could affect your fitness to practise.

3.6.3 You must inform the HPC about any significant changes to your health, especially if you have changed your practice as a result of medical advice[2].

Personal profit/gain

3.7 You must not accept favours, gifts, or hospitality from service users, their families or commercial organisations when the offer might be construed as an attempt to gain preferential treatment[36,37].

3.7.1 Your prime duty is to the service user and you should not let this duty be influenced by any commercial or other interest that conflicts with it.

3.7.2 A bequest in a will to you by a service user should be declared to your employer, where appropriate.

3.7.3 Local policies concerning gifts should be observed.

NOTE: In certain cases, the property and affairs of a service user may be subject to the authority of the Court of Protection.

Advertising

3.8 You may make direct contact with potential referring agencies in order to promote your services.

3.8.1 Dietitians should be guided by the *HPC Standards of Conduct*, *Performance and Ethics*[2] and the *Standards of Proficiency: Dietitians*[3].

3.8.2 You must take care not to make or support unjustifiable statements relating to particular products.

3.8.3 If you are involved in advertising or promoting any product or service, you must make sure that you use your scientific knowledge, clinical skills and experience in an accurate and professionally responsible way. You must not make or support unjustifiable statements relating to particular products. Any potential financial rewards to you should play no part at all in your advice or recommendations of products and services that you give to patients, clients and users.

Representation of information

3.9 You must give a true account of your qualifications, education, experience, training and competence and the services you can provide.

3.9.1 You shall not convey any information you know, or have reasonable grounds to believe, to be false, fraudulent, deceptive or untrue.

3.9.2 If you become aware that information which you have given about your employment is false you should notify the appropriate authority.

Sustainability

3.10 Public accountability and respect for the environment

3.10.1 You have a responsibility to The Association, to tax payers, to the wider community and to the environment not to waste resources. You should demonstrate due regard for the sustainable management of resources at your disposal and should use resources responsibly and efficiently as is practicable.

Section Four

Professional Competence and Standards

Professional competence

4.1 You shall achieve and maintain high standards of competence.

4.1.1 You are responsible for the maintenance of your own professional competence and knowledge of the laws affecting your practice[2].

4.1.2 You must only provide services for which you are qualified by education, training and/or experience, and which are within your professional competence and scope of practice[2,4,38].

4.1.3 If you are asked to act up or cover for an absent colleague you must identify and decline to undertake any aspect of work which you know or believe to be outside the scope of your clinical competence. Such duties should not be undertaken in the absence of adequate supervision and training[2,4].

4.1.4 Dietitians seeking work for which their training or experience is insufficient or out of date have a responsibility to ensure that adequate self-directed learning, training and supervision takes place[38].

Delegation

4.2 Dietitians who delegate treatment or other procedures must be satisfied that the person to whom these are delegated is competent to carry them out. Such persons may include students, support workers or volunteers. In these circumstances the dietitian will retain ultimate responsibility for the service user[2,40,41].

4.2.1 Dietitians must provide supervision appropriate to the level of competence of the individuals for whom they have responsibility.

4.2.2 When delegating work to others, dietitians have a legal responsibility to determine the knowledge and skill level required to perform the delegated task.

4.2.3 The dietitian is accountable for the delegation of the task, and the support worker/student is accountable for accepting the delegated task, as well as being responsible for his/her actions in carrying it out.

Collaborative practice

4.3 You will respect the needs, working practices, skills and responsibilities of others with whom you work.

4.3.1 You should acknowledge the need for multi-professional collaboration to ensure the provision of well-coordinated services delivered in the most effective way. In so doing the unique contribution of each profession should be acknowledged.

4.3.2 Dietitians must refer service users to, or consult with, other service providers when additional knowledge and expertise is required.

4.3.3 With the exception of seeking a second opinion, it is in the interests of good service user care and best practice that there should be one dietitian taking overall responsibility for the assessment and treatment of a service user for any one episode of care.

4.3.4 When more than one dietitian is involved in the treatment of the same service user, they must liaise with each other and agree explicit areas of responsibility.

Continuing Professional Development

4.4 It is your responsibility to develop your knowledge and skills and keep yourself up to date[2,3,39].

4.4.1 You must continue to develop and maintain your professional knowledge and skills.

4.4.2 You should keep a record of your professional development[25,39].

4.4.3 You should set annual objectives in partnership with your line manager or appropriate professional peer as part of the appraisal process.

4.4.4 You must engage in a range of CPD activities of which a key component is practice supervision[2,25,26]. A minimum recommendation is at least one session every two months. Further guidance on practice supervision can be found in the *BDA Practice Supervision Guidelines September 2008*[42].

4.4.5 It is your duty to ensure that your practice is evidence based, wherever possible.

Dietetic student education

4.5 Dietitians have a professional responsibility to participate in the education of dietetic students.

4.5.1 Dietitians should ensure they have adequate training and skills to be a competent trainer before training dietetic students.

4.5.2 Dietitians should treat all students with fairness and respect.

4.5.3 Dietitians should ensure that they promote student-centred learning and that the training they offer is appropriate to the student’s level of education and training.

4.5.4 When accepting a student for placement, dietitians should have a clear understanding of their role and responsibility and those of the student and the educational institution.

4.5.5 Dietitians should regularly evaluate the quality of their training and strive for continuous improvement.

Development of the profession

4.6 Dietitians should promote an understanding of, and contribute to, the development of dietetics.

4.6.1 Dietitians have a responsibility to contribute to the continuing development of the profession by critical evaluation, audit and research.

4.6.2 Dietitians undertaking research and audit must always address the ethical implications and refer to local protocols.

4.6.3 Dietitians undertaking research or audit have a responsibility to share their findings in order to inform or change practice.

Acknowledgements

This document has been based on the Code of Ethics and Professional Conduct for Occupational Therapists 2000, the Chartered Society of Physiotherapy Rules of Professional Conduct 2002 and the Nursing and Midwifery Council Code of Professional Conduct 2002 and the Society of Radiographers Code of Conduct and Ethics 2007.

The Code of Professional Conduct was revised by Najia Qureshi, Professional Development Officer on behalf of the Professional Development Committee of The British Dietetic Association.

Please direct any enquiries on this document to the Education and Professional Development Section of the Association.

September 2008

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BDA
The Association
of UK Dietitians

Code of Professional Conduct

Introduction

The British Dietetic Association proudly represents the whole of the dietetic workforce in the UK, and is the only body to do so. The Code of Professional Conduct applies to all members who may be dietitians, dietetic support workers, dietetic students or nutritionists, and applies to all the roles and settings in which they work. It sets out the high standards of behaviour required of BDA members. Members have an obligation to adhere to the standards within this Code, and those of their regulator (HCPC, SENr), their employer, and educational institution as appropriate.

The Code is based on three core standards:

1. Values

Members will respect an individual's needs, values, culture and privacy, and act with integrity, honesty and openness.

2. Practice

Members will put the interests of their service-users first, practise safely and effectively, and identify and manage risk.

3. Knowledge and Skills

Members will seek to promote best practice, based on the most up-to-date knowledge, practice and evidence, whist developing and pushing the boundaries of dietetics and dietetic services.

The standards are necessarily broad and cannot provide definitive answers to every situation a member may encounter over the course of their career. They have been written in such a way as to provide members with the freedom to advance, develop, and innovate practice in their chosen area of nutrition and dietetics, centered on the needs and expectations of their service users.

1. Values

Members will respect an individual's needs, values, culture and privacy, and act with integrity, honesty and openness.

The BDA places these values at the heart of professional behaviour, and they describe core expectations for all members whatever the setting, sector or role in which they choose to practice. Ethical and moral dilemmas will routinely arise over the course of a career in dietetics. In most situations it will be clear and easy to demonstrate professional behaviour. However, there will inevitably be times when challenges will require deeper thought and personal reflection in order to safeguard service users from unprofessional behaviour. The BDA expects members to proactively engage in peer support, discussions, practice supervision, and use all other tools available to them to ensure they uphold these values.

Members will:

- Ensure services which do not discriminate, are provided to all individuals with particular regard to any characteristics protected under law including: age, disability, gender reassignment, sex and sexual orientation, religion and belief, race, pregnancy and maternity, marriage and civil partnership.
- Respect the rights of individuals to make informed choices.
- Adhere to the laws governing mental capacity, and ensure that the rights and best interests of those who lack capacity are always at the centre of the decision making process.
- Respect the confidence and trust placed in them in their relationships with service users.
- Promote a professional relationship and maintain appropriate professional boundaries between themselves and service users.
- Treat their service users and colleagues with compassion and empathy, fairness, honesty, courtesy, respect and in good faith.
- Ensure that they do not exploit relationships with clients for emotional, sexual or financial gain.
- Be impartial, objective and honest in their actions towards their service users.
- Be aware of personal biases, and reflect on how personal perspectives may influence their practice.
- Behave in a way that promotes confidence in the profession.
- Not accept private financial benefits or favours, which could be interpreted as an attempt to gain preferential treatment, or present a conflict of interest.
- Advocate for the health and welfare of their service users.
- Be open and honest if things go wrong.

2. Practice

Members will put the interests of their service users first, practise safely and effectively, and identify and manage risk.

The scope of the profession is constantly evolving to meet the demands of services, service users and other social, economic and environmental factors. Each dietetic intervention will be different, with competing and conflicting demands. The BDA expects members to be aware of the many factors that will have an influence on their practice, including food, nutrition and health policy, standards, rules and regulations, healthcare systems, national guidelines and industry standards. Members must only undertake activities which fall within their scope, in a way that is collaborative, safe and effective and will strive to secure the best outcomes from nutrition and dietetic interventions.

Members will:

- Ensure appropriate consent has been given for any dietetic intervention.
- Respect and safeguard confidentiality of service user information.
- Be able to articulate the limits of their personal scope of practice and practise within them.
- Work within the current scope of dietetics, and look to influence the evolving scope of the profession.
- Provide high quality, cost efficient services based on the needs of the population and service users.
- Be accountable for their decision making, given that they have a moral and legal obligation for the provision of safe and competent service delivery.
- Report and escalate unsafe and unethical practice, and support colleagues who appropriately notify the relevant authorities of such practice.
- Take appropriate action if there are concerns about the safety and wellbeing of a service user.
- Respect the collaborative nature of comprehensive health care with recognition and respect for the perspective and expertise of other health professionals.
- Not use inaccurate or misleading ways to promote their services or products.
- Behave safely, responsibly, legally and ethically online, particularly in relation to social networking sites.
- Provide services within the legal requirements of professional indemnity cover, occupational health, welfare and safety and workplace requirements.
- Delegate work only to those who have the knowledge and skills to undertake the work safely and effectively.
- Accept responsibility for their own physical and mental health, in order to practise safely.

3. Knowledge and skills

Members will seek to promote best practice, based on the most up-to-date knowledge, practice and evidence, whist developing and pushing the boundaries of dietetics and dietetic services.

Dietary modification is at the core of dietetic practice. The skills of the dietetic workforce lie in assessing the needs of an individual, community or population, the risks and challenges, and deciding how they may best be addressed in those particular circumstances. The dietetic workforce is unique in being able to manage, lead and support nutrition and dietetic interventions by using sound evidence, practice and reasoning. Members have a personal responsibility to maintain and advance their own knowledge and skills by undertaking regular continuing professional development. The BDA expects members to contribute to the development of the nutrition and dietetic evidence-base within their own scope of practice.

Members will:

- Recognise the limits of their own competence, and refer on to an appropriate provider if necessary.

- Undertake CPD and practice supervision, so as to continually reflect, update, evaluate and extend professional knowledge and skills appropriate to their role and promote emotional resilience.

- Communicate appropriately and effectively with service users and colleagues.

- Practise within current evidence and practice-base.

- Limit the provision of advice about alternative therapies to those who voluntarily seek it, and actively discourage therapies which might be harmful.

- Understand and respect diversity of nutrition and dietetic practice and promote an ecological, social and economic environment which supports health and wellbeing.

- Interpret, apply, participate in or generate research and audit, to enhance practice and develop a unique body of dietetic knowledge.

- Demonstrate leadership within their scope of practice, for example through problem solving, enhanced service delivery, or role extension.

- Ensure that outcome measures demonstrate the value of dietetic intervention.

- Contribute to the learning and development of students and colleagues, as appropriate to member’s role.

The Association
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The Association
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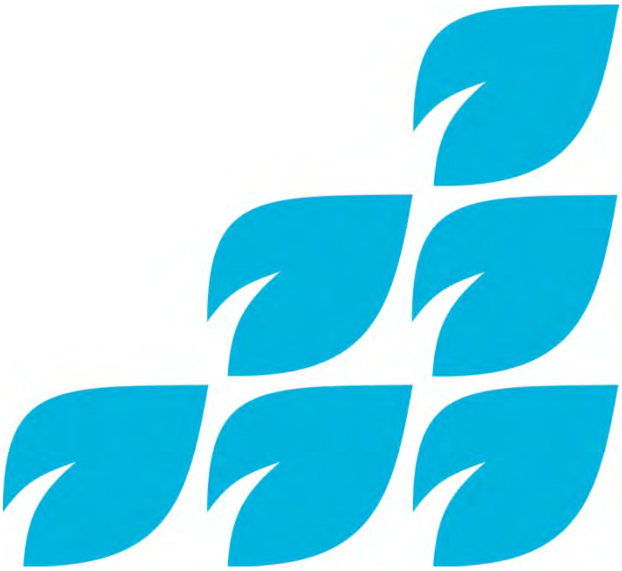
Guidance for Dietitians for Records and Record Keeping



Contents

1 What is the purpose of this document?

Record keeping is a fundamental part of professional practice. Whatever the type of work you do you need to keep records. The purpose of this document is to provide record keeping guidance for the individual dietitian and other members of the dietetic team. It replaces the *Joint BDA/Dietitians Board Guidance on Standards for Records and Record Keeping* (2001)[1].

The principles are applicable to all areas of practice. The guidance does not define a rigid framework, nor is it designed as an auditable standard; it aims to inform you of key record keeping issues. The ultimate responsibility for record keeping lies with you, as an autonomous and accountable practitioner using your professional judgement, to decide what is relevant and what should be recorded.

A requirement of your professional practice is that that you must follow the relevant legislation. It is essential for you to be aware of the local organisational policies and procedures that apply to record keeping within your particular work setting.

You need to be aware of the range of individuals who could potentially access the record and read what you have written. These could include other members of the multi-disciplinary team, the patient, the patient’s carers, social workers, audit staff, lawyers and their legal team and others. Remember that if you haven’t written down what you have done it might as well not have happened.

The Health Professions Council (HPC) Standards of conduct, performance and ethics (2008)[2] states that:

> *“You must keep accurate records. Making and keeping records is an essential part of care and you must keep records for everyone you treat or who asks for your advice or services. You must complete all records promptly. If you are using paper-based records, they must be clearly written and easy to read, and you should write, sign and date all entries.”*

The *BDA Code of Professional Conduct* (2008)[3] and *The BDA Professional Standards for Dietitians* (2004)[4] make reference to record keeping and underpin the HPC Standards.

2 What is a record?

Records are a reminder of what has happened. They must be accurate, up-to-date and accessible by those who need to see them at the time, and in the place where they are needed.

An NHS record is anything which contains information (in any media) which has been created or gathered as a result of any aspect of the work of NHS employees – including consultants, agency or casual staff. Records are not just patient (care) records but include patient cards, minutes of meetings, research and audit data, x-rays, personnel files, CPD portfolios, care plans, diaries and e-mails. A record may be in a paper, electronic (including memory stick) or other media format.

A **health record** is defined in section 68 (2) of the Data Protection Act 1998[5] as:

> *"A record consisting of information about the physical or mental health or condition of an identifiable individual made by, or on behalf of, a health professional in connection with the care of that individual."*

A **shared record** is a single record to which all members of the multi-disciplinary healthcare team involved in the care of an individual make entries. A **care record** is anything that makes reference to the care of an individual. There are no single templates or models for health, shared or care records.

Service users have the right to request access to their records and in healthcare should be made aware of their content by actively involving them in the planning and implementation of their care.

3 The purpose of a record

Record keeping is an essential, integral part of practice and is a legal requirement. Good record keeping helps to promote high standards of professional practice and is a reflection of a safe practitioner. Records must be:

- complete
- accurate
- relevant
- accessible (to those with the right of access)
- timely.

Any document that records any aspect of care (a record) can be used as evidence in a court of law, to investigate a complaint at a local level or at professional hearings, e.g. Public Inquiries such as The Kennedy Report (from the Bristol Inquiry)[6] and The Health Professions Council Fitness to Practise Hearings[7]. Courts of law tend to adopt the view that "if it is not recorded, it has not been done".

Records have a secondary function for audit, research, public health and service planning.

4 Who owns the record?

The ownership of the record depends on your particular work setting.

Records of NHS organisations (and those of predecessor bodies to NHS organisations) are defined as public records under the terms of the Public Records Act 1958[8] sections 3(1)-(2). NHS records are not owned by the NHS organisation that created them.

In England, The Secretary of State for Health owns all records, including GP records. The Personal Child Health Record (aka "The Red Book") belongs to the principle carer, e.g. the parent of the child. General practice notes are technically owned by the local health authority and/or by the Department of Health. Chief Executives and senior managers of all NHS bodies are personally accountable for records management within their organisation and have a duty to make arrangements for the safe-keeping of those records.

In Scotland NHS records are managed under the overall guidance and supervision of the Keeper of the Records of Scotland.

Where a professional is contracted to provide a clinical service to another organisation, contractual conditions will normally specify the legal owner of any records kept.

In the private sector, records are the property of the employer. Notes for private patients may be the property of the consultant or the private hospital.

For clinical records, if you have treated the patient and entered information into the record, you must have reasonable access to the record; particularly if, after leaving that employer, a complaint or allegation is made against you.

5 Quality of record keeping

In the NHS Chief Executives and Senior Managers are personally responsible for the quality of records management within their organisation.

The quality of record keeping is a reflection of the standard of professional practice. Good record keeping is the mark of the skilled and safe practitioner while careless or incompetent record keeping often highlights wider problems with the individual's practice (NMC, 2005).

> *"The quality of your record keeping is also a reflection of the standard of your professional practice. Good record keeping is a mark of the skilled and safe practitioner, whilst careless or incomplete record keeping often highlights wider problems with the individual's practice."*
>
> Nursing & Midwifery Council. Record Keeping Guidance. Advice sheet. Updated July2007

5.1 Good record keeping

Good record keeping ensures that:

- You can work with maximum efficiency without having to waste time hunting for information
- There is an audit trail which enables any record entry to be traced to a named individual at given date/time with the secure knowledge that all alterations can be similarly traced
- Those coming after you can see what has been done, or not done, and why
- Any decisions made can be justified or reconsidered at a later date.

5.2 Risk

If records are in a poor condition, mistakes are more likely to be made and any defence will be weaker in the case of litigation. Contemporaneous, clear and accurate notes/records will reduce this risk. The legal view is generally that if it isn't recorded there is no proof that it happened.

Using records as part of routine clinical supervision and regular audits of record keeping are ways of monitoring standards of record keeping.

Many Health Profession Council (HPC) hearings[7] have a record keeping element to them, referred to in the 2006 fitness to practise annual report[10], as a "misconduct" element including:

- Poor record keeping
- Failure in communication
- Breach of confidentiality – providing information to those who are not entitled to it
- Acting beyond scope of practice
- Failure to get informed consent.

The Healthcare Commission in 2007[11] highlighted that 3% of complaints were directly about record keeping and many more mentioned record keeping alongside other issues. In their response to this report, The Medical Defence Union (MDU)[12], commented that they were aware of a number of complaints where poor records have caused problems with continuity of patient care and have created difficulties with doctors in recalling their actions (for example, where advice given over the telephone is not recorded).

5.3 General principles for the completion of patient/care records

5.3.1 Style

You should:

- Use a style that is appropriate to the type of intervention/meeting
- Use factual, clear, accurate and unambiguous language
- Try to avoid using jargon
- Be objective and avoid casual subjective remarks
- Avoid abbreviations or terminology that might not be understood
- Remember that an individual has the right to request to see their care record.

5.3.2 Use of abbreviations in care records

The BDA does not have a definitive list of abbreviations. The use of abbreviations varies both nationally, regionally and locally and also among groups of different health professionals. Some NHS organisations have produced a locally agreed list of abbreviations. It is good practice to check with your line manager, healthcare records committee (or equivalent body), or clinical risk manager if your organisation has such a list.

5.3.3 Content

You must:

- As a minimum follow local policy and guidance
- Maintain records to an agreed standard of good practice
- Complete the record as **soon as is possible** after the consultation or event. Agreed local policy or procedure should be followed. Good practice is for you to aim to do this by the end of the working day, where individual circumstances allow. Remember that “not having time” is not a defence for not maintaining the record
- Date and sign each new entry; there must be a means of identifying the signature and designation of the person making the entry to the record. Keeping an up-to-date departmental log sheet of staff names and signatures is recommended
- Sign in full the first time you make an entry to a record. Subsequent entries can be initialled

- Write neatly and legibly and use black ink (this photocopies clearly unlike coloured inks). Never use pencil as this can be erased or fade over time
- Record details of information given
- Rough notes are part of the record unless their contents are transcribed into the main body of the record. After transcription the rough notes can be destroyed using the disposal process for confidential waste.

Specific to clinical records

You must:

- Document the evidence for, or the reasonable basis for, any decision that you have taken relating to the individuals care in order to justify the decisions you have taken
- Document the source of referral
- Document relevant conversations with other healthcare professionals and family/carers.

The notes are an accurate record that should not be modified. A correction may be added to at a later date if this is necessary.

5.3.4 Mistakes/amendments

You must follow local policy. The following is good practice:

- Draw a single line through the entry so that the original entry is still clearly visible
- Initial and date the amendment
- Make a margin note against the entry explaining the reason for the amendment
- Never use eraser/white out liquid, or permanently remove the original entry on a patient record in any way
- If a major correction is necessary you should explain the reason for this.

6 Making a care record: responsibility of the individual dietitian

The HPC standards of conduct, performance and ethics[2] state that:

> *"Making and keeping records is an essential part of care and you must keep records for everyone you treat or who asks for your advice or services."*

If you are employed by the NHS, you are responsible for any records which you create for use in the performance of your duties. All individuals who record, handle, store or otherwise come across information, have a personal, common law duty of confidentiality to patients and to their employer. The duty of confidence continues even after the death of patients and after you have left the NHS.

You are required to provide accurate, current, comprehensive and concise information which justifies the decisions you make for the treatment, care and support provided or planned for the patient/client, by providing:

- Accurate, current and comprehensive information concerning the condition and care of the individual and associated observations
- A record of any problem that arises and any actions subsequently taken
- Chronological evidence of the care required, action taken by the dietetic team member and the patient/service users response
- A record of any factors e.g. physical, psychological or social that appears to affect the service user
- A record of the sequence of events and the reasons for any decisions made
- A way of capturing data which can be used to support a number of secondary purposes e.g. quality assurance, research and clinical audit, service management and public health information
- A baseline record against which improvement or deterioration may be judged
- A demonstration of evidence-based practice
- A vehicle for good communication and dissemination of information within the multi-disciplinary team
- A basis for continuity of care
- Proof that legislation has been met.

Additionally, the information contained in a record is only of use if you have:

- Accurately recorded the information in the first place
- Ensured that it is available to those who need to see it
- Written it in such a way that others can understand your actions so they can act appropriately.

6.1 Delegation and counter-signing

The HPC Standards (HPC) standards of conduct, performance and ethics[2] state that:

> *"Whenever you give tasks to another person to carry out on your behalf you must be sure that they have the knowledge, skills and experience to carry out the tasks safely and effectively. You must not ask them to do work which is outside their scope of practice.*
>
> *"You must always continue to give appropriate supervision to whoever you ask to carry out a task. You will still be responsible for the appropriateness of the decision to delegate. If someone tells you that they are unwilling to carry out a task because they do not think they are capable of doing so safely and effectively, you must not force them to carry out the task anyway."*

The decision to delegate and countersign must be a reasoned, individual decision, taking account of country, regional or local practice, policy and guidance. The ultimate responsibility about when and how delegation and countersigning takes place lies with you as the supervising dietitian.

Countersigning does not absolve you of your responsibility. Supervision records are important and should be documented to the same standards as care records.

If you delegate activities to another person (e.g. student, support worker or health trainer) you should:

- Ensure that they have received appropriate training and are sufficiently competent to do the delegated task
- Ensure that supervision is adequate
- Ensure that there is a system in place to ensure the accuracy of the record (medical/multi-disciplinary (shared)/dietetic), i.e. that what has been done has been accurately recorded.

You may decide that the delegation includes them documenting their actions without the requirement to have their records countersigned. Alternatively you may decide to countersign their entries. This may not necessarily mean that their records require countersignature on a daily basis. It may be more appropriate for this to take place at the time when you routinely review their work.

It is advisable to use your full signature when countersigning rather than initialling.

6.1.1 Team members undergoing training/assessment of competence

These include dietetic students, support workers, junior workers, returnees to the profession and dietitians working under HPC Conditions of Practice. Local policy should be checked as there may be formal arrangements for new staff, returnees and those who are on a career break etc.

6.1.1.1 Support worker

Whilst the support worker is being trained, or whilst their competence is being assessed, i.e. work has not yet been fully delegated to them, you may take the decision to countersign any record that they make until they have been assessed and deemed competent.

6.1.1.2 Student

The HPC Standards of conduct, performance and ethics[2] state that:

> *"You have a duty to make sure, as far as possible, that records completed by students under your supervision are clearly written, accurate and appropriate."*

A student is not formally judged to be competent until the end of their placement. The registered dietitian is still accountable for all patient care that a student undertakes whilst under supervision. Supervision can be carried out at a distance; where the student is not directly observed but reports back to the supervisor on a regular basis. You may decide to countersign any record that they make in line with local policy.

7 Responsibility of the organisation

7.1 Care records

All NHS records are public records under the terms of Public Records Act[8] and must be kept in accordance with a number of statutory and NHS guidelines. NHS organisations must have policies and procedures in place governing access to information, and for the storage, retention and destruction of records. These will apply whether the record is paper-based, electronic or stored in other formats such as memory sticks, CD, DVD, tapes, microfiche, etc.

The employing organisation is the owner of the record. The information contained within the record remains confidential and the individual whose record it is has the right to limit access to specific categories of information recorded about them.

7.1.1 Private sector

In the private sector, records are the property of your employer. However if you have treated the patient you must have reasonable access to that record; this is particularly important if, subsequent to leaving this employment, a complaint or allegation is made against you.

8 Security

8.1 General principles

You must be extremely vigilant in safeguarding records and take all reasonable steps to ensure this (also see section 11.0) including:

- Following local policy for the storage, transport and security of care records. In the absence of any policy guidance should be sought from your line manager
- Storing records safely (e.g. in a lockable filing cabinet)
- Using filing systems to enable easy retrieval
- Where it is not possible for NHS community staff to return records to the staff base/records department at the end of a working day, they should be stored overnight in their home. Under no circumstances should records be left in vehicles overnight.
- When records are left in a vehicle you should lock them in the boot and ensure that they are not visible
- Maintaining confidentiality at all times. Do not take other patients'/clients' records into the home of another
- Do not leave records unattended in insecure areas
- Informing the organization's Caldicott Guardian immediately of any loss or misplacement of any document that is used to record patient information.

8.2 Electronic and computer records

You must safeguard records by following national and local policy. This includes:

- Logging in and out of sessions
- Using passwords appropriately. You must not share these with other people; this may result in disciplinary action being taken against you
- Regularly changing your password in accordance with local policy
- Ensuring the information displayed on the computer is not visible to those who do not have authorisation to view
- Do not store unencrypted patient information on personal storage systems such as laptops or memory sticks.

8.3 Retention and disposal of records (NHS)

Each organisation must have a retention/disposal policy covering all records held by the organisation, including electronic records. The length of retention varies according to the type of record and its importance to the organisation's business. All records must be stored securely until minimum retention periods have expired. Retention periods are listed in national guidance (see further reading).

If you are self-employed, then any record you have made relating to the care of a patient should be retained for at least eight years for an adult and until the date of a child's 21st birthday.

Under the Freedom of Information Act 2000 (see further reading Section 9: The legal status of a record), procedures for the disposal of records must be documented. Records of disposal must be kept indicating what has been destroyed/transferred, when and by whom. This is to ensure that the organisation is aware of those records that have been destroyed and are therefore no longer available.

Most NHS records are confidential records and it is vital that confidentiality is safeguarded at every stage. It is the responsibility of the NHS organisation to ensure that the methods used throughout the destruction process provide adequate safeguards against the accidental loss or disclosure of the contents of the records.

9 The legal status of a record

All UK records are subject to the requirements of the Data Protection Act 1998[5]. The Data Protection Act 1998 is not confined to NHS health records – it applies equally to the private health sector and to health professionals' private practice records.

In England the Public Records Act 1958[8] requires all NHS employees to be responsible for any records that they create or use in the course of their duties and these are public records.

In Scotland all NHS records are owned by Scottish Ministers on behalf of the Crown. They are therefore subject to the provisions of the Public Records (Scotland) Act 1937[13].

In Northern Ireland all HPSS records are public records under the terms of the Public Records Act (Northern Ireland) 1923[13a].

10 Information governance

Information governance provides a framework for handling and protection of personal information, paper or electronic, in a confidential and secure manner to appropriate ethical and quality standards. In summary:

- The interests of service users come first.
- People's information should be stored in a secure manner – this includes any rough/working notes relating to their care.
- Service users have a right to confidentiality – informed consent and personal autonomy should underpin the provision of health and social care.
- If you are providing care you must comply with legislation and meet the HPC standards.

10.1 Consent

The ability to obtain informed consent is a requirement of both the HPC Standards of Proficiency for Dietitians and the HPC Code of Conduct, Performance and Ethics[2]. The BDA documents *Good practice in consent: A guide for dietitians* (BDA 2002[14] – under review 2008) and *Code of Professional Conduct*[3] underpin these documents.

Consent to treatment does not necessarily have to be given verbally, i.e. formally, but can be implicit e.g. as shown by a patient co-operating with being weighed.

You must make sure that service users are fully aware if, and why, any information about them is to be shared or disclosed and to whom that information will be given. You should also tell them what the likely impact of not doing this will be upon their care or the services they will receive.

You must take particular care not to disclose health information about any third parties when this is shared or disclosed without their specific informed consent.

10.1.1 Mental Capacity Act (England and Wales) 2005[15]

This has wide ranging consequences for all health and social care practitioners who work with people who may lack capacity to make specific decisions. If patients lack the capacity to make specific decisions you are required to record if, how and why they reached a decision, how they are involved in the decision making process and you need to be able to justify your actions in relation to those decisions.

10.1.2 Children

Personal information about children and families held by professionals is subject to a duty of confidence, and should normally not be disclosed without the consent of the subject. However, the law permits the disclosure of confidential information necessary to safeguard a child.

The BDA Code of Professional Conduct (2008)[3] and the BDA Guidance on Consent (2008)[14] provide more detailed guidance on consent.

10.2 Confidentiality

The ability to maintain confidentiality is a requirement of both the HPC Standards of Proficiency for Dietitians[16] and the HPC Code of Conduct, Performance and Ethics[2].

The HPC's *Confidentiality: Guidance for Registrants* (2008)[17] provides advice to registrants about some of the issues around handling information and advises that it is your duty as a registrant to respect and safeguard the confidentiality of service users at all times. This is both:

- A professional responsibility because the HPC standards are there to protect the public. Breaches of confidentiality can affect your HPC registration.
- A legal responsibility because of principles established by law which say that professionals have an obligation of confidentiality to those with whom they have a professional relationship. Legislation also states how information should be kept, handled and disclosed.

On NHS premises confidential records should be kept in a locked cupboard or filing cabinet, and the room should be locked when not in use. Access should be limited to designated staff and movement of records tracked either manually or electronically. Care records should not be left unattended in public areas.

Security and confidentiality must be maintained when transporting records and local policy must be always be followed. Good practice includes:

- Not leaving records on display in a vehicle but locking them securely in the boot
- Use of a lockable container when transporting records, such as a briefcase, to physically protect the record from damage and to prevent unauthorized access
- Not taking a service user's record into the home of another.

Care should be taken to protect confidentiality when leaving messages on any answer phones, in message books or responding to requests for information by telephone.

If you are using identifiable information from care records for a secondary purpose, e.g. for audit or research within the work setting, you should make your data anonymous by removing the individual's identifiable details. The use of anonymised data will not breach confidentiality or other legal requirements. Under these circumstances use of data that does not identify an individual is not regarded as confidential.

11 The NHS Electronic Record

11.1 General principles

- Electronic health records have the potential to improve the accuracy of healthcare documentation and information transfer.
- Healthcare professionals need comprehensive and accurate data on service users at the point-of-care if they are to provide a high quality service. Electronic health records can aid in this by replacing difficult to access, and often illegible, paper-based records.
- The improved record keeping, legibility and access of electronic records can help to avoid the inconvenience of lost records, data recapture and re-entry and reduce the risk of recording errors.
- The introduction of the electronic record offers many potential benefits for the NHS, including a reduction in clinical errors and improved patient safety
- The primary purpose of recording information is to support patient care. Holding and accessing information about service users and their interactions with clinical teams is critical to providing safe and effective care

11.1.1 Security and Confidentiality

- The NHS has a duty to ensure the personal information it keeps is held securely and handled in accordance with both the Common law duty of confidence and the Data Protection Act 1998[5].
- Security is a major concern. Any system which makes it easier to access data inevitably make it easier for unauthorized individuals to gain access. Similarly, the more people that access a record increases the risk of breaching confidentiality.

- For the most part the principles that underpin the legal and professional aspects of record keeping are similar for paper and electronic patient records. You should only access a record if you have a legitimate right to do so.
- Computerised health records are documents under law and as such are disclosable.

The risk of error increases if both paper and electronic records co-exist as this raises issues about keeping both sets of records up to date. However the reality is that parallel records may remain for some time. Where both computer and paper systems are maintained, the information held must be consistent.

The British Medical Association and NHS Connecting for Health (England) have produced joint guidance on protecting electronic patient information[18]. This guidance is applicable to all healthcare professionals across the UK and covers:

- Use of e-mail – only NHS mail accounts should be used for exchanging confidential patient information unless it is encrypted. For sensitive information, delivery and read receipts should also be requested so that you can ensure the information has been received safely.
- Using a laptop or mobile device – you have a duty to ensure that you take appropriate precautions to protect the laptop and the data it contains. This includes reducing the risk of theft, using passwords and installing encryption software to protect sensitive data.

11.2 National development of the electronic record

The UK countries are taking different approaches to development of the NHS Electronic record. A brief overview is given below. More detail can be found on the national websites listed in the references.

11.2.1 England

The NHS Care Records Service (NHS CRS)[19] will deliver an individual electronic record for each patient to ensure that:

- All the records of an individual patient's care are kept in one place
- The record can be securely shared between different parts of the local NHS
- The record will be available to the authorised health and social care professional at the time and place that the patient is seen.

For each individual the NHS Care Records Service will develop:

- A Detailed Record (held locally)
- The Summary Care Record (held nationally) which will be available to authorised NHS staff across the NHS in England.

The Care Record Guarantee, launched in 2004[20], sets out the commitments that will govern information held in linked electronic record systems across England.

- Access will only be possible with an NHS Smartcard, with a Pass code.
- Access will only be allowed following appropriate training and is dependant upon your role.

- You will only be able to access a care record if you are involved in that patient's care (this is called a legitimate relationship).
- Every time someone accesses a patient's record, a note will be made automatically of who, when and what they did (an audit trail).
- Alerts will be triggered automatically both to deter misuse of access privileges and to report any misuse when it occurs. When access is not justifiable, the person responsible for overseeing patient confidentiality in your NHS organisation, "the Caldicott Guardian"[21], will take action, which may include disciplinary procedures, and telling the patient where appropriate.
- Disciplinary action may also lead to an HPC hearing.
- Patients can access this information through a formal "data protection subject access request". Patients will also be able to access their Summary Care Record using the secure website Health-Space.

11.2.2 Northern Ireland

The Informatics & Communications Technology (ICT) Strategy[22] has two major, interlocking themes for ICT development:

- Electronic Care Records
- Electronic Care Communications.

The emphasis of the Strategy is on these themes, but the importance of ICT as a means to access other information and the need to sustain and modernise ICT in other areas is also recognised.

11.2.3 Scotland

Scotland's national e-Health programme[23] is focusing on delivering a comprehensive health information system built around the electronic health record (EPR). E-Health includes a wide range of ICT applications and uses, from health information on the Internet through to tele-health.

11.2.4 Wales

Informing Healthcare[24] is a Welsh Assembly Government programme set up to improve health services in Wales by introducing new ways of accessing, using and storing information. Informing Healthcare will:

- Introduce new ways of working
- Contribute to an increase in staff time (less time wasted via paper-based activities)
- Provide an opportunity for all to acquire new skills
- Allow staff to access and use the latest evidence and best practice routinely
- Ensure communication with other NHS colleagues across geographical areas will be easier and more effective
- Reduce the risk of errors with improved Information Technology systems support
- Improve the flows of information
- Enable access to computer based tools, freeing more time for service improvement and patient care.

12 FAQ Section

12.1 I am a private practitioner

The principles are the same whatever your work setting. The Data Protection Act 1998[5] is not confined to NHS health records. It applies equally to the private sector and to health professionals private records.

12.2 Do I still have to keep my own dietetic records?

There must be a complete record of the patient episode. NHS dietitians have often kept their own detailed records in addition to the main multi-disciplinary patient record. You do not need to keep a separate dietetic record unless there is a specific need to, e.g. if it is not feasible to remove the multi-disciplinary single patient record from the hospital for community use, or because insufficient detail can be recorded in the single multi-disciplinary record. It may not be necessary to record all the details already in the patient record on the additional dietetic record, e.g. duplicating a patient's past medical history word-for-word may be inappropriate. You do need to ensure that an accurate summary of the care/advice given is recorded in the main patient record. If you are keeping separate dietetic records, although you do not need to record all details word for word, there needs to be sufficient detail for another dietitian to be able to use the record effectively.

Professional colleagues are responsible for recording your advice but you should also keep a record of this.

12.3 What is my obligation to ensure that the advice and input to clinical and other records that I give on a consultative basis is comprehensively and accurately recorded? Should I rely on my professional colleagues to do this?

There is a difference between giving informal advice, e.g. one to one with a colleague, and giving advice as a result of a formal request for a second opinion.

If you have given informal advice it may not be practical for you to document that you have done this directly into the patient/service user record – after all, your advice is not necessarily the only appropriate course of action. Ultimately, as an autonomous practitioner, each dietitian is responsible for their own actions and competence, and whilst consulting others can be extremely helpful, it is the responsibility of the dietitian caring for the patient to make their own final decision.

You may wish to record details of such advice in a personal log or diary as a personal record.

If you are asked to give a formal second opinion you will be asked to do this in writing and will have access to all the information relating to that individual. In this case you should document the advice you give in their record.

12.4 Telephone advice to service users

You should not leave advice for a service user on an answer phone. This can breach confidentiality and what you have said may be misinterpreted by the service user or a third party.

12.5 Who owns the patient record?

All NHS records are public records under the terms of Public Records Act[8] and must be kept in accordance with a number of statutory and NHS guidelines.

In the private sector, records are the property of your employer. However if you have treated the patient and entered information into the record you must have reasonable access to the record; particularly if, after leaving the employing organisation, a complaint or allegation is made against you.

12.6 Can patient information be reproduced and used for training purposes, e.g. for inclusion in a student portfolio?

The HPC Standards of conduct, performance and ethics (2008)[2] gives clear guidance stating that:

> *"You must treat information about service users as confidential and use it only for the purpose they have provided it for. You must not knowingly release any personal or confidential information to anyone who is not entitled to it and you should check that people who ask for information are entitled to it."*

Students should not remove and use confidential material from their work placement outside the workplace.

12.7 I work for an independent organisation, outside the NHS. How does this guidance apply to me?

This guidance is to support best practice when keeping clinical records. In the private sector, all records are the property of the employer. If you are required to keep clinical records as part of your job it is your responsibility as an HPC-registered professional to keep these records up to date and complete them accurately. You should use your employer's guidance and clinical judgement to determine the level of information you need to record.

Be aware that if you are questioned about your record keeping your answers may be used as evidence in a subsequent disciplinary against you.

13 References and further reading

1.0 What is the purpose of this document?

1. Joint BDA/Dietitians Board Guidance on Standards for Records and Record Keeping July 2001
2. The Healthcare Professions Council Standards of conduct, performance and ethics July 2008 www.hpc.uk.org
3. BDA Code of Professional Conduct 2008 www.bda.uk.com
4. The BDA Professional Standards for Dietitians 2004 www.bda.uk.com

2.0 What is a record?

5. Data Protection Act 1998 www.opsi.gov.uk/Acts

3.0 The purpose of a record

6. Learning from Bristol: the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984 -1995 Final report 2001 www.bristol-inquiry.org.uk/final_report/report/index.htm

7. Health Professions Council fitness to practise hearings www.hpc-uk.org/complaints/me/

4.0 Who owns the record?

8. The Public Records Act 1958 www.nationalarchives.gov.uk/policy/act/system.htm

Further reading:

- The Medical Defence Union (MDU) General advisory guidance: Guide to can I see the record clinical notes and patient access (undated) www.the-mdu.com/associatedArticles/canisee.pdf

5.0 Quality of record keeping

9. Nursing & Midwifery Council record keeping guidance. Advice sheet. Updated July 2007 www.nmc-uk.org/aFrameDisplay.aspx?DocumentID=3170
10. The HPC Fitness to Practice Annual Report 2006 page18. Breaches of the standards of conduct, performance and ethics www.hpc-uk.org/assets/documents/1000132549372FTPAnnualReportV4.pdf

11. Healthcare Commission. Annual report 2006/2007. Improving healthcare for patients through the annual health check. www.healthcarecommission.org.uk/_db/_documents/HC_Annual_Report_2006-2007.pdf
12. Medical Defence Union press release1st February 2007. Healthcare commission complaints report www.themdu.com/Search/hidden_Article.asp?articleID=1612&contentType=Media+release&articleTitle=Healthcare+commission+complaints+report.

Further reading

- Generic medical record-keeping standards. Health Informatics Unit, The Royal College of Physicians (RCP) 2007
- Essence of Care: Patient Focused Benchmarks for Clinical Governance. Record Keeping. NHS Modernisation Agency 2003. www.cgsupport.nhs.uk/PDFs/articles/Essence_of_Care_2003.pdf

- NHS-Litigation Authority Risk Management Standards for Acute Trusts and Mental Health & Learning Disability Trusts, April 2008 www.nhsla.com/
- Clinical Governance and Risk Management National Overview October 2007. NHS Quality Improvement Scotland 2007 www.nhshealthquality.org/nhsqis/3741.html

- Healthcare Standards for Wales 2005. Healthcare Inspectorate Wales www.hiw.org.uk/page.cfm?orgid=477&pid=15775
- HPSS Controls Assurance Standard Records Management April 2006 Northern Ireland www.dhsspsni.gov.uk/records_06.doc

8.3 Disposal of Records (NHS)

Further reading

- Records Management best practice in relation to the creation, use, storage, management and disposal of NHS records July 2008 www.scotland.gov.uk/Publications/2008/07/01082955/0

- Records Management: NHS Code of Practice Part 1 and Part 2 Department of Health 5 April 2006 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4133200

- Department of Health, Social Services and Public Safety (2004), *Good Management, Good Records*, Department of Health, Social Services and Public Safety, www.dhsspsni.gov.uk/dhs-goodmanagement.pdf

9.0 The legal status of a record

13. Public Records (Scotland) Act 1937 www.nas.gov.uk/recordKeeping/publicRecordsScotlandAct1937.asp

13a. Public Records Act (Northern Ireland) 1923.

www.opsi.gov.uk/RevisedStatutes/Acts/apni/1923/capni_19230020_en_1

Further reading

- Freedom of Information Act 2000 www.foi.gov.uk
- Freedom of Information website www.foi.nhs.uk/home.html

- Access to Healthcare Records 1990
  www.dh.gov.uk/assetRoot/04/03/51/94/04035194.pdf
- The Access to Health Records (Northern Ireland) Order 1993
  http://www.legislation.hmso.gov.uk/si/si1993/Uksi_19931250_en_2.htm

10.0 Information Governance

Further reading

- Department of Health (England) 2006. Records Management: NHS Code of Practice. The Stationery Office, London
  www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4131747
  The Code offers detailed guidance on:
  - the management of all NHS record types,
  - the day-to-day use of NHS records,
  - minimum retention period schedules for NHS records.

  The Code replaces:
  - HSC 1999/053 - For the Record,
  - HSC 1998/217 - Preservation, Retention and Destruction of GP General medical Services Records Relating to patients (Replacement for FHSL (94)(30),
  - HSC 1998/153 - Using Electronic Patient Records in Hospitals: Legal Requirements and Good Practice.

- NHS Information Governance Guidance on Legal and Professional Obligations.
  Department of Health (England) 2007
  http://site320.theclubuk.com/en/Publicationsandstatistics/Publications/PublicationsPolic yAndGuidance/DH_079616
- The Caldicott Report
  www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/ PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4068403&chk=jsKw07
- Department of Health Caldicott Guardians 1999 Department of Health: London (Health Service Circular: HSC 1999/012)
- HSC 2000/009: Data Protection Act 1998: protection and use of patient information
  Department of Health (England) March 2000
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10.1 Consent

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Home Enteral Tube Feeding for Adults with a Learning Disability

Produced by: The Enteral Tube Feeding in the Community for Learning Disabilities (ETFiC4LD) Group, a sub-group of the Specialist Mental Health Group of the British Dietetic Association.

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CONTENTS

Appendices

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BDA Specialist PENG members

And last but by no means least our clients and their carers.

"It's important to treat her as you would anyone else, to be treated as well as anybody. By that I mean as a person who is ill and who has a disability. Not to see the disability before anything else; not to think there is nothing there worth the bother. She is a person first, the same as you, as anybody. You need to know that."

(A parent)

Executive summary

This Consensus Statement is intended to inform and support the practice of dietitians who are not undertaking a specialist learning disabilities (LD) role but do care for adults with a LD within their caseload. The Statement may be a useful resource for other professionals and student dietitians.

It is well documented that most people with LD have greater health needs than the rest of the population including mental illness, epilepsy, physical and sensory limitations, dental disease, thyroid disorders, heart disease, dysphagia, obesity and under-nutrition (Welsh Office, 1996; Kennedy, 1997; Bryan et al., 2000; DH, 2007A;NPSA,2004; Bernall, 2005; Melville et al., 2005).

The health gains associated with good nutritional care include improved quality of life and improved disease outcomes (Astor and Jeffreys, 2000; DH, 2004). Whilst papers investigating specific benefits relating to adults with LD on enteral tube feeding and their carers were not found during the period of the literature review, the following extracts from interviews with carers echo some of the positive outcomes noted in the literature for other client groups (Peterson et al.,2006; McGrath et al.,1992):

“He is much happier now and laughs out loud and he has put on a bit of weight. It’s easier for me as I can eat, as I am not feeding someone else at the same time.”
(A parent)

“Disappointing to know he needed the PEG as he loved his food. But hand on heart thankful it needed to be done as we know now he won’t choke. [It] has taken away the ‘fear factor’ for him and the staff. Caring for him was very stressful and distressing. [It’s a] bonus for everyone.”
(A carer)

The literature review revealed a dearth of research in the area of enteral tube feeding within this unique client group. Evidence was found to support five of the 15 key questions designed to inform the focus for the search. Details on recommendations for future research can be found in the Summary & Conclusion.

The Statement, though of some length, contains information which the authors feel is relevant to the client group and highlights particular differences in approach for the practitioner to consider. Wherever possible, signposting to acknowledged gold standards of dietetic practice are made throughout the document and Good Practice Points (GPP) are indicated within the text.

1.0 Introduction

1.1 Scope

This Professional Consensus Statement has been developed as a good practice guide for dietitians whose caseload includes adults who have a learning disability, living in the community and have a clinical need for enteral tube feeding.

Though the majority of clients will have in situ a gastrostomy tube and receive total nutritional support, many variations exist. Gastrostomy feeding may be adjunctive, used ad-hoc to provide nutrition and/or hydration and/or medication post-epileptic seizure or during periods of challenging behaviour where food and/or fluid refusal may be the presenting clinical picture (Burton et al.,2008). The most common type of enteral feeding tube used is a PEG tube but some clients due to their complex conditions may not tolerate an endoscopic procedure therefore require assessment for a Radiological Inserted Gastrostomy (RIG). It should also be noted that as more children with LD are making the transition to adult services, many have undergone fundoplication and often require a different route of feeding such as a Jejunostomy. The numbers of these seen in the community setting is increasing. As Percutaneous Endocsopic Gastrostomy (PEG) is the most frequently placed enteral feeding tube for long-term use (NICE,2006) for this reason we have focused on PEG within this document.

People who have a learning disability are nutritionally vulnerable for a number of reasons. At one end of the spectrum, factors include social isolation, limited nutritional knowledge and budgeting/cooking skills of self and carers and reduced ability to understand and apply health messages.

At the other end are those with profound and multiple learning disabilities (PMLD) who are non-ambulatory and totally dependent on a range of carers. Many decisions regarding their health and social care may need to be made in their best interests. Physiological anomalies, polypharmacy, multiple diagnoses and dysphagia are also common amongst this client group (DH,2007A).

1.2 Definition of a learning disability

The definition of a learning or intellectual disability includes all of the following dimensions (WHO, 1992).

1. A significant intellectual impairment with an intellectual quotient (IQ) more than two standard deviations below the general population, i.e. an IQ below 70 on a recognised IQ test;

and

2. Deficits in social functioning or adaptive behaviour, i.e. how well a person’s coping skills allow for the everyday social demands present within their own environment. Formal assessments include the Vineland Adaptive Behaviour Scales and the AAMR Adaptive Behaviour Scales;

and

3. Are present before adulthood i.e. age 18yrs;

and

4. Are life long.

There will be local variations on the above definition. For example the Health Inspectorate Wales (HIW) review of services for people with a learning disability highlights the use of IQ alone is not sufficient to define this population (HIW, 2007).

1.3 Specialist services/extended roles

People with LD have an expectation and a right to access core services as well as specialist teams for learning disabilities (DH,2007B; Bamford, 2005; LDAG,2001; Scottish Executive,2000). Whether living at home, which could be parental, supported/assisted accommodation or within a residential setting, support should be available by such specialist teams who help clients live an ordinary life within their local community. The division of what is considered core and specialist is not (and indeed should not be) clear cut and robust working relationships between both teams are essential for the provision of a seamless service for this client group. The registered dietitian is pivotal to service provision and the knowledge, skills and role of the specialist within LD include:

- Advising on nutritional requirements, particularly energy as evidence indicates that clients with a LD and an enteral feeding tube in situ have reduced energy requirements
- When assessing nutritional status, having the knowledge and experience to interpret height, weight and anthropometric measurements for this client group
- Working without established guidelines or procedure in relation to LD but always within locally accepted scope of practice
- Using a holistic approach to assess, problem-solve and ensure that health and social needs are met
- Using appropriate health facilitation skills within the therapeutic framework
- Contributing to the application of a legal framework
- Identifying, referring and working in partnership with health and social care colleagues, agencies and organisations
- Addressing inequalities in health and social care
- Advocating both formally and informally
- Using augmented communication
- Working in dynamic environments and with service users who display unpredictable or behaviours that challenge.

1.4 Methodology

This professional statement is based on a systematic review of the available literature undertaken between October 2006 and August 2007. The aim of the review was to look at the evidence supporting the assessment, monitoring, complications and ethical issues specific to adults who have LD, who require enteral tube feeding for nutrition and/or hydration and/or medication. Fifteen key questions were drawn up to focus the literature review (Appendix 2). The search strategy included the following databases:

Cochrane Library
Medline
EMBASE
CINHAL
PUBMED
AMED

The adoption of a consistent approach to the critical appraisal of the resultant documentation contributes to the robustness of this Statement. All reviewers followed the qualitative and quantitative guides to critiquing research (Ryan et al., 2007A, 2007B). The grading system for evidence based guidelines was also followed (Harbour and Miller, 2001). A cross-over system was employed in that papers were randomly allocated to two groups of reviewers (the authors) who independently appraised each paper. Cross-over occurred within each group to match outcome. Consensus of the critical appraisals was reached at the critical appraisal meeting of all reviewers in January 2008 before finalising the evidence tables in May 2008 (Appendix 1), referenced to the key questions (Appendix 2).

Seventeen papers were found which were directly related to the client group, of which thirteen were single case studies. Few were directly related to nutrition apart from energy expenditure which was investigated in five papers (a combined total of 66 participants). The literature review confirmed the authors' perception that little robust research had been conducted looking at the specific healthcare needs of this unique client group. See Evidence Table in Appendix 1.

1.5 User involvement

The Service Users Advisory Group was set up to ensure that people with LD can give their views about the services they use. Their first report, *Nothing about us without us*, (DH, 2000) seeks to re-affirm the importance of inclusion by advocating user involvement in service provision. Working in partnership with our clients should enable us to provide the best service within our resources, to meet the needs of our clients.

Experiences from carers for clients receiving home enteral tube feeding and who have LD have been included in the text. A range of dietetic and other professional colleagues have been involved in the peer review of this document.

In formulating this Consensus Statement the authors confirm they have followed the BDA Ratification Process (BDA, 2006).

2.0 Decision making

This section of the Consensus Statement aims to give examples of issues that may arise and guidance on how legislation is applied to people with LD. Legislation exists to provide a legal framework for decision-making on behalf of adults who lack the capacity to make specific decisions for themselves. It also provides the means for adults, with the capacity to do so, to plan ahead in the event of future incapacity.

Readers are recommended to refer to the relevant legislation pertaining to their geographical work base as legislation differs slightly between countries:

- **Scotland**: The Adults with Incapacity Act (Scottish Parliament, 2000)
- **England & Wales**: The Mental Capacity Act (DH, 2005)
- **Northern Ireland**: Seeking Consent (DHSSPS, 2003)

Relevant excerpts from the legislation are included here as it is core to the care for a person with LD.
The Short Reference Guide for Psychologists and Psychiatrists (BPS, 2007) is recommended as a brief summary of the main points of legislation and is a brief guide to its implementation for clinicians. This Guide is applicable to England & Wales. The following is extracted from the Guide:

"The Principles set out at the beginning of the Act guide the process of assessment and of substitute decision-making:

- A person must be assumed to have capacity until it is established that s/he lacks capacity.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because s/he makes an unwise decision.
- When decisions are made on behalf of someone who lacks capacity, they must be made in his/her 'best interests'.
- When decisions are made on behalf of someone who lacks capacity, the less restrictive alternative must be considered to attain the goal specified.

The Act defines capacity as follows:
An adult can only be considered unable to make a particular decision if:

He or she has 'an impairment of, or disturbance in, the functioning of the mind or brain', whether permanent or temporary;
AND He or she is unable to undertake any of the following steps:

- Understand the information relevant to the decision;
- Retain that information;
- Use or weigh that information as part of the process of making the decision;
- Communicate the decision made (whether by talking, sign language or other means).

The Functional Approach

A functional approach must be taken. This means that someone's ability to make a decision is determined by assessing whether they can undertake the steps above; it is not determined by their diagnosis nor by the apparent wisdom of their decision. Decision-making capacity is decision-specific and time-specific.

Best interests

In considering what is in someone's best interests when making a decision, the following should be taken into account:

- Whether and/or when the person is likely to regain capacity and whether the decision or the act to be undertaken can wait;
- How to encourage and optimise the participation of the person in the decision;
- The past and present wishes, feelings, beliefs, values of the person and any other relevant factors;
- Views of other relevant health, family, carer and social representatives. The decision should be perceived to be in the 'best interest of the client and not that of the family or carers'.

Where a person lacks the capacity to make decisions about a change in accommodation or about serious medical treatment and has no family or friends, there is a duty to appoint an Independent Mental Capacity Advocate (IMCA) to help inform the determination of 'best interests'."

The Scottish Act allows for application of “Welfare Guardian”, who may be granted full or partial powers under the Act (Scottish Parliament, 2000). Should there be no welfare guardian, the general practitioner in consultation with the team may complete an “adults with incapacity form” which enables treatments to take place. In emergency situations the medical person can act without consultation of the team. In Northern Ireland, those close to the incapacitated individual should be involved in the decision making process as detailed in “Seeking Consent” (DHSSPS, 2003).

In instances where there is no legal guardian the decision should be reached with consultation of all health, family, carer and social representatives. The convening of a multidisciplinary meeting is good practice to allow all to participate in decision making. This must be documented.

2.1 Assessments

Assessments need to be carried out, and it is good practice to involve carers in the assessment process and to communicate openly (GPP). In order to treat, the issue of gaining informed consent must be fully explored.

2.2 Consent from Client

Q: If the client gives consent, how can you be sure they understand what they are agreeing to? It is not enough to assume that they are consenting by attending your clinic or present at a domiciliary visit.

Consider:

- Does your client understand the information they have been given?
- Does your client fully understand the implication(s) of your intervention?
- Does he/she have the ability to make an informed decision about treatment?
- Do you have the skills and knowledge to make this assessment of capacity?

These are just some of the questions you will need to ask before starting to treat a client who has LD. You may need the support of one or more of the following (and the carer) to assess level of understanding and how the client communicates:

- Speech and language therapist (SLT)
- Clinical psychologist and/or
- Specialist learning disabilities multidisciplinary team (MDT) (see Appendix 3). They may be able to assist with providing information in an accessible format to either help the client make their choice or determine if they are able to do so.

It is important to remember that a client should not be treated as unable to make a decision unless all practicable steps to help him/her have been taken without success.

2.3 Case Studies

2.3.1 Case study 1: Where a client is able to give consent

A 42-year-old female has severe athetoid cerebral palsy and a history of chest infections due to aspiration. She lives in her own home supported by care staff. There is a history of low weight and weight loss (Body Mass Index (BMI) 13). Videofluroscopy has shown she is at significant risk with liquids and all textures. The SLT has recommended that non-oral feeding be commenced using enteral tube feeding.

The dietitian and SLT worked jointly with the client to give her the opportunity to demonstrate capacity to consent using the following approach:

- Pictorial information to explain the treatment
- Sufficient time to understand the information about the procedure, risks, benefits and implications
- Opportunity to ask questions
- The client was asked to demonstrate understanding, reasoning and recall using a "TalkingMats" format. A series of mats was used to explore concepts of meals, health and "things that may help" in relation to the client's swallow. Mat 3 is shown in Fig. 1 below.

Fig 1. TalkingMats format – Mat 3 showing 'things that may help'

Unsure about benefits of
puree food
fortified food

Ready to discuss

Avoid Foods

PEG

No help
(Left to right)
Positioning
Moist foods
Small meals
Finger foods
Thickened drinks
Syrup medicines

Printed with permission of the AAC Research Unit,
Department of Psychology, University of Stirling

Theme Symbol - things that may help

This client felt that suggestions such as changing position, having small meals and so on (see red box) would not help her. She was unsure (middle column) about the benefits of having modified textures and supplementing foods to help stop her weight loss. After exploring these issues around problems with her eating and swallowing, the client decided to consider PEG placement (symbols under yellow smiling face). PEG information symbols were then used to focus discussion to help her make an informed decision (modified extract from TalkingMats & Alternative Eating and Drinking Booklet, AAC Research Unit).

A photograph of the TalkingMats was taken as evidence of capacity to consent to PEG feeding and recorded in the medical notes.

The following members of the MDT were also involved in this client's care:

- GP – responsible for medical care (this could also be a Gastroenterologist or consultant in charge)
- Social worker – to address changes in care package
- Care staff – to ensure package of care could be met
- Family – to enable them to understand the rationale for the treatment and to express their views.

Consider:

If the client refused this intervention, what would be the consequences? The client with capacity is able to make "unwise" decisions and have these decisions upheld. Care should be taken as some clients may be unable to give consent due to communication problems, but still have capacity to make decisions. The team must make careful assessment of each individual case.

If a client **does not** have capacity to make an informed decision then first consider whether the carer, relative or social worker has legal guardianship or power of attorney which entitles them to consent on specific issues on behalf of the client.

If yes, then the relevant paperwork will be required to be put in place for each specific treatment. The MDT team should explain the treatment options and gain consent from the client's legal representative.

2.3.2 Case Study 2: Client lacks capacity and has no legal guardian / power of attorney

The client is a 29-year-old female with PMLD requiring a spinal jacket/brace and is cortically blind. She has severe chewing and swallowing difficulties, is totally dependant for all care needs and lives with her elderly parents. She responds to tone of voice and enjoys being spoken to.

She is underweight with a BMI of 17 and does not manage to meet her nutritional and fluid requirements. She has major weight fluctuations associated with ill-health. She has been assessed as having a compromised chest with frequent chest infections and has commenced thickened drinks and puree diet.

Q: How would you progress with discussing enteral tube feeding?

As you are unable to directly discuss or ask her for her consent, use this checklist as a guide:

(i) Decision making

- Are there any other (less invasive) alternatives to enteral tube feeding and have these been tried and documented?
- What is the aim of the intervention?
- Who will make this decision? Who would you need to consult (MDT /family/carers/ medical staff/advocate)?
- Is urgent action required due to acute clinical condition? If this is the case then it may only require the medical team to fulfil the legislative process for such situations.
- What information will the decision makers require?
- Will the treatment be of benefit or burden to her?
- Would she attempt to pull the tube out?

(ii) Practical issues relating to support

- What support will her family require?
- Will the care package need to be re-assessed to support the intervention?
- Will her placement at home/day care/respite care be able to undertake the treatment in a safe manner?
- What additional tasks are required and who will undertake these?
- What are the training needs and how will these be met?
- What support is needed around eating and drinking skills? Consider involvement with SLT to work on skills and oral function.
- What additional equipment will be required? Consider all aspects of equipment not just ancillaries for enteral tube feeding e.g. adaptation of her spinal jacket/brace for feeding tube access.
- What are the barriers, if any, to enteral tube feeding and how can they be addressed?

2.4 The Role of Advocacy

An advocate enables a client to get their views across. They may be a friend, family member or independently appointed following a referral to an advocacy group or services. Anyone can advocate on behalf of an individual but if they are emotionally involved with the client, impartiality may not be possible. The advocate should contribute to the decision making process on the client's behalf however where conflict occurs it should be remembered that their views whilst listened to, have no legal status in relation to consent.

In some cases their views may conflict with others who are in the decision making process. As the client's representative they should be included in client specific MDT meetings to discuss what is perceived to be in the client's "best interests".

IMCAs or Mental Health Officers (MHOs) in Scotland have undergone formal training as stipulated by the legislation. Such training enables them to assist with decision making in the best interests of clients who cannot make decisions by themselves, or with clients who have no family or friends who could be part of the joint MDT decision-making process.

2.5 Ethical issues: end of life – withdrawing and withholding artificial nutrition and hydration

The following is an extract from the British Medical Association (BMA) website. Readers are recommended to refer to the full document (BMA, 2007).

"The BMA's guidance on withholding and withdrawing artificial nutrition and hydration provides advice for health professionals about the range of factors that should be taken into account in making these difficult decisions. The guidance is very clear that oral nutrition and/or hydrations should continue to be offered to all patients who are able to swallow.

"Where there is a problem with the swallow it advised that careful thought be given as to whether artificial feeding should be provided or continued. The guidance is based on the premise that the primary goal of medicine is to benefit the patient."

It is essential where such decisions are considered that a multi-professional and multi-agency meeting be arranged together with key family members, advocate and any other significant others to discuss fully the concerns and agree on the best way forward. All discussions and decisions must be fully documented.

3.0 Meeting the client's needs

3.1 Establishing a client on an enteral tube feed

Establishing appropriate care and feeding regimens to best suit the client's needs and wishes includes extensive training and continual support to a multitude of carers. These are accessed within a variety of venues within the community.

Therefore to ensure continuity of care, effective training and education of both clients and carers is essential to the successful implementation of an enteral tube feeding regimen. The client's and carers' training needs should be assessed as early as possible.

It is documented that clients with LD accessing general practice can require up to quadruple the usual time required for consultation (Chambers et al., 1998). In a local audit undertaken in 2007 following the change of the enteral feeding pumps, the contractor recorded it had taken twice as long to re-train and change the pump for people who had a LD as compared to the general population. This was due to the complexity of the required individual care packages.

Twenty-nine different people including family and health care providers/carers from a multitude of agencies were trained (See Table 1).

Services such as day care and college may not have any experience with tube feeding and may view it as a threat or indeed not part of their traditional role. If perceived as a role extension then undertaking a risk assessment of this element of care which may also include an agreed competency based training programme would be necessary for HETF to take place in a supported care environment (GPP).

Table 1: Example of number of training contacts

Carer / Venue	Relationship	Role	Training Pump	Bolus	Feed Regime /Fluid	Trouble Shooting	PEG/Tube Site
Family	Grand-mother	Provides care and support at home	Y	Y	Y	Y	Y
	Mother/Father	Provides care and support at home	Y	Y	Y	Y	Y
	Sibling(s)	Provides care and support at home including feeding Bolus	Y	Y	Y	Y	Y
Day Service	Manager + staff x 4+	Provides heath and social care	Y	Y	Y	Y	Y
	Drivers of Transport x2	Collects and transports Client to and from Day Service. If feed is running they need to know how to respond to pump alarms	Y	N	N	Y	Y
Outside Care Agency	Carer to support at home 3+ staff	Provide all care and personal support to client and family at home	Y	Y	Y	Y	Y
District Nurses*	Nursing and Assessment x 2	Provide support to change Balloon Gastrostomy	Y	Y	Y	Y	Y
Respite	x6+ staff	As with family	Y	Y	Y	Y	Y
College	X4+ staff	Provide support with aspects of social care and feeding	Y	Y	Y	Y	N

*In other localities this role may be undertaken by a home enteral feeding company nurse.

"When her care package was put in place tube feeding was made such a big thing of.. Why? It shouldn't be a big issue, it's part and parcel of that person and staff should be trained. PEG training should be part of mandatory training for carers." (A parent). A sample training checklist for carers is shown in Table 2.

Table 2: Training Checklist for training carers

Area to be covered	When	By whom
Pre-PEG education • What is a PEG? • The procedure • Risks and benefits • Consent issues • Oral hygiene • Overview of aftercare of PEG • Regimens/admin of medication • Ongoing support networks and monitoring • Provision of feed and equipment	Start as soon as PEG is discussed as option.	Could be dietitian, nutrition nurse, SLT or most appropriate person from primary or secondary care. Could also utilise home enteral feeding company nurse.
Post-PEG education Care of the PEG tube –first 7-14 days then after site is healed. This will include: • Flushing of tube • Care of the skin and stoma site • Oral hygiene • The feed regimen (bolus/ pump or combination) • Admin of medications • Supply of equipment and feed • Troubleshooting e.g., blocked tube, changing PEG ends etc, skin/ stoma problems, faulty equipment • Monitoring and ongoing support • Contact numbers	Start as part of pre-PEG education but go into more detail once PEG placed. Some aspects of care will be ongoing and part of the reassessment process during monitoring visits. It is important that whenever possible education is competency-based and appropriate to the carer's abilities and responsibilities with the client.	Depending on local provision the lead clinicians could be the nutrition nurse and dietitian. However the community nurse/home enteral feeding company nurse may take the lead.

Issues to consider

Variations in practice can occur for a number of reasons. Carers are not a homogenous group and can be family members, friends, registered or non-registered staff. Where practicable, a multi-professional and multi-agency meeting would be of great advantage to reduce discrepancies in the implementation of enteral tube feeding practices (GPP). If this is not feasible during the in-patient phase then ideally it should be done as soon as possible after discharge.

This allows for as many key people to understand the rationale for the enteral tube feeding regimen; the impact on the client's quality of life; discuss their own roles and responsibilities and have the opportunity to express any concerns. However should there be local access to a dietitian specialising in LD, the client may already be known to their service and he/she needs to be part of the decision-making process pre-PEG. This will also enhance pre-planning and a seamless discharge home.

Where there is conflict to the implementation of recommendations and variances in practice by a carer/group of carers, it is recommended that the dietitian should document:

- The advice provided
- Relevant SLT assessments, videofluroscopy findings including any documentation that supports the dietetic therapeutic recommendation(s)/intervention(s)
- Training given to reinforce practice as this may need to be revised

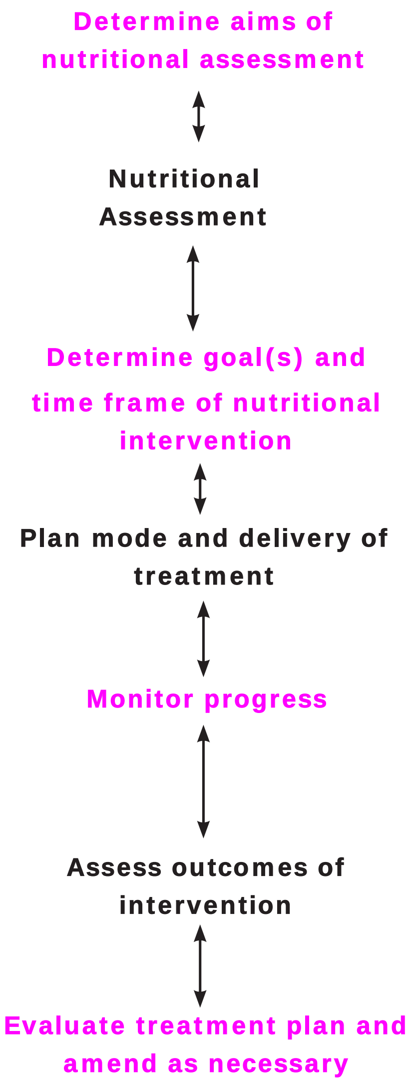
- Variations in practice as compared to the recommendations
- Expected consequences and concerns.

And should:

- Inform the wider MDT including GP and/or medical lead
- Call an MDT meeting to support resolving the conflict
- Seek clinical supervision.

Nutrition Assessment and Intervention

Figure 2. Assessment & Intervention Flow chart



3.2.1 Nutrition Assessment

Weight

It is accepted that weight is fundamental to assessing nutritional status, calculating requirements and monitoring intervention and progress. Specialist weighing equipment such as a ceiling track hoist with scales or wheelchair beam scales is needed to weigh people who are non ambulatory. It is important that scales are serviced and calibrated regularly. The posture of people with scoliosis needing special seating will change over time; those who receive intensive nutritional support may require more frequent re-assessment.

It is recommended to collaborate with the physiotherapist/occupational therapist to coordinate weighing of a new wheelchair on delivery (GPP).

Record if footplates, tray, headrest have been included in wheelchair weight and remove any bags from chair prior to weighing. This weight is then valid for subsequent weight checks, providing every aspect of the chair remains the same. Any alterations to the chair will need to be documented and require a new assessment of weight as changes invalidate previous assessments.

Figure 3. Client being weighed using wheelchair beam scales

Height

It is more difficult to measure an accurate height for people with physical anomalies. Alternative methods to estimate height include measuring ulna length, knee height and supine length following the natural curvature of the spine. All surrogate markers of height have been found to be inferior to self reported height (BAPEN, 2003).

Carers could be requested to measure a client's length using a standard (non-stretching) measuring tape in privacy and report back. However accuracy is not guaranteed and the resultant height can only be used as a guide. A small unpublished study by the authors compared estimated height using ulna length with measured height of 36 HETF adults with PMLD. Estimated height using ulna length was significantly different from height measured using a tape measure while the subject was lying on their side (p<001).

Body Mass Index

The use of surrogate markers of height may affect the calculation of BMI and therefore classification of nutritional status (BAPEN, 2003). Clients may also have low bone density, altered body composition due to lack of weight bearing activity and developmental delay which are likely to affect calculation of height. The BMI of people with these conditions is lower than the standard reference ranges for health and exacerbate the degree of under-nutrition.

Taking into account the above, if BMI is used it is important to augment it with additional anthropometry to build up a picture of nutritional status (Stewart et al., 2006).

Mid Upper Arm Circumference (MUAC) and Triceps Skinfold (TSF)

In the general population, sequential measurements of MUAC and TSF are useful to monitor body composition and nutritional status in response to nutritional intervention, especially if weight is not available (Erdil, 2005). Unfortunately, it may not be possible to obtain repeatable, reliable, accurate and precise measurements for different reasons: the client may have upper limb muscle contractures, the non-dominant arm is not apparent, physical anomalies may mean that bony reference points are difficult to locate and the procedure may cause distress to the client.

Standard reference tables (Bishop et al. 1981) are based on an average American population who have a different body composition and stature to people with LD and physical impairments. The authors are not aware of any reference standards specific to this population to which the values can be compared. This is an area for future research.

Subjective Global Assessment (SGA)

Clients are assessed using subjective and non-specific parameters such as the ability to perform daily activities, checking subcutaneous fat stores, signs of muscle wasting, reported loose clothing, jewellery or dentures to rank them into one of three categories (Detsky et al., 1987). For guidance on SGA, refer to the Pocket Guide to Clinical Nutrition produced by the Parenteral and Enteral Nutrition Group (PENG) (Todorovic and Micklewright, 2007). In these instances such visual/clinical impressions should be recorded for example: “Appears normally nourished/over nourished/under nourished.”

As with BMI, the presence of physical anomalies, low bone density due to lack of weight bearing activity, developmental delay and reduced mobility will impact on an individual’s overall body composition. For example, a person who does not have any lower body or limb movement but is able to move their upper body and limbs will not have a uniform body composition. By looking just at their lower limbs they would be incorrectly classed as undernourished. It is important to assess whole body nutritional status.

3.2.2 Nutritional Requirements

The literature review did not reveal evidence to support specific nutrient requirements for the LD population. Nonetheless whilst there is a body of evidence (Dickerson et al 2003; Dickerson et al., 2002A; Dickerson et al.,1999; Gervasio et al 1997; Johnson et al., 1997) to indicate that people with severe neuro-developmental disabilities have lower energy needs, there is insufficient evidence to influence dietetic practice and this is an area for future research.

As with the general population, people with LD are vulnerable to nutritional deficiencies and related health consequences, for example Vitamin D deficiency and osteoporosis normally associated with institutional living (Fu Wong et al., 2006). However blood tests for vitamins and minerals can be unreliable and may not be representative of actual body stores. There is no substitute for a thorough assessment of intake and supplementation is recommended if intake (and, in the case of Vitamin D, exposure to sunlight) does not match requirements.

Energy

PENG (Todorovic and Micklewright, 2007) recommend using the Schofield Equation (Schofield, 1985). Knowledge of anthropometric, dietary history and ambulatory status will augment Schofield to determine energy needs and help prevent overestimation of requirements.

Standard equations and stress factors are an objective starting point to estimate energy and protein requirements. Ambulatory status is an important determinant of energy expenditure so it may be necessary to apply clinical judgment and be more conservative with energy supply for clients who are non-ambulatory (GPP). This has been demonstrated in local practice where a modest energy deficit of 50kcal a day in a non-ambulant client resulted in an unexpected 1.1 kg weight loss within the first month. Where clinical judgement is applied, monitoring using the appropriate parameters and frequency is even more important (GPP). Any changes made to energy intake should be modest due to dramatic impact on outcomes as highlighted above (GPP).

Johnson and colleagues studied the measured Total Energy Expenditure (TEE) by indirect calorimetry in 30 free living adults with cerebral palsy. TEE was highly variable between individuals and ambulation status was a significant predictor of TEE (Johnson et al., 1997).

A case study by Gervasio and colleagues showed that energy requirements were lower in a neurodevelopmentally disabled adult due to low body temperature (Gervasio et al., 1997). This was later confirmed by Dickerson and colleagues who studied six adults with severe neuro developmental disabilities with chronic hypothermia and PEG feeding. Indirect calorimetry measurements showed energy requirements were lower in clients with low body temperature (Dickerson et al., 2003). The authors also studied the effects of upper extremity posturing on measured Resting Energy Expenditure (REE) of non ambulatory tube fed adults with severe neuro-developmental disabilities. REE was 28% lower in those with contractures compared with those who had movement in upper extremities (Dickerson et al., 2002B). On the other hand the presence of trauma such as pressure damage can increase REE even in people with low body temperature (Liu et al., 1996).

Although small studies, they raise questions about the validity of prediction equations of assessment and calculation of requirements for people with PMLD. Actual energy provision may need to be markedly reduced as illustrated by the following case study from dietetic practice.

3.2.3 Case Study 3

A 43-year-old female, living in a nursing home, is totally dependent on staff for all her healthcare needs. She has severe PMLD with a neuro-degenerative condition, epilepsy and dysphagia. She is non-ambulatory, without upper or lower limb movements, apyrexial with the absence of infection. Dietary intake was modified to Texture C (BDA, 2002) and normal fluids.

Dietary assessment revealed food refusal and inadequate nutritional intake. She was unable to take the prescribed dose of oral anticonvulsant medication to control her epilepsy and suffered repeated chest infections due to downward aspiration.

After a PEG was placed in 2003, she was advised to be Nil By Mouth (NBM) by the SLT and her health and epilepsy control subsequently improved and her weight was maintained on an enteral tube feed providing 400kcal per 24hrs.

Usual weight: 28-30kg.
Estimated height: 1.2m but considered unreliable to calculate BMI.

Aim of nutritional assessment

To determine current dietary adequacy and nutritional status to use as a baseline for future intervention.

Goals of nutritional intervention

Nutritional adequacy and improved seizure control.

Mode and delivery of treatment

PEG insertion and total nutritional support.

Figure 4: Nutritional requirements using Schofield Equation

Energy	
30 x 8.3 + 846 =	1095
Stress factor	0
10% DIT* and Activity	109
Total	1204 kcal

Protein requirements	
0.75g/ kg	23.0g

Fluid	
30-35ml/kg	900-1050ml

*Dietary Induced Thermogenesis

The predicted 24 hour energy requirement was 1200kcal. This was considerably in excess of her pre PEG oral intake and could have resulted in unacceptable weight gain. Due to her small stature and being non-ambulatory any weight gain could be predominately over her abdominal cavity thus impeding respiratory function.

Her energy and protein requirements were met with 400ml of a “Complete” 1 kcal/ ml feed met. Her energy requirements were met for weight maintenance but the minimum requirement for sodium, potassium, chloride, magnesium, copper, selenium and vitamin B6 was not met. The feed was supplemented with a vitamin and mineral preparation to meet her Lower Reference Nutrient Intake (LRNI). There is a need for a suitable preparation complete in minerals and vitamins in liquid form suitable for administration via enteral feeding tubes.

Protein

It is recommended to estimate protein requirements using stress factors (Todorovic and Micklewright, 2007). It is important to consider protein and micronutrient provision in a non-ambulatory patient with low energy needs where there is a high risk of developing pressure areas as the volume of feed required to meet energy needs may not always supply sufficient protein. A maintenance programme supporting pressure relief measures should be assessed and instigated by the appropriate member of the MDT (GPP).

Micronutrients and trace elements

Recommended micronutrient intakes are levels to prevent deficiency and are based on studies in the general healthy population (DH, 1991). In illness, requirements are likely to be raised (Shenkin, 2000). Micronutrients have a wide ranging function and suboptimal levels may impair function before signs of deficiency are seen.

Low serum Vitamin D levels were reported in 122 people with LD in a long-stay hospital ward in Hong Kong in 2006 by Fu Wong and colleagues (Fu Wong et al., 2006). Institutional lifestyle was reported to be a cause of low Vitamin D however for non-ambulatory clients the risk of such a deficiency still remains. Biochemical evidence of macro and micronutrient deficiency has been highlighted in people receiving HETF (MacDonald, 1989; McWhirter, 1994; Bannerman, 2001) and copper deficiency (Oliver et al., 2005).

The volume of proprietary feed to meet and not exceed the energy requirements of people with very low energy needs may not provide the Reference Nutrient Intake (RNI), Estimated Average Requirements (EARs) or LRNIs of all nutrients. Currently, evidence is lacking whether the RNI, EAR or the LRNI is more applicable to individuals with LD on HETF.

It is possible that protein, vitamin and mineral requirements parallel energy requirements but the literature search did not reveal evidence of the micronutrient needs of this unique population. A similar dilemma has been reported by Carter (2006) in children with severe cerebral palsy.

The dietitian is best placed to assess the individual’s nutritional intake, requirements and potential deficiencies. It is important to inform the professional with overall responsibility for medical care – usually the GP or consultant – about the findings of nutritional assessment with suggestions for appropriate action to safeguard the person’s nutritional status (GPP).

Even though it is prudent to aim to meet RNI, the LRNI is appropriate to achieve for a small sub group of the population. Confirmation of nutritional status by biochemical monitoring may be necessary if the nutrient intake does not meet minimum requirements or clarification is required. If requirements cannot be met with prescribed feed alone, then supplementation including electrolytes may be required.

Fluid

Particular care needs to be paid to fluid balance as clients with LD are more at risk if they are unable to communicate signs of dehydration (Dickerson and Brown, 2005). There may be a need to compensate for additional losses, for example if client is a mouth breather or does not swallow their saliva. Fluid requirements are estimated as per standard protocol (Todorovic and Micklewright, 2007) and adjusted according to individual client need. Constipation and diarrhoea will also increase requirements. Detection and prevention of dehydration rely on subjective and biochemical monitoring as Carbamazepine, for example, lowers serum sodium (Dickerson and Brown, 2005).

The long-term (over) use of phosphate enemas can also lead to dehydration (MacDonald et al., 1989). Conversely, over- prescription of enteral tube feeds can result in fluid overload, reflux (oesophageal/gastric) with associated upward aspiration and undesired (and rapid) weight gain which can compromise respiratory function and mobility.

3.2.4 Other issues to consider during assessment

Re-feeding Syndromes

NICE (2006) gives guidance for identifying, addressing and preventing re-feeding syndromes though local guidelines may be in place in relation to the more well-known classical “Re-feeding Syndrome” (RS). However be aware that the risk in the LD population may be higher than the general population because of severe and prolonged under-nutrition and chronic inadequate nutritional intake. There is no evidence to support this in literature.

In classical RS the biochemical abnormalities which can arise when feeding is commenced include:

Hypokalaemia
Hyperglycaemia
Hypomagnesaemia
Hypophosphataemia

….as well as clinical abnormalities such as cardiac failure and acute circulatory fluid overload.

Wernike-Korsakoff Syndrome is caused by acute thiamine deficiency and clients should be managed as for RS but with high doses of intravenous doses of thiamine and other B vitamins for three days. Readers are advised to read Section 6.6 of the NICE Guideline 32 (2006A) for more information on re-feeding syndromes. Prior to initial feeding tube insertion the risk of RS should be assessed as per local guidelines (GPP).

Medications

Clients with PMLD in particular take a large number of medications to control mood, behaviour and epilepsy on a daily basis as well as pro nata (prn) (also known as "rescue" medication). Some medications have a direct impact on nutrient absorption such as anticonvulsants and osmotic laxatives (see Table 3). Neuroleptics (antipsychotics) cause pharyngeal weakness and dystonia, whilst some of the tricyclic antidepressants such as Amitriptyline, have an effect on saliva production resulting in xerostomia (dry mouth). Medication reviews are important to discuss the impact of new drugs as well as the continued combination of current medications. Readers are recommended to refer to *Administering Drugs via Enteral Feeding Tubes: A Practical Guide* and associated leaflets for patients, carers and general practitioners (BAPEN, 2004).

Table 3: Types of medications and effect on nutritional status

Class	Examples	Impact
Anticonvulsants/ Antiepileptics	Carbamazepine Phenytoin*	Impaired folate absorption. *Interacts with tube feed. Feed to be stopped 2hr pre and post dosage.
Antipsychotics/ Neuroleptics	Olanzapine, Rispiridone, Haloperidol	Gastrointestinal disturbances, Rapid weight gain. Also affects integrity of swallow.
Anxiolytics	Diazepam, Lorazepam	Constipation, diarrhoea, increased salivation, vomiting
Antidepressants	Amitriptyline Fluoxetine*	Constipation, weight gain, decreased salivation. *changes in blood glucose
Antimuscarinics	Dicycloverine HCL Hyoscine	Constipation, vomiting
Hypnotics	Chloral Hydrate Temazepam	Gastric irritation
Mood stabilisers	Lithium	Weight gain, oedema
Osmotic laxatives	Movicol, Lactulose	Long term use can interfere with the absorption of fat-soluble vitamins.

Note: This list is intended as a guide and is not exhaustive

Post-PEG complications

Very few papers were found to support the premise that post-PEG complications are more common in clients with PMLD. Such complications include aspiration pneumonia, oesophageal reflux, chronic loose stools and tube misplacement (Castel et al., 2005; Flanagan and McAloon, 2003; Byard & Couper, 2001; DeVogelaere et al., 2000 and Lohiya et al., 2000). Clients who are NBM are more prone to bacterial overgrowth as lack of saliva and reduced swallowing has been shown to increase gastric pH (O'May et al.,2003), also gastric colonisation per se may increase risk of pneumonia in people who are already prone to chest infections (Heyland,1998).

In practice clients with LD and severe scoliosis often receive long-term antibiotic therapy to counteract the debilitating effects of frequent chest infections due to aspiration. Lohiya and colleagues describe the use of fundoplication in an adult with PMLD who suffered antibiotic resistant aspiration pneumonia (Lohiya et al., 2000). Sub optimal oral hygiene resulting in increased pathogenic activity was cited for the continual aspiration.

Oral hygiene is a key component of the pre- and post-PEG training and education programme and emphasis on the impact on health needs to be fully understood by carers.

3.3 Monitoring

National guidance for monitoring tube feeding is produced by BAPEN (Todorovic and Micklewright, 2007; NICE, 2006; CREST, 2004). While these documents underpin the fundamentals of monitoring, this section aims to highlight the differences in health care needs influenced by the presence of LD and gives recommendations to ensure effective monitoring.

The client's nutritional status, degree of LD and other variables such as the impact of their environment, social situation and (as we have seen in Table 1) multiple carers at multiple venues will necessitate a different approach. The number of people involved can be as many as 60 including registered and non-registered carers, GP, psychiatrist, district nurses, LD and nutrition nurses and Allied Health Professionals (AHPs).

Monitoring should always include the client, as they may be able to articulate their views with support from a carer (GPP).

People with PMLD will be totally dependent upon carers to identify and recognise symptoms and problems, respond appropriately and report their progress. The sheer number and turnover of people involved in care makes monitoring, effective communication and dissemination of recommendations particularly challenging. Effective multidisciplinary and multiagency team working is essential for consistent good quality care.

3.3.1 Frequency of Monitoring

The aim of monitoring is to enable the client to achieve and maintain optimal health outcomes, reduce complications and unnecessary acute admissions (Erdil et al., 2005; Thomson et al., 2002; Schurink et al., 2001; Rabeneck et al., 1996).

NICE (2006) recommends HETF is monitored every three-to-six months, or more frequently if there is a change in condition. This necessitates the dietitian being informed of any changes in order to ascertain the appropriate frequency of monitoring. The dietitian may not be routinely informed of alterations in the client's clinical condition, health, wellbeing and social situation. Indeed the carers or family may be unaware of changes in health as the client may not be able to communicate these to them. Carers may not be aware of the significance of changes and therefore not communicate them.

For these reasons, the dietitian needs to be more vigilant and proactive in monitoring and reviews are likely to be needed more frequently than the general population. The frequency of monitoring is the decision of the managing dietitian on an individual client basis, tailored to meet their needs and determined by local standards.

It is recommended that monitoring is undertaken every three months (GPP).

3.3.2 What

A recommended list of parameters for monitoring is available (BAPEN Todorovic and Micklewright, 2007; NICE, 2006; CREST, 2004). See Appendix 4 for a sample checklist.

- **Weight:** Intensive monitoring of weight is important to prevent adverse weight gain especially in the early stages of enteral tube feeding. Weight monitoring can be used to evaluate intervention and thus enable adjustment of nutrient provision according to clinical need. People who need intensive nutritional support to improve nutritional status may require joint monitoring from the physiotherapist/occupational therapist for re-assessment. Depending on the client and circumstances at the time of nutritional assessment, plotting of sequential weights on a regular basis in conjunction with SGA may be the best that can be achieved (GPP).

- **BMI MUAC and TSF:** As discussed earlier (see Nutritional Assessment) these are rarely used with clients who have PMLD. If used, how often they are measured depends on individual clinical need and the usefulness in monitoring such indices.

- **Bowel function:** Enquiring about bowel function can lead to a plethora of non-standardised descriptions which mean different things to different people. Constipation is a frequent problem for people with LD and increases the risk of seizure activity (Thomas and Bishop, 2007; Dean, 2001) but it often goes unrecognised by carers because it is “normal” for the client. Contributing factors are poor gut motility, chronic inadequate fluid and fibre intake, chronic laxative usage, lack of physical activity and medication side effects. When enteral tube feeding is commenced, there is a risk of faecal impaction and vomiting despite adequate nutrition and fluid. Bowel function needs to be monitored to prevent complications. By providing adequate nutrition and fluid, the need for laxatives can be reduced. With regard to diarrhoea, this can occur due to a pre-existing bowel disorder, a side effect of medication, infection or too rapid a feed rate (CREST, 2004) and needs to be addressed as per local protocols. Diarrhoea may also be due to colonisation of helicobacter and, though experience indicates that people with LD are more prone to H-Pylori, there is no evidence to support this in the literature. By adopting a standardised way of describing bowel function there is less ambiguity and the standard of choice is the Bristol Stool Chart (Lewis and Heaton, 1997) (GPP).

- **Biochemistry:** Recommendations for monitoring biochemistry are given by BAPEN (Todorovic and Micklewright, 2007) and they apply to this population. As with any other treatment and intervention, taking blood for biochemistry should only be requested if there is a clinical need and clear benefit to the client. Venupuncture may present problems such as distress, challenging behaviour, the need for restraint and difficulty obtaining a sample due to poor venous access. NICE (2006) recommends biochemistry at least annually; however the MDT needs to assess risks versus the benefit to the client. If the client requires regular monitoring of anticonvulsant blood levels, it may be possible for both clinical needs to be addressed by one blood sampling session (GPP).

It is often the case that the dietitian is the only health professional to routinely monitor the client and for this reason it is considered good practice to check (by observation or questioning the carers) the stoma site and identify any training needs with the carer (**GPP**). This holistic approach can help to identify potential problems and is an opportunity to involve and empower the carer to adopt suitable aspects of monitoring.

3.3.3 Who

NICE (2006B) states that monitoring should be undertaken by the healthcare professional with relevant skills and training in nutritional support. The dietitian is best placed to lead but the profession practitioner carrying out the monitoring will vary across the country. In some cases monitoring may be delegated to competent support staff.

3.3.4 Where

Monitoring may be done wherever is most appropriate and could involve visits to see the client and carers at multiple venues. Face-to-face contact in the client's own home allows an invaluable assessment of how the client and their carers are coping with the feeding system and also provides reassurance and support (Brown, 2006; Madigan et al., 2002).

The greatest numbers of problems are reported within the first few days at home (Mensforth, 1999). Following discharge post-PEG insertion, a telephone call within one working day (of receipt of referral) and a domiciliary visit within five working days are recommended (GPP).

3.3.5 How

- Involve the client and carers in setting the goals of dietetic intervention and evaluation of progress.
- Discuss frequency of visits to help them understand the dietetic role, realise mutual expectations and agree level of support.
- Explain when to contact the dietitian or other Heath Care Professional.
- Give emergency and routine contact numbers.
- Provide information about relevant aspects of enteral tube feeding, in the most appropriate format such as:
    - feeding regimen;
    - care of stoma;
    - correct use of equipment (NPSA, 2007);
    - skin integrity;
    - oral hygiene;
    - trouble shooting guide;
    - safe administering of medicines;
    - storage and method of supply of equipment and ancillaries.

And, finally, be prepared for the unexpected!

It is not uncommon to arrive at a visit with pre-determined aims and objectives, but leaving without achieving any of them. During the visit, the dietitian may be asked to assist in areas that are outside traditional dietetic practice, for example reading a letter written in English during a visit with an interpreter, or advocating for a move to healthier living conditions. Also, problems such as poor compliance to recommendations may become apparent and will need to be dealt with as a matter of immediacy.

Concerns may arise in relation to vulnerable people at risk from their environment. It is essential that the dietitian discusses any concerns with their line manager and follows protocols for the protection of vulnerable adults. This may not appear to be a role for the dietitian but by taking a holistic approach during a review and acting as a single point of access to the service, this eases the burden on the carers and helps reduce barriers. Such unresolved issues can have an indirect effect on optimising nutritional status.

On the other hand, unexpected improvements and progress may become apparent requiring aims and objectives to be reviewed.

One last point – do not underestimate the value of telephone contacts and being available.

“We feel involved in his nutrition and we keep a constant vigil on regurgitation. Feel we can ring anytime for advice or if concerned about anything, feel it’s okay to ask the question. She’s always there at the end of the phone.” (Carers, 2008)

“I am totally involved. With me I was left to get on with it when it was done but knew the dietitian was there as support….my back-up if I get stuck.” (A parent, 2008)

4.0 Training and Education

As previously stated, clients with LD have greater health needs than the general population and those requiring an enteral feeding tube are more likely to have complex health, physical, social and psychological needs. Specialist community services need to be in place to provide continuous support during the period of enteral tube feeding (Rouse et al., 2002).

4.1 Approach

Co-ordinated care from the multi-disciplinary team (NICE, 2006) is essential to ensure that correct and timely assessment, referral and pre and post enteral tube placement training and education happens (see Table 2). The multi-disciplinary team could consist of the:

- GP
- Dietitian
- Speech and language therapist
- Psychologist
- Community/LD nurse
- Community and hospital-based nutrition nurse specialist
- Pharmacist
- Consultant gastroenterologist
- Other health professionals who might need to be involved at various stages of the process.

In the event there is no provision for a multi-disciplinary team decision, then the lead clinician has to ensure that as many involved parties (both professional and informal) are consulted to ensure the decision to proceed to PEG placement is in the client's best interests and that all relevant aspects are covered and considered in the assessment process from which a management plan is formulated and agreed. A single clinician should not take sole responsibility for a PEG referral.

In order to achieve a co-ordinated approach several things need to be in place:

- A responsive specialised community service
- Good planning strategies
- Effective working partnerships between health, social and other agencies.
- Seamless transitions between primary and secondary care
- Good communication networks
- Shared referral criteria.

4.2 Needs of clients

As with any other group the following areas need to be carefully considered and the training needs for the clients identified (NICE 2006B). In this client group there is more emphasis required in certain areas as detailed below:

- Ethical, legal, consent issues – these can be particularly complex and require multi-disciplinary and multi-agency collaboration and if necessary advocacy should be explored.

- Potential risks and benefits for the client not the carer.
- Nutritional needs/indications for nutritional support.
- Options available i.e. oral/enteral/parenteral.
- Where and when to seek advice.

Hannon (2004) states that “better pre-admission assessment improves learning disabilities care”. This can also be applied to training and education for enteral tube feeding.

4.3 Pre-PEG assessment, training and education

Whilst there is an inconsistency of service provision countrywide, it is essential that people with LD and their carers, both formal and non-formal, receive adequate information pre-procedure to be able to make an informed choice and be able to be involved in the consent process. Such information needs to include the effect on the client’s health, psychological and social well being. Placement of an enteral feeding tube has a knock-on effect to many aspects of the client’s care such as:

- Timing of personal hygiene care
- Timing of therapeutic interventions e.g. physiotherapy, hydrotherapy, rebound
- Suitability of drug preparations*
- Timing of medications in relation to the feed*
- Transport to and from day centre/activities

** With reference to White and Bradnam, 2007.*

It is important to be realistic about the impact enteral tube feeding can have on the family/carers as initially it could increase stress and heighten anxiety. This needs to be managed in a proactive and supportive way by the appropriate MDT member as ongoing support needs to be more than skin care and nutritional guidance (Sullivan et al., 2004).

“It was a case of information overload. There was a lot happening; we were in hospital and it was stressful. I went for the easiest option which was using a syringe as the pump was too much to take in at the time.” (A parent)

“We felt inadequate and wondered if we could do it for him.”
(A carer)

Remember that carers will have different levels of skills, knowledge and concerns, a one-size-fits-all approach will not meet everyone’s needs and aspirations.
The pre-PEG assessment, carried out by a suitably experienced practitioner, will identify the training and educational needs of all those who will be involved in the management of the tube, feeding and medication regimens. In complex cases such as those involving clients with PMLD this ideally should include the consultant who is to place the tube. Prior knowledge of the specific tube type and client risks specific to the procedure will inform pre-placement training.
Identified training and educational needs can then be addressed in the period of time leading up to the placement of the tube with post-procedure training continuing to ensure confidence and competency is achieved. Recognition of the family’s/carers’ contribution is essential and their needs also assessed and met. They can prove to be a valuable resource due to their in depth knowledge of the client and this should be utilised in the planning of all aspects of care.

4.4 Training and education areas to be covered

Training packages should be individualised for each client whilst being underpinned by a competency framework to ensure recognised standards of good practice are met and adhered to (GPP). The use of supporting literature in an accessible format (NICE 2006), is advisable to reinforce knowledge and used as an ongoing resource.

The training must be carried out by a competent practitioner with relevant experience who can observe practice. It is the legal duty of the carer's employer (which could be an agency or private provider) to ensure they access this training and are assessed within their own policies and protocols as competent. Client-specific training is required in situations where carers are non-registered. NICE (2006) states:

"Patients in the community having enteral tube feeding, and their carers, should receive training and information from members of the multidisciplinary team on:

- *The management of the tubes, delivering systems and the regimen, outlining all procedures related to setting up feeds, using feed pumps, the likely risks and methods for troubleshooting common problems and be provided with an instruction manual (and visual aids if appropriate).*
- *Safe administration of medications following locally agreed guidelines and risk assessment of individual clients.*
- *Both routine and emergency telephone numbers to contact a healthcare professional who understands the needs and potential problems of people on home enteral tube feeding.*
- *The delivery of equipment, ancillaries and feed with appropriate contact details for any homecare company involved."*

It is apparent, professionally and legally, that relatives and non registered carers can be educated in the management of enteral tube feeding which includes the provision of a prescribed feed and medication. The person who receives instruction is responsible for carrying out the task to the set standard. Suggested areas of training to be addressed are detailed in Appendix 5. Specific approaches and techniques need to be considered when clients display challenging behaviour and will form part of the multi-professional, multi-agency risk assessment.

4.5 Post-PEG/Enteral tube placement procedure

Following tube placement, ongoing training and support is vital particularly in the initial post procedure period and should be carried out by a competent practitioner.

“Felt like we were left to our own devices a bit. If I needed any help, someone would visit but would have appreciated a planned visit before the tube was placed so I knew someone was going to come and visit and check things were okay. Could have done with this in the first couple of weeks when you don’t know if you are doing things correctly.” (A parent)

“I’m a bit gung-ho – I will give it a go. Either she stayed in hospital longer or I got on with it. Looking back I needed more training…no input when I got home at all. I was shown once and then let loose.” (A parent)

Once the client is established on the regimen, monitoring protocols need to be put into place as per local dietetic standards. Review of the training needs should be undertaken at least annually. However this may be more frequent if the client’s situation changes e.g. alterations to a care package, residence or the enteral tube feeding/medication regimen (GPP).

5.0 Summary and Conclusion

Brown defines the specialist practitioner as one who consolidates and develops understanding of the health needs of a given population built upon a rigorous evidence base (Brown, 2001). In the absence of the latter, this Consensus Statement is a small step towards developing an understanding of the specific nutritional health needs of adults on home enteral tube feeding and who have LD.

At present, the level of the evidence base is that of best practice and the Good Practice Points are highlighted throughout the text as a guide for practitioners.

It is apparent from the lack of published data specific to this client group that further research is necessary in order for us to understand and respond to their needs and aspirations.

Recommended areas of research include:

- Is it possible to design and validate standard reference tables for clients with LD?

If the energy needs are reduced as shown by available evidence and clinical practice:

- Can this be expressed scientifically/mathematically to underpin meaningful assessment of nutritional status and nutritional requirements?
- Is this reduced energy need reflective of protein and other macro and micro nutrients? How can nitrogen balance be measured in clients who have PMLD?
- Are the rate of complications greater in clients with LD? Can this be stratified within sub-groups?
- Qualitative Research into QOL of clients with LD.

To name but a few, refer to Appendix 2 for unanswered key questions which would benefit from research.

The number of adults with LD on home enteral feeding is unknown but increasing as more children with complex needs and LD are surviving into adulthood and accessing adult services. Just over 2% of the population have LD but only 0.5% access service (DH, 2007B). These administrative norms are currently used in absence of demographic data to gain an estimation of the client base.

Sharing good practice is essential to move forward and could begin by the LD regional interest groups within the BDA MHG coming together to set an agenda for joint audit and research. With a relatively small client base as reflected by the number of available research papers, it would seem expedient for rigour to consider multi-centre audit and research projects both intra and inter-professional.

People who have LD present with a wide range of cognitive and physical abilities and wish to have access to services which have long been available to the non-disabled population in order to have an equitable quality of life (Learning Disability Advisory Group, 2001; Thompson and Pickering, 2001).

The skills challenge for any health professional is to provide – by observation and discussion – an evidence-based yet flexible and practicable intervention that includes and meets the aspirations and needs of each client. However, inclusion needs to be broader with the involvement of clients and their carers in service planning including audit and research as well as enabling individuals to make their own informed choices (DH, 2007B).

The National Health Services within the United Kingdom have a responsibility to commission mainstream services that, as well as specialist learning disability services, address the health inequalities of people who have LD.

In conclusion, maintaining long-term therapeutic interventions such as HETF for clients with LD is an increasing resource challenge for dietitians and nurses, whether in specialist teams or generic core services. Members of the LD specialist team have the flexibility to support, advise and in some cases undertake joint care with mainstream services, as well as provide a specialist service for those clients whose learning disability impacts significantly on their health and social care.

The formulation and adoption of this consensus statement is a small yet important step towards raising the profile of the nutritional needs of this client group, in particular those who are unable to enjoy satisfying their nutritional needs via the oral route.

"It was disappointing to know that he needed a PEG as he **loved** *his food, so the 'Mmmn'* [lip smacking] *factor had to go."* (A carer)

"It was just a top-up at first but over the years feeding was more difficult and she has learnt to live with it now – we all have." (A parent)

"Some things haven't improved as we used to enjoy eating out at restaurants. It's a shame he doesn't enjoy that anymore. But he is much happier now." (A parent)

6.0 Glossary

AHPs – Allied Health Professionals including dietitians, speech and language therapists, occupational therapists, physiotherapists, orthoptists, registered with the Health Professions Council (HPC).

BMI – Body mass index for relating a person's body weight to their height. The body mass index (BMI) is a person's weight in kilograms (kg) divided by their height in meters (m) squared.

Contractures – An abnormal, often permanent shortening, as of muscle or scar tissue, that results in distortion or deformity, especially of a joint of the body.

Dietary Induced Thermogenesis – The predicted rise in body temperature following ingestion of food.

Dual diagnosis – where a client has both mental health and LD. The mental health national service framework should be followed.

Fundoplication – Surgical intervention to relive chronic reflux, often involves pinning the stomach much higher, thus reducing the likelihood of placing a device into the stomach as it may be pinned under the rib cage.

GPP – Good Practice Point. Based on a consensus of best practice.

Jejunostomy – A surgical procedure to create an opening through the abdominal wall (a "stoma") into the small intestine (the "jejunum"). Used for enteral feeding when it is necessary to bypass the upper gastrointestinal tract.

Kyphosis – Curving of the spine that causes a bowing of the back, which leads to a hunchback or slouching posture.

LRNI – Lower reference nutrient intake. This aims to define minimum nutrient requirements; this amount will only be sufficient for a small percentage of the standard population (about 2.5%) with low needs and will not be enough for most people. Individual intakes below the LRNI are likely to be inadequate.

MUAC – Mid-Upper Arm Circumference. Measurement of the non-dominant* arm midway between the shoulder and the elbow; can be used as a determinant of muscle mass.
*If right handed, the non dominant arm is the left arm. This is the gold standard used as defined by Bishop et al 1981.

PEG – A percutaneous endoscopic gastrostomy is an endoscopic procedure for placing a tube into the stomach through the abdominal wall. The procedure is performed in order to place a gastric feeding tube as a long-term means of providing nutrition to patients who cannot productively take food orally.

PMLD – Profound and multiple learning disabilities; that is, a person with more than one learning disability where their main learning disability is profound.

Re-feeding Syndromes – syndromes consisting of metabolic disturbances that occur as a result of reinstitution of nutrition to patients who are starved or severely malnourished.

RIG – A radiological inserted gastrostomy refers to a tube being inserted radiologically (opposed to an endoscopic procedure i.e. PEG). It is indicated for patients who have obstructing lesions in the upper GI tract, which prohibits the passage of an endoscope, or where tumour seeding is a risk. Sedation is required for clients who have LD even if they have poor respiratory function. Sedation is not generally required for the standard population.

RNI – Reference nutrient intake. The RNI is the amount of a nutrient that is enough to ensure that the needs of nearly all the group (97.5%) are being met. By definition, many within the group will need less. If an individual is consuming the RNI of a nutrient, they are unlikely to be deficient in that nutrient.

Scoliosis - A curvature of the spine, either congenital or acquired by very poor posture, disease or muscular weakness due to certain conditions such as cerebral palsy or muscular dystrophy.

SLT – Speech and language therapist; a specialist who evaluates and treats communication disorders and swallowing problems.

TSF – Triceps skinfold thickness. A measurement of subcutaneous fat taken by measuring skinfold thickness at specific sites including triceps, biceps, subscapular and ileac crest.

Vulnerable Adults – A person who is 18 years old or over, and who is or may be in need of community care services by reason of mental or other disability, age or illness and who is or may be unable to take care of him/herself, or unable to protect him/herself against significant harm or serious exploitation.

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Useful websites

BAPEN – www.bapen.org.uk

BDA MHG – www.dietitiansmentalhealthgroup.org.uk

Best Interest Guidance – www.bps.org.uk

Clear. For advice & training regarding making information accessible – www.clearforall.co.uk

Health indictors for people with learning disabilities – www.pomonaproject.org

Journal abbreviations – http://images.isiknowledge.com/help/WOS/O_abrvjt.html

Mental Capacity Act 2005 Short Reference Guide – www.bps.org.uk

PENG – www.peng.org.uk

RCN – www.rcn.org.uk

TalkingMats – www.talkingmats.com

EVIDENCE TABLE: Papers relating to Key Questions.

Appendix 1

References in magenta have not been used in text

Key Question 1 : How informed consent is obtained.

There were no papers found in literature search relating to this question.

Key Question 2 : Complications specific to learning disabled clients receiving enteral feeding.

Reference	**Study Type**	**Evidence Level**	**Population and number**	**Intervention**	**Comments relating to key question No. 2**
Byard, R.W. & Couper, R.T.(2001).Acute gastric dilation and spastic quadriparesis. *J. Pediatrics.* **139**,166	Case Report	Level 3	One individual with a LD- 20 year old male.	n/a – patient died.	Refers to complications with PEG feeding in patient with CP & LD.
Dickerson, R.N., Brown, R.O., Gervasio, J.G. et al (1999) Measured energy expenditure of tube-fed patients with severe neurodevelopmental disabilities. *J Am Coll Nutr.* **18,** 61-68.	Prospective Study	Level 2++	20 :14 adults 6 children	Measurement of resting energy expenditure (REE) in non-ambulatory tube-fed patients with severe neurodevelopmental disabilities – found requirements were lower.	Patients with severe neurodevelopmental disabilities have lower REE.
Dickerson, R.N., Brown, R.O.,(2005). Long term enteral nutrition support and the risk of dehydration. *Nutr Clin P.* **20**, 646-653	Case study	Level 3+	1 subject profound mental retardation, spastic quadriplegia, NBM, jejunostomy	Treatment of a patient with suspected fluid overload and subsequent dehydration.	L D more at risk of dehydration if they are unable to communicate that they are dehydrated.
Flanagan, N.M. & McAloon, J. (2003) Gastric volvulus complicating cerebral palsy with kyphoscoliosis. *Ulster Med J.* **72,** 118-120.	Case report	Level 3-	1 young adult with CP	Case study of an 18 CP male with gastric volvulus a life threatening complication.	Successful novel use of PEG to extend life.
Lohiya, G-S., Tan-Figueroa, L. & Kuhler, H. (2000).Aspiration pneumonia and antibiotic resistant infections in a man with severe developmental disabilities: How much care is enough? *J Intell Dev Disabil.* **25,** 83-89.	Case report	Level 3	One individual with severe physical & learning disabilities.	Fundoplication, antibiotics, tube replacement.	In people with a LD, pneumonia is the leading cause of death due to aspiration.
Pitsinis, V. & Roberts, P. (2003) Gastrocolic fistula as a complication of percutaneous endoscopic gastrostomy. *Eur J Clin Nutr.* **57,** 876-878.	Case report	Level 3	One individual with severe learning & physical disabilities.	Advice re. reinsertion of PEG.	Rotation of stomach – type of complication which is associated more with LD.
Yarze, J.C. 7 Scalia, P.G. (1997) Feeding jejunostomy button replacement. *Gastrointest Endosc.* **46,** 191-192.	Letter	Level 4	One individual with a LD – 23 year old female.	Replacement of tube	Refers to complications with PEG feeding in patients with CP & LD.

Key Question 3 : Exacerbation of gastric reflux.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 3
Castel, H., Tiengou, L-E. Besancon, I et al.(2005) What is the risk of nocturnal supine enteral nutrition? *Clin Nutr*.**24**, 1014-1018.	Prospective cross-over study (pilot)	Level 2-	Adults. 16 (6 with reflux)	GERD in mechanically ventilated	Positioning seems irrelevant to episodes of reflux.
Lohiya, G-S., Tan-Figueroa, L., Kuhler, H. (2000) Aspiration pneumonia and antibiotic resistant infections in a man with severe developmental disabilities: How much care is enough? *J Intell Dev Disabil.* **25**, 83-89.	Case report	Level 3	One individual with severe physical & learning disabilities.	Fundoplication, antibiotics, tube replacement.	Fundoplication performed to reduce risk of reflux.

Key Question 4 : Other complications.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 4
Byard, R.W. & Couper, R.T.(2001) Acute gastric dilation and spastic quadriparesis. *J. Pediatrics.* **139**, 166.	Case Report	Level 3	One individual with a LD- 20 year old male.	n/a – patient died.	Acute gastric dilation/gastric gas bloat.
De Vogelaere, K., De Backer, A., Vandenplas, Y. & Deconinck,P. (2000) Gastroileocutaneous Fistula: An unusual complication of percutaneous endoscopic gastrostomy. *Endoscopy.* **32**, S3-4.	Single case report	Level 3-	1 adult with LD and scoliosis	First Placement of PEG	4 months post insertion complications of misplacement occurred ie PEG had disappeared
Erdil,A., Saka,M., Ates,Y. et al. (2005) Enteral nutrition via percutaneous endoscopic gastrostomy and nutritional status of patients ; Five-year prospective study. *J. of Gastroen Hepatol.* **20**, 1002-1007.	Prospective study	Level 2+	85 patients – 22 female, 63 male (1 child), who had inadequate oral intake due to various underlying diseases.	PEG feed & observation of complications & effect on nutritional status.	Major & minor complications documented -comparable to other similar studies.

Flanagan, N.M. & McAloon, J. (2003) Gastric volvulus complicating cerebral palsy with kyphoscoliosis. *Ulster Med J.* **72**, 118-120.	Case report	Level 3-	1 young adult with CP	Case study of an 18 CP male with gastric volvulus a life threatening complication.	Successful novel use of PEG to extend life.
Heyland, D.K. (1998) Nutritional support in the critically ill patient. *Evid- Based Crit Care Med.* **14**, 423-440.	Systematic Review	Level 1-	Review of RCTs. Total of 58 papers met criteria.	TPN & EN in critically ill patients.	Paper states EN promotes gastric colonisation with potentially pathogenic bacteria & may ↑ risk of pneumonia – may be significant in LD clients who are already prone to chest infections.
Lohiya, G-S., Tan-Figueroa, L., Kuhler, H. (2000) Aspiration pneumonia and antibiotic resistant infections in a man with severe developmental disabilities: How much care is enough? *J Intel De vDisabil.* **25**, 83-89.	Case report	Level 3	One individual with severe physical & learning disabilities.	Fundoplication, antibiotics, tube replacement.	Pneumonia as result of aspiration. Sub-optimal oral hygiene → ↑ in pathogens . ↑ gastric fluid retention - ? cause of continual aspiration.
McGrath, S.J., Splaingard, M.L., Alba, HM. et al.(1992) Survival and functional outcome of children with severe cerebral palsy following gastrostomy. *Arch Phys Med Rehab.* **73**, 133-137.	Retrospective and prospective case note	Level 2-	61. Children CP	PEG in long term care	Complications following procedure eg dumping.
O' May, G.A., Reynolds, N., Smith, A.R. et al (2003) Effect of pH and antibiotics on microbial overgrowth in the stomachs and duodena of patients undergoing percutaneous endoscopic gastrostomy feeding. *J Clin Microbiol.* **43**, 3059-3065.	Prospective case analysis	Level 2	(30) 20 – new and 10 undergoing PEG replacement	Gastric & duodenal aspirates post placement.	The effect of gastric pH on the composition of aspirate microbiotas – no oral intake leads to lack of saliva production & peristalsis and reduced swallowing increases gastric pH & reduces nitrite concentrations → microbial overgrowth.
Pitsinis, V. & Roberts, P. (2003) Gastrocolic fistula as a complication of percutaneous endoscopic gastrostomy. *Eur J Clin Nutr.* **57**, 876-878.	Case report	Level 3	One individual with severe learning & physical disabilities.	Advice re. reinsertion of PEG.	Notes minor & major complications & early & late complications which can arise in PEG feeding. Fistula between stomach & transverse colon.

Rabeneck,L.. Wray,N.P. and Petetrsone, N.J. (1996) Long term outcomes of patients receiving percutaneous endoscopic gastrostomy tubes. *J Gen Intl Med.* **11**, 287-293.	Retrospective cohort study	Level 2-	7369 PEG adults – analysis of case notes 1990 – 1992.	PEG	Complications such as aspiration pneumonia, as a result of procedure, abscesses and death.
Schurink, C.A.M., Tuynman,H., Scholten, P. et al (2001) Percutaneous endoscopic gastrostomy: complications and suggestions to avoid them. *Eur. J. Gastroenterol Hepatol.* **13**,819-823.	Prospective cohort	Level 2+	Adults 263. Head & neck malignancies.	PEG	Prevention of complications depends on patient selection, procedure techniques and follow-up.
Yarze, J.C., Scalia, P.G. (1997) Feeding jejunostomy button replacement. *Gastrointestol Endosc.* **46**, 191-192.	Letter	Level 4	One individual with a LD – 23 year old female.	Replacement of tube	Dislodgement of feeding tube & replacement by button.

Key Question 5 : Specific medication related issues

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 5
Clarke, D.M., Wahlqvist, M.L., Strauss, B.J.G. (1998) Undreating and undernutrition in old age: integrating bio-psychosocial aspects. *Age Ageing.* **27,** 527-534.	Review of prevalence studies	Level 1+	Review of 18 studies conducted in long term care facilities & acute hospitals.	Looks at physical & psychological factors leading to undernutrition. Suggestions on measures for screening.	Drugs causing taste & smell impairment would also apply to LD.
Dickerson, R.N., Brown, R.O.(2005) Long term enteral nutrition support and the risk of dehydration. *Nutr Clin P.* **20**, 646-653.	Case study	Level 3+	1 subject profound mental retardation, spastic quadriplegia, NBM, jejunostomy	Treatment of a patient with suspected fluid overload and subsequent dehydration.	Carbamazepine lowers serum sodium level making it more difficult to interpret blood results.
Lohiya, G-S., Tan-Figueroa, L., Kuhler, H. (2000). Aspiration pneumonia and antibiotic resistant infections in a man with severe developmental disabilities: How much care is enough? *J Intel & Dev Disabil.* **25,** 83-89.	Case report	Level 3	One individual with severe physical & learning disabilities.	Fundoplication, antibiotics, tube replacement.	Antibiotic resistant bacteria – many antibiotics needed. Suggested drug therapy given.

O' May, G.A., Reynolds, N., Smith, A.R. et al (2003) Effect of pH and antibiotics on microbial overgrowth in the stomachs and duodena of patients undergoing percutaneous endoscopic gastrostomy feeding. *J. of Clin Microbiol.* **43,** 3059-3065.	Prospective case analysis	Level 2	(30) 20 – new and 10 undergoing PEG replacement	Gastric & duodenal aspirates post placement.	Staphylocci, E.Coli, & Candida spp. were isolated only from antibiotic treated patients.
Rodman, D.P., Stevenson, T.L., Ray, T.R. (1995) Phenytoin malabsorption after jejunostomy tube delivery. *Pharmacotherapy.* **15,** 801-805.	Case series	Level 3 -	1 subject – mental retardation, cerebral palsy, epilepsy, unilateral hemiplegia, jejunostomy.	Route of phenytoin administration changed to via jejunostomy following suspected aspiration pneumonia.	Consider bioavailability of medications especially anticonvulsants when choosing route of tube feeding as epilepsy is frequent diagnosis in LD patients. It is normal practice to allow 2 hours either side of phenytoin dose to improve bioavailability.
Zafonte R., Lombard, L., Elovic, E. (2004) Antispasticity medications – uses and limitations of therapy. *Am. J. Phys. Med. Rehabl.* **83**, S50-S58.	Review & analysis	Level 3	Comparisons of different drugs used for spasticity.	Oral versus IV .	Some medications used for spasticity would be given to clients with LD. Referring to route of administration i.e. oral route as opposed to IV.

Key Question 6 : Rate of complications v non-LD population

Reference	**Study Type**	**Evidence Level**	**Population and number**	**Intervention**	**Comments relating to key question No. 6**
De Luis, D.A., Aller, R., de Luis, J. et al (2003) Clinical and biochemical characteristics of patients with home enteral nutrition in an area of Spain. *Eur J Clin Nutr.* **57**, 612-615.	Prospective observational study.	Level 2+	102 recruited over 3 yrs. 81 on oral nutritional support and 21 -tube fed. Pts. with head/ neck cancer, CVA/dementia, other tumours, anorexia, dysphagia.	Most were on oral nut. Support – only 21 tube fed.	Results show favourable outcome as so many were only on oral nut. support & made good recovery with regard to nutritional status. Those tube fed had lowest survival rate but also had poorest prognosis – not reflective of LD population on EN.

Key Question 7 : Benefits to clients

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 7
Flanagan, N.M. and McAloon, J. (2003) Gastric volvulus complicating cerebral palsy with kyphoscoliosis. *Ulster Med J.* **72,** 118-120.	Case report	Level 3-	1 young adult with CP	Case study of an 18 CP male with gastric volvulus a life threatening complication.	Successful novel use of PEG to extend life.
Kennedy M., McCrombie, L., Dawes, P et al., (1997) Nutritional support for patients with intellectual disability and nutrition/ dysphagia disorders in community care. *J Intel Disabil Res.* **41**, 430-436.	Review of results of a 1986 paper	Level 4	Adults with intellectual disability; 318 inpatients and 99 community	Observation of nutritional status.	Under nutrition due to non-protein energy deficit. Improvements in QOL documented. Efforts to increase non-protein energy intake are required. Key point: Improvements in nutritional status may not reduce mortality rate of vulnerable patients with severe nutrition/dysphagia problems. Patients who can feed
McGrath, S.J., Splaingard, M.L., Alba, H.M. et al.(1992) Survival and functional outcome of children with severe cerebral palsy following gastrostomy**.** *Arch Phys Med Rehab***. 73,** 133-137.	Retrospective and prospective case note	Level 2-	61. Children CP	PEG in long term care	1 yr survival rates higher than adults and children who were mentally retarded. Decreased feeding time of 1.5hrs for carers perceived as good outcome
Rabeneck,L.. Wray,N.P. & Petetrsone, N.J. (1996) Long term outcomes of patients receiving percutaneous endoscopic gastrostomy tubes. *J Gen Int Med.* **11**, 287-293.	Retrospective cohort study	Level 2-	7369 PEG adults – analysis of case notes 1990 – 1992.	PEG	What are the benefits to survival., QOL? Need for ethical dimensions to be explored. One of the first papers looking at outcomes rather than just the safety issues of the procedure itself.
Rouse, L., Herrington, P. Assey, J. et al.(2002) Feeding problems, gastrstomy and families: a qualitative pilot study. *Brit J Learn Disabil.* **30**, 122-128.	Pilot Study	Level 3-	2 LD Adults with PEG. Interviews with professionals and parents	Qualitative analysis of interviews.	Need for early intervention re support for clients and carers. Better communication required.

Schurink, C.A.M., Tuynman,H., Scholten, P. et al. (2001)Percutaneous endoscopic gastrostomy: complications and suggestions to avoid them. *Eur J Gastroenterol Hepatol.* **13,** 819-823.	Prospective cohort	Level 2+	Adults 263.Head & neck malignancies.	PEG	Importance of follow up by nutrition team.
Sleigh, G. & Brocklehurst, P. (2004) Gastrostomy feeding in cerebral palsy: asystematic review. *Arch Dis Child*. **89**, 534-539.	Systematic review	Level 2++	25 papers	Gastrostomy/jejunostomy feeding in CP - Children	Lack of evidence to support assumption that G or J is a necessary, safe and effective treatment.
Thomson, M.A., Carver, A.D. & Sloan, R.L. (2002) Percutaneous endoscopic gastrostomy feeding in a district rehabilitation service. *Clin Rehab.* **16,** 215-220.	Retrospective case review	Level 2-	42. 16 – 64yrs	PEG for 6 years	Many patients deny severity of their swallowing which delays consent to PEG. Importance of follow up by Nutrition team.
Wendland, B.E., Greenwood,C.E., Weinber, I. & Young, K.W.H. (2003) Malnutrition in institutionalized seniors: the iatrogenic component. *J Am Geriatr Soc.* **51**, 85-90.	Retrospective case studies	Level 3	Adults. Elderly. 23 cognitively impaired	Analysis of food eaten	Individuals (in care) who are able to eat independently need 2000Kcal in order to achieve RDAs.

Key Question 8 : Benefits to Carers

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 8
Peterson, M.C., Kedia, S, Davies., P. et al. (2006) Eating and feeding are not the same: caregiver's perceptions of gastrostomy feeding for children with cerebral palsy. *Dev Med Child Neurol.* **48**, 713-717.	Controlled trial	Level 2+	26 caregivers of children	Examined perceptions of feeding and adherence to feeding recommendations for care givers	Negative response from 18 care givers when PEG was recommended. However 21 went on to report improvement once PEG commences. Useful for healthcare professionals in understanding carers concerns.

Rouse, L., Herrington, P. Assey., J et al.(2002) Feeding problems, gastrstomy and families: a qualitative pilot study. *Brit J Learn Disabil*. **30**, 122-128.	Pilot Study	Level 3-	2 LD Adults with PEG. Interviews with professionals and parents	Qualitative analysis of interviews.	Need for early intervention re support for clients and carers. Better communication required.
Sullivan, P.B., Juszezak,E., Bachlet, A.M.E. et al. (2004) Impact of gastrostomy tube feeding on the quality of life of carers of children with cerebral palsy. *Dev Med Child Neurol.* **46,** 796-800.	Prospectve cohort	Level 2++	57 children with CP	Gastrostomy feeding	Improvements from baseline in QOL for carers. Ongoing support needs to be more than skin care and nutritional guidance.

Key Question 9 : Benefits to specific client groups within the LD population.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 9
Clarke, D.M., Wahlqvist, M.L. & Strauss, B.J. G. (1998) Undereating and under nutrition in old age: integrating bio-psychosocial aspects. *Age and Ageing.* **27**, 527-534.	Review of prevalence studies	Level 1+	Review of 18 studies conducted in long term care facilities & acute hospitals.	Looks at physical & psychological factors leading to undernutrition. Suggestions on measures for screening.	Could be applied to aging LD clients especially Down's syndrome.
Wendland, B.E., Greenwood,C.E., Weinber, I. & Young, K.W.H. (2003) Malnutrition in institutionalized seniors: the iatrogenic component. *J Am Geriatr Soc.* **51**, 85-90.	Retrospective case studies	Level 3	Adults. Elderly. 23 cognitively impaired	Analysis of food eaten	Individuals (in care) who are able to eat independently need 2000Kcal in order to achieve RDAs.

Key Question 10 : How benefit/burden ratio is assessed.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 10
Sullivan, P.B., Juszezak,E., Bachlet, A.M.E. et al. (2004) Impact of gastrostomy tube feeding on the quality of life of carers of children with cerebral palsy. *Dev Med Child Neurol.* **46,** 796-800.	Prospectve cohort	Level 2++	57 children with CP	Gastrostomy feeding	Improvements from baseline in QOL for carers. Ongoing support needs to be more than skin care and nutritional guidance.

Key Question 11 : Choice of equipment used.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 11
Muramatsu,H., Koike,K. & Teramoto,A. (2002) Benefits of percutaneous endoscopic button gastrostomy in neurological rehabilitation therapy. *Inter J Rehab Res.* **25,** 157-161.	Cohort study	Level 2+	11 patients with severe stroke/ traumatic brain injury who were unable to swallow.	PEG button placed following period of N/G feeding & progress in rehabilitation observed.	PEG button inserted after complications arose from N/G feeding. Workers state PEG button better tolerated than conventional PEG in relation to activities in daily living.
Yarze, J.C., Scalia, P.G. (1997) Feeding jejunostomy button replacement. *Gastroenterol Endosc.* **46,** 191-192.	Letter	Level 4	One individual with a LD – 23 year old female.	Replacement of tube	Details specific tubes & techniques.

Key Question 12 : Choice of placement on enteral feeding tubes.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 12
Erdil,A., Saka,M., Ates,Y. et al. (2005) Enteral nutrition via percutaneous endoscopic gastrostomy and nutritional status of patients ; Five-year prospective study. *J Gastroenterol Hepatol.* **20,** 1002-1007.	Prospective study	Level 2+	85 patients – 22 female, 63 male (1 child), who had inadequate oral intake due to various underlying diseases.	PEG feed & observation of complications & effect on nutritional status.	Study supports finding by other workers that PEG feeding is preferable to N/G.

Muramatsu,H., Koike,K. & Teramoto, A. (2002) Benefits of percutaneous endoscopic button gastrostomy in neurological rehabilitation therapy. *Inter J Rehab Res.* **25,** 157-161.	Cohort study	Level 2+	11 patients with severe stroke/ traumatic brain injury who were unable to swallow.	PEG button placed following period of N/G feeding & progress in rehabilitation observed.	PEG button enhanced quality of life & progress in rehabilitation, nutritional status & serum albumen.
Silas, A.M., Pearce, L.F., Lestina, L.S. et al (2005) Percutaneous radiologic gastrosomy : A comparison of indications, complications and outcomes in 370 patients. *Eur J Radiology*, **56**, 84-90.	Retrospective evaluation.	Level 2	370 patients – 177 gastrostomies endoscopically placed & 193 fluoroscopically by radiology.		Endoscopic & fluoroscopic gastrostomy tube placement safe & effective. More minor complications in PEG group could be attributed to lack of antibiotic therapy & routine antibiotics should be considered.
Taylor,H.M.(2002) Pneumonia frequencies with different enteral tube feeding access sites. *Am Assoc Mental Retardations.* **107**, 175-180.	Retrospective cohort	Level 2-	30 mixed tube feeds. 5 of these were JEJ 25 Gastrostomy	Incidence & frequency of pneumonia	They had statistically significant less episodes of pneumonia in the JEJ group. $P=0.0014$ Quality of the medical noted was commented on being poor.

Key Question 13 : **How monitoring/evaluation is undertaken.**

Reference	**Study Type**	**Evidence Level**	**Population and number**	**Intervention**	**Comments relating to key question No. 13**
Dickerson, R.N., Brown, R.O.,(2005) Long term enteral nutrition support and the risk of dehydration. *Nutr Clinl P.* **20**, 646-653.	Case study	Level 3+	1 subject profound mental retardation, spastic quadriplegia, NBM, jejunostomy	Treatment of a patient with suspected fluid overload and subsequent dehydration.	Reinforces the importance of detection and prevention of dehydration using a range of subjective and laboratory measurements. Only some of the parameters recommended are readily available in the community and these are existing good practice. There is the opportunity to empower carers to detect the risks and signs of dehydration and respond appropriately.

Gervasio, J.M., Dickerson, R.N., Brown, R.O. et al (1997) Chronic hypothermia and energy expenditure in a neurodevelopmentally disabled patient : A case study. *Nutr Clin P.* **12**, 211-215	Case study	Level 3+	1 subject – profound mental retardation, spastic quadriplegia, NBM, gastrostomy with hypothermia.	Measurements of resting energy expenditure (REE) by direct calorimetry and gradual reduction of tube feed volume to prevent continued excessive weight gain.	Highlights the importance of close monitoring of nutritional status and frequent revisiting goals of nutritional support to prevent excessive weight gain.

Key Question 14 : How nutritional status is assessed.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 14
Dickerson, R.N., Brown, R.O., Gervasio, J.G. et al (1999) Measured energy expenditure of tube-fed patients with severe neurodevelopmental disabilities. *J Am Coll Nutr.***18**, 61-68.	Prospective Study	Level 2++	20 :14 adults 6 children	Measurement of resting energy expenditure (REE) in non-ambulatory tube-fed patients with severe neurodevelopmental disabilities – found requirements were lower.	REE measured & found to be significantly lower than predicted as estimated by Harris Benedict. Fat free mass best way of predicting REE. 2 equations developed which are more precise than conventional formulas.
Dickerson, R.N., Brown, R.O., Hanna, D.L. et al. (2003) Energy requirements of non-ambulatory tube-fed adult patients with cerebral palsy and chronic hypothermia. *Nutrition.* **19**, 741-746.	Case series	Level 3+	6 adults with severe neuro developmental disabilities & chronic hypothermia.	Indirect calorimetry measurements on PEG	Assessment of energy requirements lower in clients with low body temperature.
Dickerson, R.N. & Brown, R.O.(2005) Long term enteral nutrition support and the risk of dehydration. *Nutr Clin P.* **20,** 646-653.	Case study	Level 3+	1 subject profound mental retardation, spastic quadriplegia, NBM, jejunostomy	Treatment of a patient with suspected fluid overload and subsequent dehydration.	Recommends assessment of hydration status using a range of subjective, objective and laboratory measurements to assess hydration status. Only some of the parameters recommended are readily available in the community and these are existing good practice.
Erdil,A., Saka,M., Ates,Y. et al. (2005) Enteral nutrition via percutaneous endoscopic gastrostomy and nutritional status of patients ; Five-year prospective study. *J Gastroenterol and Hepatol.* **20,** 1002-1007.	Prospective study	Level 2+	85 patients – 22 female, 63 male (1 child), who had inadequate oral intake due to various underlying diseases.	PEG feed & observation of complications & effect on nutritional status.	Range of anthropometric measurements recorded. MAC & TSFT considered preferable to other parameters of nutritional wasting in patients. Schofield formula used. Continuous feeding regime.

Liu, M.H., Spungen, A.M., Fink, L. et al (1996) Increased energy needs in patients with quadriplegia and pressure ulcers. *Adv Wound Care.* **9**, 41-45.	Pilot RCT	Level 2+	48 patients. 16 with quadriplegia and pressure ulcers, 16 with quadriplegia but no pressure ulcers and 16 healthy non-spinal cord injured subjects (control).	Resting energy expenditure (REE) in 16 individuals with quadriplegia and pressure ulcers compared with energy expenditure in 16 individuals with quadriplegia but no pressure ulcers.	REE measured by indirect calorimetry. REE higher in subjects with quadriplegia + pressure ulcers – requirement for increased caloric intake compared with subjects with no pressure ulcers – 23kcal/kg/day.

Key Question 15 : How nutritional requirements are addressed.

Reference	**Study Type**	**Evidence Level**	**Population and number**	**Intervention**	**Comments relating to key question No. 15**
Dickerson, R.N., Brown, R.O., Gervasio, J.G. et al (1999) Measured energy expenditure of tube-fed patients with severe neurodevelopmental disabilities. *J Am Coll Nutr.* **18**, 61-68.	Prospective Study	Level 2++	20 :14 adults 6 children	Measurement of resting energy expenditure (REE) in non-ambulatory tube-fed patients with severe neurodevelopmental disabilities – found requirements were lower.	REE measured & found to be significantly lower than predicted as estimated by Harris Benedict. Fat free mass best way of predicting REE. 2 equations developed which are more precise than conventional formulas.
Dickerson R.N., Brown, R.O., Hanna, D.L. et al. (2002A) Effect of upper extremity posturing on measured resting energy expenditure of non ambulatory tube-fed adult patients with severe neurodevelopmental disabilities. *JPEN*. **26**, 278	Single Cohort	Level 2-	24	Resting energy expenditure (REE) P=<0.01	28% lower REE in those with contractures compared with those who had movement in upper extremities p=<0.01 - Small client study group - Uses Harris-Benedict equation Raises questions on validity of Nutritional assessment & calculating requirements with people with complex physical health needs

Dickerson, R.N., Brown, R.O., Hanna, D.L. et al (2002B) Validation of a new method for estimating resting energy expenditure of non-ambulatory tube-fed patients with severe neurodevelopmental disabilities. *Nutrition.* **18,** 578-582.	Single cohort	Level 2-	15 subjects – profound mental retardation, spastic quadriplegia, gastrostomy.	Measurement of resting energy expenditure (REE) by indirect calorimetry. Assessment and comparison of bias and precision of the Arlington Developmental Centre Equations and Harris Benedict Equation to estimate REE.	ADC-2 equation most suitable for predicting REE for adults with fixed contractures, but it still overestimated requirements but not as much as the Harris Benedict equation. ADC equations use skin folds to assess fat free mass but they and Harris Benedict are not used routinely in LD population. Study design not rigorous.
Dickerson, R.N., Brown, R.O., Hanna, D.L et al. (2003) Energy requirements of non-ambulatory tube-fed adult patients with cerebral palsy and chronic hypothermia. *Nutrition.* **19**, 741-746.	Case series	Level 3+	6 adults with severe neuro developmental disabilities & chronic hypothermia.	Indirect calorimetry measurements on PEG	Assessment of energy requirements lower in clients with low body temperature.
Dickerson, R.N., Brown, R.O.,(2005) Long term enteral nutrition support and the risk of dehydration. *Nutr Clin P.* **20,** 646-653.	Case study	Level 3+	1 subject profound mental retardation, spastic quadriplegia, NBM, jejunostomy	Treatment of a patient with suspected fluid overload and subsequent dehydration.	Reinforces techniques to estimate fluid requirements.
Erdil,A., Saka,M., Ates,Y. et al. (2005) Enteral nutrition via percutaneous endoscopic gastrostomy and nutritional status of patients ; Five-year prospective study. *J Gastroenterol Hepatol.* **20**, 1002-1007.	Prospective study	Level 2+	85 patients – 22 female, 63 male (1 child), who had inadequate oral intake due to various underlying diseases.	PEG feed & observation of complications & effect on nutritional status.	Range of anthropometric measurements recorded. MAC & TSFT considered preferable to other parameters of nutritional wasting in patients. Schofield formula used. Continuous feeding regime.

Fu Wong, S.T. et al. (2006) A survey of levels of Vit.D level in people with learning disabilities in a long stay hospital ward in Hong Kong. *J Intel Disabil.* **10**, 47 -59.	Case series	Level 3	Population 122.	Measured of Vitamin D serum levels. Before & after the increase in tube feed volume.	Vitamin levels slightly better in tube fed clients but not significantly. Institutional lifestyle was reported to be a cause of low vit D. Reviewers comments: To many variables in diet. Normal., soft & Tube. Data lacking on anti-convulsant treatment. Highly reliant on old case notes & family self reporting questionnaire to clients sun exposure. Females had a lower level of Vit D.
Gervasio, J.M., Dickerson, R.N., Brown, R.O. et al (1997)Chronic hypothermia and energy expenditure in a neurodevelopmentally disabled patient : A case study. *Nutr Clin P.* **12**, 211-215.	Case study	Level 3+	1 subject – profound mental retardation, spastic quadriplegia, NBM, gastrostomy witrh hypothermia.	Measurements of resting energy expenditure (REE) by direct calorimetry and gradual reduction of tube feed volume to prevent continued excessive weight gain.	Assessment of energy requirements lower in clients with low body temperature.
Liu, M.H., Spungen, A.M., Fink, L. et al (1996) Increased energy needs in patients with quadriplegia and pressure ulcers. *Adv Wound Care.* **9,** 41-45.	Pilot RCT	Level 2+	48 patients. 16 with quadriplegia and pressure ulcers, 16 with quadriplegia but no pressure ulcers and 16 healthy non-spinal cord injured subjects (control).	Resting energy expenditure (REE) in 16 individuals with quadriplegia and pressure ulcers compared with energy expenditure in 16 individuals with quadriplegia but no pressure ulcers.	REE measured by indirect calorimetry. REE higher in subjects with quadriplegia + pressure ulcers – requirement for increased caloric intake compared with subjects with no pressure ulcers – 23kcal/kg/day.

Hierarchy and Quality Rating of evidence (Harbour and Miller, 2001).

1 Meta-analysis, systematic reviews, randomized controlled trials(RCTs).

2 Systematic reviews of case control or cohort studies, case control or cohort studies.

3 Non-analytical studies eg case reports, case series.

4 Expert opinion.

++ Most/all methodological criteria met, low risk of bias.

+ Some criteria met, high risk of bias

- Few or no criteria met, high risk of bias.

Key Questions: **Appendix 2**

In adults with LD who are fed via the enteral route is there evidence of:

1. How informed consent is obtained*
2. Complications specific to learning disabled clients receiving enteral feeding?
3. Exacerbation of gastric reflux *
4. Other complications*
5. Specific medication related issues
6. Rate of complications v non -LD population*
7. Benefits to the clients
8. Benefits to carers
9. Benefits to specific client groups within the LD population *
10. How benefit/burden ratio is assessed*
11. Choice of equipment used *
12. Choice of placement of Enteral feeding tubes
13. How monitoring/evaluation (follow-up) is undertaken
14. How nutritional status is assessed**
15. How nutritional requirements are addressed**

*** Specific recommendations for Adults with LD not found in literature review. These are areas for future research.**
However GPPs based on the clinical experiences of the LD practitioners within ETFiC4LD are to be found within the Statement.

**** Energy only**

Appendix 3

Core Members of a Specialist LD Team

- Dietitian
- Speech and language therapist – dysphagia
- Speech and language therapist – communication
- Clinical psychologist
- Consultant psychiatrist – epilepsy management
- Occupational therapist
- Physiotherapist
- LD community nurse – medication/epilepsy
- Social worker

Appendix 4

Home Enteral Tube Feeding Monitoring Checklist

	Parameter	Date	Date	Date	Date	Date	Date	Date
a	Weight							
b	Reassess requirements if weight change 5%							
c	BMI							
d	Mid arm circumference (MAC)							
e	Triceps skinfold (TSF)							
f	Oral intake							
g	Oral hygiene							
h	Appropriateness of current feed regimen							
i	Feeding tube							
j	Stoma site							
k	General health and wellbeing							
l	Medications							
m	GI symptoms							
n	Urine output							
o	Bowel function							
p	Skin integrity							
q	Biochemistry							
r	Supplies of feed, equipment and ancillaries							
s	Training needs of the carers							
t	Social situation							

Key tick = no problems NBM = nil by mouth S/N = see dietetic notes

Enter date of review in next available column from left to right. Under date, enter abbreviation from key for each parameter.

Appendix 5

Essential Components of a Training Package

- Risks and benefits of procedure
- Tube placement procedures and specific risks
- Tube management (care of the stoma, tube, flushing etc)
- Regimen (bolus, pump or combination)
- Oral intake (as assessed by speech and language therapist
- Use of pump
- Troubleshooting (basic skills to deal with common problems e.g. pump problems, tube blockage, sore skin etc.)
- How feed and equipment is obtained
- Contact details (who, when ,why)
- Support networks

The British Dietetic Association
5th Floor, Charles House, 148/9 Great Charles Street
Queensway, Birmingham B3 3HT
Tel. 0121 200 8080 - Fax: 0121 200 8081
info@bda.uk.com - www.bda.uk.com

Mental Health Group

Eating Disorders Learning Disability Mental Illness

The British Dietetic Association

Weight Management for Adults with a Learning Disability Living in the Community

April 2011, Review date April 2014.

Consensus Statement

Produced by The Learning Disabilities Obesity Group (LDOG)
A task & finish group of the BDA Mental Health Group

Members of LDOG:
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Contents

Executive Summary

This consensus statement is intended to inform and support the practice of dietitians who are not undertaking a specialist learning disabilities (LD) role, but within their caseload care for adults with LD who are overweight / obese. The dietitian has a key role within the multi disciplinary team (MDT) to ensure concordance in approach for the management of nutrition-related conditions. The statement may also be a useful resource for other members of the MDT and their students.

People with LD experience a higher burden of ill health (and poorer outcomes) than the general population. According to the Disability Rights Commission (2006) they are 2½ times more likely to suffer health problems and 4 times as many die from preventable diseases. The range of health needs includes mental illness, epilepsy, an array of physical and sensory limitations (including impaired sense of touch, temperature, pain, taste and smell), dental disease, thyroid disorders, heart disease, binge-eating disorder (BED), dysphagia, under-nutrition and obesity, (Carnaby, 2009, Department of Health (DH), 2009A, Wallace & Schluter, 2008, DH, 2007, Bernall, 2005, Melville *et al*, 2005, Hove, 2004, National Patient Safety Agency (NPSA), 2004, Bryan *et al*, 2000, Kennedy, 1997).

The health gains associated with good nutritional care include enhanced quality of life and improved disease outcomes (DH, 2004, Astor and Jeffreys, 2000). People with LD however, must be enabled as much as possible to make informed decisions and steps taken to ensure that this client group has access to both mainstream and specialist services as and when required.

Sixteen key questions (Appendix 1) were addressed and evidence was found to support eleven of these. Recommendations for future research can be found in the Summary & Conclusion.

The Statement contains information which the authors feel is relevant to the client group and highlights particular differences in approach from the general population for the practitioner to consider. Wherever possible, signposting is made to acknowledged gold standards of dietetic practice throughout the document and Good Practice Points (**GPP**) are indicated within the text. These are based on a consensus of practice agreed by the authors and relate to sections 1-4 within the statement i.e. Introduction; Decision making and consent; Meeting the client's needs and Meeting the carer's needs.

This document will be reviewed by the BDA Mental Health Group (MHG) in 2014, or sooner should robust evidence become available which impacts on clinical practice.

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BDA Office staff
BDA Specialist DOM UK members
BDA Specialist MHG members
Colleagues within authors' networks
Reference group members

The authors would also like to acknowledge their respective employing organisations for their support.

And last but by no means least, our clients and their carers.

"He's worked really hard at trying to cut down on his food…it's not easy…..and he just gave me the biggest hug of my life, lifted me off the ground and said he couldn't wait to get back to swimming"

A parent on reporting a significant weight loss, after many months of dietetic intervention.

Schedule of figures

Schedule of tables

Schedule of good practice points (GPP)

NB: These GPPs are derived from a consensus of practice and as such are graded evidence level 4 (See page 81 for explanation of evidence levels). The GPPs should not be taken out of context, please refer to the relevant text within this document.

Section 1. Introduction:

Nevertheless insufficient evidence should not be used as justification for the non-provision of services for people with LD (**GPP**).

Section 2. Decision making and consent:

In determining capacity to consent, it is essential to involve both clients and carers in the assessment and treatment process and to communicate openly (**GPP**).

Decision-making capacity is decision-specific and time-specific (**GPP**).

*Wherever possible it is advisable to encourage clients to use the term 'overweight' but not at the expense of their comprehension (***GPP***).*

It should be noted that the client with capacity is able to make 'unwise' decisions and have these decisions upheld (**GPP**).

Section 3. Meeting the client's needs:

In such cases weight maintenance may be the best outcome, ensuring that the intake is nutritionally sound which in itself confers positive benefits such as relief from constipation, better mood and 'feeing better' (**GPP**).

*Mencap, People First and other advocacy organisations which exist in local communities will be a good first point of contact as well as the Community Learning Disability Team (*CLDT) (**GPP**).

Adaptation of group activities such as bingo where the numbers are substituted with fruit and vegetables, is a simple method of imparting healthy eating messages and introducing a degree of 'healthy' competition when using the Eatwell Plate model (FSA, 2009) (**GPP***).*

Leaflets highlighting the obesogenic nature of the more commonly used drugs combined with key health promotion messages should be available in all clinic settings (**GPP**).

Though conventional weight maintenance regimes emphasise a high fibre and high fluid intake, this is of critical importance in this client group (**GPP**).

Some clients have difficulties taking sufficient fluid. Therefore encouraging higher intakes of fruits and vegetables, with their naturally high fluid content, may be the preferred option rather than promoting too much insoluble fibre in the form of wholegrain foods (**GPP**).

It is important to have an appreciation and understanding of the skills base, values and belief systems of carers and to use this state of reality 'not as a stick but a golden carrot' for targeted and supportive training (**GPP**).

SIGN (2010), DOM UK (2007) and NICE guidance (2006) on obesity recommend a tripartite interactive model for effective weight management interventions (**GPP***).*

Ask clients to say in their own words what they understand from the information you have given (**GPP**).

However, it is advisable that the client's suitability to access such schemes is assessed before recommending such activity (**GPP***).*

Standard pre-appointment processes may need to be adapted as it can be more effective and efficient to telephone the client/carer to make the appointment (**GPP***).*

Also consider if the appointment needs to be at the beginning or end of a clinic session, to help to reduce the client's anxiety levels (**GPP**).

To aid attendance, telephone and remind client/carer the working day before the appointment (**GPP***).*

The information will also need to be in an accessible format to aid client understanding and compliance (**GPP**).

Where it is not possible to meet the specific needs of people with LD through adapting mainstream services, then referrals to a local specialist CLDT can be considered (**GPP***).*

Any discussion on anti-obesity medication or invasive interventions needs to be discussed fully with the client, their carers and key members from the specialist CLDT (**GPP**).

Experience suggests that fortnightly or monthly reviews would be the most effective, as leaving clients any longer leads to diminished interest and poor compliance (**GPP**).

For clients not accessing specialist equipment, local arrangements may be made with advice from the GP or CLDT (**GPP**).

To reach an ideal BMI may be a totally unrealistic goal for such individuals though to achieve a 5 -10% weight loss would be a pragmatic, meaningful outcome (**GPP**).

If BMI is to be used in people with Profound and multiple learning disability (PMLD), it would be more suitable for the client in these circumstances to use the lower end of the ideal (**GPP**).

Achieving a weight loss of between 5% and 10% would be a more appropriate, realistic and achievable goal, irrespective of the degree of obesity (**GPP***).*

If training needs for staff are identified, referral to the CLDT should be considered. Alternatively they could access available community training schemes which include within the programme aspects of choice, informed decision making and duty of care (**GPP**).

Section 4. Meeting the carer’s needs:

Any activity will of course need to be tailored to the preferences and abilities of the individual (**GPP**).

Melville and colleagues (2008) highlighted the need for carers to be trained on the principles of a healthy diet and the current national recommendations for physical activity and suggested that this could be incorporated into an induction course at the beginning of employment (**GPP**).

Care staff should not dictate what an individual can choose, but it is essential that a person with LD be given appropriate information about healthy food and the benefits so that they can make informed choices (**GPP**).

It is recommended that no more than 2-3 key changes be made at a time (**GPP**).

Any client-specific information whether healthier lifestyle guidelines, an individualised nutritional care plan and/or behavioural techniques should be cascaded (with the client’s consent) to all relevant persons involved with the client’s care, as well as other members of the client’s supporting CLDT (**GPP**).

There are many steps where inconsistencies can occur, so having a schematic of key people involved in the health and well-being of the client is a critical factor in increasing the success of any prevention or intervention (**GPP**).

1.0 Introduction

1a) Scope

This professional consensus statement has been developed as a good practice guide for dietitians whose caseload includes adults with a learning disability (LD), who are living in the community and are overweight / obese. However other health and social care professionals, carers and students might also find this document useful.

The advice and guidance within this document are not applicable for people with Prader Willi Syndrome (PWS), those who have a higher level autistic spectrum disorder (ASD) such as Asperger's, or other specific learning difficulties (SpLD) such as Attention Deficit Disorder (ADD), Attention Deficit Hyperactive disorder (ADHD) dyslexia, dyscalculia, dyspraxia and speech and language delay.

Government policy is aimed at encouraging people with LD to access generic services. This means that healthcare professionals, including dietitians are more likely to see people with LD in general clinics within primary and secondary care (Edwards, 2007, Sowney & Barr, 2004, Powrie, 2003). There has also been a major move away from institutionalised paternalistic care, so that people with LD are enabled to live within the community supported by a variety of health and/or social care packages dictated by individual need. However, the unforeseen increase in the level of obesity (which is more prevalent than the general population) as a consequence of the change in domicile is impacting on people's health and quality of life (Melville *et al*, 2008, Henderson, 2008, Ito, 2006, Rimmer & Yamaki, 2006, Yamaki, 2005, Emmerson, 2005, Robertson *et al*, 2000).

Adults with LD are more nutritionally vulnerable than the general population for a number of reasons. These may include:

- Restricted income/poverty
- Inappropriate/poor living conditions
- Food 'deserts' – poor or limited availability in disadvantaged areas
- Difficulties with travel and transport
- Social isolation
- Social exclusion
- Limited training for healthcare staff about LD
- Limited nutritional knowledge of person with LD and carers
- Limited budgeting/cooking skills of person with LD and carers
- Reduced ability to understand and apply health messages, read or understand food labels
- Reduced ability/opportunity to make informed choices
- Dependence on others for food and drink adequacy and provision

- Dependence on others for eating and drinking

Physiological anomalies, polypharmacy, diagnostic overshadowing, multiple diagnoses and dysphagia are also common amongst this client group (DH, 2007).

Additionally, people with profound and multiple learning disabilities (PMLD) are totally dependent on a range of carers, many of whom do not have the knowledge or skills to enable them to provide a well balanced diet for their clients (Melville *et al,* 2009). Many decisions regarding their health and social care may need to be made in the client's best interests.

1b) Definition of a learning disability

The definition of learning or intellectual disability includes all of the following dimensions (WHO, 1992):

A significant intellectual impairment with an intellectual quotient (IQ) more than 2 standard deviations below the general population i.e. an IQ below 70 on a recognised IQ test.

and

Deficits in social functioning or adaptive behaviour that significantly impact on how well a person's coping skills allow for the everyday social demands which present within their own environment. (Formal psychological assessments may include the Vineland Adaptive Behaviour Scales and the AAMR Adaptive Behaviour Scales).

and

Are present before adulthood i.e. age 18 years ***and are life-long.***

There will be local variations on the above definition and it must be remembered that the use of IQ alone is not sufficient to define this population (HIW, 2007).

1c) Specialist services/extended roles

People with LD have an expectation and a right to access core services as well as specialist LD teams (DH, 2009A, DH, 2007B, Bamford, 2005, Learning Disabilities Advisory Group (LDAG) LDAG, 2001, Scottish Executive, 2000). Whether living at home, which could be parental, supported/assisted accommodation or within a residential setting, support should be available by such specialist teams who help clients live an ordinary life within their local community. The division of what is considered core and specialist is not (or indeed should not be) clear cut and robust working relationships between both teams are essential for the provision of a seamless service for this client group. The registered dietitian is pivotal to service provision.

The knowledge, skills and role of the specialist dietitian within LD includes:

- Advising on nutritional requirements in particular energy, as many clients present with extremes of both overweight and underweight due to complex difficulties

- Having the knowledge and experience to interpret height, weight and anthropometric measurements when assessing nutritional status for this client group

- Working without established guidelines or procedures in relation to LD, but always within locally accepted scope of practice

- Using a holistic approach to assess, problem-solve and ensure that health and social needs are met

- Using appropriate health facilitation skills within the therapeutic framework

- Contributing to the application of a legal framework

- Identifying, referring and working in partnership with health and social care colleagues, agencies and organisations

- Addressing inequalities in health and social care

- Advocating both formally and informally

- Using augmented/alternative communication

- Working in dynamic environments and with service users who display unpredictable behaviours that challenge

1d) Methodology

Sixteen key questions were drawn up to focus the literature review (Appendix 1) undertaken between July 2009 and January 2010 on papers from the year 2000 onwards. The aim of the review was to look at the evidence supporting the assessment, monitoring, complications and ethical issues specific to adults who have LD and who were overweight / obese. The search strategy included the following databases:

ASSIA
CINAHL
Cochrane Library
Ovid Database – including Medline
Barbour Index
Clinical Evidence
Emerald Health Business Full Text Elite
TRIP

(Full details of the search terms are available from the authors).

Evidence was found to support eleven of the key questions (Appendix 2).

The adoption of a consistent approach to the critical appraisal of the resultant documentation contributes to the robustness of this statement. All reviewers followed the qualitative and quantitative guides to critiquing research (Ryan *et al*, 2007A, 2007B). The grading system for evidence based guidelines was also followed (Harbour and Miller, 2001). A cross-over system was employed in that papers were randomly allocated to 2 groups of reviewers (the authors) who independently appraised each paper. Cross-over occurred within each group to match appraisal outcomes.

Consensus of the critical appraisals was reached at a meeting in January 2010 before finalising the evidence tables in May 2010 (Appendix 2). Twenty two papers were discarded, one because of lack of objective data and the remainder as they were not relevant to people with LD (Appendix 3). Forty two papers were reviewed and graded as follows:

Level 2 ++	1
Level 2+	10
Level 2-	19
Level 3	4
Level 4	8

(See page 81 for description of the evidence levels)

The literature review confirmed the authors' perception that little robust research including evaluation of longer-term weight loss strategies had been conducted specific to the healthcare needs of this client group. Nevertheless insufficient evidence should not be used as justification for the non- provision of services for people with LD (**GPP**).

1e) User involvement

The Service Users Advisory Group was set up to ensure that people with LD can give their views about the services they use. Their first report '***Nothing about us without us'*** (DH, 2000) sought to re-affirm the importance of inclusion by advocating user involvement in service provision. Working in partnership with our clients should enable us to provide the best service within our resources, to meet their needs.

Experiences from clients and carers have been included in the text. A range of dietetic and other health and social care professionals have been involved in the peer review of this document.

In formulating this consensus statement the authors confirm they have followed the BDA Ratification Process (BDA, 2010).

2.0 Decision making and consent

This section of the consensus statement aims to give examples of issues that may arise and give guidance on how legislation is applied to people with LD. The issue of consent always needs to be obtained for dietary interventions, and when dealing with the general population consent is customarily obtained verbally. In clients with cognitive impairment, i.e. those with LD, however, the issue about capacity to consent needs to be explored fully. In determining capacity to consent, it is essential to involve both clients and carers in the assessment and treatment process and to communicate openly (**GPP**).

Assessments can be carried out without considering whether the client has ability to give consent to treatment, but in order to treat, **the client's capacity must be determined.** Determining capacity to consent must always be time and decision specific. It is important to remember that a person should not be treated as unable to make a decision unless all practicable steps to help him/her have been taken without success. This includes the use of alternative forms of communication, for example:

- Straightforward language
- Body language
- Eye pointing
- Symbolised information
- Signing

Also:

- Give extra time to process the information
- Try repeating the question if no response after 10 seconds

Legislation exists to provide a legal framework for decision-making on behalf of adults who lack the capacity to make specific decisions for themselves. It also provides the means for adults, with the capacity to do so, to plan ahead in the event of future incapacity.

Readers are recommended to refer to the relevant legislation pertaining to their geographical work base as legislation differs slightly between countries:

- **Scotland**: The Adults with Incapacity Act (Scottish Parliament, 2000)
- **England & Wales**: The Mental Capacity Act (DH, 2005)
- **Northern Ireland**: Seeking Consent (Department of Health, Social Services and Public Safety (DHSSPS), 2003)

Relevant excerpts from the legislation are included here as it is core to the care for a person with LD.

The Short Reference Guide for Psychologists and Psychiatrists (BPS, 2007) is recommended as a brief summary of the main points of legislation and is a brief guide to its implementation for clinicians. This Guide is applicable to England & Wales, and reflects the principles underpinning the Scottish Act.

The following is extracted from the Guide:

The Principles set out at the beginning of the Mental Capacity Act (MCA) guide the process of assessment and of substitute decision-making:

A person must be assumed to have capacity until it is established that s/he lacks capacity.

A person is not to be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success.

A person is not to be treated as unable to make a decision merely because s/he makes an unwise decision.

When decisions are made on behalf of someone who lacks capacity, they must be made in his/her 'best interests'.

When decisions are made on behalf of someone who lacks capacity, the less restrictive alternative must be considered to attain the goal specified

The MCA defines capacity as follows:

An adult can only be considered unable to make a particular decision if:

He or she has 'an impairment of, or disturbance in, the functioning of the mind or brain', whether permanent or temporary;

AND

He or she is unable to undertake any (one or more) of the following steps:

Understand the information relevant to the decision;

Retain that information (despite use of prompts); use or weigh that information as part of the process of making the decision;

Communicate the decision made (whether by talking, sign language or other means).

The Functional Approach

A functional approach must be taken. This means that someone's ability to make a decision is determined by assessing whether they can undertake the steps above; it is not determined by their diagnosis nor by the apparent wisdom of their decision. Decision-making capacity is decision-specific and time-specific (**GPP**).

Best interests

In considering what is in someone's best interests when making a decision, the following should be taken into account:

Whether and/or when the person is likely to regain capacity and whether the decision or the act to be undertaken can wait;

How to encourage and optimise the participation of the person in the decision;

The past and present wishes, feelings, beliefs, values of the person and any other relevant factors;

Views of other relevant health, family, carer and social representatives. The decision should be perceived to be in the 'best interest of the client and not that of the family or carers'.

Where a person lacks the capacity to make decisions about a change in accommodation or about serious medical treatment and has no family or friends, there is a duty to appoint an Independent Mental Capacity Advocate (IMCA) to help inform the determination of 'best interests'.

The clinician should consult with paid and unpaid carers, as well as the client's general practitioner (GP) to determine if a dietetic treatment specific or overarching certificate of incapacity has been completed. The latter has generally been put in place for people with PMLD, as many of these clients have permanent cognitive impairment. In some instances the client may have an advocate. Information on the role of advocacy is covered at the end of this section.

It is also recommended that other relevant professionals from the specialist community learning disabilities team (CLDT) are approached whose core skills include assessment for capacity (e.g. speech and language therapist (S&LT), clinical psychologist, psychiatrist, LD community nurse /care manager). In many cases the issue of capacity is generally decided by multi-disciplinary/agency working.

If a client **does not** have capacity to consent, then first consider whether the carer, relative or social worker has legal guardianship or power of attorney which entitles them to consent on specific issues on behalf of the client.

The Scottish Act allows for application of a 'Welfare Guardian', who may be granted full or partial powers under the Act (Scottish Executive, 2000). Should there be no Welfare Guardian; the general practitioner, in consultation with the team may complete an "Adults with Incapacity" form which enables treatments to take place. In emergency situations the medical person can act without consulting with the team. In Northern Ireland, those close to the incapacitated individual should be involved in the decision making process as detailed in 'Seeking Consent' (DHSSPS, 2003).

In instances where there is no legal guardian, the decision should be reached with consultation of all health, family, carer and social representatives. The convening of a multidisciplinary meeting is good practice to allow all to participate in decision making. This must be documented as well as any decisions made.

Table 1 lists the key documents for carers on the issue of consent.

Table 1 – Documents for carers (consent)

Country	Title of Document
England and Wales	Making Decisions: A guide for family, friends and other unpaid carer (Department for Constitutional Affairs, 2005A). Making Decisions: A guide for people who work in health and social care (Department for Constitutional Affairs, 2005B).
Northern Ireland	Seeking Consent: Working with people with learning disabilities (DHSSPS, 2003).
Scotland	Caring and consent: information for carers ((NHS Scotland, 2009).

The Role of Advocacy

An advocate enables a client to get their views across. They may be a friend, family member or independently appointed following a referral to an advocacy group, services or statute. Anyone can advocate on behalf of an individual, but if they are emotionally involved with the client, impartiality may not be possible. The advocate should contribute to the decision making process on the client's behalf. However where conflict occurs it should be remembered that their views whilst listened to, have no legal status in relation to consent.

In some cases their views may conflict with others who are in the decision making process. As the client's representative, they should be included in client specific multi-disciplinary/agency meetings to discuss what is perceived to be in the client's "best interests".

Statutory Independent Mental Capacity Advocates (IMCAs) have undergone formal training as stipulated by the legislation under the English/Welsh Act (DH, 2005). Such training enables them to assist with decision making in the best interests of clients who cannot make decisions by themselves or with clients who have no family or friends who could be part of the joint multi-disciplinary/agency decision-making process. In Scotland a Mental Health Officer may be involved in this decision making process. In Northern Ireland family and carers involved with a particular client meet with the relevant health and social care professionals and decide the way forward, acting in the client's "best interests".

Ethical issues

It is essential that any concerns raised about the ethical approach of managing obesity in any adult with LD should be discussed fully at a multi-disciplinary and multi-agency meeting. Where appropriate, this should include key family members and an advocate to ensure that all are working in a consistent manner to ensure that the best interests of the client are met at all times. All discussions and decisions must be fully documented.

Case Study A

Client has capacity to give consent.

A 25-year-old lady with bi-polar disorder and LD has been seen by the psychiatrist. The psychiatrist has assessed the lady as having an IQ of 55 but her social skills give the impression she is more able. However, the psychiatrist opinion is that the client can give consent if a combination of symbolised and straightforward language is used. The client's psychiatric treatment involved commencing on Olanzapine, an anti-psychotic medicine that is known to cause excessive weight gain. As a precaution the psychiatrist has referred to the dietitian for weight reducing advice. The lady lives on her own, but each week has carer support for 10 hours over meal times. At present she has a body mass index of 35kg/m^2 (weight = 68kg; height = 1.4m). She regularly experiences joint pain on exertion and there is a strong family history of diabetes.

What happened in practice:

Pre-assessment

Points considered

Q: Is there any additional information you need to know prior to carrying out assessment and treatment?

A: Psychiatrist and GP confirmed that the client was able to give consent. Carers, psychiatrist and LD S&LT advised that the client would require simplified information supported with the use of symbols.

Q: Do you have an appropriate approach/resource to enable the client to be involved in the decision-making process?

A: S&LT advised that the client already had experience in using Talking Mats$^{\text{TM}}$ - a communication aid used in assessing an individual's understanding and for obtaining opinions. Clients functioning at 3 information carrying words (words that carry the weight of the meaning) and above are able to use a Talking Mat$^{\text{TM}}$ effectively (Murphy and Cameron, 2008).

Assessment

The Talking Mat$^{\text{TM}}$: Key points to weight loss (see useful resources, page 56) used open questions to determine barriers facing the client to lose weight. The tool also helped gain vital information on the client's opinions, knowledge and skills, as well as areas where she was willing to make lifestyle changes. See figure 1 for information given by the client.

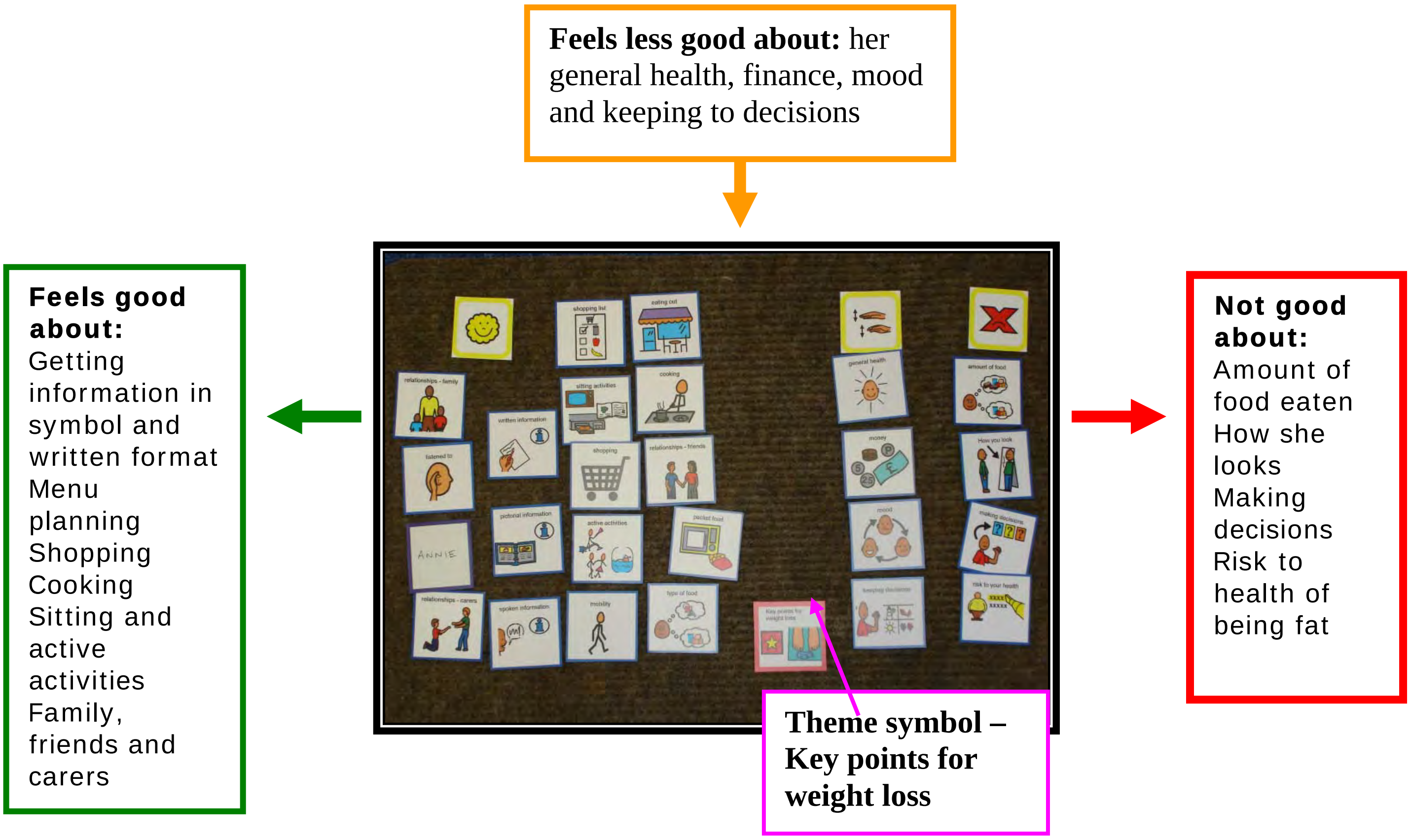
Please note that the term 'fat' is used because this client had difficulty grasping the concept of being overweight but could identify with being fat. Wherever possible it is advisable to encourage clients to use the term 'overweight' but not at the expense of their comprehension (**GPP**).

Points considered

Q: Does your client understand the information they have been given?

A: Yes, the client's verbal comments were reflected by her placement of the symbol on the mat. The client used the Talking Mat$^{\text{TM}}$ to demonstrate that she had a good support network and was actively involved in the various aspects of food provision and menu planning (see symbols placed under 'feels good about' column in figure 1). She enjoyed an assortment of active and sedentary activities, but needed persuasion to undertake the former, otherwise she would just sit around.

Figure 1 Copy of client's completed Talking Mat™



Feels less good about: her general health, finance, mood and keeping to decisions

Feels good about:
Getting information in symbol and written format
Menu planning
Shopping
Cooking
Sitting and active activities
Family, friends and carers

Not good about:
Amount of food eaten
How she looks
Making decisions
Risk to health of being fat

Theme symbol – Key points for weight loss

Source: McIntosh, P. & Cameron, L. (unpublished).

The client's placement of the symbol 'risk to health' (of being fat) under the 'not good' column indicated that her concern regarding future health could be a possible motivating factor towards making lifestyle changes. Not liking 'the way she looked' and feeling that her 'general health' could be better, are other potential positive 'reinforcers' for this lady to lose weight.

The client recognised that low mood in the past affected her food intake, but felt her mood was better now. She also mentioned that she ate when bored:

"I eat when I'm hungry and I eat when I'm bored. I'm bored most days"
Client response to the question 'What do you feel about the amount of food you eat?

Q: Does your client fully understand the implication(s) of your intervention?

A: Yes, the client identified areas she was willing to make changes in and where she would require support.

Q: Does she have the ability to make an informed decision about dietary treatment?

A: Yes, psychiatric assessment has indicated ability to give consent, which is supported by the rest of the MDT team and in the client's response to the Talking Mat™.

Q: **Do you have the skills and knowledge to make this assessment of capacity?**

A: Yes, this is a collaborative opinion between the dietitian, the psychiatrist and the CLDT S&LT. Also the dietitian had been trained in the use of Talking Mats™.

Q: **Have you documented clearly your means of gaining consent and how the client consented to your intervention?**

A: Opinions of family, carers, LD team professionals and the psychiatrist were fully documented in dietetic notes, and identified that the least restrictive option was offered. Photograph of completed Talking Mat™ given to client with another included in dietetic/ team notes.

Treatment

Points to consider

Q: **How would you progress with discussing how the client wishes to lose weight?**

A: Completion of the Talking Mat ™ identified areas for lifestyle changes and appropriate cross-referrals (this was the client's means of giving consent for involvement of other health and social care professionals).

A referral was sent to social work to review her care package, as extra funding for additional carers' hours would provide the support required to increase activities/exercises. Also the carers would be able to reinforce the decisions she'd made around lifestyle changes – an area she recognised she needed help with. A physiotherapy referral was also made to ensure any planned exercise programmes met her mobility and health needs.

The client agreed to a further appointment with the dietitian to look at portion sizes, i.e. an appropriate size of plate to limit portion sizes and provision of the Scottish Nutrition and Diet Resources Initiative (SNDRi) Exercise and Treat Chart (useful resources, page 56) which encourages daily exercise as well as limiting foods high in fat and sugar.

As this client identified she needed support to make and keep to decisions, a training session was set up for carers to identify how they could best support the client to meet treatment aims. The carers opted to monitor progress by monthly weight checks undertaken at the local supermarket; use of a graphical weight chart that identified target weight loss; charting daily exercise activities and recording use of foods high in fat and sugar.

Q: **Have you documented implementation of the intervention and monitored agreed outcomes?**

A: Yes, all recorded in dietetic notes and client's health action plan.

Remember:

The client may refuse dietary or other therapeutic intervention despite being aware of the complications of obesity. It should be noted that the client with capacity is able to make 'unwise' decisions and have these decisions upheld (**GPP**). It is imperative that the client's decision to not participate is supported and documented.

Case Study B

Client does not have capacity to give consent

The client is a 39-year-old gentleman with PMLD and hemiplegia. He has no verbal communication and uses minimal body language. According to the clinical psychologist, the client functions at less than one year of age and as such is unable to act on even 1 information carrying word (i.e. words that carry the weight of the meaning).

The client lives at home with elderly parents who have always consented to treatment on his behalf. The gentleman attends a local day centre three days a week. He is a wheelchair user, receiving physiotherapy sessions once a week at the day centre.

His main interests are music and food. He has a body mass index of 36kg/m^2 *(weight = 97kg; height = 1.64m). He recently had pneumonia and his left lung is compromised as a result, weight loss would help with his respiratory function.*

What happened in practice:

Pre-assessment

Points considered

Q: **Is there any additional information you need to know prior to carrying out assessment and treatment?**

A: Psychologist's assessment ascertained that the client is unable to give consent in all areas of his wellbeing.

Q: **Do the main carers/parents have the legal powers to give consent on the client's behalf?**

A: No. A multi-disciplinary/agency meeting to determine what intervention is in the client's best interest was arranged, also to discuss the GP's concern that the client's weight was severely affecting his health.

Assessment

Points to consider

Q: How will you establish what is in the client's best interest? Discuss:

- What information the decision makers will require?
- Current energy intake and weight gain trend highlighted
- Aim of dietary intervention
- Extent of dietary changes required
- Burden versus benefit - client
- Burden versus benefit - carers

A: A multi-disciplinary and multi-agency meeting, which included his parents and day care key worker was held. At the meeting it was noted that the present dietary intake and activity regime would contribute to further weight gain. This would impact on current and future health and has the potential to impact on the feasibility of the client remaining at home. The health and social benefits of small sustained weight loss were discussed. There was some resistance from parents who felt it was unethical to restrict food as this was their son's main area of pleasure in life. The introduction of slow, but steady change in energy content of the client's diet, e.g., changing from full fat to semi-skimmed milk was however acceptable to the parents. It was agreed by all present that in the first instance a weight maintenance programme would be in his best interests as this would improve his quality of life and minimise his health risks, enabling him to stay in his own at home.

Q: Have you documented clearly the decision to treat?

A: Minutes of the multi-disciplinary/agency meeting circulated to all group members (including GP and physiotherapist) for inclusion in their case notes.

Q: Can treatment now commence?

A: No, not until the legal documentation has been completed – refer to the various Acts previously mentioned. In this case, the documentation was completed by the GP and a copy was included in the dietetic notes.

Treatment

Points to consider

Q: **How would treatment be put in place? Discuss:**

- Which method(s) could be used to communicate intervention to family and carers?
- What timescale is required?
- How would you record client's, carers' and family's views on the proposed intervention?
- How would you resolve any disputes and what actions would be required?
- What actions would be needed if family/carers disagree with the recommendations of the health and social care professionals?

A: Written dietary advice was provided to carers – in this instance, family and day care staff – with a copy placed in dietetic notes. Low fat and low sugar food and drink options were tested with the client and all were readily accepted except for lighter hot chocolate drinks. This choice did not affect the client's overall nutritional intake and plenty of other fluids were offered and consumed. The proposed and accepted changes were recorded in the health records and the GP informed.

The dietitian delivered training to day care staff on their duty of care to implement the dietary recommendations. It took a month to complete the training due to the number of staff involved and resulted in a consistent approach by carers. The gentleman not only maintained his weight which was the primary goal, he did manage to lose 5kg over a period of time (5% weight loss). This weight loss has been maintained a year later.

Q: **Have you documented implementation of the intervention and monitored agreed outcomes?**

A: Yes, dietetic intervention recorded in dietetic notes and health action plan, with copy of dietary treatment plan forwarded to the GP. Daily food plan provided to parents and day care staff. Day care staff also agreed to monitor his weight monthly as they had access to wheelchair scales. A graphical weight chart provided by the dietitian, also acted as a positive reinforce for the carers and parents.

Remember:

Clients with PMLD do not have the ability to access their own food and drink, relying on their carers to make appropriate choices. If carers consistently ignore dietary treatment plans they are failing in their duty of care. This needs to be raised initially with the keyworker, then their managers. If this needs to be taken further please contact your local CLDT for advice.

3. Meeting the client's needs

3a. Prevention

i. Specific Needs

People with mild LD are more likely to become obese than people with more severe LD (RCN, 2006, Melville *et al*, 2008). Evidence indicates that people with LD tend to become overweight at an earlier age and stay overweight, whereas the general population tend to become more overweight with age (Gale *et al*, 2009, Bhaumik *et al*, 2008). There are many factors that can predispose people with LD to developing obesity, including specific syndromes such as Down syndrome (Peterson *et al, 2008,* Henderson *et al,* 2007, Hawkins & Look, 2006, Chapman *et al,* 2005, Frey *et al, 2005, Frey, 2004,* Illingworth *et al, 2003,* Draheim *et al, 2002,* Beart *et al, 2001,* Jeffreys, 2000).

Table 2: Factors predisposing to obesity in LD

Attitudes of carers	Boredom	Communication difficulties
Hypothyroidism*	Lack of knowledge	Lack of skills including literacy
Lack of power/control over own life	Limited access to exercise	Low income
Medication	Mental Illness	Misuse of food as rewards or motivators to engage in activities
Provision of poor diet	Poor self-esteem	Sedentary lifestyle/altered body composition

*thyroid check every 2 years in Down syndrome (Levy *et al,* 2006).

Levels of obesity are less prevalent in adults with PMLD but can occur. Inability to exercise is one factor, together with the consumption of excess energy, an existing lower resting metabolic rate (RMR) and small stature which can all lead to unwanted weight gain. In such cases, weight maintenance may be the best outcome, ensuring that the intake is nutritionally sound which in itself confers positive benefits such as relief from constipation, better mood and 'feeing better' (**GPP**).

Abdominal obesity can be a problem in those who are fed via the gastrostomy route if energy requirements are over estimated. It is important to note that energy requirements for these individuals are often lower than for the general population of comparable weight and height (Fairclough *et al*, 2008).

Primary Care Health Checks have been introduced for people with LD since 2006 (2006 Wales, 2008 NI and 2009 England). Even so, closer support and partnership working is still needed between primary care and the specialist CLDTs (Powrie, 2003). Health surveillance uptake has been found to be poor and thus many people with LD are missing out on access to important and potentially life improving screening and advice (Henderson, 2008, Levy *et al,* 2007, Edwards, 2007, Levy *et* al, 2006).

Public health campaigns, leaflets and advertising which are available for the general population may not reach people with LD because the information may not be in an accessible format, either as a hard copy or via the Internet. When planning any public health campaign it is important to consider how to reach all members of the locality, including those with LD. McGuire and colleagues recommend that carers themselves need to be the primary target for public health measures due to their influence on client choice (McGuire *et al,* 2007). Mencap, People First and other advocacy organisations which exist in local communities will be a good first point of contact as well as the Community Learning Disability Team CLDT (**GPP**).

The written word, even in an accessible format, must not be relied upon as the best or indeed only medium for communication. Adaptation of group activities such as bingo where the numbers are substituted with fruit and vegetables, is a simple method of imparting healthy eating messages and introducing a degree of 'healthy' competition when using the Eatwell Plate model (FSA, 2009)(**GPP**).

Fig. 2 Health promotion group activity

"Yes, it gives you more encouragement and you can talk to them about it- the weight and things. It's more motivation I suppose."

Client's response when asked if they would like to join an LD healthy eating group to lose weight.

As people with LD are often dependent on others to plan menus, shop for and cook their food, these significant others would be useful to target in any health promotion activity. Frequently, carers have little knowledge about healthy eating themselves, and many myths about healthy eating get passed on and become part of 'custom and practice' in the care setting. The role of the carers in prevention (and intervention) should not be overlooked as their own food beliefs, eating experiences and behaviours are imparted to the client which places an interesting perspective on 'client choice' (Smyth & Bell, 2006). Sometimes the clients are better informed on aspects of their own diets than the carers themselves:

"If I am not allowed it why is it put on my plate?"

A client's response to food given to her by carers when she is on a weight reducing diet.

The impact of medications is often overlooked, with antipsychotic and anti-depressant medications known to induce undesired and rapid weight gain (Burton *et al, 2008,* Khazaal *et al,* 2006*,* Birt, 2003). See table 3. It would therefore be beneficial for information to be available to the prescribers so that they are aware of the potential weight gain side effects of such medication. Leaflets highlighting the obesogenic nature of the more commonly used drugs combined with key health promotion messages should be available in all clinic settings (**GPP**).

"I never knew that my son's medication could affect his weight. I have constantly felt that health professionals were blaming me for his overeating and his weight gain.
A parent's response on receiving advice on weight gain and medications.

Medication side effects also include chronic constipation, a frequent problem for people with LD, which increases the risk of seizure activity though often goes unrecognised by carers because it is 'normal' for the client (Fairclough *et al,* 2008). Contributing factors also include poor gut motility, chronic inadequate fluid and fibre intake, chronic laxative usage and lack of physical activity. Constipation can add from 0.5 to 1.5kg of weight and needs to be taken into account when weight maintenance is being considered (Crawley, 2007).

Though conventional weight maintenance regimes emphasise a high fibre and high fluid intake, this is of critical importance in this client group (**GPP**). Some clients have difficulties taking sufficient fluid. Therefore encouraging higher intakes of fruits and vegetables, with their naturally high fluid content, may be the preferred option rather than promoting too much insoluble fibre in the form of wholegrain foods (**GPP**).

ii Social Care, Day Services, Respite

Whilst providing a good range of services for people with LD, social care services can unwittingly contribute to the problems of obesity. Day services often have a disjointed approach to healthy eating, and may run their own healthy eating sessions, whilst still having a tuck shop containing a large variety of high energy snacks, and a dining room serving unhealthy meals.

'Community involvement' is a mantra which is rightly promoted, but more often than not results in visits to shopping centres, garden centres, supermarkets and cafes with the aim of having snacks or meals. These are often energy dense and expensive, leaving even less money for healthy meals or accessing other community activities such as swimming, bowling and so on.

Respite care may be a useful opportunity for people with LD to experience different foods and to see how to eat a healthier diet. It depends, however on the quality of the service, and the number of times that respite is offered. It also relies on the respite service passing on information about their healthy eating plan to the client's usual carers and vice versa.

Table 3: Weight Gain of some commonly prescribed drugs in LD

Drug	Condition	Weight change
Sodium Valporate	Bipolar / Epilepsy	+ 1.2 – 5.8kg
Lithium	Bipolar / Depression	+ 4kg
Clozapine	Schizophrenia	+ 4.2 – 9.9kg
Olanzapine[1]	Schizophrenia	+ 2.8 – 7.1kg
Risperidone	Psychoses	+ 2.1 – 2.3kg
Ziprasidone	Schizophrenia	- 2.7 – 3.2kg (not as effective)
Prednisolone	Muscle relaxant	+ 2kg
Nortriptyline	Depression	+ 3.7kg
Doxepin	Depression	+ 2.7kg
Amitriptyline	Depression	+ 1.7kg

Adapted from Leslie *et al,* 2007

[1] After 1 year weight gain can be as much as 14kg

iii. Other providers

Paid carers/support workers often struggle to define their role, especially when the issue of ‘choice’ is so far reaching. Some see their role as protecting the person’s (with LD) long-term health, and so work hard to ensure healthy choices are made. Others see their role as promoting choice, and as long as they enable their client to make a choice, or their client can be seen to be making choices (healthy or unhealthy) they have fulfilled their role. The issue of ‘human rights’ is also cited, as people with capacity have the right to make unhealthy choices. Staff also need to remember, however that they have a duty of care to ensure their client’s health needs are met and should endeavour to facilitate informed choices as much as possible.

At a local level, managers of services need to be made aware of the role staff have in supporting people with LD, especially around their food choices. They should enable staff to access appropriate training as recommended by the CLDT, instead of expecting staff just to ‘know’. Support staff have the same access to TV and media advertising as the clients they support and may be equally confused by it, so they need access to clear advice – either from government sources such as ‘Change 4 Life’, primary care or their local dietitians. See alsoeee Useful Resources on page 55.

Many carers already have the skills and knowledge to promote good eating habits and should be encouraged to share good practices within their teams. In some circumstances there may be a need to address specific issues pertaining to carers such as:

- Varying levels of interest in food and exercise
- Having little or no experience in planning healthy menus
- Understanding that their clients do not require the same amount of food as they do and so providing smaller portions can be acceptable

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- Bringing their own theories and idiosyncrasies to the meal provision process
- Perceiving clients as less fortunate than themselves and through guilt overfeeding the client
- Perceiving clients as not having fulfilled lives and seeking to redress this in some way using food
- Using ‘it’s the client’s choice’ as an excuse to provide/access less healthy food.

It is important to have an appreciation and understanding of the skills base, values and belief systems of carers and to use this state of reality ‘not as a stick but a golden carrot’ for targeted and supportive training (**GPP**). Empowering carers is as important as empowering their clients. As well as providing information on nutrition, teaching the techniques in table 4 can help clients and carers to make positive lifestyle changes (Crawley, 2007).

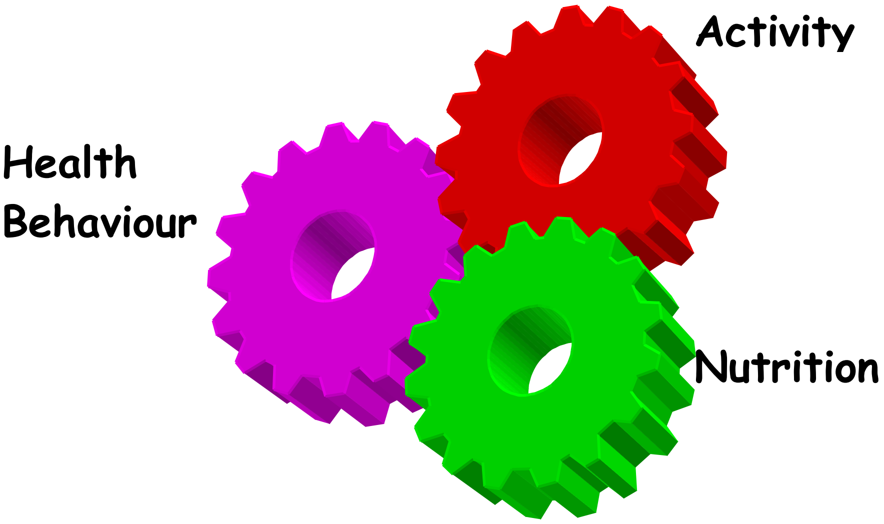
Table 4 – Techniques to support behaviour change

Technique	Actions
Availability & Convenience	• Chop fruit and vegetables and place them beside the client when they are watching TV or listening to music. • Make sure there is always cooled tap water in the fridge at eye level, in attractive bottles. • Make healthy options more accessible and visible in kitchen areas, offer at start of meal times and snack times. • Only offer salt at the table if client asks for it. • Encourage activity by ensuring appropriate clothing, footwear and sports equipment are easily accessible.
Replacement	• Use puréed fruit as a sauce for ice cream instead of sugar based sauces. • Use reduced fat cheese instead of full fat cheese. • Use higher fibre white bread (or wholemeal) instead of standard white bread. Roast or oven bake part boiled potatoes using reduced fat oil spray. • Reduced-fat spreads and low-sugar/sugar-free drinks. • Grill or bake foods instead of frying.
Fading	• If sugar is usually used in drinks, add slightly less sugar over time. • Dilute squashes a little more and offer water instead of squash when the client asks for a drink. • Replace some biscuits on a plate with fruit, gradually increasing the amount of fruit over time. • Reduce the salt in cooking over time. • Encourage people to walk to one bus stop further away on regular journeys.
Association	• Link happy and fun events to healthy food choices.
Role modelling	• Take part in the desired behaviour and exhibit enjoyment, positive attitude at all times.
Involvement	• In menu planning and shopping. • In safe cooking such as food preparation. • Household activities such as washing, cleaning and gardening.

Adapted from Crawley, 2007

3b. Intervention

i. Specific Needs



Much of the evidence about obesity and LD describes the prevalence and the level of LD associated with obesity (Henderson, 2008, Henderson *et al*, 2007, Melville *et al*, 2005, Melville, 2008, Yamaki, 2005). Little evidence describes robust effective weight loss interventions, whether the resource is designed for the whole population and includes adapted approaches for people with LD, or the resource is targeted specifically for people with LD wishing to lose weight.

Evidence that people with LD who are more independent (i.e. have fewer support hours), are more likely to be obese (Levy, 2006) is contradicted by other studies that suggest those living in supported accommodation are more likely to be overweight/obese (Moore *et al,* 2004). In another study Levy and colleagues found that those people with LD who live with family have higher tendency for obesity (Levy *et al,* 2007).

It would seem reasonable therefore to assume that whether living with family, alone, or in supported living any weight loss intervention would essentially have to include support and motivation from carers (Hamilton *et al,* 2007). In addition, as a means of preventing obesity or limiting any further increases in weight, all paid carers ought to have mandatory induction training regarding implementing healthy lifestyle choices as a routine duty of care (Melville *et al,* 2009). Training programmes on nutrition under the umbrella of health and social care are available throughout the UK. See page 57.

Marshall and colleagues reported that moderate weight loss can be achieved and factors which aid success included teaching behavioural techniques, (portion sizes, eating patterns etc), involving support staff and increasing physical activity (Marshall *et al,* 2003). People with LD often collaborate when making decisions and this review highlighted the importance of motivated and informed carers being best placed to support weight management. Temple and colleagues found that perceptions of motivation very often differ between carers and clients, with carers underestimating levels of motivation (Temple *et al,* 2007). This illustrates the need for an holistic approach when designing interventions.

There is some evidence that describes barriers to healthy lifestyle choices and the lack of education of people with LD and carers alike on guidelines for healthy lifestyles and how to implement them (Henderson, 2008, Edwards, 2007, Rimmer & Yamaki, 2006, Yamaki, 2005).

One review of weight loss interventions for people with LD indicated that the factors related to successful weight reduction included dietary changes, the teaching of behavioural techniques, the involvement of clients and support staff, increased physical activity and the sharing of nutritional and health information (Hamilton *et al,* 2007).

SIGN (2010), DOM UK (2007) and NICE guidance (2006) on obesity recommend a tripartite interactive model for effective weight management interventions (**GPP**):

- Dietary change with a 600 kcal deficit/day
- Increased levels of physical activity
- Use of behavioural methods to support change in behaviour

These collective guidance documents are targeted at general populations and do not consider the needs of people with LD. Their generic nature will not automatically promote health improvements and may even increase the health inequalities experienced by this group (Aldrich *et al,* 2003).

Ellis and colleagues concluded that people with LD can lack the understanding of the benefits of healthy eating and physical activity and therefore have limited motivation for health improvement to embark on a weight loss intervention (Ellis *et al*, 2006). Interestingly, this view is not supported by the following statement:

"Didn't know backache, hip pain due to overweight. Never heard of cancer caused by overweight. Booklet may help people to decide to lose weight because don't want any of these things"
Client's response to audit of SNDRi symbolised diet sheet 'Do you want to stay fat?'

Additionally, a recent study piloting an adapted weight loss intervention programme specifically for adults with LD has shown positive results in the short term, with approximately 50% of participants achieving a minimum of 5% weight loss post intervention (Spanos *et al,* 2010). So there is evidence starting to emerge supporting the authors' clinical experience that successful weight loss can be achieved by people with LD. On the other hand, many people with PMLD will not have the knowledge/skills of how to implement a weight loss programme to good effect. They are likely to require support workers/family present throughout an intervention to motivate, to aid understanding and to support the intervention (Hamilton *et al*, 2007).

It is important to remember how information is interpreted. Advice may be taken literally or choice may be limited to a suggestion given. For example, 'you can have an occasional treat like chocolate', could be interpreted as only chocolate is a treat, (what about pastries, cakes, biscuits?). The term 'occasional' is abstract and subjective so could be daily or weekly, or even hourly dependant on the client's own understanding of the concept of time. Ask clients to say in their own words what they understand from the information you have given (**GPP**). Don't be tempted to use the fact that the client can repeat what you have just said as a measure of understanding as many people with LD are often quite adept at recalling those words spoken most recently i.e. what is known as ‘recency effects’ (Kroese *et al,* 1998).

With regard to activity, it is reported that people with LD are less active than the general population (Hawkins & Look, 2006). Clients are often prevented from being physically active by a variety of reasons of which you need to be aware. These include financial difficulties, transport barriers, a shortage of staff, or staff/ carers themselves not wanting to be physically active. Also those clients with limited mobility or those with PMLD have even less opportunity to increase their physical activity. Specialist physiotherapists from the CLDT should be involved in providing a range of active and/or passive exercises (to prevent contractures) for the client, though the impact in terms of energy expenditure of the latter will probably be minimal.

Investigate any local schemes such as Bikeability, Rebound and other fitness opportunities such as dancing and horse riding which provide inclusive opportunities for people with a range of disabilities. It is advisable however, that the client’s suitability to access such schemes be assessed before recommending such activity (**GPP**).

Fig. 3 Recommendations when consulting in a 1:1 setting.

When consulting in a 1:1 setting…

- ⇒ Expect first appointment for getting to know the client and gaining trust
- ⇒ Collect information on the client’s social and family network so you know the key people with whom to liaise i.e. care manager, social worker, day service, college, respite, sitters, family, other healthcare workers currently involved
- ⇒ Allow at least 30 minutes per consultation
- ⇒ Keep distractions to a minimum
- ⇒ Discourage accompanying person (if any) from answering for client and where possible to sit behind the client.
- ⇒ Use straightforward language
- ⇒ Pace your delivery
- ⇒ Ask open questions using no more than 2 information carrying words at a time
- ⇒ Count to ten after each question (if needed) to give client time to reply
- ⇒ Re-phrase questions to make sure client not just repeating your last word
- ⇒ Use visual aids to reinforce the spoken word such as food models, photographs and symbols
- ⇒ Limit any areas for change to a maximum of 3
- ⇒ Use symbols or photographs and font 14, Arial, Comic Sans, Univers, Tahoma or Verdana in written communication
- ⇒ Obtain the client’s consent to send copies of recommendations and any supporting information to care manager for distribution to day services and respite as appropriate
- ⇒ Wherever possible review with same accompanying person for consistency

Standard pre-appointment processes may need to be adapted as it can be more effective and efficient to telephone the client/carer to make the appointment (**GPP**). Also consider if the appointment needs to be at the beginning or end of a clinic session, to help to reduce the client's anxiety levels (**GPP**). Partial booking and similar procedures can be confusing, but if contacting by telephone is not feasible, use a minimum of (straightforward) words in the appointment letter. To aid attendance, telephone and remind client/carer the working day before the appointment (**GPP**).

Group sessions

There is some consensus that group sessions for people with LD and carers are effective (Marshall *et al*, 2003), as are those which incorporate increased physical activity (Chapman *et al*, 2008). Mainstream weight-loss group interventions can be accessed by people with LD with support from carers. However it is important that the carers take the opportunity to re-iterate the key messages and make sure the client feels part of the group. The information will also need to be in an accessible format to aid client understanding and compliance (**GPP**).

"No, I prefer to do it on my own. I went to one group before but I didn't think what they were talking about was to do with me."
Client's response when talking about her previous attempts to lose weight by attending a mainstream group in her local community.

It is important to highlight that people with LD want to be (and should be) seen as equal citizens in their communities and wherever possible would prefer to access the same health services as everyone else (Mencap, 2004). The label 'learning disability' encompasses a wide range of abilities from mild to profound and it is important to ensure that choice is available. Where it is not possible to meet the specific needs of people with LD through adapting mainstream services, referrals to a local specialist CLDT can be considered (**GPP**). (See Appendix 4 for membership). Weight loss interventions which are available for the general population include commercial group sessions, prescribed medication and bariatric surgery. No evidence was found on any of these interventions being accessed by people with LD. Any discussion on anti-obesity medication or invasive interventions needs to be discussed fully with the client, their carers and key members from the specialist CLDT (**GPP**).

Fig.4 Recommendations when consulting in a group setting.

When consulting in a group setting…

⇒ Plan first session for solely getting to know the clients and gaining trust

⇒ Limit membership to no more than 10 clients

⇒ Encourage carers to attend, although it is not necessary to exclude any clients who attend without support

⇒ 2 people to run a session

⇒ Allow a maximum of 2 hrs per session with a break in between

⇒ Keep to one theme per session

⇒ Plan a maximum of 6 sessions with no more than 3 key themes for whole programme

⇒ Keep distractions to a minimum

⇒ Discourage accompanying person (if any) from answering for client

⇒ Use straightforward language

⇒ Pace your delivery

⇒ Ask open questions using no more than 2 information carrying words at a time

⇒ Count to ten after each question to give client time to reply

⇒ Re-phrase questions to make sure client is not just repeating your last word

⇒ Ask clients to repeat tasks given to them

⇒ Use visual aids and activities such as food models, photographs and symbols to reinforce the spoken word

⇒ Limit any areas for change in individual action plans to a maximum of 3

⇒ Use symbols or photographs and font 14, Arial, Comic Sans, Univers, Tahoma or Verdana in written communication

⇒ Make sure that copies of activities, work completed and any supporting information are available in individual take home files/folders for client to share with carers

⇒ Review

See Appendix 5 for a sample group session plan and Appendix 6 for a sample information sheet in accessible format.

Monitoring

Regular monitoring of progress is essential for clients with LD in order to sustain motivation. The carers should follow the monitoring protocol as advised by the dietitian which may include frequency of weight checks, food and fluid charts, and menu structure. Experience suggests that fortnightly or monthly reviews would be the most effective, as leaving clients any longer leads to diminished interest and poor compliance (**GPP**). On-going dietetic review is of course not necessary though some adjustments to the timeline in any local pathways should be considered, remembering that the first appointment may be a ‘getting to know you’ session. Once the key messages have been understood by the client/carer and actions and targets agreed, further dietetic reviews may be undertaken at the discretion of the clinician but with discharge in mind, not ongoing care.

Weight

Weight is commonly used to measure effectiveness. Other techniques are discussed later in the text. It is probably more practical to check weight using stand-on scales, but for those with poor mobility or balance problems, seated or hoist scales are an alternative. For wheelchair users, wheelchair beam or platform scales can be used. It is essential that an accurate weight for the wheelchair is initially obtained taking into account attachments such as headrests and foot supports. Any changes to the wheelchair will mean that the chair will have to be reweighed. For clients not accessing specialist equipment, local arrangements may be made with advice from the GP or CLDT (**GPP**).

Height

Height allows for the calculation of BMI and should be measured using a stadiometer for those clients able to stand straight. It will be more difficult to measure an accurate height for people with physical anomalies such as kyphosis and/or scoliosis. Alternative or surrogate markers of height such as measuring ulna length, knee height (suitable only if normal muscle mass, bone length/density attained) and supine length have been found to be inferior (even when normal muscle mass, bone length is present) to self/carer reported height if available (BAPEN, 2003). Carers could be requested to measure a client’s length using a tape measure in privacy, and report back. However accuracy is not guaranteed and the resultant height must only be used as a guide.

BMI

Body Mass Index (BMI) is useful guide to the degree of overweight/obesity but must be treated with caution where an individual has altered body mass. To reach an ideal BMI may be a totally unrealistic goal for such individuals though to achieve a 5 – 10% weight loss would be a pragmatic and meaningful outcome (**GPP**).

Also BMI is not always an accurate predictor of body fat or fat distribution (SIGN, 2010). Clients with PMLD are more likely to have muscle wastage of their extremities and greater visceral adiposity and thus a greater risk of coronary heart disease (CHD) and respiratory problems (Draheim, 2006). If BMI is to be used in people with PMLD, it would be more suitable for the client in these circumstances to use the lower end of the ideal (**GPP**).

Similarly using mid upper arm circumference (MUAC) and triceps skin fold (TSF) to measure body composition (and nutritional status) in response to a nutritional intervention may also be inappropriate (Fairclough *et al*, 2008). Achieving a weight loss of between 5% and 10% would be a more appropriate, realistic and achievable goal irrespective of the degree of obesity (**GPP**) and would confer positive health gains for the individual (SIGN, 2010, DOM UK, 2007, NICE, 2006).

ii. Social care, day opportunities, respite

Care staff/support workers are crucial to the success of implementing dietary guidelines. However they often lack the knowledge themselves to support healthy choice making, and training/education is essential for this staff group. (Melville *et al,* 2009). Care staff are central to the motivation and influencing of people they care for, especially around promoting choice and optimising their health from both a prevention and intervention perspective (Smyth & Bell, 2006).

People with LD access a variety of activities during the day which range from paid employment and voluntary work to day services provided by statutory or voluntary organisations. Building - based day services are becoming less the norm for people with LD, who are increasingly accessing existing community services with support workers. It is worth noting that accessing community services can be interpreted by staff as visiting cafes and coffee shops often by using transport rather than walking. Also staff may struggle to find alternative outings for people with LD such as bowling, walking groups, visiting exhibitions.

iii. Other Care Providers

Supported care is specific to each individual and can include help with shopping, budgeting, cooking or personal care.

Care providers are commissioned to provide support by social work services and are monitored through local authorities. Similar to social care, respite and day service providers, purchased care provider staff often have limited knowledge in nutritional and physical activity guidelines, (Melville *et al, 2008*), and will require training and support. From clinical experience, a commonly reported barrier to increasing physical activity is that opportunities are lost through staff shortages, preventing support to attend activities outside the home environment. Physical activity can be perceived to be a low priority in supported living settings.

If training needs for staff are identified, referral to the CLDT should be considered. Alternatively they could access available community training schemes which include within the programme aspects of choice, informed decision making and duty of care (**GPP**).

4. Meeting the carer's needs.

4a. Parents and families

If the person with LD is living in the family home, family members should work together in encouraging a healthy balanced diet and regular meal pattern. If the person with LD is in an environment where there are no set meals and all that is available are snack type foods, ready meals or takeaways, the individual will only know this type of food and be unaware of the long-term effects on general health. Family members should be discouraged from providing extra treats e.g. biscuits or crisps, thinking they are being kind or generous. A consistent supportive approach to healthy eating behaviour is important.

At home and in other settings, food can be used either as a reward for good behaviour or to prevent the escalation of challenging behaviour. Food tends to be the most important thing to many in this client group and identifying a significantly meaningful alternative can be difficult.

Education around physical activity is also important and the support of the family is essential. Many clients will sit watching television or playing computer games unless prompted to exercise. They need to be given the opportunity to be more active, as well as the right support. However interactive computer games that require exercise, dancing or movement whilst sitting may be useful, depending on the client's abilities. Low impact activities such as walking to the park and activity clubs in the evenings are an ideal way of increasing physical activity and particularly useful in circumstances where parents are themselves unable to participate. Any activity will of course need to be tailored to the preferences and abilities of the individual (**GPP**).

Care staff

As previously stated, people with LD require support and motivation from their care staff or family members to help them understand and implement any dietary or physical activity recommendations. The health knowledge and skills of care staff are therefore important factors to be considered if they are expected to provide support and motivation to people with LD. Melville and colleagues (2008) highlighted the need for care staff to be trained on the principles of a healthy diet and the current national recommendations for physical activity, and suggested that this could be incorporated into an induction course at the beginning of employment **(GPP)**. A number of barriers have also been highlighted which prevent adults with LD from participating in physical activity (Henderson *et al*, 2007, Messent *et al*, 2000). The majority of these barriers could also be addressed via education and training.

It is important to work together to ensure that people with LD are supported to make informed choices and to understand the importance of healthy eating and regular physical activity. Care staff should be encouraged to provide a positive influence in collaboration with others, including family members and health/social care professionals. In order to support people with LD to make good choices around food and drink, it is essential that family friends and any staff supporting the client are confident themselves about what constitutes a healthy diet. Care staff should not dictate what an individual can choose but it is essential that a person with LD be given appropriate information about healthy food and the benefits so that they can make informed choices (**GPP**).

Fig 5 gives an example of a framework for care staff to help them make changes toward a healthy lifestyle for their clients either for prevention or specific interventions. These changes need to be introduced slowly especially if the client has behaviours which challenge and where any change in routine can be seen as a threat. It is recommended that no more than 2-3 key changes be made at a time (**GPP**). (NB: The behavioural techniques tabled on page 30 may also be useful for care staff).

Fig 5 A checklist for care staff

Checklist for change

- ⇒ Introduce small changes/new foods over a period of time
- ⇒ Praise for even very small changes made by the client
- ⇒ Tasting sessions for new foods are an idea to familiarise service users with changes to menus
- ⇒ Have discussion forums with service users to get their opinions
- ⇒ Work and plan menus together
- ⇒ Avoid confrontation – do not demonise any particular foods or drinks
- ⇒ Allow less healthier foods in restricted quantities at specified times
- ⇒ Avoid food as rewards if possible
- ⇒ Investigate ways of increasing activity levels and make it interesting e.g. gardening projects where service users can grow fruit and vegetables then enjoy eating their produce

It is however important to stress to care staff that not 'one size fits all' though having planned menus based on healthier eating together with a positive approach to exercise will make it easier to incorporate any individual action plans which may be needed.

Volunteers

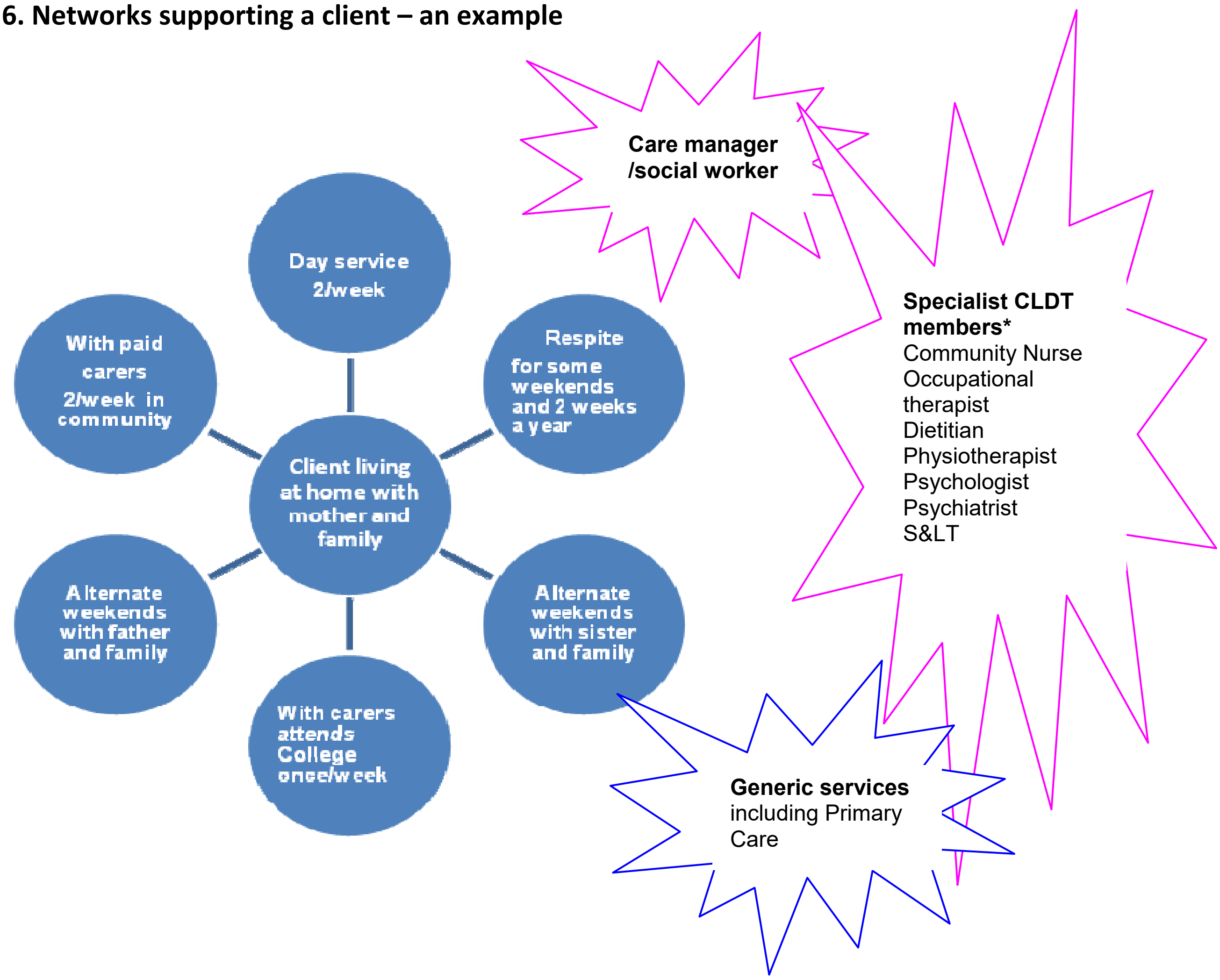
Many other individuals are involved in supporting people with LD, often in a voluntary capacity e.g. staff at Gateway Clubs, self advocacy groups and even befrienders. All these individuals should have knowledge of healthy eating so they can advise clients on a healthier diet and discourage unhealthy snacking. While a great many of these clubs do provide activity sessions, the end of the social event is often rounded off with crisps and fizzy drinks.

Communication

Training in communication is vital for all carers and staff - using signs, symbols, pictures, photographs, food models and the *Talking Mat*^{TM} are all useful approaches. The S&LT can advise on various ways of overcoming any particular communication problems.

Any client specific information whether healthier lifestyle guidelines, an individualised nutritional care plan and/or behavioural techniques should be cascaded (with the client's consent) to all relevant persons involved with the client's care as well as other members of the client's supporting CLDT (**GPP**). The social context of health can be quite complex in its supporting systems (see Fig 6). There are many steps where inconsistencies can occur, so having a schematic of key people involved in the health and well-being of the client is a critical factor in increasing the success of any prevention or intervention (**GPP**).

Fig 6. Networks supporting a client – an example



*** not many have a specialist dietitian as a core member**

5. Summary & Conclusion

There are many barriers to effective weight management especially within the LD population. From the literature and authors' experience, examples together with possible solutions for adults with LD, are summarised in Table 5.

Table 5 – Examples of barriers and possible solutions.

Barriers	**Possible solutions**
Client access to exercise/activities.	• Link with day services, social/support workers • Referral to LD physiotherapy for appropriate exercises • Referral to LD OT for range of local activities suitable for LD clients • Access to exercise referral programmes • Person-centred planning • Health Action Plan/Health Passport
Client access to healthier choices	• Training of carers • Check transport arrangements • Supported shopping • Person-centred planning
Client access to mainstream services in primary and secondary care.	• Carers supporting clients to attend appointments • Health professionals to institute telephone • reminders and visual appointment cards to aid compliance
Carer obliviousness to health implications of obesity	• Encouraging managers of provider organisations to release staff to staff to attend training programmes • Making/adapting or purchasing appropriate resources
Non compliance	• Training carers • Alternative provision such as groups; shopping
Inaccessible information	• Appropriate use of resources in accessible format • Consult with LD S& LT with referral for communication plan for client and carers
Insufficient money	• Involve social worker/care manager to review benefits • Also OT and support workers to devise in consultation with client a 'client a money management plan' i.e. budgeting
Too much available income	• Involve social worker/care manager to consider financial constraints as part of 'best interests' • Also OT and support workers to devise in consultation with client a 'client a money management plan' i.e. budgeting
Low self-esteem, Past abuse	• Discuss with LD community nurse / clinical psychologist/psychiatrist/care manager
Boredom	• Day/evening classes, voluntary • Work such as vocation skills centre • Care manager/social worker to review package
Poor cooking skills (client)	• Referral to LD OT for cooking skills • Accessing LD/mainstream day/evening classes
Poor cooking skills (carer)	• Encouraging managers of provider organisations to release staff to staff to attend training programmes
Client disempowered by carers	• Discuss with S&LT. Use of alternative/augmentative communication to gain client's opinions; share with consent with carers

NICE (2006) recommends research to develop evidence for the effectiveness of multi-component interventions for obesity management in disadvantaged groups, including people who have disabilities. Brown defines the specialist practitioner as one who consolidates and develops understanding of the health needs of a given population built upon a rigorous evidence base (Brown,2001). In the absence of such data it is recommended that the Good Practice Points (**GPP)** highlighted throughout the text are used as a guide for practitioners.

Possible areas for research include:

- Specific LD weight loss interventions
- Specific LD obesity integrated care pathway
- Binge Eating Disorder
- Robust scoping and outcomes evaluation of access to generic mainstream weight loss programmes
- Longer term evaluations of adapted or generic mainstream weight loss interventions and maintenance programmes
- Cost/benefit analysis of weight loss interventions for LD
- Relationship between obesity and environment
- Design, delivery and evaluation of validated education programmes for carers
- Effective communication strategies for carers

“I write ‘milk’, ‘eggs’, ‘bread’, ‘dinner’ on the shopping list, but the carers don’t get the dinners I like.”
Client who relies on carers to do his shopping but cannot spell ‘spaghetti bolognaise’, etc.

As a profession we do need to improve our history in publishing and sharing areas of good practice. One way of overcoming this could be to have an LD good practice page on the public page of the BDA Mental Health Group (MHG) website. Dietitians could submit a précis of their work together with contact details so sharing of ideas, audits or developments could take place.

In conclusion, people who have LD present with a wide range of cognitive and physical abilities and wish to have access to services, which have long been available to the non-disabled population, in order to have an equitable quality of life (LDAG, 2001, Thompson and Pickering, 2001).

The skills challenge for any health professional is to, by observation and discussion, provide evidence–based yet flexible and practicable interventions that include and meet the aspirations and needs of each client. Participatory research (and service planning and delivery) with people with LD is essential to explore their experiences of local services and garner a more realistic picture of their health and well-being needs (DH,2009A, DH2009B, Powrie, 2003).

It has been recognised for some time that people with LD can be informative, critical and reliable service users, provided that effective interview methods are employed (Kroese *et al,*1998). Closer working partnerships with primary, secondary and specialist teams, together with local advocacy groups could make inclusion a realistic objective for safeguarding health improvements for people with LD.

The National Health Services within the United Kingdom have a responsibility to commission mainstream services that, in conjunction with specialist LD services, address the health inequalities of people who have LD. Maintaining effective and longer term public health and therapeutic interventions for clients with LD is an increasing resource and intellectual challenge for dietitians whether working in specialist teams or generic core services.

The provision of services based on clearly defined work streams, objectives and core business is essential for future proofing within a modernisation framework. Adoption of the GPPs and the philosophy of inclusion, which underpins this document, may support redesign of current nutrition & dietetic departments within existing resources, thus enabling the needs of this client group to be addressed within mainstream services.

The formulation and adoption of this consensus statement is a small step towards developing an understanding of the specific nutritional health needs of adults who have LD and who are overweight/obese.

“I don’t feel comfortable and its not good for my heart. It’s not easy on my own, I tried and if I lose weight it feels great.”
A client’s contribution in a group discussion on ‘food and my health’.

6. Glossary

Active exercise: is an exercise in which the client exerts force to complete an action, e.g. walking, swimming unaided. The carer is typically a supervisor and provides little to no assistance to the client unless a problem arises, i.e. fall.

BMI Body mass index for relating a person's body weight to their height. BMI is a person's weight in kilograms (kg) divided by their height in meters (m) squared.

Contractures An abnormal, often permanent shortening, as of muscle or scar tissue, that results in distortion or deformity, especially of a joint.

Diagnostic overshadowing where presenting symptoms are put down to a person’s learning disability, rather than looking for another cause.

Dyslexia A learning difficulty that causes problems with learning language-based skills. People have trouble with reading, writing and spelling, can also affect concentration, short term memory, maths, coordination and communication skills. Dyslexia has no reflection on intelligence more the ability to access that intelligence.

Dyscalculia A learning difficulty comprehending mathematics.

Dyspraxia A learning difficulty which affects the planning of what to do and how to do it. It is associated with problems of perception, language and thought.

Dual diagnosis Where a client has both mental health problems and LD. The mental health national service framework should be followed.

GPP Good Practice Point. Based on a consensus of best practice.

Information carrying words An information-carrying word is any word in a sentence that *must* be understood in order to follow an instruction. Here is an example *‘Give me the ball’* .The person asking holds out their hand, with only a ball in front of them. The addressee does not *have to* understand any words, because the person has *shown* them what they want. This statement has *no information-carrying words.* If there were to be a *ball* and a *book* and the same question was repeated, the addressee needs to know the difference between ‘ball’ and ‘book’. This has *one information-carrying word level*. Messages can have varying numbers of information carrying words depending how they are said and what ‘clues’ are provided**.**

Health Action Plan (HAP) A Health Action Plan is a personal plan about what a person with LD can do to keep healthy. HAPs help to make sure people get the services and support they need.

Kyphosis Curving of the spine that causes a bowing of the back, which leads to a hunched back or slouching posture.

Learning Difficulty See Specific Learning Difficulty for definition.

Learning Disability See page 11 in text.

MUAC Mid-Upper Arm Circumference. Measurement of the non-dominant *arm midway between the shoulder and the elbow; can be used as a determinant of muscle mass.
*if right handed, the non dominant arm is the left arm.

PAL Physical Activity Level. Total energy cost of physical activity throughout the day, expressed as a ratio of BMR. Calculated from the physical activity ratio for each activity, multiplied by the time spent in that activity. A desirable PAL for health is considered to be 1.7; the average in the UK is 1.4. Activity levels are divided into Inactive (no daily exercise); Light (some daily exercise at work or tasks around the home/garden); Moderate (6 hrs on feet or regular strenuous exercise) and Heavy (labouring job or athletes in training).

Passive exercise is an exercise in which the physiotherapist (or carer) exerts force on the client to complete an action, e.g. assisted range of motion (ROM) exercises. The physiotherapist is physically moving a client's body to prevent thrombosis and muscle atrophy.

PMLD Profound and Multiple Learning Disabilities; A person with more than one learning disability where their main learning disability is profound. All people with PMLD will have great difficulty communicating. Many will have additional sensory or physical disabilities, complex health needs or mental health difficulties.

Polypharmacy Use of multiple medicinal products and refers to problems that can occur when a person is taking more medications than are actually clinically needed; or even if all are clinically indicated the term is also used to describe the ‘pill burden’ when too many medications are taken. The most common results of polypharmacy are increased adverse drug reactions and drug-drug interactions. Polypharmacy is most common in people with multiple medical conditions.

PWS Prader Willi Syndrome is a complex genetic disorder present from birth characterised by excessive and uncontrollable appetite for food and drink; learning disability, low muscle tone, emotional instability and immature physical development.

RMR Resting metabolic rate. RMR resting metabolic rate is closely related to Basal Metabolic Rate (BMR) and is the background energy required for basic metabolic functions when lying quietly awake. It is more practical than BMR because it does not have to be measured at the time of minimal expenditure in the early hours of the morning. RMR represents 60-70% of the total daily energy expenditure after subtraction of the energy used for activity and dietary thermogenesis.

RNI Reference nutrient intake. The RNI is the amount of a nutrient that is enough to ensure that the needs of nearly all the group (97.5%) are being met. By definition, many within the group will need less. If an individual is consuming the RNI of a nutrient, they are unlikely to be deficient in that nutrient.

Scoliosis A curvature of the spine, either congenital or acquired by very poor posture, disease or muscular weakness due to certain conditions such as cerebral palsy or muscular dystrophy.

S&LT Speech and Language Therapist; a specialist who evaluates and treats communication disorders and swallowing problems.

Specific Learning Difficulty (SpLD) A lack of progression with learning to read, write and spell and/or numeracy, contrary to the expectation built up by the normal development in other areas, with evidence that the problem is severe and persistent, despite appropriate learning opportunities. (ref: www.doncaster.gov.uk/Images/SpLD%20GUIDELINES_tcm2-53423.doc

TSF Triceps skinfold thickness. A measurement of subcutaneous fat taken by measuring skinfold thickness at specific sites including triceps, biceps, subscapular and ileac crest.

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Suggested further reading

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Useful Resources

ABMU Health Board. LD booklets http://www.wales.nhs.uk/sitesplus/863/page/41509
BDA - CED Franchise Course Introduction to Mental Health, Learning Disabilities and Eating Disorders www.bda.uk.com

BDA MHG. www.dietitiansmentalhealthgroup.org.uk

Best Interest Guidance. www.bps.org.uk

Bristol community (LD) dietitians. LD information http://www.briscomhealth.nhs.uk/bristol-learning-difficulties

Clear. For advice & training regarding making information accessible. www.clearforall.co.uk

Color Library Collection – Food (2003), Winslow Press, Tel.: 0845 230 2777

Food, Fitness, Fun! A training pack in weight management for people with learning disabilities, (2000) Pavilion Publishing. Available at www.pavpub.com

Health Action Plans
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Learningdisabilities/DH_4001807

Health indictors for people with learning disabilities. www.pomonaproject.org/

Map of Medicine for Obesity Pathway. Access without password available at http://eng.mapofmedicine.com/evidence/map/index.html

Mencap guidelines for accessible writing available at: www.mencap.org.uk

Mental Capacity Act 2005 Short Reference Guide. www.bps.org.uk

NHS Fife My Cook Book – coloured photographs of each stage of preparation.
[redacted]

Obesity Pathway http://eng.mapofmedicine.com/evidence/map/obesity_in_adults1.html

Obesity Toolkit available at www.heartforum.org.uk or www.fph.org.uk.

PMLD Link *(2009) Health Care. 21 (3). 64.* For article on menu planning

Pocket Colour Cards – Snack time (2003), Winslow Press, Tel.: 0845 230 2777

RCN. http://www.rcn.org.uk

Ready, S. (2006) *Care pathway for the management of overweight and obesity.* Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4134408

SNDRi (Scottish Nutrition and Dietetic Resource Initiative) www.gcal.ac.uk

Swanton, K. & Frost, M. (2007) *Lightening the load: Tackling overweight and obesity. A toolkit for developing local strategies to tackle overweight and obesity in children and adults*. London. DH.

Symbols www.mayer-johnson.com

Talking Mats and weight Management. www.talkingmats.com

Training programmes:

Agored Cymru for accredited nutrition course modules available at: www.ocnwales.org.uk
Highfield Publications for nutrition and training products (currently level 2 foundation and level 3 intermediate/supervisory for nutrition) available at
http://www.highfield.co.uk/products/sector/nutrition-health/

QCF (Qualifications and Credit Framework) NVQs in Health and Social Care Levels 2-3 Diplomas in Health and Social Care are aimed at individuals working with adults and children across all social care settings. The qualifications provide specialist routes for learning disabilities or dementia care. (Nutrition units in development) more information on QCF available at
http://www.edexcel.com/quals/NVQ-competence-based-qcf/hsc/Pages/default.aspx

REHIS - The Royal Environmental Health Institute Scotland for accredited course modules in nutrition available at: www.rehis.com

Royal Society for Public Health available at
http://www.rsph.org.uk/en/qualifications/index.cfm

Appendix 1

Key Questions:

Key Question 1 : What is the incidence of obesity in adults with learning disability (LD) and how does it compare to the general population?

Key Question 2 : What factors contribute to obesity in adults with LD? Consider medication, genetics, endocrine disorders, type and level of activity undertaken, type and level of support from carers, degree of independence, level of knowledge.

Key Question 3: What co-morbidities and complications relate to/are associated with obesity in adults with LD? (Are they any different to the general population e.g. DM?)

Key Question 4 : How is the readiness to change best assessed in obese adults with LD?

Key Question 5 : What combinations of interventions are most effective for weight loss in adults with LD?

Key Question 6 : What is the level of knowledge and understanding of individuals delivering weight management interventions to adults with LD?

Key Question 7 : What are the outcomes (lifestyle changes, altered BMI) when obese adults with LD are treated by LD dietitians compared to generalist dietitians or dietitians who have specialised in obesity?

Key Question 8 : In obese adults with LD, where other interventions have failed, what is the evidence of effectiveness of Orlistat and Sibutramine?*

Key Question 9 : In obese adults with LD what is the effectiveness of bariatric surgery

Key Question 10 : What are the health benefits of weight loss in adults with LD?

Key Question 11 : In adults with LD who have achieved weight loss, which are the most effective support interventions in promoting weight maintenance?

Key Question 12 : How is obesity measured in adults with LD?

Key Question 13 : What screening tools are available for adults with LD to prevent weight gain/promote weight loss?

Key Question 14: What is the prevalence of Binge Eating Disorder (BED) in obese adults with LD? Are standard obesity interventions adequate for those who have BED, or do they require additional/alternative support?

Key Question 15 : What are the outcomes (lifestyle changes, altered BMI) when the dietary treatment of obese adults with LD is carried out in individual consultations compared to group sessions with other obese adults with LD, compared to group sessions with other obese adults?

Key Question 16 : What are the considerations for achieving weight loss/maintenance in obese adults with LD who are enterally fed or receive nutritionally complete supplements?

Key: **No evidence found to address these questions.**

*** Literature review undertaken pre January 2010 when this medication was withdrawn from use.**

Appendix 2

EVIDENCE TABLE : Papers relating to key questions

Key Question 1 : What is the incidence of obesity in adults with learning disability (LD) and how does it compare to the general population?

Reference	**Study Type**	**Evidence Level**	**Population and number**	**Intervention**	**Comments relating to key question 1.**
Bhaumik, S., Watson, L.M., Thorpe, C.F., Tyrer, F. & McGrother, C.W. (2008) Body mass index in adults with intellectual disability: distribution, association and service implications: a population based study. *J Intell Disabil Res*. **53**, 287-298.	Population based prevalence study.	Level 2+	Adults with learning disability. 661 (59%) males & 458 (41%) females. 59% lived in residential care had 20% had Down Syndrome.	Health checks carried out on subjects to determine incidence of overweight/ obesity.	28% were overweight & 20.7% obese. Obesity almost twice as prevalent in women (29%) as in men (15%). Associated with living independently/with family, ability to feed/drink unaided, being female, hypertension, Down Syndrome, mild learning disability & the absence of cerebral palsy. Higher than figures for general population.
Draheim, C.C. (2006) *Cardiovascular Disease Prevalence and risk factors of person with mental retardation. Ment Retard Dev Disabil Res Rev.* **12**, 3-12.	Review	Level 4	Review of literature on cardiovascular disease (CVD) prevalence in adults with mental retardation living in community settings.	Literature review.	This study provides the evidence that CVD is of major concern in adults with mental retardation, especially those who live in the community & highlights current strategies used in general populations are ineffective in combating the disease in this client group.
Ellis, L.J., Lang, R., Shield, J.P.H., Wilkinson, J.R., Lidstone, J.S.M., Coulton, S. & Summerbell, C.D. (2006) Obesity and disability – a short review. *Obesity Reviews.* **7**, 341-345.	Literature review	Level 4	n/a	n/a	Very limited information relating to papers on learning disability. Shows need for more research in this field.
Emerson, E. (2005) Underweight, obesity and exercise among adults with intellectual disabilities in	Non-experimental study	Level 2-	1542 adults with LD.	Data collection from audit based reviews of supported	The study identified need for targeted programmes to address the issues of physical inactivity & poor diet in client group. Also highlighted problem of

supported accommodation in Northern England. *J Intell Disabil Res.* **49***,* 134-143.				accommodation. Comparative data from adults who do not have LD – Health Survey, England 1998 & 2001.	obesity in LD & underweight as a problem in the younger client group.
Gale, L., Naqvi, H. & Russ, L. (2009) Asthma, smoking and BMI in adults with intellectual disabilities: a community-based survey. *J Intell Disabil Res*. **53**, 787-796.	Cross sectional survey	Level 2-	1097 patients with learning disability, over age 16 years from 28 GP practices in Bristol PCT.	Data collected from medical notes in GP practices. Info on BMI only available fro 62.8% of patients.	Survey looked at levels of smoking & raised BMI in people with learning disability who also had asthma – people with LD who have asthma are 2.6 times more likely to die from asthma than those who do not have LD. Higher BMI found in females with LD. Proportion of adults who had a BMI>30 was nearly 10% higher than the general population.
Henderson (2008) Overweight status, obesity and risk factors for coronary heart disease in adults with intellectual disability. *J. of Policy and Practice in Intellectual Disabilities***. 5**, 174-177.	Mixed methodology - retrospective case record in 2005 & comparison with data collected in 2001.	Level 2-	100 adults with ID & 2526 non-ID.	Data collected from medical records over 4 month period in 2005. Age, height, weight, BP, CHD risk factors were recorded. For comparison, data from a country wide adult health survey in 2000-01 were used.	Obesity greater in ID population but combined overweight & obesity the same as general population.
Melville, C. A., Cooper, S. & Morrison, J. (2008) The prevalence & determinants of obesity in adults with intellectual disability. *JARID.* **21***,* 425-437.	Cross sectional study.	Level 2+	Adults with learning disabilities in a defined area of Glasgow.	Data collected & compared with results from the Scottish Health Survey (general population) 2003.	Women with LD more likely to be obese than men. People with mild LD more likely to be obese than those with profound LD. Men & women with Down Syndrome (DS) are significantly more likely to be overweight / obese than those with LD but no DS. Women living independently in a deprived area have increased likelihood of obesity but this is not the case for men. Incidence of overweight in LD population greater at an earlier age than for general population.

Moore, K., McGillivray, Illingworth, & Brookhouse, (2004) An investigation into the incidence of obesity and underweight among adults with an intellectual disability in an Australian sample. *J Dev Disabil.* **29**,306-318.	Cross sectional study	Level 2-	41 females & 52 males with mild to severe learning disability – relatively small sample.	BMI assessed & results compared to general population figures.	41.4% of females were overweight and 36.6% obese (compared to 28.8% and 18.2% respectively from the general population). 30.8% of males were overweight & a further 30.8% obese (compared to 45.2% & 18.5% respectively for the general population). No significant difference between males & females. Levels of overweight/obesity varied across living conditions with the highest prevalence being in those living in carer assisted accommodation.
Rimmer, J. & Yamaki, K. (2006) Obesity and intellectual disability. *Ment Retard Dev Disabil Res Rev.* **12***,* 22-27.	Review article	Level 4	n/a	n/a	Paper summarised results gained from other surveys & tried to discuss reasons for the increased prevalence of obesity in adults with LD. Mainly focused on papers from USA but also included studies from Ireland & Germany.
Yamaki, K. (2005) Body weight status among adults with intellectual disability in the community. *Ment Retard.* **43**, 1-10.	Cross sectional survey	Level 2-	Adults with LD who live outside of formal services i.e. non-institutionalised.	Data on health status collected through personal interview.	Women & middle aged adults with LD reported higher rate of obesity than men and young adults with LD. Differences not generally significant. Overall, presence of obesity significantly higher in adults with LD.

Key Question 2 : What factors contribute to obesity in adults with LD? Consider medication, genetics, endocrine disorders, type and level of activity undertaken, type and level of support from carers, degree of independence, level of knowledge.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question 2.
Beart, s., Hawkins, D., Stenfert Kroese, B. et al. (2001). Barriers to accessing leisure opportunities for people with learning disabilities. *Brit J Learn Disabil.* **29**, 133-138.	Descriptive focus groups using semi-structured interviewing technique.	Level 3	29 adults with mild/moderate learning disability.	Semi-structured interviews to determine which activities they wished to access and the perceived barriers to leisure access.	Activities tended to be centred around day centre activities rather than pursuits carried out at home. Lack of transport and carer/friend support were identified as main barriers to accessing activities.
Chapman, M.J., Craven, M.J. & Chadwick, D.D. (2008) Following up Fighting fit: The long-term impact of health practitioner input on obesity and BMI amongst adults with intellectual disabilities. *J Intell Disabil.* ***12**, 309-323.*	Prospective pre/post quasi-experimental design.	Level 2-	Adult learning disability – input group n=33 and a comparison group n= 40.	Data on BMI collected at baseline, 6 months, 1 year & 6 years.	Mean BMI in the non-input group rose initially, stabilized & then decreased. Input group showed improvements in obesity levels & lost more weight than the non-input group but findings no statistically significant. Small sample size. No dietetic input – physio dealt with weight issues. Study did show positive response to exercise & health promotion activities.
Chapman, M.J., Craven, M.J. & Chadwick, D.D. (2005) Fighting fit?: An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. *J Intell Disabil*. **9**, 131-144.	Pre-/post-intervention study with a comparison group.	Level 2-	Adult learning disability. 50 in non-input group 38 in input group	The input group received advice from a Healthy Living Coordinator on ways of improving their diet & lifestyle. The non-input group received no advice.	Input group showed significant weight loos over 12 month period whereas non-input group gained a little weight. No matching for groups. Many different factors looked at and not clear which was most beneficial.
Draheim, C.C., Williams, D.P. & McCubbin, J.A. (2002) Physical activity, dietary intake and insulin resistance syndrome in non-diabetic	Cohort Study	Level 2+	145 participants with mild to moderate LD.	Screened for hyperinsulinaemia, hypertriglyceridaemia, LDL cholesterol,	Positive correlation between overweight & abdominal obesity and incidence of hyperinsulinaemia and other risk factors. First study of its kind & gives grounds for further research into

adults with mental retardation. *Am J Ment Retard.***105***, 361-375.*				hypertension & abdominal obesity. Also questionnaire looking at dietary habits & physical activity.	health behaviours, insulin resistance and CVD.
Edwards, M.(2007) Caring for patients with a learning disability. *Practice Nurse,* 17, 38-41.	Review article.	Level 4	n/a	n/a	Levels of obesity higher in clients with mild learning disability & in females. Reasons : poor diet, lack of physical activity & side effects of antipsychotic drugs as well as genetic conditions e.g. Down's Syndrome.
Emerson, E. (2005) Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England. *J Intell Disabil Res.* **49***,* 134-143.	Non-experimental study	Level 2-	1542 adults with LD.	Data collection from audit based reviews of supported accommodation. Comparative data from adults who do not have LD – Health Survey, England 1998 & 2001.	The study identified need for targeted programmes to address the issues of physical inactivity & poor diet in client group. Also highlighted problem of obesity in LD & underweight as a problem in the younger client group.
Frey, G.C. (2004) Comparison of physical activity levels between adults with and without mental retardation. *J Phys Act Health.* **1**, 235-245.	Prospective non-experimental cohort.	Level 2-	22 adults with mild mental retardation (MR), 17 sedentary adults with no MR and 8 active adults with no MR.	Activity levels recorded by accelerometer plus a daily activity diary for sedentary activities.	Results suggest adults with MR have similar Physical activity levels (PALS) to sedentary adults without MR. Should have included a group of active adults with MR for meaningful comparison. Small sample numbers & BMI in MR group significantly higher than in other 2 groups.
Frey, G.C., Buchanan, A.M. & Rosser Sandt, D.D. (2005) 'I'd rather watch TV' : An examination of physical activity in adults with mental retardation. *Ment Retard.* **43**, 241-254.	Interpretive ethnography	Level 2+	12 adults with mental retardation plus 2 job supervisors and 4 parents.	Individuals interviewed regarding their physical activity levels and what they saw as barriers to physical activity. Information reinforced	Usual concerns over general level of fitness, money, transport were shown to be barriers to physical activity but more importantly, lack of knowledge about the benefits of physical activity, negative support and lack of guidance from carers was a major factor.

				by using data from accelerometers.	
Hawkins, A. & Look, R. (2006) Levels of engagement and barriers to physical activity in a population of adults with learning disabilities. *Brit J Learn Disabil.* **34**, 220-226.	Semi-structured interviews.	Level 2-	19 adults with learning disability – 84% female, 16% male, from 5 group homes.	Staff recorded physical activity levels of those participating in study.	Following recording done by staff, barriers to physical activity were determined. Client's lack of understanding of the benefits of physical activity was most significant barrier with financial constraints being another major barrier. Service users were not questioned about their perspective on barriers to physical activity.
Henderson, A., Lynch, S.A., Wilkinson, S. & Hunter, M. (2007) Adults with Down's syndrome: the prevalence of complications and health care in the community. *Brit J Gen Pract.* **57***,* 50-55*.*	Retrospective case note review.	Level 2-	Adults with Down's syndrome age 18-61 yrs. 64 in sample.	Data obtained from the primary care records.	The paper highlighted the need for regular health checks for individuals with Down's syndrome. Medical problems highlighted but obesity not listed as one of them contrary to authors saying that 20% had a BMI of greater than 35.
Illingworth, K., Moore, K. & McGillvray, J. (2003) The development of the nutrition and activity knowledge scale for use with people with an intellectual disability. *J Appl Res Intell Disabil.* **16***,* 159-166.	Cross sectional survey.	Level 2+	73 participants chosen from 4 facilities offering adult training & 1 facility providing 24 hour care to people with a learning disability.	The development of a nutrition & activity knowledge scale – 18 questions related to healthy eating & exercised were asked.	Nutrition & Activity Knowledge Scale (NAKS) developed. Knowledge levels about nutrition appeared to be low using NAKS, but when respondents were asked about 'good and bad foods', they could tell researchers the answers. Showed no real understanding of nutritional reason for why a food was good or bad; usually because 'my carer said so'.
Levy, J.M., Botuck, S., Damiani, M.R., Levy, P.H., Dern, T.A. & Freeman, S.E. (2006) Medical conditions and healthcare utilization among adults with intellectual disabilities living in group homes in New York City. *J Policy Pract Intell Disabil.* **3***,* 195-202.	Retrospective health record analysis.	Level 2-	103 case notes of adults with intellectual disability living in 22 group homes.	Healthcare records examined for data relating to weight, height, BMI, level of intellectual disability and other health related conditions.	People who were obese (36.9%) and overweight (33%) displayed more frequent challenging behaviours than those of normal/underweight. A sedentary lifestyle & poor food choices linked with increased independence are cited a reasons for high rates of obesity.
Levy, J.M.; Botuck, S. & Rimmerman,	Bivariate	Level 2-	52 adults with	Age, gender, race, living	70% of the individuals were overweight/obese with

A. (2007) Examining outpatient health care utilization among adults with severe or profound intellectual disabilities living in an urban setting : A brief snap shot. *J Soc Work Disabil Rehab.* **6**, 33-45.	regression analysis.		intellectual disabilities who live in New York City, who exclusively utilized a community based medical practice.	situation, level of ID, autism, cerebral palsy, sensory impairment & self injurious behaviour were obtained form individuals' most recent Developmental Disabilities Profile.	a marginally higher incidence in those who lived with their family as opposed to group homes. Less medical complications were found in the group with Down's Syndrome. Those living at home utilized less medical appointments than those living in group homes. The authors acknowledge need to decrease obesity among adults with ID in order to maintain general health & more education should be offered to families & carers.
McGuire, B.E., Daly, P. & Smyth, F. (2007) Lifestyle and health behaviours of adults with an intellectual disability. *J Intell Disabil Res.* **51**, 497-510.	Prospective cross sectional postal questionnaire.	Level 2-	Questionnaire sent to 250 primary carers of individuals with LD. 125 in residential settings and 125 in parental homes.	Questionnaire	Study results indicate good health behaviours around fat & sugar intake as compared to general population but poorer activity levels and a less healthy diet overall. (Low fruit & veg & low unrefined CHO intake). Choice and decision making did not seem to influence health behaviours or home setting
Marshall, D., McConkey, R. & Moore, G. (2003) Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. *J Adv Nurs.* **41**, 147-153.	Pilot/ observational study.	Level 2-	Study 1 : sample – 464 aged 10+ - individuals with LD attending special schools & day centres. Study 2 : sample 25 – adults in day centres.	Study 1 : Health screening – 200 were referred on to their GP with various problems. Study 2 : individuals were involved in group sessions where support & advice was given on healthy diet & lifestyle.	Weight loss was greater among those attending the group sessions compared with those seen by their GP or given advice by nurse at the screening clinic. Study highlighted need for carers & people with a LD to be actively involved in deciding on a healthy diet & becoming involved in suitable exercise regimes.
Melville, C.A., Cooper, S-A., McGrother, C.W., Thorp, C.F. & Collacott, R. (2005) Obesity in adults with Down Syndrome : a case control study. *J Intell Disabil Res.* **49**, 125-133.	Case control study	Level 2+	247 matched pairs of adults with Down Syndrome (DS) & those without DS but with intellectual disability.	Height, weight & BMI measured in order to compare the two groups and determine the incidence of overweight/ obesity.	Results showed that women with DS were more likely to be overweight/obese than non-DS women and men with DS were more likely to be overweight but not obese compared with non-DS. It was noted that non-DS group had higher incidence of underweight.

					Recommendations – to look at long term health effects of people with DS being overweight/obese & developing education on healthy lifestyle for this group.
Melville, C. A., Cooper, S. & Morrison, J. (2008) The prevalence & determinants of obesity in adults with intellectual disability. *JARID.* **21***,* 425-437.	Cross sectional study.	Level 2+	Adults with learning disabilities in a defined area of Glasgow.	Data collected & compared with results from the Scottish Health Survey (general population) 2003.	Women with LD more likely to be obese than men. People with mild LD more likely to be obese than those with profound LD. Men & women with Down Syndrome (DS) are significantly more likely to be overweight / obese than those with LD but no DS. Women living independently in a deprived area have increased likelihood of obesity but this is not the case for men. Incidence of overweight in LD population greater at an earlier age than for general population.
Messent, P.R., Cooke, C.B. & Long, J. (2000) Secondary barriers to physical activity for adults with mild and moderate learning disabilities. J *Learn Disabil.* **4**, 247-263.	Structured in-depth interviews.	Level 2+	24 adults with mild to moderate learning disability. Residential managers & carers also helped with interviews.	Each participant interviewed	Primary barriers identified in line with previous studies – staff unclear about policy/ guidelines for physical activity; financial constraints; location of leisure facilities; options available to this client group. Secondary barriers – staff unclear about how to interpret 'ordinary living principles'; lack of training for staff on 'ordinary living principles'; competing tensions between parents and professional carers; provision of integrated/segregated leisure opportunities; 'age-appropriateness' of activities offered.
Peterson, J.J., Janz, K.F. & Lowe, J.B. (2008) Physical activity among adults with intellectual disability living in community settings. *Prev Med.* **47***,* 101-106.	Objective study.	Level 2-	131 adults with mild or moderate ID living in community based supported living.	Individuals fitted with Omron pedometers & number of steps/day counted over period of 1 week. Noted time of	Results showed that very few individuals met the required recommendation of 10,000 steps/day. Those with moderate ID had a lower step count than those with mild ID. Participants were generally more active on weekdays when out at work,

				day when person most active & on which days i.e. week days compared to weekends.	compared with evenings & weekends. Weight/BMI not measured therefore no link could be made between weight & physical activity. Recommendations – development of physical activity programmes, for evenings & weekends & not necessarily gender specific.
Robertson, J., Emerson, E., Gregory, N., Hatton, C., Turner, S., Kessissoglou,S. & Hallam, A. (2000) Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Res Dev Disabil.* **21***,* 469-486.	Cross sectional study.	Level 2+	540 people with LD in either village communities, residential campuses or dispersed housing schemes. Data on 500 was completed.	Figures gathered for diet, exercise, weight, smoking & drinking habits and mental health. Sub-group for Down's syndrome.	Findings showed that poor diet & physical inactivity levels were high in client group & obesity more prevalent in women. Recommends looking at ways of increasing physical activity levels to reduce risk factors for poor health & trying to promote diet higher in fruit, veg & CHO.
Temple, V.A. & Walkley, J.W. (2007). Perspectives of constraining and enabling factors for health-promoting physical activity by adults with intellectual disability. *J Intell Dev Disabil.* **32***,* 28-38.	Qualitative focus groups.	Level 3	Adults with intellectual disability (n=9), direct care workers (n=5), home supervisors (n=15 total), managers (n=4) and parents (n=7).	Focus group interviews.	Perceptions of motivation differ between carers, parents & adults with intellectual disability. Carers said those with ID lacked motivation, preferred sedentary lifestyles & are unwilling to participate in physical activities (PA). Being part of a team & wining medals was perceived very positively. Study identifies need for motivating people with ID with associated social, financial & political support. Gap in knowledge between PA staff who have little understanding of ID & ID staff who have little knowledge of PA needs of this client group.

Key Question 3: What co-morbidities and complications relate to/are associated with obesity in adults with LD? (Are they any different to the general population e.g. DM?)

Reference	**Study Type**	**Evidence Level**	**Population and number**	**Intervention**	**Comments relating to key question 3.**
Chapman, M.J., Craven, M.J. & Chadwick, D.D. (2005) Fighting fit?: An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. *J Intell Disabil*. **9**, 131-144.	Pre-/post-intervention study with a comparison group.	Level 2-	Adult learning disability. 50 in non-input group 38 in input group	The input group received advice from a Healthy Living Coordinator on ways of improving their diet & lifestyle. The non-input group received no advice.	Input group showed significant weight loos over 12 month period whereas non-input group gained a little weight. No matching for groups. Many different factors looked at and not clear which was most beneficial.
Draheim, C.C. (2006) Cardiovascular Disease Prevalence and risk factors of person with mental retardation. *Ment Retard Dev Disabil Res Rev.* **12**, *3-12.*	Review	Level 4	Review of literature on cardiovascular disease (CVD) prevalence in adults with mental retardation living in community settings.	Literature review.	This study provides the evidence that CVD is of major concern in adults with mental retardation, specially those who live in the community & highlights current strategies used in general populations are ineffective in combating the disease in this client group.
Draheim, C.C., Williams, D.P. & McCubbin, J.A. (2002) Physical activity, dietary intake and insulin resistance syndrome in non-diabetic adults with mental retardation. *Am J Ment Retard.**105**, 361-375.*	Cohort Study	Level 2+	145 participants with mild to moderate LD.	Screened for hyperinsulinaemia, hypertriglyceridaemia, LDL cholesterol, hypertension & abdominal obesity. Also questionnaire looking at dietary habits & physical activity.	Positive correlation between overweight & abdominal obesity and incidence of hyperinsulinaemia and other risk factors. First study of its kind & gives grounds for further research into health behaviours, insulin resistance and CVD.

Edwards, M.(2007) Caring for patients with a learning disability. *Practice Nurse,* 17, 38-41.	Review article.	Level 4	n/a	n/a	Respiratory disease cited as most common cause of death in people with a learning disability with CHD the second most common.
Henderson (2008) Overweight status, obesity and risk factors for coronary heart disease in adults with intellectual disability. *J. of Policy and Practice in Intellectual Disabilities.* **5**, 174-177.	Mixed methodologies – retrospective case record in 2005 & comparison with data collected in 2001.	Level 2-	100 adults with ID & 2526 non-ID.	Data collected from medical records over 4 month period in 2005. Age, height, weight, BP, CHD risk factors were recorded. For comparison, data from a country wide adult health survey in 2000-01 were used.	Obesity greater in ID population but combined overweight & obesity the same as general population. Dyslipidaemia higher in ID. BP the same for both groups. Physicians prescribe diet more often & less exercise in ID than non-ID.
Henderson, A., Lynch, S.A., Wilkinson, S. & Hunter, M. (2007) Adults with Down's syndrome: the prevalence of complications and health care in the community. *Brit J Gen Pract.* **57**, 50-55.	Retrospective case note review.	Level 2-	Adults with Down's syndrome age 18-61 yrs. 64 in sample.	Data obtained from the primary care records.	The paper highlighted the need for regular health checks for individuals with Down's syndrome. Medical problems highlighted but obesity not listed as one of them contrary to authors saying that 20% had a BMI of greater than 35.
Ito Jun-ichi. (2006) Brief research report – Obesity and its related health problems in people with intellectual disabilities. *J Policy Pract Intell Disabil.* **3**, 129-132.	Non-experimental study	Level 2-	342 males & 184 females with ID aged over 18. 195 support staff made up the general population group. Sample group were from residential campus group living or community group homes.	Weight, height, & BMI were taken plus blood tests for glucose tolerance, dyslipidaemia, liver diseases & hyperuricaemia. Blood pressure was also recorded.	In younger men there was a significant incidence of hyperuricaemia & less than half of those with the problem were obese. Non-alcoholic fatty liver also found to be most prevalent in younger males – figures suggested relationship between abnormal liver tests & obesity with antipsychotic & antiepileptic medication playing a role. Obesity was more prevalent in older women living in the community group homes c.f. those in institutes. Those in institutes also had lower incidence of hyperglycaemia, hypertension & dyslipidaemia.

Marshall, D., McConkey, R. & Moore, G. (2003) Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. *J Adv Nurs.* **41***,* 147-153.	Observational study.	Level 2-	Study 1 : sample – 464 aged 10+ - individuals with LD attending special schools & day centres. Study 2 : sample 25 – adults in day centres.	Study 1 : Health screening – 200 were referred on to their GP with various problems. Study 2 : individuals were involved in group sessions where support & advice was given on healthy diet & lifestyle.	Weight loss was greater among those attending the group sessions compared with those seen by their GP or given advice by nurse at the screening clinic. Study highlighted need for carers & people with a LD to be actively involved in deciding on a healthy diet & becoming involved in suitable exercise regimes.
Stanish,H. & Draheim, C.C. (2007) Walking activity, body composition and blood pressure in adults with intellectual disabilities. *J Appl Res Intell Disabil.* **30***,* 183-190.	Experimental cohort study.	Level 2+	103 adults with ID aged 19-65 years.	Research looks at benefit of walking in individuals with intellectual disability & whether this population group is reaching the target of 10,000 steps/day. Examines health benefits of walking, measuring body composition & BP.	The interesting finding was that the ones who did achieve 10,000 steps or more/day did not display the health benefits of improved body composition and low BP that one would have expected. They tended to have the highest BP & body weight. This may be due to a poor diet in this group combined with low intensity of exercise. The group showing most benefit were those walking between 7500–9999 steps/day.
Wallace, R.A. & Schluter, P. (2008) Audit of cardiovascular disease risk factors among supported adults with intellectual disability attending an ageing clinic. *J Intell Dev Disabil.* **33***,* 48-58.	Retrospective analysis of medical charts :2002 - 2005.	Level 2-	155 adults with LD, over age of 40, charts reviewed. 8 had diagnosed CVD.	Incidence of hypertension, elevated glucose, elevated cholesterol, overweight/obesity, smoking & physical inactivity checked.	Recommendations made – intervention programmes should concentrate on physical activity & lowering body weight. Link between CVD risk factors & LD syndromes not proven.

Key Question 4 : How is the readiness to change best assessed in obese adults with LD?

No evidence was found to answer this question.

Key Question 5 : What combinations of interventions are most effective for weight loss in adults with LD? Consider diet alone, diet plus physical activity and with/without behavioural interventions.

Reference	**Study Type**	**Evidence Level**	**Population and number**	**Intervention**	**Comments relating to key question 5.**
Bradley, S. (2005) Tackling obesity in people with learning disability. *Learn Disabil Pract*. **8**, 10-14.	Cohort study	Level 2-	9 people with LD.	Questionnaires used to gather baseline information.	Questionnaires impractical for this group as many needed help from carers which resulted in bias answers. Weight changed in 7 out of 9 participants. Those who increased exercise achieved most weight loss. Biggest subjective change was increased fruit & veg. consumption.
Chapman, M.J., Craven, M.J. & Chadwick, D.D. (2005) Fighting fit?: An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. *J Intell Disabil*. **9**, 131-144.	Pre-/post-intervention study with a comparison group.	Level 2-	Adult learning disability. 50 in non-input group 38 in input group	The input group received advice from a Healthy Living Coordinator on ways of improving their diet & lifestyle. The non-input group received no advice.	Input group showed significant weight loss over 12 month period whereas non-input group gained a little weight. No matching for groups. Many different factors looked at and not clear which was most beneficial, although it does state that diet & exercise can assist weight loss.
Emerson, E. (2005) Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England. *J Intell Disabil Res.* **49***,* 134-143.	Case control study.	Level 2+	1542 adults with LD.	Data collection from audit based reviews of supported accommodation. Comparative data from adults who do not have LD – Health Survey, England 1998 & 2001.	The study identified need for targeted programmes to address the issues of physical inactivity & poor diet in client group. Also highlighted problem of obesity in LD & underweight as a problem in the younger client group.

Hamilton, S., Hankey, C.R., Miller,S., Boyle, S. & Melville, C.A. (2007) A review of weight loss interventions for adults with intellectual disabilities. *The International Association for the Study of Obesity* Obesity reviews. **8,** 339 – 345.	Review	Level 4	n/a	n/a	This paper is a review of existing evidence.
Jeffreys, K. (2000) Managing and treating obesity in people with learning disability. *Lear Disabil Pract.* **2***,* 30-34.	Review article.	Level 4	n/a	n/a	The aim of this paper was to highlight the key principles and the role for nurses in managing & treating obesity in people with LD. Recommendations were not actually tested so it poses question as to how realistic they will be to achieve weight loss.
Marshall, D., McConkey, R. & Moore, G. (2003) Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. *J Adv Nurs.* **41***,* 147-153.	Pilot study	Level 2-	Study 1 : sample – 464 aged 10+ - individuals with LD attending special schools & day centres. Study 2 : sample 25 – adults in day centres.	Study 1 : Health screening – 200 were referred on to their GP with various problems. Study 2 : individuals were involved in group sessions where support & advice was given on healthy diet & lifestyle.	Weight loss was greater among those attending the group sessions compared with those seen by their GP or given advice by nurse at the screening clinic. Carer and client education is required alongside provision of suitable exercise & healthy eating activities to ensure weight loss & weight maintenance.
Oathamshaw, S.C. (2007) Delivering cognitive behavioural therapy in community services for people with LD : difficulties, dilemmas, confounds. *Adv Ment Health Learn Disabil.* **1***,* 22-25.	Case report	Level 3	n/a	n/a	An assessment of cognitive skills is necessary to ensure the client can engage in CBT but can also be useful in guiding therapy and decisions about appropriate interventions. Changes in the environment around the client and support system may undermine successful therapy and necessitate a change in planned interventions & underlines the importance of working closely with the client's social and health carers.

Tasse, M.J. (2006) Functional behavioural assessment in people with intellectual disabilities. *Current Opinion in Psychiatry.* **19***,* 475-480*.*	Review article	Level 4	n/a	n/a	Paper discusses behavioural problems, & the fact that success in reducing behavioural problems is linked to understanding of the function of the problem behaviour. A functional behaviour assessment must always be carried out.
Wilner, P. (2006) Readiness for cognitive therapy in people with intellectual disabilities. *J Appl Res Intell Disabil.* **19***,* 5-16.	Expert opinion	Level 4	n/a	n/a	Paper details cognitive behaviour therapy and how it can be modified for use with ID. Need to look at lots of factors such as ability, self-efficacy, motivation, not only of the client, but also family/carers.

Key Question 6 : What is the level of knowledge and understanding of individuals delivering weight management interventions to adults with LD?

Reference	**Study Type**	**Evidence Level**	**Population and number**	**Intervention**	**Comments relating to key question 6.**
Chapman, M.J., Craven, M.J. & Chadwick, D.D. (2005) Fighting fit?: An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. *J Intell Disabil*. **9**, 131-144.	Pre-/post-intervention study with a comparison group.	Level 2-	Adult learning disability. 50 in non-input group 38 in input group	The input group received advice from a Healthy Living Coordinator on ways of improving their diet & lifestyle. The non-input group received no advice.	Input group showed significant weight lose over 12 month period whereas non-input group gained a little weight. No matching for groups. Many different factors looked at and not clear which was most beneficial.
Edwards, M.(2007) Caring for patients with a learning disability. *Practice Nurse,* 17, 38-41.	Review article.	Level 4	n/a	n/a	Levels of obesity higher in clients with mild learning disability & in females. Reasons : poor diet, lack of physical activity & side effects of antipsychotic drugs as well as genetic conditions e.g. Down's Syndrome.
Marshall, D., McConkey, R. & Moore, G. (2003) Obesity in people with	Observational study.	Level 2-	Study 1 : sample – 464 aged 10+ -	Study 1 : Health screening – 200 were	Weight loss was greater among those attending the group sessions compared with those seen by their

intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. *J Adv Nurs.* **41***,* 147-153.			individuals with LD attending special schools & day centres. Study 2 : sample 25 – adults in day centres.	referred on to their GP with various problems. Study 2 : individuals were involved in group sessions where support & advice was given on healthy diet & lifestyle.	GP or given advice by nurse at the screening clinic. Study highlighted need for carers & people with a LD to be actively involved in deciding on a healthy diet & becoming involved in suitable exercise regimes.
Melville, C.A., Hamilton, S., Millar, S., Boyle, S., Robinson, N., Pert, C. & Hankey, C.R. (2009) Carer knowledge and perceptions of healthy lifestyles for adults with intellectual disabilities. *J Appl Res Intell Disabil.* **22***,* 298-306.	Cross sectional survey	Level 2-	63 carers selected – 61 completed study.	Questionnaires completed on carers' knowledge of healthy diet, recommendations for physical activity and barriers to physical activity within the client group they work with.	It was found that carers generally had a low level of knowledge on recommendations for a healthy diet and physical activity, with greater importance being put on the health benefits of a healthy diet than physical activity. Study served to highlight the need for training of carers in the field of healthy diet and recommendations for physical activity and suggests that this should be incorporated into the induction course at beginning of employment.

Key Question 7 : What are the outcomes (lifestyle changes, altered BMI) when obese adults with LD are treated by LD dietitians compared to generalist dietitians or dietitians who have specialised in obesity?

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question 7.
Chapman, M.J., Craven, M.J. & Chadwick, D.D. (2005) Fighting fit?: An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. *J Intell Disabil*. **9**, 131-144.	Pre-/post-intervention study with a comparison group.	Level 2-	Adult learning disability. 50 in non-input group 38 in input group	The input group received advice from a Healthy Living Coordinator on ways of improving their diet & lifestyle. The non-input group received no advice.	Input group showed significant weight loos over 12 month period whereas non-input group gained a little weight. No matching for groups. Many different factors looked at and not clear which was most beneficial. The paper does not compare outcome of treatment between health & non-health professionals & does

					not mention dietitians.
Wallace, R.A. & Schluter, P. (2008) Audit of cardiovascular disease risk factors among supported adults with intellectual disability attending an ageing clinic. *J Intell Dev Disabil.* **33**, 48-58.	Retrospective analysis of medical charts :2002 -2005.	Level 2-	155 adults with LD, over age of 40, charts reviewed. 8 had diagnosed CVD.	Incidence of hypertension, elevated glucose, elevated cholesterol, overweight/obesity, smoking & physical inactivity checked.	Recommendations made – intervention programmes should concentrate on physical activity & lowering body weight. Link between CVD risk factors & LD syndromes not proven.

Key Question 8 : In obese adults with LD, where other interventions have failed, what is the evidence of effectiveness of Orlistat and Sibutramine?

No evidence was found to answer this question.

Key Question 9 : In obese adults with LD what is the effectiveness of bariatric surgery?

No evidence was found to answer this question.

Key Question 10 : What are the health benefits of weight loss in adults with LD?

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question 10.
Draheim, C.C., Williams, D.P. & McCubb (2002) Physical activity, dietary intake and insulin resistance syndrome in non-diabetic adults with mental retardation. *Am J Ment Retard.**105**, 361-375.*	Cohort Study	Level 2+	145 participants with mild to moderate LD.	Screened for hyperinsulinaemia, hypertriglyceridaemia, LDL cholesterol, hypertension & abdominal obesity. Also questionnaire looking at dietary habits & physical activity.	Positive correlation between overweight & abdominal obesity and incidence of hyperinsulinaemia and other risk factors. First study of its kind & gives grounds for further research into health behaviours, insulin resistance and CVD.
Marshall, D., McConkey, R. & Moore, G. (2003) Obesity in people with	Observational study.	Level 2-	Study 1 : sample – 464 aged 10+ -	Study 1 : Health screening – 200 were referred on to their GP	Weight loss was greater among those attending the group sessions compared

intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. *J Adv Nurs.* **41***,* 147-153.			individuals with LD attending special schools & day centres. Study 2 : sample 25 – adults in day centres.	with various problems. Study 2 : individuals were involved in group sessions where support & advice was given on healthy diet & lifestyle.	with those seen by their GP or given advice by nurse at the screening clinic. Study highlighted need for carers & people with a LD to be actively involved in deciding on a healthy diet & becoming involved in suitable exercise regimes.

Key Question 11 : In adults with LD who have achieved weight loss, which are the most effective support interventions in promoting weight maintenance?

No evidence was found to answer this question.

Key Question 12 : How is obesity measured in adults with LD? (Consider height, weight, BMI, waist circumference.)

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question 12.
Bhaumik, S., Watson, L.M., Thorpe, C.F., Tyrer, F. & McGrother, C.W. (2008) Body mass index in adults with intellectual disability: distribution, association and service implications: a population based study. *J Intell Disabil Res*. **53**, 287-298.	Population based prevalence study.	Level 2+	Adults with learning disability. 661 (59%) males & 458 (41%) females. 59% lived in residential care had 20% had Down Syndrome.	Health checks carried out on subjects to determine incidence of overweight/obesity.	28% were overweight & 20.7% obese. Obesity almost twice as prevalent in women (29%) as in men (15%). Associated with living independently/with family, ability to feed/drink unaided, being female, hypertension, Down Syndrome, mild learning disability & the absence of cerebral palsy. Higher than figures for general population.
Chapman, M.J., Craven, M.J. & Chadwick, D.D. (2005) Fighting fit?: An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. *J Intell Disabil*. **9**, 131-144.	Pre-/post-intervention study with a comparison group.	Level 2-	Adult learning disability. 50 in non-input group 38 in input group	The input group received advice from a Healthy Living Coordinator on ways of improving their diet & lifestyle. The non-input group received no advice.	Input group showed significant weight loos over 12 month period whereas non-input group gained a little weight. No matching for groups. Many different factors looked at and not clear which was most beneficial.

Levy, J.M.; Botuck, S. & Rimmerman, A. (2007) Examining outpatient health care utilization among adults with severe or profound intellectual disabilities living in an urban setting : A brief snap shot. J Soc Work Disabil Rehab. ***6****, 33-45.*	Bivariate regression analysis.	Level 2-	52 adults with intellectual disabilities who live in New York City, who exclusively utilized a community based medical practice.	Age, gender, race, living situation, level of ID, autism, cerebral palsy, sensory impairment & self injurious behaviour were obtained form individuals' most recent Developmental Disabilities Profile.	70% of the individuals were overweight/obese with a marginally higher incidence in those who lived with their family as opposed to group homes. Less medical complications were found in the group with Down's Syndrome. Those living at home utilized less medical appointments than those living in group homes. The authors acknowledge need to decrease obesity among adults with ID in order to maintain general health & more education should be offered to families & carers.
Marshall, D., McConkey, R. & Moore, G. (2003) Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. *J Adv Nurs.***41***,* 147-153.	Observational study.	Level 2-	Study 1 : sample – 464 aged 10+ - individuals with LD attending special schools & day centres. Study 2 : sample 25 – adults in day centres.	Study 1 : Health screening – 200 were referred on to their GP with various problems. Study 2 : individuals were involved in group sessions where support & advice was given on healthy diet & lifestyle.	Weight loss was greater among those attending the group sessions compared with those seen by their GP or given advice by nurse at the screening clinic. Study highlighted need for carers & people with a LD to be actively involved in deciding on a healthy diet & becoming involved in suitable exercise regimes.
Melville, C. A., Cooper, S. & Morrison, J. (2008) The prevalence & determinants of obesity in adults with intellectual disability. *JARID.* **21***,* 425-437.	Cross sectional study.	Level 2+	Adults with learning disabilities in a defined area of Glasgow.	Data collected & compared with results from the Scottish Health Survey (general population) 2003.	Women with LD more likely to be obese than men. People with mild LD more likely to be obese than those with profound LD. Men & women with Down Syndrome (DS) are significantly more likely to be overweight / obese than those with LD but no DS. Women living independently in a deprived area have increased likelihood of obesity but this is not the case for men. Incidence of overweight in LD population greater at an earlier age than for general population.

Moore, K., McGillivray, Illingworth, & Brookhouse, (2004) An investigation into the incidence of obesity and underweight among adults with an intellectual disability in an Australian sample. *J Dev Disabil.* **29**,306-318.	Cross sectional study	Level 2-	41 females & 52 males with mild to severe learning disability – relatively small sample.	BMI assessed & results compared to general population figures.	41.4% of females were overweight and 36.6% obese (compared to 28.8% and 18.2% respectively from the general population). 30.8% of males were overweight & a further 30.8% obese (compared to 45.2% & 18.5% respectively for the general population). No significant difference between males & females. Levels of overweight/obesity varied across living conditions with the highest prevalence being in those living in carer assisted accommodation.

Key Question 13 : What screening tools are available for adults with LD to prevent weight gain/promote weight loss?

No evidence was found to answer this question.

Key Question 14: What is the prevalence of Binge Eating Disorder (BED) in obese adults with LD? Are standard obesity interventions adequate for those who have BED, or do they require additional/alternative support?

Reference	**Study Type**	**Evidence Level**	**Population and number**	**Intervention**	**Comments relating to key question 14.**
Hove, O. (2004) Prevalence of eating disorders in adults with mental retardation living in the community. *Am J Ment Retard.* **109***,* 501-506.	Non-experimental cross sectional survey.	Level 2-	311 adults with mental retardation in receipt of local services in an area of Norway.	Questionnaire retrospective over 3 months.	Eating disorders more prevalent in adults with mental retardation than general population. BED is the most common. The diagnostic criteria used was the DC-LD developed by the Royal College of Psychiatrists which has 7 classifications of eating disorders & separates BED from other eating disorders.

Key Question 15 : What are the outcomes (lifestyle changes, altered BMI) when the dietary treatment of obese adults with LD is carried out in individual consultations compared to group sessions with other obese adults with LD, compared to group sessions with other obese adults?

Reference	**Study Type**	**Evidence Level**	**Population and number**	**Intervention**	**Comments relating to key question 15.**
Chapman, M.J., Craven, M.J. & Chadwick, D.D. (2005) Fighting fit?: An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. *J Intell Disabil*. **9**, 131-144.	Pre-/post-intervention study with a comparison group.	Level 2-	Adult learning disability. 50 in non-input group 38 in input group	The input group received advice from a Healthy Living Coordinator on ways of improving their diet & lifestyle. The non-input group received no advice.	Input group showed significant weight loos over 12 month period whereas non-input group gained a little weight. No matching for groups. Many different factors looked at and not clear which was most beneficial.
Marshall, D., McConkey, R. & Moore, G. (2003) Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. *J Adv Nurs.* **41***,* 147-153.	Observational study.	Level 2-	Study 1 : sample – 464 aged 10+ - individuals with LD attending special schools & day centres. Study 2 : sample 25 – adults in day centres.	Study 1 : Health screening – 200 were referred on to their GP with various problems. Study 2 : individuals were involved in group sessions where support & advice was given on healthy diet & lifestyle.	Weight loss was greater among those attending the group sessions compared with those seen by their GP or given advice by nurse at the screening clinic. Study highlighted need for carers & people with a LD to be actively involved in deciding on a healthy diet & becoming involved in suitable exercise regimes.
Melville, C. A., Cooper, S. & Morrison, J. (2008) The prevalence & determinants of obesity in adults with intellectual disability. *JARID.* **21***,* 425-437.	Cross sectional study.	Level 2+	Adults with learning disabilities in a defined area of Glasgow.	Data collected & compared with results from the Scottish Health Survey (general population) 2003.	Women with LD more likely to be obese than men. People with mild LD more likely to be obese than those with profound LD. Men & women with Down Syndrome (DS) are significantly more likely to be overweight / obese than those with LD but no DS. Women living independently in a deprived area have increased likelihood of obesity but this is not the case for men. Incidence of overweight in LD population greater at an earlier age than for general population.

Key Question 16 : What are the considerations for achieving weight loss/maintenance in obese adults with LD who are enterally fed or receive nutritionally complete supplements?

No evidence was found to answer this question.

Table 6. Hierarchy and Quality Rating of evidence

Levels of Evidence	Description
1	Meta-analysis, systematic reviews, randomized controlled trials(RCTs)
2	Systematic reviews of case control or cohort studies
3	Non analytical studies e.g. case reports, case series
4	Expert opinion
++	Most/all methodical criteria met, low risk of bias
+	Some criteria met, high risk of bias
-	Few or no criteria met, high risk of bias

Source: (Harbour and Miller, 2001)

Appendix 3

List of rejected papers

Booth, D.A., Blair, A.J., Lewis, V.J. & Baek, S.H. (2004) Patterns of eating and movement that best maintain reduction in overweight. *Appetite. **43***, 277-283*.*

Bulik, C.M., Brownley, K.A., & Shapiro, J.R. (2007) Diagnosis and management of binge eating disorder. *World Psychiatry.* 6, 142-148.

Burke, L.E. (2006) PREFER Study: a RCT testing treatment preference and 2 dietary options in behavioural weight management – rational, design and baseline characteristics. *Contemp Clin Trials.* **27***,* 34-38.

Dale, K.S., McAuley, K.A., Taylor, R.W., Williams, S.M., Farmer, V.L, Hansen, P., Vorgers, S.M., Chisholm,W. & Mann, J.I. (2009) Determining optional approaches for weight maintenance: a randomised control trial. *CMAJ.* **180***,* E39-46.

Donnelly, J.E., Blair, S.N., Jakicic, J.M., Manore, M.M., Rankin, J.W. & Smith, B.K. (2009) Appropriate physical activity intervention strategies for weight loss and prevention of weight regain for adults. Med Sci Sports Exerc*.* **41***,* 459-471.

Gorin, A.A., Phelan, S., Wing, R.R., & Hill, J.O. (2004) Promoting long-term weight control: does dieting consistency matter? Int J Obes (Lond*).* **28***,* 278-281*.*

Halford, J.C.G. and Harrold, J.A. (2008) Neuropharmacology of human appetite expression. Ment Retard Dev D R*.* **14***,* 158-164.

Hawley, G., Horwath, C., Gray, A., Bradshaw, A., Katzer, L., Joyce, J. & O'Brien, S. (2008) Sustaining of health and lifestyle improvements following non-dietary randomised trial in overweight women. *Prev Med.* **47***,* 593-599.

Houston,D.K., Ding,J., Nicklas,B.J. Harris, T.B., Lee, J.S., Nevitt, M.C., Rubin, S.M., Tylavsky, F.A. & Kritchevsky, S.B. (2009) Overweight and obesity over the adult life course and incident mobility limitation in older adults; the health, aging and body composition study. *Am.J. Epidemiol.* **169***,* 927-936.

Kannabiran,M. and Sing,V. (2008) Metabolic syndrome and atypical antipsychotics: a selective literature review. *German J Psychiatry.* **11***,* 111-122.

Mann, T., Tomiyama, A.J., Westling, E., Lew, A.M., Samuels, B. & Chatman, J. (2007) Medicare's search for effective obesity treatment: diets are not the answer. *Am. Psychol.* **62***,* 220-233.

Marchesini, G., Marzocchi, R. & Grave, R.D. (2006) Outcome research in obesity: lessons from QUOVADIS study. *Drug Develop Res.* **67***,* 260-270.

Mark, A.L. (2006) Dietary therapy for obesity is a failure and pharmacotherapy is the future: a point of view. *Clin Exp Pharmacol P.* **33***,* 857-862*.*

McLean, N. Griffin,S., Toney, K. and Hardeman, W. (2003) Family involvement in weight control, weight maintenance and weight loss interventions: A systematic review of RCTs. *Int J Obes (Lond).* **27***,* 987-1005.

Noel, P.H. and Pugh, J.A. (2002) Management of overweight and obese adults. *BMJ,* **325**, 757-761.

Oathamshaw, S.C. (2007) Delivering cognitive behavioural therapy in community services for people with LD : difficulties, dilemmas, confounds. *Advances in MH & LD. **1**,* 22-25.

Poynor, L. (2008) Steps to fitness: a health and well-being pilot project. *Learn Disabil Pract.* **11***,* 10-15.

Rimmer,J.H., Riley,B.B. & Rubin,S.S., (2001) A new measure for assessing the physical activity behaviours of persons with disabilities and chronic health conditions: the physical activity and disability survey. *Am J Health Promot.* **16**, 34-45.

Schattner, M.A. (2005) Long term enteral nutrition facilitates optimisation of body weight. *JAPEN* **29***,* 198-203.

Van Dorsten, B. & Lindley, E.M. (2008) Cognitive and behavioural approaches in treatment of obesity. Endocrinol Metab Clin N Am*.* **37***,* 905-922.

Vogels, N., Diepvens, K. & Westerterp-Plantenga, M.S. (2008) Predictors of long term weight maintenance. *Obes Res.* **13***,* 2162-2168.

Waleekhachonloet, O-A., Limwattananon, C., Limwattananon, S & Gross, C.R. (2007) Group behaviour therapy versus individual behaviour therapy for weight control management in overweight & obese women living in a rural community. *Obes Res Clin Pract. **1**, 223-232.*

Appendix 4

Core Members of a Specialist CLDT

- Clinical Psychologist
- Community Nurse
- Consultant Psychiatrist
- Dietitian
- Occupational Therapist
- Physiotherapist
- Social worker/care manager
- Speech & Language Therapist - Communication
- Speech & Language Therapist - Dysphagia

SAMPLE GROUP LESSON PLAN

Appendix 5

GROUP: **HEALTHY EATING IS FUN GROUP. SESSION 2 OF 5** LOCATION: DATE:

AIM: Increase awareness of dental hygiene and healthy foods **SUGAR AND TEETH**

OBJECTIVE(s): PARTICIPANT'S TO DISCUSS ORAL HYGIENE
TO EXPLORE SUGAR IN THE DIET AND IN RELATION TO THE 3 FOOD MODEL
TO PARTICIPATE IN DISCUSSIONS AND EXERCISES

TIME	TOPIC / PLAN OF SESSION	METHOD	RESOURCES	ASSESSMENT/EVIDENCE
2.OO - 2.05	WELCOME BACK, Introduction to session	TUTOR LEAD		FEEDBACK
2.05– 2.20	DISCUSS TEA DIARIES	GROUP DISCUSSION	FLIP CART & PENS (fit foods into 3 food model drawn on chart)	PARTICIPATION/ FEEDBACK
2.20 – 2.30	WHY WE NEED TO EAT RIGHT (RECAP from last week)	GROUP DISCUSSION	FLIP CHART & PENS	PARTICIPATION Q & As
2.30 – 2.50	LOOKING AFTER YOUR TEETH	DEMONSTRATION	TEETH MODEL & BRUSH; samples	PARTICIPATION Q & As
2.50 – 2.55	BREAK			
2.55 – 3.15	SUGAR IN THE DIET	SUGAR GAME	HEALTHY DAY'S FOOD & DRINK CHART v HIGH SUGAR VERSION.. Jam Jars x 2; bags of sugar/cubes; teaspoons X 2.	PARTICIPATION / ANSWERS
3.15 – 3. 20	3 FOOD MODEL (time filler if required)	ODD ONE OUT	ODD ONE OUT SHEET	PARTICIPATION Q s& As
3.20 – 3.25	HOMEWORK – BREAKFAST DIARIES	INDIVIDUAL	BREAKFAST DIARIES	
3.25 – 3.30	EVALUATION. HAND OUT CERTIFICATES. FINISH	SCORE CARDS	SCORE CARDS;CERTIFICATES	SCORE CARDS

SAMPLE INFORMATION SHEET IN ACCESSIBLE FORMAT

Appendix 6

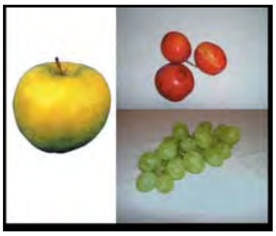
Healthy
Eating

Healthy Meal Plan

What can I have for breakfast?

Unsweetened fruit juice

or



Fresh fruit

or

Tinned fruit in natural juice

What can I have for breakfast?

Cereal

or

Porridge

with

Low fat milk

What can I have for breakfast?

Bread and low fat spread

or

Toast with low fat spread

with

a little jam or marmalade

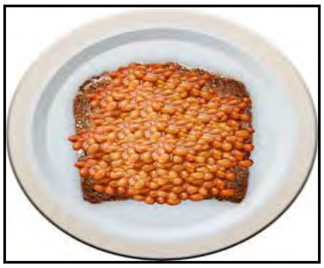
What can I have for a light meal?

Soup with bread

or

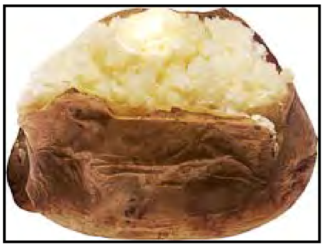
Sandwich

or



Beans on toast

What can I have for a light meal?



Jacket potato

or

Bagel with low fat cheese

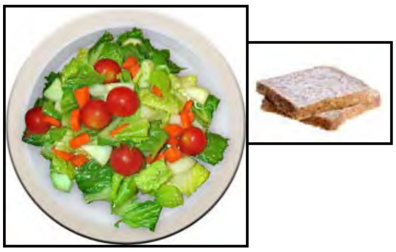
or

Toasted sandwich

And there’s more . . .

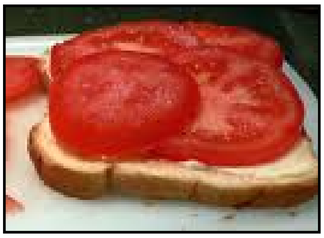
Scrambled eggs on toast

or



Salad with warm bread

or



Tomatoes on toast

What can I have for a main meal?

Spaghetti bolognaise

or

Lean meat with lots of vegetables

or

Shepherds Pie

What can I have for a main meal?

Stir fry with noodles

or

Lasagne

or

Fish pie

Remember to have lots of vegetables

What can I have for a pudding?

Low fat low sugar yogurt

or

Fresh Fruit

or

Sugar free mousse

What can I have for a pudding?

Fresh fruit salad

with

Sugar free jelly

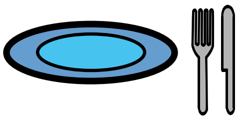
or

Unsweetened milk pudding

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board

Directorate of Learning Disability Services
Cyfarwyddiaeth Gwasanaethau Anabledd Dysgu

Developed by:



The Department of Nutrition & Dietetics

Produced in partnership with:
The National Public Health Service

National Public Health Service for Wales
Gwasanaeth Iechyd Cyhoeddus Cenedlaethol Cymru

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BDA The Association of UK Dietitians

Mental Health
Specialist Group

Information Sheet

Weight Management

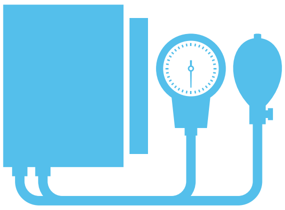
Accessible information about weight management for adults with learning disabilities

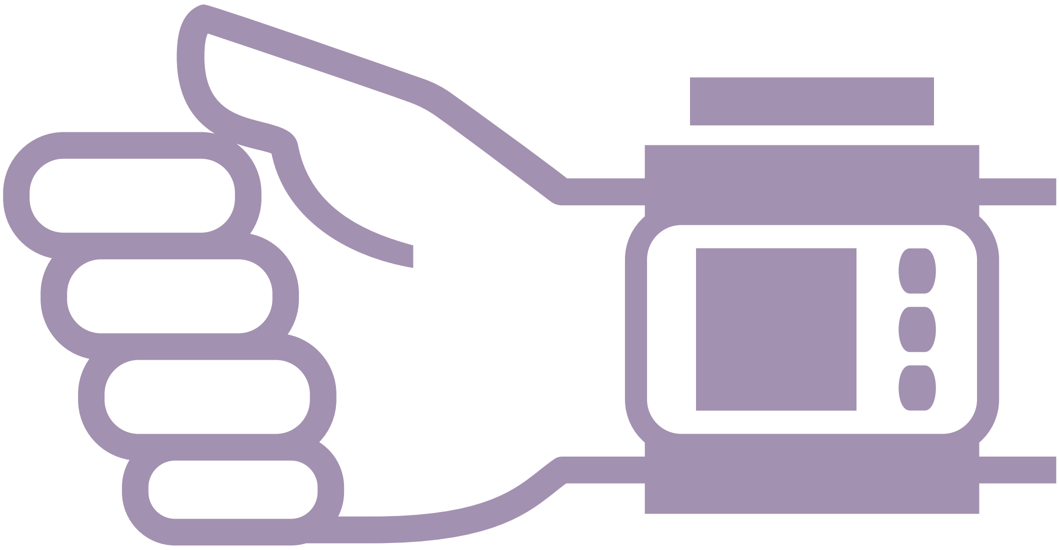
Being overweight or obese can make you:

- ✓ Breathless or tired
- ✓ Unhappy about the way you look

Being overweight/obese can lead to:

- ✓ Heart disease
- ✓ High blood pressure
- ✓ Diabetes
- ✓ Some cancers





Tips for limiting weight gain

Eat regular meals, avoid missing meals as this can lead to overeating later in the day

Make sure you include plenty of vegetables with your meals to help fill you up

Reduce your intake of treats such as chocolate, cakes, sweets, crisps and chips. Set a limit each day/ week which is less than you are having now

If you get hungry between meals, try to choose a piece of fruit or a low calorie yogurt as a snack

You need 3 meals per day, not 4 so try to keep supper as a small snack

Try to reduce the amount of takeaways you have and try to choose the healthier options when you do have a takeaway

Drink plenty of water/ tea or coffee (not sweetened with sugar)/ no added sugar/ diet or zero drinks

Only have a small glass of fruit juice once per day

Get active, move every day

Tell people what you are trying to do so they can help and encourage you. Get friends and family to make similar changes.

Tell people what you are trying to do so they can help and encourage you. Get friends and family to make similar changes.

First published: June 2017
Review Date: June 2020

Resources:
National Obesity Forum 2005. Obesity care pathway toolkit.
BDA food fact sheet. Weight Loss 2016
NICE 2014 Obesity: identification, assessment and management (CG189)

www.dietitiansmentalhealthgroup.org.uk

Document endorsed by

BDA The Association of UK Dietitians

The Nutritional Care of Adults with a Learning Disability in Care Settings

Table of Contents

Executive Summary

The importance of nutritional care for People with Learning Disabilities (PWLD) should not be underestimated. As a group, they are more at risk from obesity, problems with eating, drinking and swallowing and certain types of cancer, but at the same time, can be some of the most vulnerable members of society. They are often dependent on others to choose which foods they eat, when they eat and how much they eat. Understanding the impact of diet on health and wellbeing is paramount for those caring for or supporting PWLD.

The Professional Consensus Statement set out standards of nutritional care which care providers are expected to achieve. They give clear, concise criteria for staff to follow to be able to meet these standards and some tools to help them achieve this e.g. a weight monitoring chart and guidance on how to complete.

Training and education for carers will be paramount in attempting to achieve these standards. Senior staff should attend relevant courses, such as the REHIS Elementary Food and Health Course for Carers of Adults with a Learning Disability and have nutrition, hydration and healthy eating high on their agenda of training topics.

The Professional Consensus statement is a step towards addressing some of the health inequalities which our client group experience.

Introduction

People with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population. However life expectancy is increasing, in particular for people with Down's syndrome 2016.[3]

In 2015 there were 4.3 adults (16- 64) with a learning disability per 1000 of the general population in England known to local authorities.[1] The figure in Scotland was higher at 6.1 adults with learning disability per 1,000 adults.[2]

The median age of death for people with learning disabilities is 65 years for men and 63 years for women. Thus men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population.[4]

Difficulties with eating, drinking and swallowing have implications for health, safety and wellbeing. Among adults with learning disabilities, 40% of people with dysphagia experience recurrent respiratory tract infections. Other negative health consequences of dysphagia include asphyxia, dehydration, poor nutritional status and urinary tract infections.[4]

The most frequent cause of death in people with learning disabilities is respiratory infection often linked with difficulties with eating, drinking and swallowing.

Underweight, overweight and obesity are more prevalent than the general population.[5]

	General population (percentage)		LD population (percentage)	
Underweight	2		17	
Overweight	30 men	25 women	41 men	31 women
Obese	24 men	27 women	31 men	45 women

“With the move towards health and social care integration, services will be jointly responsible for the health and care needs of patients, to ensure that those who use services get the right care and support whatever their needs, at any point in their care journey” (Scottish Government) 2014)[6]

The National Health and Social Care standards aim to ensure that people who receive care and support get the high quality service they are entitled to. Recommendations are included about eating and drinking (National Health and Social Care Standards 2017)[7]

It is recognised that less than 10% of adults with learning disabilities in supported accommodation eat a balanced diet, with an insufficient intake of fruit and vegetables. Carers generally have poor nutritional knowledge about public health recommendations on dietary intake.[3]

There is a need to support carers in the provision of good nutritional care. This is an update of the original professional consensus statement produced in 2008 and updated in 2012. This document has been based on the framework of the HIS Food Fluid and Nutritional Care Standards Oct 2014.[8]

Aim: To review and update the 2012 Professional Consensus Statement, The Nutritional Care of Adults with a Learning Disability in Care Settings.

Objective: To review current publications in relation to learning disabilities and nutritional care. We have undertaken a systematic review of published work to develop clear and concise best practice guidelines in this field.

There are 6 standards:

Standard 1 - Consensus Statement
Standard 2 - Assessment, screening and care planning
Standard 3 - Menu design, food preparation and presentation
Standard 4 - Facilities available for eating and drinking
Standard 5 - Communication and empowerment
Standard 6 - Education and training

In developing these standards consultation has been sought from the Scottish Dietetic Learning Disability Dietetic Clinical Network, Mental Health Specialist Group of the British Dietetic Association and learning disability care providers.

Standard 1 - Consensus Statement

Standard Statement

Each organisation will implement the ‘Professional Consensus Statement. The Nutritional Care of Adults with Learning Disability in Care Settings’ to ensure that all clients receive safe, effective and person-centered nutritional care.

Rationale

- People with learning disabilities have greater health needs compared to the general population.[3,4,5,9]

- Malnutrition is an important public health problem. People with learning disabilities have a high risk of being nutritionally compromised. Whether this is due to obesity, underweight or eating and drinking difficulties.[5]

Criteria

- Each care provider has an implementation plan to improve the provision of food, fluid and nutritional care.[8]

Standard 2 – Assessment, Screening and Care Planning

Standard Statement

It is recommended that the nutritional status of every client be assessed by the care provider both on moving to a new care home and on an ongoing basis.

Rationale

Malnutrition is an important public health problem. People with learning disabilities have a high risk of being nutritionally compromised.[5]

Clients' energy intake below their nutritional needs may put them at risk of under nutrition.[4,9,10]

Clients' energy intake above their nutritional needs will put them at risk of obesity and associated health risks.[12]

The screening and assessment process help to identify under nutrition and factors that may prevent clients from eating and drinking adequately.[9,10,11]

Criteria

2.1 The nutritional care assessment should accurately identify and record:

- (a) Measured height and weight, with the date and time that these measurements were taken (if estimates are used, this should be stated and a rationale provided)
- (b) Food allergies or intolerances
- (c) Eating and drinking likes and dislikes
- (d) Therapeutic or texture-modified diets requirements
- (e) Cultural, ethnic or religious dietary requirements
- (f) Social and environmental mealtime requirements
- (g) Physical difficulties with eating and drinking, including swallowing difficulties
- (h) The need for help and support with eating and drinking, for example prompting and encouragement, equipment or community meals, and
- (i) Oral health status [22]

2.2 The nutritional care assessment includes accurate screening for the risk of malnutrition using a validated tool that is appropriate for the patient population and includes criteria and scores that indicate actions to be taken, such as the Malnutrition Universal Screening Tool (MUST) for adults.[10]

2.3 Routine nutritional screening should take place at 6 monthly intervals.

2.4 Weigh on accurate and appropriate scales.

2.5 Weigh monthly and record on annual weight monitoring chart (Appendix 1 and 2).

2.6 Information about the client's eating, drinking and nutritional care requirements is effectively communicated and accurately documented.

2.7 Should nutritional screening or assessment highlight concerns - follow local management guidance.

2.8 The assessment process identifies the need for referral to specialist services, for example dental and oral health, dietetic, occupational therapy, physiotherapy and speech and language therapy.[4,9]

Standard 3 - Menu Design, Food Preparation and Presentation

Standard Statement

Meals should be varied and nutritious, reflecting special dietary requirements and texture modification, food preferences, seasonal variation, cultural, religious considerations and any special dietary needs. They should be prepared safely and attractively presented.[7, 12]

Rationale

Client's food and fluid intake, eating and drinking pattern, specific likes and dislikes are recognised and accounted for.

Provision of suitable, nutritious food will ensure that client's nutritional requirements are met, and will help minimise food and fluid waste.

Food that is freshly prepared from raw ingredients and presented attractively is more likely to be eaten, thus optimising nutrition.

Criteria

3.1 All care staff have a responsibility to ensure optimal nutritional care for their clients.

3.2 A system is in place to ensure menus are routinely planned with client participation where possible.

3.3 Menus are based on the Eat Well Guide unless advised otherwise by a medical professional.[14]

3.4 Menus need to reflect any therapeutic dietary requirements e.g. texture modified diets, weight management diets along with clients likes and dislikes.[13,15]

Standard 4 - Facilities Available for Eating and Drinking

Standard statement

The eating environment in which the client eats must be conducive to the client's needs. Clients should never feel rushed or uncomfortable whilst eating or drinking.[7,12]

Rationale

The environment in which the clients eat is as important as the food provided, as it can have a major impact on nutritional intake.

Criteria

4.1 Assistance should be available for eating and drinking if required.

4.2 Dining areas should be available with appropriate furniture.

4.3 Dining areas must be as homely as possible to provide a relaxed environment also encouraging the social aspects of eating and drinking.

4.4 Clients are provided with the equipment and utensils for eating and drinking that meet their individual needs.

4.5 Try to ensure a quiet environment free from distractions.

Standard 5 - Communication and Empowerment

Standard Statement

Staff should communicate regularly with clients about nutritional care, food and fluid provision, using pictorial information where necessary, in order to support informed choice.[13]

Rationale

Clients have the right to the information and support they need to make informed choices.

Good communication between staff and clients around food fluid and nutritional care will result in clients nutritional needs been met.

Criteria

5.1 Information and communication about food, fluid and nutritional care are delivered in a format suitable to the client's identified communication needs.

5.2 Menu plans are based on the Eatwell Guide. [14] They are designed taking into account, not only therapeutic requirements, but also informed food choices, ethnic, cultural, religious or other preferences clients may have.

Standard 6 – Education and Training

Standard Statement

Staff have the knowledge and skills required to meet client's food, fluid and nutritional care needs.[7,13]

Rationale

Staff require information and training to ensure that the nutritional needs of clients are met.

It is important that all staff involved in the provision of food, fluid and nutritional care recognise the critical nature of this task, and receive training in nutritional care.[16]

Criteria

6.1 All staff should have a working knowledge of the principals of healthy eating e.g. Eatwell Guide

6.2 All senior staff should be trained in the specific nutritional needs of adults with learning disabilities e.g. REHIS Elementary Food and Health Course for Carers of Adults with a Learning Disability.[16]

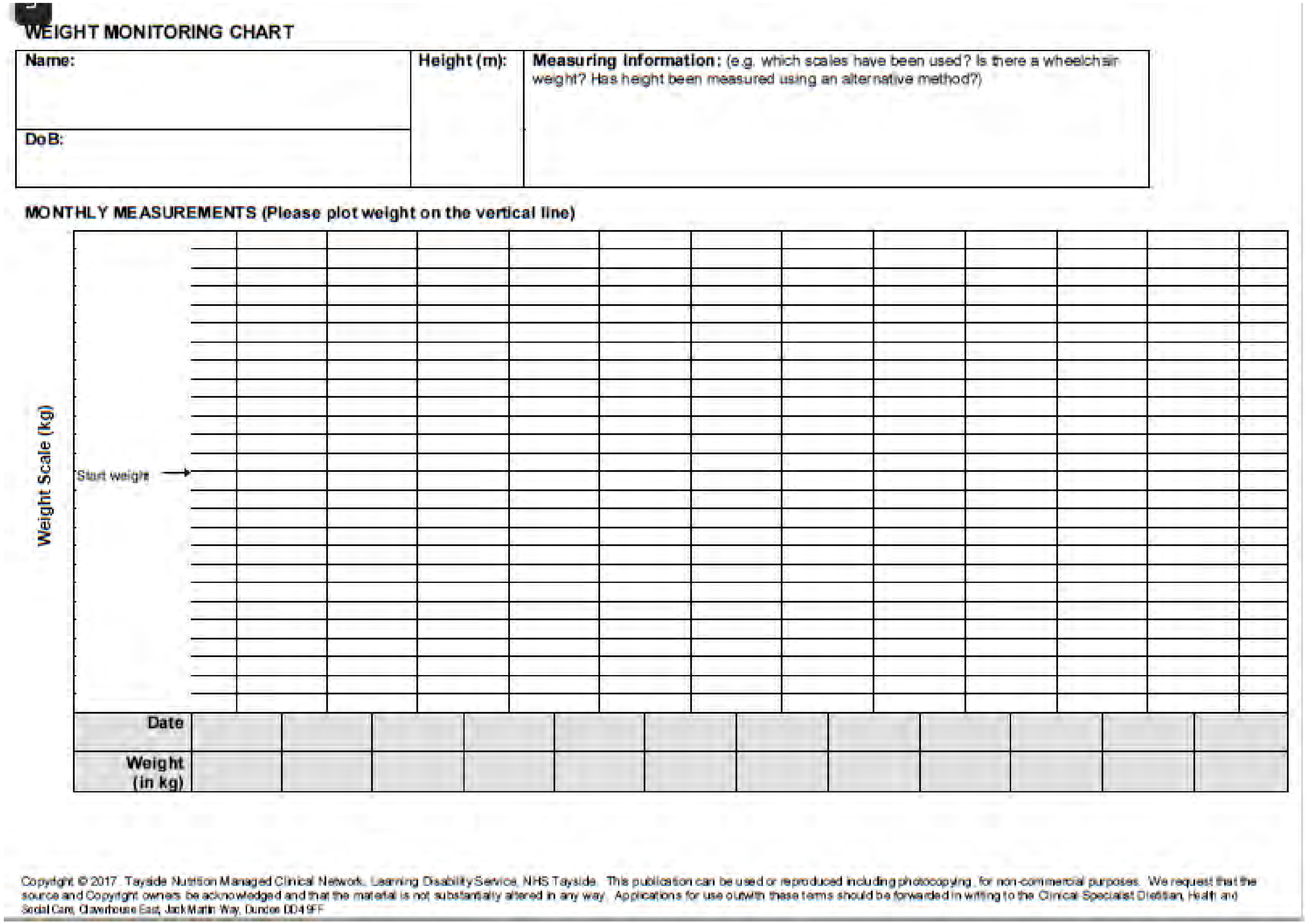
6.3 Staff should use evidence based resources when educating their clients about healthy eating e.g. Healthy Eating Healthy Living Resource, pictorial cookbooks – My Own Cookbook, Cook Your Own Takeaway, Cyrenians Good Food [18.19,20,21]

6.4 A programme of nutritional care education is regularly reviewed and updated by a senior member of staff to include

(a) The correct use of nutritional screening tools and related measurements.
(b) Risk factors for dehydration, over nutrition and under nutrition.
(c) Recognising physical difficulties with eating drinking and swallowing.
(d) Providing assistance with eating drinking and swallowing difficulties.

Appendix 1

Weight Monitoring Chart



WEIGHT MONITORING CHART

Name:

DoB:

Height (m):

Measuring Information: (e.g. which scales have been used? Is there a wheelchair weight? Has height been measured using an alternative method?)

MONTHLY MEASUREMENTS (Please plot weight on the vertical line)

Date												
Weight (in kg)												

Appendix 2

Guidelines for Using Weight Monitoring.

The weight monitoring chart has been developed to allow care staff to monitors the client's weight on a monthly basis.

To complete the chart:

1. Details the client's name and date of birth
2. Details of height in metres
3. Details of measuring information: (e.g. which scales have been used? Is there a wheelchair weight? Has height been measured using an alternative method?)
4. Record date of weight and actual weight in kg on a monthly basis
5. Complete left hand side of graph by filling in appropriate scale for weight in kg
6. Each month fill in date and mark weight with a cross on the graph, join up subsequent recordings with a line to give a pictorial representation

Appendix 3

Authors Curriculum Vitae

Janie Faulkner

Qualified in 1979 with a Post Graduate Diploma in Dietetics from Queens College Glasgow and subsequently registered with the Health and Care Professions Council. Have worked in Learning Disabilities since 1992 and involved in the production of resources and training materials for this group. MSc Certificate achieved 2011. Currently Team Lead for Learning Disability Nutrition and Dietetic service within NHS Forth Valley.

Email: [redacted]

Kirsty Hamilton

Qualified in 1983 with a BSc Nutrition and Dietetics at Queen Margaret College in Edinburgh and subsequently registered with the Health and Care Professional Council. Has been working in the field of Adults with Learning Disabilities since 1993 and involved in establishing a specialist community service across Tayside. Currently Team Lead for Learning Disability Nutrition and Dietetic service within NHS Tayside.

Email: [redacted]

Elspeth Ryan

Qualified in 1995 with a BSC Nutrition and Dietetics at Caledonian University Glasgow. subsequently registered with the Health and Care Professional Council. Has been working in the field of Adults with a learning Disability since 2000. In addition acted as NHS Fife Nutrition champion and was actively involved in the implementation of the Food Fluid and Nutritional Care Standards across NHS Fife.

Email; [redacted]

We are all active members of the Scottish Dietetic Learning Disability Dietetic Clinical Network, which to date have completed the following pieces of work:

- NDR Pictorial Diet Sheets- on ‘Are You Constipated?’, Do you want to stay fat? Healthy eating and gentle exercise.

- Group members have contributed to The Caroline Walker Trust ‘Eating Well: children and adults with learning disabilities.

- The group has been involved in the development and delivery of 2 resources:
  (a) REHIS Elementary Food and Health Course for Cares of Adults with a Learning Disability.[16]
  (b) Healthy Eating Healthy Living Pack.[17]

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Adapted from Healthcare Improvement Scotland
Food Fluid and Nutritional Care Standards - October 2014

Produced By: Dietitians working with adults with a Learning Disability and members of the Scottish Learning Disability Dietetic Clinical network supported by the British Dietetic Association Mental Health Group.

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bda.uk.com

Useful Information for Dietitians managing PWS patients

The purpose of this document is to signpost dietitians who are managing patients with PWS to reliable and useful information that will aid successful management.

For more dietetic advice please contact the PWSA UK who can pass on your question to members of the PWS Dietitian Network. If you would like to join the Network, which shares information and advice about PWS, contact [redacted]

Phases

Historically two distinct phases are characteristic of this syndrome. At birth, infants present with hypotonia and feeding difficulties and subsequently fail to thrive. More recently a large US study, Nutritional Phases in Prader–Willi Syndrome published in 2011 has proposed a more gradual and complex range of phases. In total seven different nutritional phases are described (five main and 2 sub-phases) each with distinct characteristics. It can be useful to identify the stage of the patient to help prepare families with information relevant to the next phase. A recent paper (2011) published in Paediatrics, Health Supervision for Children With Prader-Willi Syndrome lays out more generic phases of PWS to be aware of and provides a good overview.

Growth assessment

The inherent growth pattern of PWS children varies from healthy children. PWS growth is generally associated with early childhood obesity, absent pubertal growth spurt and adolescent short stature. Subsequently, plotting on WHO growth charts may make growth interpretation difficult. PWS specific charts therefore are recommended as an additional tool for evaluating growth, monitoring patterns, nutritional assessments, and recording responses to growth hormone therapy.

Over recent years several PWS specific growth charts have been proposed and produced from groups in Japan, Germany and the US. For non-growth hormone treated infants from birth to 36 months, growth charts from US data published in 2010 exist which can be useful. See Growth Standards of Infants With Prader-Willi Syndrome

In 2015 growth charts (including BMI charts) were produced from further US data for non-growth hormone treated children from 36month to 18 years. See Growth Charts for Non-Growth Hormone Treated Prader-Willi Syndrome

Use of body composition and skin fold can be useful for ongoing monitoring but no standards or reference data exists at this point specific to PWS.

Nutritional requirements

Due to low muscle tone and abnormal body composition, the child or adult with PWS requires a considerably lower energy intake than their non-PWS peers. Limited studies have evaluated the caloric requirements and calculating specific caloric requirements for PWS children is controversial. There is particular uncertainty on energy requirements for small children. A general recommendation of approximately 60% of the calories for age is a commonly used target in children.

Recommendations for caloric intake in adults with PWS for ensuring weight maintenance have evolved from 8.4–14.6 kcal/cm ht – See **Food and children with Prader-Willi syndrome** to 10.0–14.0 kcal/cm ht – See **A nutrition survey of and recommendations for individuals with Prader-Willi syndrome who live in group homes**

In clinical practice intakes of 14 kcal/cm may provide significantly over the needs of a PWS patient so working on the lower end of these recommendations (10 kcals/cm) would be the appropriate starting point.

For weight reduction, the recommended range is 6 -8kcal/cm ht.

Micronutrient requirements do not appear to be different than age matched non-PWS patients. Dietary analysis of intakes can be useful and should be part of dietetic assessment. Particular care to observe calcium, iron, zinc, Vitamin D and selenium intake is recommended as supported by several research papers in this area. See **Nutritional intakes in children with Prader - Willi syndrome and non-congenital obesity** and **Nutritient intake of young children with Prader Willi syndrome**

Dietary treatment

In the first year of life NG feeding is common, as sufficient intake maybe limited by symptoms such as hypotonia, and use of high calorie formula may be required. Care should be taken to carefully monitor intake and growth in the first year. Information on early nutrition can be found on the **Families – Dietary Management and Exercise pages** on this website (includes information on weaning, feeding and management for Birth to 2 years) and **Speech and language in PWS – Birth -2 years.**

As a result of lower caloric but similar micronutrient requirements, care must be taken in balancing the diet as the child grows. Careful dietetic attention is required in the provision of sufficient calories and nutrients for growth without an excess of calories leading to unwanted weight gain. Prevention of over- restriction particularly in the younger, more vulnerable, infant is of particular importance. Several approaches have been proposed including the simple low fat diet:

- The **Traffic light- Red yellow green** approach developed in Canada
- **Modified carbohydrate**
- **Food pyramid**
- **Food exchanges**
- And more recently an **altered macronutrient intake** has been reported as a long term strategy

No studies have compared all the different approaches to evaluate the most successful. Many agree the most important principle is finding a strategy that can be consistently followed and that consistency is the key to success.

In adulthood, the main dietary concern is obesity; many causes of premature death occur due to complications arising from massive obesity, therefore weight management is the main focus of dietary treatment.

The most effective results are seen when a strictly calorie controlled regimen is adhered to.

Care should be taken to ensure prevention of over restriction of fat (<20% of total caloric intake) which has been shown in several reviews to be associated with PWS diets and which leads to concerns of sufficient essential fatty acid intake in key periods of development.

Constipation can be common in those with PWS and the usual dietary treatments and prevention strategies can be applied and are outlined in the NICE guidelines 2010. Delayed stomach emptying also appears to be common.

Resources for families and care providers

Need to Know Nutrition - an excellent Australian produced booklet is available to download which covers many aspects of nutritional management in PWS. This is designed for families and it may be very useful to provide the link of this to parents as a reliable source of information.

The PWSA UK also has many useful publications that can be obtained via the Association including The PWS Journey articles and a specific book directed at families and care providers, Healthy Eating with Prader-Willi Syndrome

The PWSA Dietary Advisory group produced a Consensus Statement on the topic of Meeting Nutritional needs – Standards for Care Providers

Many useful DVD's have been produced. Of note Food, Behaviour and Beyond – Practical Management for the Child & Adult with PWS was produced by the Pittsburgh Partnership in partnership with PWSA USA www.pwsausa.org and the International PWS Organisation (IPWSO)

Locks for cupboard and fridges have long been recommended and actually may provide some positive security to the patient with PWS. The instigation of these is often by parental choice. A useful and concise document has been produced by the US PWS association on the practicalities.

Diet within the overall management of PWS

Many chapters and papers exist on the overarching topic of successful management. Of note a particular useful publication, Regulation of Weight in Prader-Willi Syndrome: Theoretical and Practical Considerations covers many of these areas and provides practical information that dietitians and PWS families will find very useful.

Also useful is Recommendations for the Diagnosis and Management of Prader-Willi Syndrome (2008)

Activity

Many individuals with PWS tend to prefer sedentary activities such as puzzles, word searches and computer games. However, increasing physical activity levels can increase energy expenditure and overall feelings of wellbeing. Some activities are physically difficult for those with PWS due to poor muscle strength, but walking and swimming can be accomplished by most and should be encouraged to increase energy expenditure. Exercise and Physical Activity for Children with Prader-Willi Syndrome is a very useful booklet to recommend to parents produced by an Australian group. Of particular use is Table 1 (page 9) which shows the energy cost of some common activity for children.

Supplements

There is much discussion on supplement use in the PWS population. Standard over-the-counter age appropriate multivitamins and minerals are advised in many clinics. If there is any doubt, formal nutritional analysis using programmes such as DietPlan can be very useful. Additional supplementing by parent choice is common and two supplements of particular note are carnitine and co enzyme Q10. Both have been investigated in the context of PWS. Carnitine and Coenzyme Q10 Levels in Individuals with Prader-Willi Syndrome, 2011 provides a good overview behind the theory of both of these.

The topic of **Carnitine** and **Coenzyme Q10** are discussed separately in depth on a popular website for parents called Connecting the PWS dots.

Surgery

Families may ask about bariatric procedures to address excess weight. This topic was reviewed in 2008 in the JPGN article **Critical Analysis of Bariatric Procedures in Prader-Willi Syndrome** which concluded that various surgical interventions had poor results in PWS patients in comparison with obese individuals. Diet and careful strategic management remains the most appropriate long term therapy.

Transition to adult care

Ideally a paediatric patient with PWS should be handed over and remain under an adult dietitian with an interest and experience in PWS. In some areas this may come under the remit of the Learning Disability Dietetic Team. As in paediatrics, despite years of research, no drug regimen or behaviour modification successfully and consistently curbs unsupervised over eating in adults with PWS. Monitoring in adults is as important as in paediatrics and, as the child approaches transition, education and identification of tools for adult life should be discussed and recommended.

There are 4 basic options for adult patients with PWS:
1. Living with parents or other relatives
2. Group home placement
3. Supported living services
4. Specialised residential services

Each may require different levels of nutritional and weight monitoring depending on the level of support. For example intake and weight monitoring is often well controlled in specialist residential care.
Those living in specialised residential services tend to have greater success with weight management, as diet and access to food is carefully controlled, and activity forms a major part of daily living. In addition, it is widely believed that this structured approach reduces the stress and anxiety around food and meal times, thus allowing individuals to focus and enjoy other activities.

Whatever their place of residence, the guidance on dietary restrictions is the same. It is widely acknowledged that adults with PWS probably lack **capacity** relating to food choices (when and how much) and so there is a duty of care to support the individual to manage their food intake appropriately.

Useful strategies for supporting adults with PWS include:

- Structured menu plan containing well balanced, calorie controlled guidance
- Locked kitchen and/or food cupboards
- Supervised access to kitchen and food cupboards
- Money and food should not be left lying around
- Consistent approach from all involved
- Be mindful of all opportunities to access foods, e.g. telephone ordering, shops, leftovers, bins
- Monitor weight regularly
- Non-food based rewards can be helpful in encouraging positive behaviours

A useful Australian paper from 2013, **Prader-Willi Syndrome. Care of Adults in General Practice**, describes common issues that require addressing in adult PWS patients.

There is generally limited data on the physical issues for adults with PWS but this is covered most recently in a paper from 2011 **Physical health problems in adults with Prader-Willi syndrome.**

Monitoring of weight should be done regularly and assessed by both the raw figures and in terms of BMI's. Consistent use of standard adult UK BMI charts should be used. At this time, as far as the author is aware, no PWS adult specific BMI charts exist. Although it may be more difficult for an individual with PWS to obtain a healthy weight, it is possible - and, just like the rest of the population, a BMI within the healthy weight range should be the aim.

Summary

Obesity should no longer be seen as an inevitable outcome for persons with PWS. Dietitians are key members of the child or adults support team and building good relations with families and providing reliable sources of up to date information is an important responsibility,
Weight control and even weight loss are achievable and often associated with improved behaviour (due to the establishment of routines and rules that are clear), and importantly a sense of pride and achievement for the individual with PWS.

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Additional material on dietary management for adults

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Belfast Health and Social Care Trust
caring supporting improving together

Reference No: SG 60/15

Title:	**Prioritising the Mealtime Experience (Protected Mealtimes) Policy**			
Author(s)	Patricia Sheppard, Central Nursing			
Ownership:	Brenda Creaney, Executive Director of Nursing & User Experience			
Approval by:	Standards and Guidelines Committee Trust Policy Committee Executive Team Meeting		**Approval date:**	02/03/2016 06/04/2016 20/04/2016
Operational Date:	April 2016		**Next Review:**	April 2019
Version No.	1	**Supercedes**		
Key words:	Prioritising, Protected, Mealtimes			
Links to other policies	Food, Fluid & Nutrition Policy Food Hygiene Policy for Non-Catering Staff			

Date	**Version**	**Author**	**Comments**
17/7/2013	0.1	A Dowd	First draft
21/01/2014	0.2	A. Dowd	Following a meeting with Mary Murdock
10/02/2014	0.3	A Dowd	Following discussion with B Gribben
17/02/2014	0.4	A Dowd	Comments from Mary Murdock
12/02/2015	0.5	P Sheppard	Comments from Food & Nutrition Steering Group & ADNs
8/10/2015	0.6	P Sheppard	Addition of Council of Europe Resolution Food and Nutritional Care in Hospitals - 10 Key Characteristics of Good Nutritional Care in Hospitals
23/02/2016	0.7	P Sheppard	Comments following S&G Committee

INTRODUCTION / PURPOSE OF POLICY

1.1 Background

Mealtimes are not only an opportunity to provide patients with adequate nutrition, but are also occasions to support social interaction. The therapeutic role of food within the healing process cannot be underestimated. Illness may produce profound changes in an individual's nutritional requirements, and may alter the appetite, and the ability to eat and to communicate needs. Patients who are ill are more at risk of malnutrition, which in turn may delay their recovery and increase the risk of complications However, food, even if it is of the highest quality, is only of any value if the patient actually eats it.

1.2 Purpose

'Prioritising the mealtime experience' is about ensuring that the focus by all available staff, over mealtimes, is to discontinue any non urgent activities and treatments to allow patients to eat their meals without interruption and to give ward staff the necessary time to help those who need assistance.

The policy seeks to provide a framework for mealtimes which, without impacting on the workings of the ward/clinical area, places the patient at the centre of the mealtime experience, putting food/fluids first.

Objectives

- To improve the mealtime experience for patients by allowing them to eat their meals without disruption - Protected Mealtimes **(Appendix 1).**
- To improve the nutritional care of all patients through nurses facilitating and encouraging the consumption of food and fluids.
- To ensure that patients who need assistance to consume their meals receive the support they require from nursing staff.
- To minimise risks and to ensure that mealtimes are a pleasant and relaxing social experience for all patients/clients.
- To support nurses and support staff in the delivery of food at mealtimes.
- To raise awareness of all staff to the importance of the mealtime experience for patients/clients.
- To ensure patients have a protected rest period following the midday meal.

2.0 SCOPE OF THE POLICY

This policy applies to patients/clients in healthcare settings across the BHSCT.

3.0 ROLES/RESPONSIBILITIES

Co-Directors/Service Managers

- Ensure that the policy is disseminated and implemented within their areas of responsibility.

Ward Sisters/Charge Nurses/Team Leaders/Nurse-in Charge

- Implement the policy in their own area and include in ward induction of new staff.
- Demonstrate clear leadership during mealtimes.

- Ensure that interruptions e.g. ward round, drug round, cleaning, documentation, other activities should only occur where clinically appropriate and absolutely necessary **(Appendix 2)**.
- Organise staff mealtimes to maximise the number of staff available to deliver and assist patients with eating and drinking as required.
- Ensure that, where a patient requires assistance to eat, it is documented in the patient's notes. Relatives and carers who wish to help are welcomed and encouraged to participate in mealtimes.
- Ensure that the transfer of patients should be kept to a minimum during mealtimes. However, it should be appreciated that patient flow through the system needs to be continuous.
- Communicate with Ward Support Officer regarding ward telephone cover during this time, to ensure nursing staff are not interrupted.
- Monitor ward activity during mealtimes and support staff to ensure that their practice remains consistent with the policy. This can be supported through use of 'Mealtime Observation Toolkit' **(Appendix 3)** to identify areas of good practice and areas where improvements are required.
- Develop an effective communication relationship with catering services that permits early identification and resolution of any problems with the supply of food and fluids to the ward.
- Display appropriate signage to inform all patients, staff and visitors of the mealtime periods during the day.
- Ensure that patients/relatives are made aware of the policy and ward practice as soon after admission as is reasonably possible.

All Nursing Staff (Registered & Un-registered)

- Ensure effective communication within ward teams regarding the nutritional needs of individual patients. This includes verbal communication and comprehensive documentation.
- Ensure that the Food Hygiene Policy for Non-Catering Staff is adhered to.
- Ensure that patients are given the opportunity to clean their hands before mealtimes.
- Identify patients who may be at risk of complications with eating and drinking are identified and discussed at safety briefs and handover. It is important to ensure that relatives/carers of patients 'at risk' are made aware of any risks.
- Identify staff members to provide assistance to those patients who require it.
- Make the patients/clients experience a priority during mealtimes, providing assistance, support and encouraging patients to eat and drink, as required.
- Ensure documentation relating to patient's dietary intake is completed accurately in a timely fashion.

All Staff including Medical & Allied Health Professionals

- Ensure that all non-essential duties **(Appendix 2)** cease on the ward during patient mealtimes.

4.0 KEY POLICY PRINCIPLES

Policy Principles

4.1 Directorates and individuals' recognition of responsibility and accountability in relation to ensuring all patients/clients receive adequate, nutritional food and fluids and are supported in eating and drinking in an environment conducive to an optimal mealtime experience **(Appendix 1).**

4.2 Directorates will put in place, systems and processes in relation to the implementation of this policy.

5.0 IMPLEMENTATION OF POLICY

5.1 Dissemination

This policy will be available to all staff healthcare groups.

5.2 Resources

There is no significant resource requirement.

5.3 Exceptions

None.

6.0 MONITORING

Monitoring can be undertaken as required with the use of the 'Mealtime Observation Toolkit'.

7.0 EVIDENCE BASE / REFERENCES

Promoting Good Nutrition – A Strategy for good nutritional care for adults in all care settings in Northern Ireland 2011-2016. DHSSPSNI. Updated June 2012
Get your 10 a day! – The nursing care standards for patient food in hospital. DHSSPSNI. November 2007
Council of Europe Resolution Food and Nutritional Care in Hospitals - 10 Key Characteristics of Good Nutritional Care in Hospitals http://www.bapen.org.uk/pdfs/coe_leaflet.pdf

8.0 CONSULTATION PROCESS

Food & Nutrition Steering Group
Associate Directors of Nursing
Associate Medical Directors
Central Nursing & Midwifery Team
Allied Health Professionals
Trade Unions

9.0 APPENDICES / ATTACHMENTS

Appendix 1	Key Principles in Prioritising the Mealtime Experience for Patients
Appendix 2	Essential and Non-Essential Clinical Activity
Appendix 3	Mealtime Observation Toolkit

10.0 EQUALITY STATEMENT

In line with duties under the equality legislation (Section 75 of the Northern Ireland Act 1998), Targeting Social Need Initiative, Disability discrimination and the Human Rights Act 1998, an initial screening exercise to ascertain if this policy should be subject to a full impact assessment has been carried out.
The outcome of the Equality screening for this policy is:

Major impact ☐

Minor impact ☐

No impact. ☐

SIGNATORIES

(Policy – Guidance should be signed off by the author of the policy and the identified responsible director).

Patricia Sheppard

______________________________ **Date: ____April 2016______**

Patricia Sheppard
Central Nursing Team

Brenda Creaney

______________________________ **Date: _____April 2016_____**

Brenda Creaney
Executive Director of Nursing

Appendix 1

Key Principles in Protecting Patient Mealtimes

Pre-meal

- Consideration should be given, when possible, to where patients sit to eat their meals, supporting the social aspects of mealtimes whilst respecting the preferences of the individual.

- Where communal dining facilities are available, tables should be clean and appropriately set prior to the service of food.

- Where possible, bed tables and eating areas should be cleaned appropriately and cleared of items not conducive to meal times e.g. urine bottles, commodes, sick bowls etc.

- Where required, nurses should provide patients with assistance to use the toilet prior to the service of food.

- Prior to the service of food all patients should be given the opportunity to wash their hands or use hand wipes.

- Patients should be made comfortable prior to the service of meals, and be in an appropriate eating position. The table and chair should be at an appropriate height.

- If applicable, patients' dentures should be clean and in place and other oral care provided as required.

- If applicable, patients should be provided with the adapted equipment / utensils that they require for eating and drinking e.g. feeding beakers, special cutlery etc. to meet their individual needs.

- Patients requiring assistance will be identified by the ward team prior to the service of meals.

- Staff must ensure that their hands have been appropriately cleaned prior to the service of food.

- Staff must wear correct colour of plastic aprons (green to serve food.

During Meal

- Nurses will organise their own mealtimes to maximise the number of staff available on the ward to deliver and assist patients with their meals.

- Food should be placed within a comfortable reach of the patient and where required, assistance given with opening packets, loosening lids etc.

- Patients/ clients should be given **adequate time to eat, drink and enjoy their meal.** The meal should not be rushed or interrupted unless absolutely necessary.

- Nursing staff will **make food a priority during mealtimes**, providing assistance, support and encouraging patients to eat, as required.

- Staff directly involved with patients at mealtimes should avoid answering the telephones within the vicinity of meals being served or leaving patients when providing assistance at meal times to answer the telephones - where possible. Charge Nurses will liaise with the ward clerk to ensure telephone cover at patient mealtimes. Some clinical areas may consider diverting telephones at meal times to other areas. However it is recognised that in acute areas this may be challenging.

Post Meal

- Nursing staff should **monitor the nutritional intake of all patients**. Trays or plates should not be removed without first checking how much food has been eaten. When in use, Food Record Charts should be completed.

- If the patient hasn't eaten their meal:
  (a) find out the reason and provide an alternative if appropriate

  (b) communicate and document any concerns.

- Where it is suspected that the patient's nutritional intake is inadequate a ' 3 Day Food Record Chart' should be commenced to document actual intake.

- If required, assist patients to freshen/ tidy up and check that no food has been retained in the mouth.

Appendix 2

Essential and Non-Essential Clinical Activity

Essential:
Healthcare staff must use clinical judgement when considering what constitutes **essential/urgent activity** for example:

- Patients that require urgent medical assessment
- Diagnostic tests such as CT scan, Ultrasound
- Preparing patients for planned procedures such as endoscopy, bronchoscopy, theatre.
- Patients requiring pain control
- Urgent patient transfers and admissions

Non-Essential:
All staff must ensure that delivery of essential clinical care is not compromised. Guidance on what constitutes **non-essential activity** could include, for example:

- Ward rounds (where possible)
- Routine medication administration
- Routine observations of the clinically stable patient
- Routine venepuncture
- Routine ECGs
- Routine investigations including diagnostics, unless there is a clinical indication for urgency.
- Routine ward visits by all staff groups unless assessing or treating a patient in direct relation to their eating and drinking
- Documentation by nursing staff and AHPs
- Pharmacist visits to patients
- Cleaning of the surrounding area
- Bed-making
- Ad hoc visiting
- Personal care

Appendix 3

Promoting Food and Nutrition
Observation of the meal time experience

Use your 5 senses - what can you hear, smell, see, feel, touch

This tool has been developed by the BHSCT Food and Nutrition Governance Sub Group
using information from the NHS 15 Steps, Productive Ward Meals Module
and Workplace Critical Culture Analysis Tool.

Promoting Food and Nutrition - Observation of the experience of meal time

Use your 5 senses - what can you hear , smell, see, feel, touch

This tool has been developed by the BHSCT Food and Nutrition Governance Sub Group using information from the NHS 15 Steps, Productive Ward Meals Module and Workplace Critical Culture Analysis Tool.

Patients/ Clients/Services users will all be referred to as patients in this document

Ward / department/ area **Date**

Observers:
1
2
3
4
5
6

Time observation commenced at:

Time food serving commenced at:

Time observation completed at:

Prompts to consider: Pre meal activity

- Prepare Patient
  - Toileting
  - Hand hygiene
  - Positioning
  - Drink available
  - Mouth care
  - Special equipment
  - Call Bell
- Prepare Immediate patient environment
  - Create a clutter free clean area for meals
  - Remove unnecessary items
  - Rubbish/dirty items are disposed of
- Staff Preparation
  - Staff Hand hygiene
  - Use of green apron
- General observations
- Identification of Patients who require support
- Identification of Patients who require special diets
- Identification of patients on Nil my mouth
- Identification of potential risks
- Interruptions
- Does the area feel calm or chaotic
- What action was taken regarding patients who are not on the ward
- Is there evidence of team working / with other departments
- Activities carried out to check special diets

Please record your observations below:

Prompts to consider: During Meal Time

- Observations
- Staff available
- Position of food trolley /service area
- Food Service Process
    - Who
    - How
    - Decision making
    - Issues arising
- Identification of Patients who require support
- Identification of Patients who require special diets
- Identification of patients on Nil my mouth
- Identification of potential risks
- Interruptions
    - Who
    - Why
    - Impact
- Environment conducive to meals time
- What is the atmosphere like ?
- Receipt of appropriate meals
- Patient assisted to eat their meals
    - Process/ approach
    - Person-centred Experience
    - Interactions
- Relatives/ Carers
    - Present
    - Participation
    - Interactions
- Are staff with patients
- Are patients offered extra food and drink
- Is there evidence of toileting activities where patients are eating

Please record your observations below:

Prompts to consider: Post meal time

- Clearing of trays
- Patients intake
- Observe patient intake
- Report patient intake
- Record patient intake
- Patient needs addressed
- Patient area cleared and cleaned

Please record your observations below:

Prompts to consider:
General Observations

- Use of signage - meal time
- Patient information re diets on display
- What have you noticed that builds your confidence and trust
- What is the physical environment like?
- What can I understand about the experience for patients?
- Are there indicators that carers are involved with patients?
- Is there evidence of effective team working
- How is patients dignity and privacy respected
- What has made you less confident?
    - Is the environment clean and uncluttered?
    - Waste noted and recorded

Please record your observations below:

Information Sheet

Observation of the Meal Time Experience

The Belfast Health and Social Care Trust (BHSCT) is committed to enhancing the experience of meal times for patients, clients, service users and staff. To provide important information regarding the experience, we will be observing the food service over the lunch time service on [*insert date]*

Do I have to take part?

Taking part is entirely your decision. If you choose not to take part this will be respected and will not affect your care in any way.

What will happen to me if I take part?

If you agree to take part, Trust staff will observe the meal time service and during this time will take notes. No information about individual patients, clients, service users or staff will be recorded. However, in the interest of patient/client safety, *where poor or dangerous practice is identified,* this will be raised with the senior manager from the area in order for the appropriate action to be taken.

What will happen if I agree and then change my mind?

You can change your mind at anytime and withdraw, even during the observation and your decision will be respected.

What if there is a problem?

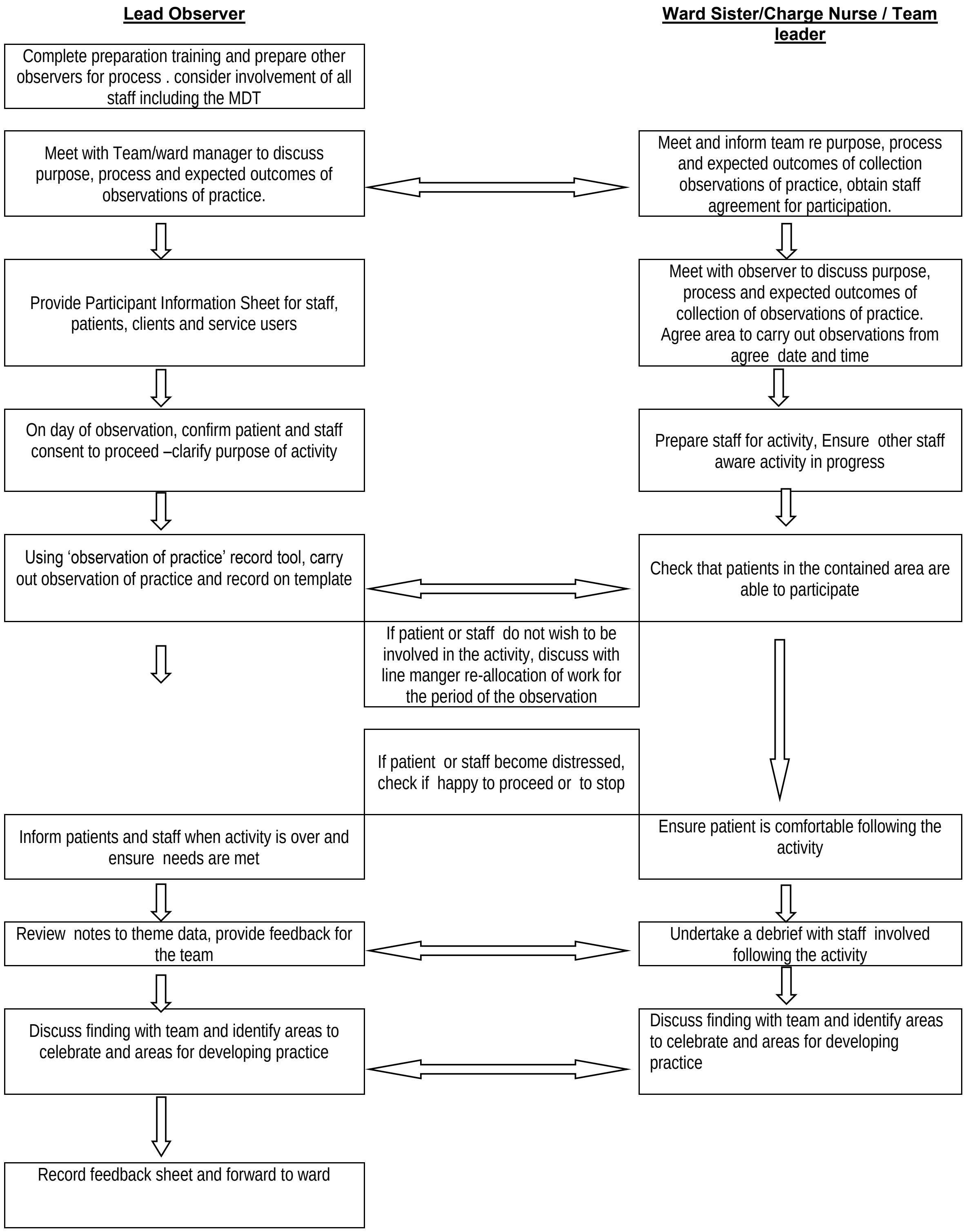
If you have concerns about any aspect of the study you can speak with Bernadette Gribben who will try to answer your questions. If you remain unhappy and wish to complain formally, you will be provided with relevant information that will enable you to do so.

What will happen to the results?

The results will be used to improve the experience of meals in the BHSCT.

Thank you for taking time to read this information.

Flow chart for 'Observations of Practice' activity - This Flow chart is derived from detailed protocols that will be adhered to by the participants (RCN, 2007)



Food and Nutrition
Observation of the mealtime experience feedback template

Ward/area/department:		**Date and Time**	
Observers:		**Feedback given to:**	

Specific comments re:	
Preparation :	
Pre meal activity:	
During meal:	
Post Meal :	
Areas of commendation :	
Areas for consideration : -	

Record prepared by :
Date: