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September 1991

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Report on the
Rehab Unit
Survey of the
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Acknowledgements

We would like to thank all the staff of Muckamore Abbey Hospital who gave of their time and energy to ensure that the Survey was completed so efficiently. Special thanks are due to Mrs Pauline McKeown and Mr Paddy Maguire for their help in collecting and compiling the data, to Mrs Molly McFadden for entering much of the information onto the computer database, to Miss Mary Drain for typing a major portion of this report, and to Mrs Edna Clarke for helping with the database preparation and for typing and producing this final version of the report. Without the help of each of these people, the project quite simply could not have been completed.

Chapter 1 : The Survey

1.1 Introduction and Aims of the Survey

In the autumn of 1989, the then Unit Management Group of Muckamore Abbey Hospital commissioned the Rehabilitation Unit to complete a survey of the entire hospital population. This was against a backdrop of increasing availability of residential placements outside the hospital, and the need for an appropriate means of identifying potential candidates for such places.

Until then, the Rehabilitation Unit had been compiling in-depth reports on the social, clinical and behavioural details of a number of hospital patients, based on intensive four-week assessment periods in the Rehabilitation Unit itself. This form of assessment had been considered invaluable as a means of highlighting both the strengths and weaknesses of residents considered likely for imminent discharge from the hospital, and indeed the four-week assessments of selected individuals continues to be a major component of the Rehabilitation Unit's function.

However, the needs of what had become a major resettlement programme were no longer being fully met by the in-depth assessments, which had tended to focus on more able patients only, and with a maximum of about forty per year. Many of the new residential facilities in the community were offering places to individuals not traditionally considered for resettlement. It was obvious, therefore, that some system needed to be developed whereby a certain amount of basic information (albeit clearly not of the detail offered by the in-depth assessments) could be collected and stored in a readily accessible format for the entire hospital population. Thus the Rehabilitation Unit Survey of Hospital Patients (referred to locally simply as "The Hospital Survey") came into existence.

In practice, it was decided to limit the survey to the longer-term population only, meaning that patients are included (for the survey is a continuing one, and is not limited simply to a single point in time) only once they have been in the hospital for a complete three-month period. Respite and temporary admissions are obviously excluded.

The aims of the survey are threefold:

- (1) To provide a database of information on every longer-term hospital resident, including basic background data (DOB, IQ, sex, home address, etc.), skills information (washing and dressing ability, for example) and clinical details (eg psychiatric history and details of current medication). Clearly, this was not so much to represent a collection of "new" information on each patient (much of which already existed, although not necessarily in written format, and perhaps in any of a variety of separate filing systems), as a collation and pulling together of information that was already known about each person. It was to be the first truly multidisciplinary exercise of its type in the hospital, however, and the resulting database was to be stored on computer.
- (2) To identify three major subgroups of residents from within the hospital population:
 - (a) Those who could be considered for discharge to (appropriate) community accommodation immediately.

(b) Those who could be considered for discharge after a further period (of up to about 18 months) of treatment and/or training within the hospital.

(c) Those who will probably require long-term hospital care.

Present (as will likely future) requirements for daycare and other specialist support services were also to be recorded.

- (3) To identify, in conjunction with the various Community Units of Management in the EHSSB and NHSSB (ie the traditional catchment population for Muckamore Abbey Hospital), an "owning" Unit of Management for every resident. The idea here was to identify the currently most appropriate Community Unit for each patient, based not only on items such as the home address at time of admission (which for at least some of the residents may well have been over twenty years ago), but also the present address of the next-of-kin, the extent and nature of any contact with the next-of-kin, and so on. Thus the aim was to update the information which the hospital currently held on its patients and to make that information as meaningful as possible to the present day situation.

Clearly it was hoped that the information provided by such a breakdown of the population would be of use not only in alerting the various Community Units to the "types" of patients (in terms of skills, abilities, etc.) suitable for discharge from the hospital - and therefore of the range of community facilities for same that the Community Units should be seeking to provide - but also in helping to clarify the role, function and requirements of any "core" hospital facility of the future. Indeed wide consultation with staff from both inside and outside the hospital took place before the information to be collected was finally decided upon.

1.2 Collecting the Information

The survey took as its starting-point all patients who on 1 January 1990 had been resident in Muckamore Abbey for at least three complete months. All subsequent admissions of at least three months have also been added to the survey, and it is intended that this practice will continue in the future.

The bulk of the data collection took place over a twelve-month period between autumn 1989 and autumn 1990. The process involved three discrete stages:

- (1) Background data (DOB, sex, date of registration as being mentally handicapped, etc.) were taken from each patient's Confidential File in the Medical Records Department.
- (2) "Contact" information (eg with the legal next-of-kin and, where a different individual might be involved, with the person most concerned with the patient on a practical, day-to-day basis as well) and skills-data (proficiency in self-help, communication, behavioural-management problems, etc.) were gathered at separate meetings with a senior member of nursing staff in each ward.

- (3) Medical data (eg psychiatric diagnosis), "placement" information (concerning the most appropriate form of residential care - for example, whether in hospital or in the community) and information about the involvement of a number of specialist services (speech therapy, for example, or physiotherapy) were all provided at a series of specially-convened multidisciplinary ward review meetings.

Full details of the entire range of information-items included in the survey are presented in Appendix I: those identified above are examples only.

A "stepwise checking" procedure was operated in gathering the data, in that data collected at an earlier stage in the process was always verified at each subsequent stage as well. All information, therefore (including the background, "contact" and skills data) was considered by the multidisciplinary teams involved with each individual.

Once the collection of information on any given patient was completed, the relevant background and "contact" data (ie all of the information which could be considered as being in any way important in determining the most appropriate Community Unit for each resident) was forwarded - anonymously - to whichever Unit had been proposed by the relevant multidisciplinary team as being the one with which the patient appeared to have the strongest ties at present. The Community Units were then free to query any proposed question of "ownership" (something which in effect happened only very rarely indeed), and thanks to a perhaps unprecedented degree of cooperation between the hospital and the various Community Units, we now have an agreed "owning" Unit of Management identified for every patient in Muckamore Abbey.

1.3 The Current Report

The survey, as has already been said, is on-going. New cases are added to it just as soon as the three-month admission criterion is satisfied, while it is hoped that the information that has already been gathered can be updated regularly at the routine Ward Review Meetings that now take place throughout the hospital.

The present report is based on the situation in the hospital as at 9 September 1991, when there was a total of 618 beds on site: 602 for admission and longer-term treatment purposes, and 16 for respite admissions. Some 557 individuals had been resident for at least three complete months, while a further 31 had been here for a lesser period than three months (and of these, 10 had been admitted directly on either a temporary or a respite basis). The remaining 30 beds were vacant - although a number of those were intentionally so, to allow for the imminent closure of villa "Firgrove".

The details presented below refer only to those 557 individuals who, by 9 September 1991, had been resident here for at least three full months. For the sake of brevity, however, they will be referred to throughout the remainder of the report quite simply as "the hospital population".

Chapter 2 : Profile of the Hospital Population

2.1 Basic Data

This section presents information on the age, sex and IQ breakdown of the hospital population, as well as details of their ward placements, their legal status (in terms of the 1986 N.I. Mental Health Order) and their length of stay in Muckamore Abbey.

2.1.1 Age, Sex and IQ

Of the 557 individuals who on 9 September 1991 had been resident in Muckamore Abbey for at least three complete months, 315 (57%) were males and 242 (43%) were females. A breakdown of the population by both age and sex is presented in Table 1.

<u>Age (Years)</u>	<u>Males</u>	<u>Females</u>	<u>Total</u>
<20	10	7	17 (3%)
20-29	77	38	115 (21%)
30-39	105	74	179 (32%)
40-49	69	54	123 (22%)
50-59	20	26	46 (8%)
60-69	22	25	47 (8%)
70-79	9	10	19 (3%)
80+	3	8	11 (2%)
<u>Total:</u>	315 (57%)	242 (43%)	557 (100%)

TABLE 1: Breakdown of the Population by Age and Sex

Only 3% of the residents were under 20 years of age (it has for a number of years now been an explicit policy of the hospital not to admit children if at all possible), although some 21% were less than 30 years old and a further 32% were aged between 30 and 40 years. Just over a fifth of the patients were at least 50 years of age, with our most senior resident being some 105 years old!

Interestingly, males outnumbered females in all age categories up to 50 years while over that limit the reverse was true. This difference in age distribution for the two sexes was statistically significant ($X^2 = 14.9$, 7df, $p < 0.04$), and indeed it parallels the trend that one would expect to find in the general population.

As far as the degree/level of mental handicap is concerned, 15 individuals (3%) had IQs over 70 and 101 (18%) had IQs in the "mild" category of handicap (ie 50-69). Of the remainder, 237 (42%) fell into the "moderate" or "severe" groupings (with IQs between 20 and 49) and 204 (37%) were "profoundly" mentally handicapped (IQ <20).

Tables 2 and 3 allow the above figures to be compared with the results of earlier surveys (in 1982 and 1986) of the Muckamore Abbey population. They show the changes in the distributions of age and IQ respectively over the course of the last nine years and confirm the widely-held impression that the population is generally becoming both older (Table 2) and less able (Table 3).

Age (Years)	1982	1986	1991		IQ	1982	1986	1991
<20	10%	7%	3%		<20	29%	32%	36%
20-49	70%	70%	75%		20-49	50%	51%	43%
50+	20%	23%	22%		50+	21%	17%	21%
<u>Total:</u>	100%	100%	100%		<u>Total:</u>	100%	100%	100%

TABLE 2: Age distribution of
the hospital population,
1982 - 1991

TABLE 3: IQ distribution of
the hospital population,
1982 - 1991

2.1.2 Ward Placement, Legal Status and Length of Stay

There were 23 wards in occupation on 9 September 1991, although one of them (Villa Firgrove) was well on the way towards meeting a closure date of 31 October 1991. Table 4 shows the bed complement of each ward (excluding respite beds) as well as the number and percentage of beds actually occupied. It also identifies which wards catered for male patients only (M), females only (F), or patients of both sexes (B). Wards have been grouped according to the "type" of resident they generally accommodate, beginning (at the top) with three wards for elderly patients, then six for physically/multiply handicapped individuals, one for younger/adolescent patients, two providing admission/short-term treatment facilities, two catering for residents requiring a "semi-secure" environment, five for behaviourally disturbed adult patients, two for disturbed/psychiatric cases, and two providing rehabilitation training.

When interpreting Table 4, one must remember the 21 non-respite cases who, although resident here on 9 September 1991, had been admitted less than three months previously: they are not featured in the table. Eight of them were in Movilla A, five in Fintona North, three in Fintona South, two in Movilla B and one each in Ennis, Rathmore and Moyle. It is clear, therefore, that Movilla A, Movilla B and Fintona North were all functioning at a level well in excess of complement, while each of the other wards (with the obvious exception of Firgrove) were either full or relatively nearly so. Taking the hospital as a whole, and including the 21 short-term cases, the overall occupancy level was some 96%. If villa Firgrove is excluded from this calculation, however, the overall occupancy level was actually over 98%.

<u>Ward</u>	<u>None-respite beds</u>			
	<u>Complement</u>	<u>Occupied</u>	<u>% Occupied</u>	<u>Sex</u>
Erne	24	24	100%	B
Ennis	23	22	96%	B
Firgrove	22	7	32%	F
Greenan	35	35	100%	F
Finglass	36	36	100%	F
Moyola	36	36	100%	M
Rathmore	31	25	81%	B
Rathmullan	31	30	97%	M
Cloonshee	32	30	94%	B
Conicar	24	23	96%	B
Movilla B	17	18	106%	M
Fintona South	17	14	82%	F
Movilla A	18	17	94%	M
Fintona North	19	17	89%	F
Cushendall	31	29	94%	M
Cushendun	34	32	94%	M
Moylena	28	26	93%	M
Foybeg	29	28	97%	F
Fennor	29	28	97%	F
Mallow	29	24	83%	M
Moyle	25	24	96%	M
Birchill	10	10	100%	B
Hillcrest	22	22	100%	B

TABLE 4: Details of each ward in the hospital

The vast majority of the patients (501, or 90% of the total) were in hospital on a voluntary basis (Northern Ireland Mental Health Order, 1986), while 41 individuals (7%) were Detained under Part II of that Order. Thirteen (2%) were on Part III Detention Orders - seven without restriction and six with imposed restrictions. The remaining two patients were on Guardianship Orders.

Tables 5 and 6 present respectively the distribution of the patients' ages at current admission to the hospital, as well as the total length of their admissions.

<u>Age at Current Admission (Years)</u>	<u>Frequency</u>	<u>Length of Current Admission (Years)</u>	<u>Frequency</u>
<5	52 (9%)	<1	30 (5%)
5- 9	88 (16%)	1- 4	54 (10%)
10-19	166 (30%)	5- 9	81 (15%)
20-39	162 (29%)	10-19	117 (21%)
40+	89 (16%)	20+	275 (49%)
<u>Total:</u>	557 (100%)	<u>Total:</u>	557 (100%)

TABLE 5: Age at current admission

TABLE 6: Length of current admission

Although the hospital now only very rarely indeed has cause to admit children to its wards, clearly that has not always been so. Indeed a majority of the current population (55%, or 306 in total) were admitted before the age of twenty, while some 52 individuals (9%) were admitted under the age of five. There is a gradual decline in the frequency of admissions over the age of 20 years, with only two patients having been admitted at an age above 70 years.

Given the past tendency for the hospital to admit children of a very young age indeed, it is perhaps not at all surprising to find (Table 6) that virtually one-half (275, or 49%) of the population had been in hospital for over 20 years. Another fifth (117, or 21%) had been in the Abbey for at least a ten-year period, while only 30 individuals (5%) had been admitted within the previous year. (Do remember again, though, that this excludes the 21 individuals who had been admitted less than three months previously.) All this is extremely important to bear in mind when it comes to decisions about rehabilitation and discharge of patients from the hospital - for a very large number of them indeed, Muckamore Abbey has been the only "home" that they have known for a substantial proportion of their lives.

Table 7 shows this particularly clearly. It represents the numbers of patients who have been in hospital for various proportions of their total lives. The distribution is fairly uniform across the four quartiles, with over 20% of the population having been in hospital for at least three-quarters of their lives. Almost 50% had been in the Abbey for more than half their lives.

<u>% of Total Life Spent in Hospital</u>	<u>Frequency</u>
<25	151 (27%)
25-49	146 (26%)
50-74	144 (26%)
75+	116 (21%)
<u>Total:</u>	557 (100%)

TABLE 7: Percentage of total life spent in hospital

For over half the population (315, or 57%), their current admission to Muckamore had been their only one. Of the remainder, 93 (17%) had had one previous admission, 48 (9%) had had two previous admissions, 30 (5%) had had three admissions earlier and 71 (13%) had had more than three previous admissions.

2.2 Sensory and Physical Data

This section presents information about the sensory and physical characteristics of the hospital population. It deals particularly with the extent of any visual, auditory, mobility or dexterity difficulties recorded.

2.2.1 Vision and Hearing

Table 8 presents details of how the population stood in terms of both vision and hearing. Eighty per cent of the residents had no reported difficulties at all in either sphere, while only one individual was both totally blind and totally deaf. Visual difficulties were recorded as being slightly more prevalent than hearing problems - although that may simply be an artefact of somewhat easier diagnosis of the former, especially in the more profoundly mentally handicapped. (The information recorded was provided by hospital staff only, and was not on the basis of specialist assessment.)

	<u>Normal Hearing</u>	<u>Poor Hearing</u>	<u>Deaf/ Almost</u>	<u>Total</u>
Normal vision	443 (80%)	25 (4%)	11 (2%)	479 (86%)
Poor vision	46 (8%)	13 (2%)	1 (0%)	60 (11%)
Blind/almost	14 (3%)	3 (1%)	1 (0%)	18 (3%)
<u>Total:</u>	503 (90%)	41 (7%)	13 (2%)	557 (100%)

TABLE 8: Multiple sensory handicap

Eighteen individuals in total (3% of the population) were reported as having substantial difficulties (ie a rating of at least "poor") in terms of both vision and hearing. Perhaps not surprisingly, the majority of these (11 of the 18) were classified as profoundly mentally handicapped, a further six fell into the category of severe/moderate mental handicap, and only one was mildly mentally handicapped.

2.2.2 Mobility and Dexterity

The degree of mobility of the population is represented in Table 9. The categories were designed to indicate the extent of human help (ie from some third-party individual) generally required by the patient to get about either on the flat only or upstairs. The use of a walking stick or frame was not considered, although wheelchair use (provided it represented the patient's customary means of mobility around the ward) was recorded.

<u>Degree of Mobility</u>	<u>Frequency</u>
Walks, no human help needed on the flat or upstairs	334 (60%)
Walks on the flat only, human help needed with stairs	81 (15%)
Uses wheelchair "independently" on the flat only	18 (3%)
Walks, but needs human help even on the flat	49 (9%)
Uses wheelchair, but needs human help even on the flat	53 (9%)
Bedfast/chairbound	22 (4%)
<u>Total:</u>	557 (100%)

TABLE 9: Degree of mobility of the population

Only 60% of the patients (334 in total) could manage independently in accommodation which includes the management of stairs, although another 99 individuals (18%) could negotiate a single-storey building quite adequately, either on foot or in a wheelchair. The remaining 22% (124 cases) would require human help even to get about on the flat, with a total of 22 individuals (4%) being either bedfast or chairbound. The implications of this for the type of accommodation that is going to be required for Muckamore Abbey patients in the future are obvious.

As far as the patients' use of their upper limbs is concerned, 70% (387) were reported as having no functional impairment at all, 13% (75) as having difficulties with at least some daily living activities and the remaining 17% (95) as having problems with the majority of daily activities.

2.3 Medical and Psychiatric Information

This section begins with some medical details on the population (particularly with respect to the incidence of epilepsy) and then goes on to look at the psychiatric status of the patients.

2.3.1 Medical Details

Approximately 60% of the population (332 individuals) were recorded as having had significant physical illnesses or disabilities, either presently or in the past. This does not take account of epilepsy, however, which was recorded separately. Seizures over the past five years only were considered and their frequency in the population is presented in Table 10.

<u>Frequency of Epileptic Seizures</u>	<u>Number of Patients</u>
Monthly (at least)	68 (12%)
Less than monthly	112 (20%)
Never/Not for 5 years at least	377 (68%)
<u>Total:</u>	557 (100%)

TABLE 10: Frequency of epilepsy in the hospital population

Clearly, just over two-thirds of the population could be considered "fit-free", while the majority of the remainder (112 individuals, or 20% of the total) have their epilepsy well controlled. There remains a sizeable number of patients, however (68, or 12%) who continue to have epileptic seizures on at least a monthly basis.

The overall physical status of the patients (ie taking into account all forms of disability and illnesses, including epilepsy) was reported as limiting the majority of daily living activities in some 24% (135) of the population. Around 17% (92) were said to have difficulties in some daily activities only, while the remaining 59% (330) were recorded as experiencing no limitations at all due to physical illness or disability.

2.3.2 Psychiatric Status

Table 11 presents details of the psychiatric diagnoses made on the hospital population, in each case by the responsible consultant psychiatrist. Conditions were recorded as being either acute, chronic, recurrent or past, although for the purposes of this present table all acute, chronic and recurrent cases have been considered together. Occasionally, patients were reported to be suffering from more than one psychiatric illness, in which case they have been recorded in Table 11 only opposite the most severe of their various conditions. Diagnoses were made on the basis of the ninth revision of the International Classification of Diseases (World Health Organisation, 1978).

<u>Psychiatric Diagnosis</u>	<u>Frequency</u>
Autism	36 (7%)
Schizophrenia	47 (8%)
Depression	13 (2%)
Manic Depression	29 (5%)
Organic Psychosis	56 (10%)
Senile Psychosis	18 (3%)
Presenile Psychosis	2 (0%)
Personality Disorder	24 (4%)
Obsessive-Compulsive	9 (2%)
Neurotic Depression	3 (1%)
Anxiety State	1 (0%)
Alcoholic Dependency	1 (0%)
A "past" diagnosis only	22 (4%)
No diagnosis	296 (53%)
<u>Total:</u>	557 (100%)

TABLE 11: Psychiatric diagnoses

- 11 -

Just over half the population (43%) were recorded as having an ongoing psychiatric disorder, with a further 4% having had a (non-recurrent) condition at some time in the past only. Some 7% were suffering from autism and 15% had been diagnosed as having one of the major psychotic disorders, ie schizophrenia, depression or manic depression.

The most frequently recorded diagnosis was of "organic psychosis", which reflects the high incidence of epilepsy already noted in the population. Senile and presenile psychosis together accounted for some 3% of the cases, while of the remaining conditions by far the most common diagnosis was of personality disorder (with some 4% of the population in total).

2.3.3 Use of Medication

The vast majority of the patients were receiving prescribed medication with only 12% of them (66) on no medication at all. Table 12 presents the numbers receiving this form of therapy for each of four specific reasons separately. It shows that more than half the population were receiving medication for physical health problems (61%), with an almost identical number (60%) receiving drugs for psychiatric/behavioural reasons.

<u>Reason for Medication Being Given</u>	<u>Frequency</u>
For health reasons (eg vitamins)	339 (61%)
For epilepsy	227 (41%)
For psychiatric/behavioural difficulties	334 (60%)
For other (unspecified) reasons	72 (13%)

TABLE 12: Patients receiving medication for various reasons

The number of patients receiving anti-epileptic medication (41% of the population) was almost 10% higher than the figure reported above for those who actually take epileptic seizures (see Table 10 for details). This would suggest that although a sizeable number of individuals had remained fit-free for at least the previous five years, they were still requiring anticonvulsant therapy to maintain continuing effective control of their epilepsy.

The majority of patients were on medications for more than just one of the four classes of reasons presented in Table 12. Although only 4% (22) were receiving preparations from all four categories, 18% (100) and 39% (216) were on medications from three and two of the categories respectively.

2.4 Skills Data

This section is in three parts. The first presents details of the patients' communication skills, the second deals with the area of continence and incontinence, and the third reports on the population's self-help skills (ie washing, dressing, feeding, shaving and care of self at menstruation).

2.4.1 Communication Skills

Table 13 presents details of the patients' communication abilities, in terms of both comprehension and expression separately. As expected, the general level of comprehension was somewhat higher than the level of expression: only 9% of the population had either no or virtually no understanding ability, whereas some 22% were unable to express themselves at even a basic level to other people. (A "basic level" was considered in this respect as referring to one's need for food, drink, warmth, etc). Conversely, just half the population (50%) were able to express themselves at more than a simply basic level, while somewhat more than that figure (57%) were recorded as having such a similarly advanced level of comprehension.

<u>Level of Comprehension/Expression</u>	<u>Frequency</u>	
	<u>Comprehension</u>	<u>Expression</u>
None or virtually none	52 (9%)	124 (22%)
At a basic level only	186 (33%)	155 (28%)
At more than simply a basic level	319 (57%)	278 (50%)
<u>Total:</u>	557 (100%)	557 (100%)

TABLE 13: Levels of comprehension and expression abilities

Almost exactly half the patients (280) used speech as their major and preferred method of expression. This is shown in Table 14, which also lists the various other methods of expression employed. A significant number (22%) did not really communicate expressively at all, while a very similar number (23%) used gestures as their preferred and major method of communication. Other methods, including Makaton or communication boards, accounted for about 5% of the population in total (ie 24 individuals).

<u>Major Method of Expression</u>	<u>Frequency</u>
Speech	280 (50%)
Gestures	129 (23%)
Sign Language (including Makaton)	10 (2%)
Communication board or device	5 (1%)
Other	9 (2%)
Nil	124 (22%)
<u>Total:</u>	557 (100%)

TABLE 14: Major methods of expression employed by the population

2.4.2 Toileting Skills

Incontinence was noted to be a very major problem in the hospital. Table 15 summarizes the position with regard to daytime and nighttime wetting and soiling episodes separately. (Incontinence due to epileptic seizures was recorded in the data, since one of the aims

of the survey has been to gauge the level of human support and supervision that each of the residents requires).

<u>Number of Episodes Per Week</u>	<u>Daytime Wetting</u>	<u>Nighttime Wetting</u>	<u>Soiling</u>
None	298 (54%)	300 (54%)	333 (60%)
1 - 2	74 (13%)	76 (14%)	63 (11%)
Over 2	185 (33%)	181 (32%)	161 (29%)
<u>Total:</u>	557 (100%)	557 (100%)	557 (100%)

TABLE 15: Frequency of incontinence

The distribution of the population over the three incontinence measures was very consistent, with encopresis (soiling) being reported for slightly fewer patients than either of the enuresis (wetting) measures: some 29% were recorded as having over two soiling episodes per week on average, while the corresponding figures for nighttime and daytime wetting were 32% and 33% respectively. Also, a somewhat greater number of patients was reported as having no problems at all in terms of soiling (ie 60%, as opposed to 54% for each of the two wetting measures).

Exactly 200 patients (36%) were recorded as having at least one accident per week in all three areas, with a somewhat higher proportion than that (48%, or 267) having no accidents at all in any domain. The remaining 90 cases (16%) were divided fairly evenly between those who had difficulties in one of the three areas only, and those who had problems in two.

In addition, 50% of the population (279 cases) were identified as being able to go to the toilet both appropriately and without assistance. A further 5% (25 individuals) were able to at least indicate their need to be taken to the toilet, and the remaining 45% (253) were totally dependent on others to be either taken to or reminded to use the toilet.

All told, therefore, the population could be more or less divided equally into those who presented no difficulties at all in terms of their continence skills, and those who presented at least some degree of difficulty (and for a sizeable number, a major degree of difficulty) with same.

2.4.3 Self-Help Skills

Table 16 indicates the patients' abilities (in terms of the amount of help they required from other individuals) in the areas of feeding, washing and dressing skills, and in shaving (males) and looking after oneself during menstruation (females). But please note that the "shaving/menstruation" column excludes all those (76) individuals for whom, because of age in the main, the item simply did not apply: that item only is based on a total population of 481, therefore, instead of the customary 557.

Level of Help Required	<u>Feeding</u>	<u>Washing</u>	<u>Dressing</u>	<u>Shaving/ Menstruation</u>
None	283 (51%)	102 (18%)	149 (27%)	68 (14%)
Some	180 (32%)	281 (50%)	250 (45%)	242 (50%)
Complete	94 (17%)	174 (31%)	158 (28%)	171 (36%)
<u>Total:</u>	557 (100%)	557 (100%)	557 (100%)	481 (100%)

TABLE 16: Level of help required in carrying out various self-help skills

As expected, a greater proportion of the population was proficient in feeding skills (51%) than in any of the other areas. Dressing came next (27%), followed by washing (18%) and then shaving/menstruation (14%). This trend was obviously reversed in terms of the percentages who needed total help in carrying out the various skills. As far as the numbers requiring partial assistance is concerned, this was the case for roughly half the population with respect to washing, dressing and shaving/menstruation, but for only about a third of the total in terms of feeding skills.

Just under a hundred patients (95, 17%) were fully proficient in each of the feeding, washing and dressing areas, while almost three times that number (265, 48%) needed at least some degree of help in all three domains. (The shaving/menstruation item has been excluded from this analysis, since as has already been mentioned it did not apply universally across the population). Of the remaining individuals, 52 (9%) were totally proficient in at least two of the three areas, and 145 (26%) could manage unaided in just one.

Again, therefore, the picture that emerges is one of a population of quite heavily dependent individuals, a large proportion of whom require a very substantial degree of assistance in daily living skills.

2.5 Behavioural Difficulties

Behavioural difficulties were recorded for each patient in terms of six separate categories: aggressive-destructive behaviour (involving physically hurting other people and/or deliberately damaging objects and/or throwing severe temper tantrums), disruptive-hyperactive behaviour (ie interfering with the actions or peace of others, albeit not involving direct physical harm), self-injurious behaviour (ie physically hurting oneself), noncompliance (refusing to carry out or to comply with clearly understood rules or requests), offensive habits (ie unusual, repetitive or bizarre behaviour that, although offensive to other people, is non-criminal), and delinquent behaviour (ie behaviour that is both offensive to others and is - at least technically - a criminal offence).

Each category was rated in terms of whether it had presented a "severe", a "mild" or "no" management difficulty over the past two years only, as defined by either the intensity or the frequency of the problem behaviour. (Information on behavioural difficulties prior to the past two years was also collected as part of the survey, and is discussed below. It was considered important to make a distinction between the two, since it is not uncommon for some of our patients to be

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admitted for really very serious offences indeed, for example, but for them then to behave in an almost exemplary manner whilst in hospital.)

Table 17 summarizes the relevant data. In terms of presenting a severe management problem, the most frequently recorded category of behaviour was disruptive-hyperactive behaviour (26% of the population), closely followed by aggressive-destructive behaviour (24%) and then by noncompliance and offensive habits (21% each). Self-injurious behaviour represented a severe management problem in 13% of the population, with delinquent behaviour coming in last at some 8% only. This relative infrequency of delinquent behaviour is not particularly surprising, however, in view of the highly supervised environment of a hospital like Muckamore Abbey.

<u>Category of Behaviour</u>	<u>Extent of Management difficulty</u>			
	<u>Severe</u>	<u>Mild</u>	<u>None</u>	<u>Total</u>
Aggressive-destructive behaviour	134 (24%)	105 (19%)	318 (57%)	557 (100%)
Disruptive-hyperactive behaviour	143 (26%)	157 (28%)	257 (46%)	557 (100%)
Self-injurious behaviour	70 (13%)	77 (14%)	410 (74%)	557 (100%)
Noncompliance	116 (21%)	154 (28%)	287 (51%)	557 (100%)
Offensive habits	116 (21%)	141 (25%)	300 (54%)	557 (100%)
Delinquent behaviour	42 (8%)	46 (8%)	469 (84%)	557 (100%)

Table 17: Severity of behaviour-management problems

Aggressive-destructive behaviour was the only category where fewer residents were reported to present a "mild" management problem than a "severe" one - a finding which, at face value, suggests that aggressive-destructive behaviour if it occurs at all is especially likely to be severe in nature. Alternatively, of course, it could simply be a reflection of underlying staff perceptions of "difficult behaviour", ie in the sense that any aggressive-destructive behaviour is more likely to be viewed as severe than as mild.

There was a significant positive relationship between each of four of the behavioural problems and IQ, ie the higher the IQ, the greater the reported frequency and severity of behavioural difficulty. Not surprisingly, this was most pronounced for noncompliance ($X^2=70$, $df=4$, $p<0.001$), closely followed by delinquent behaviour ($X^2=49$, $p<0.001$), disruptive-hyperactive behaviour ($X^2=31$, $p<0.001$) and aggressive-destructive behaviour ($X^2=14$, $p<0.01$). The corresponding relationship between IQ and offensive habits was significant in the opposite direction ($X^2=12$, $p<0.02$), while for self-injurious behaviour the relationship with IQ just failed to reach statistical significance ($X^2=8$, $p<0.08$). The brighter residents were therefore relatively over-represented in terms of noncompliance, delinquent, disruptive-hyperactive and aggressive-destructive behaviour, while the more severely and profoundly handicapped were relatively more likely to engage in offensive habits and (although not to a statistically significant degree) in self-injurious behaviour.

Table 18 summarizes the numbers of patients with severe behavioural difficulties across the various problem-categories. Although half the population (50%) were reported as having no severe behavioural difficulties at all, and a further 20% as having severe difficulties in one of the six areas only, the remaining 30% of the population (ie some 166 individuals in total) were recorded as presenting a severe behavioural problem in more than just a single area. Indeed over 10% (58 cases) had severe problems in at least four of the six areas.

<u>Number of Categories Where a Severe Behavioural Problem was Recorded</u>	<u>Frequency</u>
0	279 (50%)
1	112 (20%)
2	68 (12%)
3	40 (7%)
4	39 (7%)
5	17 (3%)
6	2 (0%)
<u>Total:</u>	557 (100%)

TABLE 18: Patients showing various numbers of severe behavioural problems

These figures clearly show a very high incidence indeed of current and recent behavioural disturbance in the population. Yet the corresponding figure for behavioural problems prior to the past two years is even higher: some 79% (437 individuals) were reported to have presented at least some degree of management difficulty previously. There would seem to have been a definite reduction over the years in the extent of behavioural problems within individual patients, therefore - although the current levels throughout the hospital as a whole remain disturbingly high.

2.6 Major Daytime Placements and Other Specialist Services

Provision of daycare and other daytime placements within the hospital complex was recently reviewed and restructured, in recognition of the vital part that these have to play in the total package of treatment and training provided for the resident population. Quite apart from daytime placements, however, a wide range of other specialist services are available to the patients. This section of the report looks in turn at the provision of major daytime placements and at other professional services, both as presently provided and in terms of likely future requirements.

2.6.1 Major Daytime Placements

Not everyone was attending off-ward placements: as can be seen from Table 19, a sizeable proportion of the population remained on the wards during the traditional (Monday to Friday, 9 am to 5 pm) "working week". Indeed just over a third (34%) were ward-based throughout the week.

<u>Daytime Placement</u>	<u>Frequency</u>
Work (whether in/outside hospital)	12 (2%)
Adult Training Centre (ATC)	216 (39%)
Profound Unit (part of the ATC)	105 (19%)
Behaviour Nurse Therapy Department (disturbed individuals)	26 (5%)
School	5 (1%)
Other/college	1 (0%)
Ward-based	192 (34%)
<u>Total:</u>	557 (100%)

TABLE 19: Major daytime placements at present

For those who did attend off-ward departments, the on-site adult training centre (ATC) provided the major daytime placement for almost two-fifths of the population (39%), with just under a further fifth (19%) attending the specialized unit for the profoundly mentally handicapped, also on-site. The Behaviour Nurse Therapy Department, which specializes in the treatment of disturbed individuals (both children and adults) catered for 26 cases (5%), while some five of the younger residents (1%) attended the special school about half a mile from the hospital complex. Twelve patients (2%) were in full-time employment, the majority of them in on-site jobs.

Not all individuals were considered as presently attending the departments which were likely to be their most appropriate placement in the longer term, however. It was anticipated that at least some of those in the Behaviour Nurse Therapy Department in particular, for example, would be able to progress to other forms of daytime placement in the foreseeable future. "Potential" daytime placements were also recorded, therefore. A recommendation for a placement different to that being presently attended was made on behalf of 238 individuals (ie 43% of the total population). The majority of these, of course, concerned the 192 who were receiving no off-ward placements at all: as Table 20 shows, ward-based daycare was considered to be the most appropriate option for only 26 of those cases. At present, therefore, the system of daytime placements in Muckamore Abbey Hospital would appear to be at least 160 places short of requirement.

<u>Daytime Placement</u>	<u>Frequency</u>
Work (whether in/outside hospital)	27 (5%)
Adult Training Centre	255 (46%)
Day Centre (for elderly patients)	36 (6%)
Profound Unit	171 (31%)
Behaviour Nurse Therapy Department	31 (6%)
School	3 (1%)
Other/college	8 (1%)
Ward-based	26 (5%)
<u>Total:</u>	557 (100%)

TABLE 20: Potential daytime placements

The only type of placement which appears in Table 20 but not in Table 19 is "day centre". The notion here is of a centre specializing in activities for elderly people. The Muckamore Abbey site has no such provision at present, although clearly there would be a demand for same: 36 individuals (6%) would appear to be most appropriately placed in such a setting. Over 65 additional places in the profound unit, as well as around 40 more in the general ATC and a further 5 in the Behaviour Nurse Therapy Department are also required to meet demand. Approximately fifteen further residents are considered capable of holding down a full-time job, with about seven more than present being identified as suitable for attendance at college or some other form of specialized daycare.

2.6.2 Other Specialist Services

A significant number of other specialist services are currently available to the hospital population. Some, however (ie dietetics and occupational therapy) are not currently provided on site. Table 21 presents the extent of both current and required input from a whole range of such professional services. Notable by its absence from the table is "mental handicap nursing". This has been deliberately omitted, however, since clearly every patient in the hospital receives the services of that particular profession.

<u>Specialist Service</u>	<u>Currently Receiving Treatment</u>	<u>On Waiting List for Treatment</u>	<u>Assessment Required</u>	<u>Input Not Required</u>
Chiropody	141 (25%)	0 (0%)	1 (0%)	415 (75%)
Dentistry	64 (12%)	35 (6%)	1 (0%)	457 (82%)
Dietetics	14 (2%)	0 (0%)	103 (19%)	440 (79%)
Medicine (General)	245 (44%)	0 (0%)	2 (0%)	310 (56%)
Medicine (Specialist)	78 (14%)	1 (0%)	7 (1%)	471 (85%)
Nursing (General)	117 (21%)	0 (0%)	0 (0%)	440 (79%)
Occupational Therapy	0 (0%)	0 (0%)	82 (15%)	475 (85%)
Orthotics	59 (11%)	1 (0%)	3 (0%)	494 (89%)
Physiotherapy	155 (28%)	1 (0%)	5 (1%)	396 (71%)
Psychiatry	272 (49%)	2 (0%)	12 (2%)	271 (49%)
Psychology	32 (6%)	2 (0%)	64 (12%)	459 (82%)
Social Work	149 (27%)	17 (3%)	92 (16%)	299 (54%)
Speech Therapy	64 (12%)	32 (6%)	18 (3%)	443 (79%)

TABLE 21: Involvement of specialist services

"Psychiatry" was taken as referring to the clinical rather than the administrative functions of same, while "Medicine (Specialist)" refers to services normally provided by a specialist medical practitioner (a neurologist, for example, or a cardiologist), irrespective of whether those services were being provided by same or by a consultant psychiatrist. Also, "Medicine (General)" refers to the traditional services of a general medical practitioner, whether actually provided by a GP or by a member of the hospital medical staff instead. Only current and active courses of treatment were considered in all cases.

The most frequently-utilised services were psychiatry (49% of the population) and general medicine (44%), followed by physiotherapy (28%), social work (27%), chiropody (25%) and general nursing (21%). Dentistry and speech therapy had the largest waiting lists (6% of the population each), while the two professions currently not directly available on-site (dietetics and occupational therapy) were reported to be required for at least assessment purposes in the case of some 19% and 15% of the population respectively. Social work (16%) and psychology (12%) were also recorded as "assessment required" in a sizeable number of cases.

Most residents were in receipt of more than just a single specialist service. Around a quarter (25%, or 141 cases) were currently receiving treatment from two of the services available, with a further 18% (98) being treated by three different professions. The largest number of services providing active treatment simultaneously was eight (in the case of two individuals only), while 23% of the population (127) were being seen by one profession only and approximately 10% (54) were not receiving any form of active specialist treatment at all. A number of these latter individuals were either on a waiting list or due to be referred for specialist assessment, however, meaning that only 4% of the population (23 patients) were considered as not requiring even an assessment from any of the specialist services listed.

Almost half the patients (49%, 271) were reported as likely to require the continuing support of a local Community Mental Handicap Team following their possible discharge from the Abbey, with only 4% (23 individuals) likely not to require such follow-up. The remainder of the population (47%, 263) were considered unlikely to be discharged in the foreseeable future and so were not recorded in terms of that particular item. Clearly, though, ongoing specialist involvement is likely to be required, and for some quite considerable time, by the vast majority of patients discharged from the hospital.

Chapter 3 : Population Subgroups

The information presented in the previous chapter of this report gives a broad indication of the major characteristics of the hospital population as a whole. In examining needs for care, however, the focus must be on individuals or on groups of individuals with similar needs.

Three different classification systems are discussed in this present chapter. The first is by "care group", whereby hospital staff identified patients who shared sufficient basic characteristics (in terms of type of accommodation required, care practices, etc.) as to yield useful, albeit broad subgroupings. The second classification system is by "dependency level" (ie as recommended by the Development Team for the Mentally Handicapped, DTMH), which focuses on skill deficits, level of supervision required, etc. And the third method is by "placement category", which highlights whether each patient's individual needs could be best met in hospital or in a community setting and if the latter, the degree of support and care considered likely to be required to sustain such a placement.

3.1 Care Groups

Eight separate care groups were identified, with each patient being assigned to a single care group only: the elderly mentally handicapped, the multiply handicapped (ie physically as well as mentally handicapped), adolescents, those in need of admission and short-term treatment facilities, those requiring a semi-secure environment, the behaviourally disturbed, those with chronic/recurrent psychiatric illnesses, and those awaiting discharge or receiving specific rehabilitation training.

A hierarchial approach was adopted in assigning individuals to care groups, in which age and physical handicap were given precedence. Patients requiring admission/short-term treatment facilities, as well as those needing a semi-secure environment were relatively easily identified, although there was considerable overlap between the behaviourally disturbed and the chronic psychiatric populations in particular. Ultimate assignment to a single care group was on the basis of overriding or major care-requirements, and was undertaken by the appropriate consultant psychiatrist.

Table 22 presents the numbers of individuals in each care group. The multiply handicapped represented the biggest single grouping, with over a quarter of the population (ie 28%). The behaviourally disturbed constituted almost a further quarter (24%), with the rehabilitation/pre-discharge (19%) and the elderly (12%) groupings also representing sizeable numbers of patients. The adolescent care group was the smallest (2%), although this is not at all surprising in view of the already-noted relatively small number of younger patients in the hospital. Also not surprisingly, only 3% of the population were recorded as requiring the very specialized semi-secure type of environment which Muckamore Abbey currently provides to the mentally handicapped on a regional basis. Just over 8% of the population were recorded as having chronic-recurrent psychiatric illness as their major presenting feature and care-requirement.

<u>Care Group</u>	<u>Frequency</u>
Elderly	64 (12%)
Multiply handicapped	153 (28%)
Adolescent	12 (2%)
Admission/short-term treatment	25 (4%)
Semi-secure	17 (3%)
Behaviourally disturbed	136 (24%)
Chronic/recurrent psychiatric	46 (8%)
Rehabilitation/pre-discharge	104 (19%)
<u>Total:</u>	557 (100%)

TABLE 22: Distribution of the population in terms of care groups

The figures presented for the admission/short-term treatment care group must be viewed alongside the fact that this present report is concerned only with those individuals who had been in Muckamore Abbey for longer than three complete months by the target date of 9 September 1991. A large majority of the 21 non-respite cases who had been here for less than that period could also be assigned to the admission care-group, of course, which would therefore yield a relatively higher proportion of short-term treatment cases in the hospital than the 4% (25 individuals) reported in Table 22.

The number of patients in each care group within specific wards in the hospital is presented in Table 23. The wards have been grouped in terms of the major category of patients generally catered for, and in an order that parallels the care groups themselves: wards catering predominantly for elderly patients are listed first, therefore, followed by those dealing mainly with the multiply handicapped, then adolescents, admission/short-term treatment, semi-secure, behaviourally disturbed, chronic psychiatric and pre-discharge/rehabilitation.

Although wards do generally accommodate patients predominantly from one particular care group, only in one ward (Rathmullan) was the entire population from a single grouping. A further five wards drew their populations from only two care groups, while in the case of some nine wards altogether were the patients spread across as many as five or six different care groups. There is clearly scope for at least a certain degree of rationalization of the specialist services provided by individual wards, therefore.

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	Care Groups*								Total
	ELD	MLT	ADL	ADM	SSC	DIS	CRP	RHB	
Erne	20	4							24
Ennis	17	1				1	2	1	22
Firgrove	5	2							7
Greenan	8	19				1	4	3	35
Finglass	5	24				7			36
Moyola	8	21	1			5		1	36
Rathmore		24						1	25
Rathmullan		30							30
Cloonshee		17	3			5	1	4	30
Conicar		3	6			8		6	23
Movilla B		1		3	3	6	2	3	18
Fintona South				8		1	3	2	14
Movilla A				6	9		1	1	17
Fintona North				6	5	3	1	2	17
Cushendall		3		1		14	1	10	29
Cushendun		1	2			14	4	11	32
Moylena						23	1	2	26
Foybeg						15	4	9	28
Fennor						16	5	7	28
Mallow	1	2		1		7	3	10	24
Moyle		1				10	9	4	24
Birchill							1	9	10
Hillcrest							4	18	22
Total:	64	153	12	25	17	136	46	104	557

* (ELD = Elderly; MLT = Multiply handicapped; ADL = Adolescent;
 ADM = Admission/short-term treatment; SSC = Semi-secure; DIS = Disturbed;
 CRP = Chronic/recurrent psychiatric; RHB = Rehabilitation/pre-discharge)

TABLE 23: Number of patients in each care group, by ward

3.2 Dependency Levels

The Development Team for the Mentally Handicapped (DTMH) have produced a questionnaire/rating form to help identify four separate dependency levels amongst a population of (hospitalized) mentally handicapped individuals. The items are concerned mainly with behavioural difficulties and mobility and continence skills, but also include self-help skills, legal status (ie whether voluntary or detained) and frequency of epilepsy. Psychiatric status or personality factors are not considered, however. The four dependency levels indicated by the measure (ie from Level 1, the least dependent category, to Level 4) are detailed in Appendix II.

Every item from the DTMH form was incorporated directly into our own survey questionnaire, thereby enabling us to classify each resident precisely in terms of the DTMH system. The resulting frequency distribution is presented in Table 24.

<u>DTMH Dependency Level</u>	<u>Frequency</u>
Level 1	4 (1%)
Level 2	71 (13%)
Level 3	25 (4%)
Level 4A	124 (22%)
Level 4B	258 (46%)
Level 4C	75 (14%)
<u>Total:</u>	557 (100%)

TABLE 24: Distribution of the population in terms of DTMH dependency levels

Level 1 individuals are considered by the DTMH to be generally suitable for immediate discharge from hospital - either to a group home or to some other form of relatively independent community living, but without the need for any specialized facilities for management. Needless to say, in view of the large number of residents who have already been discharged from Muckamore Abbey over the past number of years, only a very small minority (1%, or just 4 individuals) of the present population fell into DTMH Level 1.

The DTMH consider Level 2 patients to be suitable for immediate discharge to a "traditional" type of hostel setting and, after a short period of pre-discharge training whilst there, to move on to a group home or other form of independent living in the community. Just over an eighth of the hospital population (13%) were assigned to DTMH Level 2.

Level 3 individuals are generally considered to require a further period of intensive training in a hospital setting prior to discharge, and then to continue to need a fairly substantial degree of support and supervision thereafter. Only 4% of the population fell into DTMH Level 3.

The remaining 82% (ie the vast majority) of the population were assigned to Level 4 in the DTMH system, which generally indicates a need for long-term residential care of a very highly supervised nature indeed. The major presenting difficulty in Level 4A is one of mobility, while in Levels 4B and 4C the main problems are with behaviour and continence respectively. The numbers of patients in these three sub-categories of Level 4 were in turn 124 (22%), 258 (46%) and 75 (14%). The need for supervision because of behavioural difficulties in particular, therefore, is especially apparent.

Table 25 summarizes the relationship between dependency levels (with Levels 1, 2 and 3 combined) and care groups in the hospital population. It shows that, in all eight care groups, the number of Level 4

<u>Care Group</u>	<u>DTMH Levels 1,2,3</u>	<u>DTMH Levels 4A,4B,4C</u>	<u>Total</u>
Elderly	22 (4%)	42 (8%)	64 (12%)
Multiply handicapped	13 (2%)	140 (25%)	153 (28%)
Adolescent	1 (0%)	11 (2%)	12 (2%)
Admission/short-term treatment	4 (1%)	21 (4%)	25 (4%)
Semi-secure	0 (0%)	17 (3%)	17 (3%)
Behaviourally disturbed	2 (0%)	134 (24%)	136 (24%)
Chronic/recurrent psychiatric	10 (2%)	36 (6%)	46 (8%)
Rehabilitation/pre-discharge	48 (9%)	56 (10%)	104 (19%)
<u>Total:</u>	100 (18%)	457 (82%)	557 (100%)

TABLE 25: Crosstabulation of DTMH dependency levels and care groups

individuals exceeded that for the other three levels combined. This was most pronounced for the semi-secure, behaviourally disturbed, multiply handicapped and adolescent groupings. Substantial minorities from the chronic psychiatric, the elderly and (in particular) the rehabilitation care groups did fall into Levels 1, 2 or 3, however.

The relationship between dependency level and level of intellectual functioning is summarized in Table 26. As expected, Levels 1, 2 and 3 were all more frequently encountered in the mildly mentally handicapped population (IQ 50+) than in the profoundly mentally handicapped (IQ <20). Distribution within Level 4B (which was characterized primarily by behavioural difficulties) was similarly related to IQ, while the opposite was true for each of Levels

<u>DTMH Level</u>	<u>IQ</u>		
	<u>50+</u>	<u>20-49</u>	<u><20</u>
Level 1	2 (2%)	2 (1%)	0 (0%)
Level 2	22 (19%)	45 (19%)	4 (2%)
Level 3	11 (10%)	9 (4%)	5 (3%)
Level 4A	8 (7%)	41 (17%)	75 (37%)
Level 4B	69 (59%)	119 (50%)	70 (34%)
Level 4C	4 (3%)	21 (9%)	50 (24%)
<u>Total:</u>	116 (100%)	237 (100%)	204 (100%)

TABLE 26: Relationship between DTMH dependency level and IQ

4A (mobility problems) and 4C (incontinence difficulties): they were both encountered considerably more frequently amongst the profoundly mentally handicapped. This difference between the IQ groups in terms of distribution of DTMH dependency levels was highly significant ($X^2 = 118$, $df = 10$, $p < 0.001$).

The breakdown of dependency levels by individual wards within the hospital is shown in Table 27. Wards are listed in the same order as in previous tables, although here percentages rather than absolute numbers of patients are presented.

	DTMH Dependency Level						Total
	<u>1</u>	<u>2</u>	<u>3</u>	<u>4A</u>	<u>4B</u>	<u>4C</u>	
Erne	0	25	0	50	4	21	100%
Ennis	4	50	0	14	18	14	100%
Firgrove	0	0	14	71	0	14	100%
Greenan	0	17	11	37	20	14	100%
Finglass	0	3	6	58	19	14	100%
Moyola	0	14	3	28	33	22	100%
Rathmore	0	0	0	80	4	16	100%
Rathmullan	0	0	0	90	3	7	100%
Cloonshee	0	0	0	27	17	57	100%
Conicar	0	22	0	4	61	13	100%
Movilla B	0	6	11	0	83	0	100%
Fintona South	0	7	14	7	71	0	100%
Movilla A	0	6	6	0	88	0	100%
Fintona North	0	6	6	0	88	0	100%
Cushendall	0	3	0	7	66	24	100%
Cushendun	0	12	6	0	69	13	100%
Moylena	0	4	0	0	92	4	100%
Foybeg	4	11	11	0	61	14	100%
Fennor	0	11	0	0	89	0	100%
Mallow	0	29	0	4	42	25	100%
Moyle	0	17	0	0	83	0	100%
Birchill	0	0	30	0	70	0	100%
Hillcrest	9	45	14	0	32	0	100%

Table 27: Dependency levels within wards

The data are fairly self-explanatory. The ten wards designated primarily for the care either of behaviourally disturbed individuals, adolescents, or those requiring either admission/short-term treatment or semi-secure facilities (ie those listed between Conicar and Fennor in Table 27) all had over 60% of their patients in DTMH Level 4B. Indeed, half of those wards had over 80% of their patients identified at that particular dependency level. Only Birchill (70%, one of the two wards in the hospital specializing in rehabilitation training) and Moyle (83%, catering predominantly for psychiatric cases) had a similarly high percentage of DTMH Level 4B patients.

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Levels 4A (mobility problems) and 4C (continence difficulties) were particularly prevalent in the nine wards listed first in Table 27 (ie those dealing specifically with elderly and multiply handicapped individuals). One of the wards for elderly patients, however (Ennis), had over half its population assigned to Levels 1 or 2. Only Hillcrest (the other ward providing specialized rehabilitation training) had an equally high percentage of such relatively independent patients: 9% in Level 1, 45% in Level 2 and 14% in Level 3.

3.3 Placement Categories

Each multidisciplinary ward review team had been asked to indicate what it considered to be the most appropriate form of residential placement for the various patients under its charge, both immediately and in approximately 6-18 months' time. Four options were available, depending on locality (ie whether in hospital or in the community) and on the amount of supervision and support considered likely to be required.

Table 28 presents the relevant data. The various options are listed in order of increasing supervision, with fairly independent community accommodation at the top and hospital care at the bottom. Indeed each of the first three options relate to community provision, with only the last of the four referring to hospital care. The phrase "community accommodation" has been used to signify any type of facility in the community, whether registered as a nursing home or as a residential home.

<u>Proposed Form of Residential Accommodation</u>	<u>Frequency</u>	
	<u>Now</u>	<u>6-18 Months</u>
Community accommodation providing minimum supervision	4 (1%)	15 (3%)
Community accommodation providing moderate supervision	15 (3%)	35 (6%)
Community accommodation providing maximum supervision	157 (28%)	237 (42%)
Hospital care	381 (68%)	270 (48%)
<u>Total:</u>	557 (100%)	557 (100%)

TABLE 28: Proposed residential accommodation, both now and in a further 6-18 months approximately

Just over two-thirds of the population (68%) were recorded as likely to require hospital care for at least the next few months, although significantly fewer than that (48%) were envisaged as needing hospital provision on a longer-term basis. There were corresponding increases in the overall proportions of the population considered most appropriately placed in all three types of community accommodation over the next number of months, although the vast majority of those deemed suitable for discharge were recorded as requiring a "maximum" degree of supervision: 89% of the 176 individuals who could be discharged immediately, and still some 83% of the 287 recorded as appropriately placed in the community by the end of the next year-and-

a-half. The implications of this for the types of residential accommodation that will need to be provided in the various Community Units over the next while are obvious, with a tendency towards higher rather than lower levels of staffing and general support.

Table 29 summarizes, in terms of "hospital" and "community" provision only (ie without a further breakdown of the various community options into differing levels of support provided), the recommended residential placements for each patient both now and in a further 6-18 months'

Proposed Residential Placements

<u>Now</u>	<u>6-18 Months</u>	<u>Frequency</u>
Hospital	- Hospital	269 (48%)
Community	- Community	176 (32%)
Hospital	- Community	112 (20%)
<u>Total:</u>		557 (100%)

TABLE 29: Proposed residential placements, both now and in a further 6-8 months approximately

time. One patient was actually considered as suitable for community placement immediately, but likely to deteriorate to the extent of requiring long-term hospital care within the next year or so. For the sake of simplicity, however, he will be considered throughout the remainder of this report as belonging to the first of the three subgroups presented in Table 29.

Almost half the population (48%) were identified as being likely to require hospital care on a continuing and probably long-term basis. A further third (32%) were recorded as being suitable for immediate discharge from the hospital. And the remaining fifth (20%) were reported as requiring a further period of treatment and/or training inside the hospital before eventual (ie in about 6-18 months' time) discharge into the community. These three groupings will be referred to extensively throughout the remainder of this report, and for ease of reference will hereafter be called simply the "long-term hospital" group, the "community" group and the "short-term hospital" group respectively.

Notwithstanding the overall levels of dependency and disability encountered in the population as a whole, it is clear from Table 28 that a good many of the patients - slightly in excess of half of them, in fact - had been identified as being most appropriately cared for in the longer term in community rather than in hospital facilities. As such, it is likely that any proposed "core" hospital of the future could be anything up to 50% smaller in size than the present establishment.

χ^2 tests were used to identify distinguishing characteristics of the placement category subgroups. They compared the three groupings across all appropriate variables separately, and the results of each test are summarized fully in Appendix III. Variables which indicated significant differences between the three subgroups are discussed below, in the following three sections of this report.

Just before then, however, it is perhaps worth noting that a number of variables did not suggest any significant differences between the three subgroups. These included sex, number of previous admissions to Muckamore Abbey, vision and hearing abilities, use of aids or appliances, epilepsy frequency (and use of medications for same), and requirement or receipt of services from speech therapy, occupational therapy, physiotherapy, orthotics, dietetics and dentistry. In terms of each of these thirteen variables, therefore, all three placement category subgroups may be considered as essentially paralleling the distribution of the population as a whole.

3.3.1 The Long-Term Hospital Group

This is the group which, provided it does indeed prove possible to secure appropriate community accommodation for every patient identified as suitable for discharge, will form the major part of any proposed core hospital of the future. Interestingly, it was also the group which most closely approximated the overall current population in terms of IQ: a third (33%, 89 individuals) were profoundly mentally handicapped (IQ <20), almost a half (45%, 122) were in the severe/moderate category of handicap (IQ 20-49), and about a fifth (22%, 58) had IQs over 50.

The long-term hospital (LTH) group tended to have more individuals over the age of 40 years (53%), although fewer who had been admitted to hospital before the age of 10 years. Relatively fewer had been in hospital for under one year (1% only).

Perhaps surprisingly, patients in the LTH group tended to be better than the population as a whole in terms of language skills, with a smaller proportion having no comprehension and/or expression abilities at all. More of them used speech (56%). As far as toileting and self-help skills were concerned, they tended to require a certain degree of assistance, rather than to be either completely proficient or completely dependent on others.

The major distinguishing feature of the LTH group, however, was the tendency for them to have a significantly higher proportion of severe behavioural problems. Indeed of the six behavioural categories considered, only in the case of delinquent behaviour were fewer than 10% recorded as presenting a severe management problem. Conversely, well over a third of cases were identified as such for both aggressive-destructive and disruptive-hyperactive behaviour. Significantly more of them were reported to have had a history of past behavioural problems too.

Severe psychiatric illnesses were also more common in the LTH group, with relatively more cases of the major psychoses (ie schizophrenia, depression and manic depression: 19%), organic psychosis (13%) and dementia (6%) than in the population as a whole. Correspondingly fewer individuals in this subgroup (43%) had never been attributed a psychiatric diagnosis at all.

Use of medication was more common in the long-term hospital group, with only 6% on no medication whatever. This trend was evident for all classes of medication (save for epilepsy), although it was particularly pronounced in the case of psychiatric/psychological problems.

Not surprisingly, in view of the high incidence of behaviour problems already commented upon, the majority of patients in the LTH group (64%) fell into Level 4B on the DTMH dependency system. This compares with a figure of only 46% for the hospital as a whole. Levels 1, 2 and 3 were relatively under-represented, on the other hand, as indeed was Level 4C (incontinent patients). The core hospital of the future is very likely to have a higher proportion of behaviourally disturbed residents, therefore, although with a smaller number of individuals with incontinence difficulties.

Apart from an increased incidence of disturbed individuals (including those who require a semi-secure environment), the elderly care group was also particularly represented in the long-term hospital group. There were fewer multiply handicapped and rehabilitation cases, however.

The majority (64%) of patients who were currently attending no off-ward daytime placements were from the long-term hospital group, although increased provision in the form of Behaviour Nurse Therapy Department and day centre places had already been proposed for them. Of the other professional services available, social work was identified as being relatively unlikely to be required by the LTH group, while general nursing, general and specialist medicine, psychiatry and chiropody were all recorded as being particularly appropriate and necessary.

3.3.2 The Community Group

Patients resettled from Muckamore Abbey in the past have tended to be relatively able and less dependent. Those identified as being suitable for immediate discharge in the present survey also included a relatively large proportion of DTMH Level 1 and 2 individuals (26% of the community subgroup only, or 60% of the entire hospital population of Level 1 or Level 2 individuals). A significant number (32%) were from the rehabilitation/pre-discharge care group too.

The majority of patients in the community subgroup, however, were considerably less able and more dependent than these. Indeed 30% of them were in DTMH Level 4A (mobility problems), with a further 27% in Level 4C (incontinence difficulties). Almost half of them (47%) were from the multiply handicapped care group.

It is clear, therefore, that the community group represents at least two discrete subgroups of individuals - the relatively independent, and those who, although of very low ability and with a marked degree of dependence on others, nevertheless present with no significant additional problems as to require them to be cared for in a hospital environment.

Both subgroups did share at least one common characteristic, however: they showed relatively few behavioural problems of any kind (either presently or in the past). They were also less likely to have had any history of psychiatric disturbance - particularly involving the major psychoses - or to be in receipt of medication of any kind (excluding anti-epileptic medication, of course, which was independent of placement category).

Almost half the community group (48%) were profoundly mentally handicapped (IQ 20), and a relatively large number of them (39%) had been admitted to hospital before the age of 10 years. (These figures compare with 37% and 25% for the hospital as a whole.) Also, significantly more of the community group had been in Muckamore Abbey for more than 20 years (58%, as compared to an overall hospital figure of 49%).

Relatively few of the patients in this group were fully ambulant (46%), while significantly more of them were reported as having additional physical disabilities or illnesses, and with corresponding limitations on their daily living activities. Communication, toileting and self-help skills were all relatively less advanced in the community group than in either of the other two placement categories, and indeed they were totally absent in a substantial number of cases.

Not surprisingly, the major daytime placement need for this group was noted in a significant number of cases to be a profound unit (38% immediately, 47% in the future). Social work was identified as being particularly appropriate, with each of psychology, psychiatry, general nursing, general and specialist medicine and chiropody being required to a lesser degree than for the hospital as a whole.

3.3.3 The Short-Term Hospital Group

The short-term hospital (STH) group was in many ways the opposite of the community group - or at least of the major part of the community group. There were fewer profoundly mentally handicapped individuals, for example, and proportionally more with IQs over 50 (27% and 33% respectively). They also tended to be relatively younger, with not so many over the age of 40 years. Indeed, just over a third (34%) were in their 20s, with another third (35%) in their 30s.

Relatively more had been admitted to Muckamore Abbey in their 20s (28%), although their most common age of admission was between 10 and 19 years (31%). They formed the major part of those patients from all three subgroups who had been in hospital for less than five years (46%) and, in particular, for less than one year (67%).

Significantly fewer STH patients were in hospital on a Voluntary basis (74%, as opposed to well over 90% for each of the other two placement subgroups). Patients detained under Part II in particular of the N Ireland Mental Health Order (1986), were correspondingly over-represented (21%).

Physical health and ability was relatively better in the STH group than in either of the others. More of them were fully ambulant (78%) and language, toileting and self-help skills were all relatively more advanced. A greater proportion was receiving no medication at all (21%, as opposed to an overall hospital figure of 12%). This was especially true for medications prescribed for health-related reasons.

There was relatively more psychiatric illness in the short-term hospital group, with over a third (34%) of all cases of schizophrenia in the hospital. Aggressive-destructive behaviour, offensive habits and self-injurious behaviour were encountered with neither greater nor lesser frequency than in the population as a whole, although delinquent behaviour in particular was relatively more common in the STH group (12% presenting with a mild management problem in that area, and a further 13% with a severe behaviour problem). Noncompliance was considered a problem in relatively more of this group than in either of the others (62%), as indeed were mild (although not severe) incidents of disruptive-hyperactive behaviour. Previous episodes of behavioural difficulties (ie prior to the past two years) were also recorded with greater frequency in the short-term hospital group (88%).

Fewer STH patients were assigned to DTMH Levels 4A or 4C, with proportionally greater numbers in Level 4B (56%) and Level 3 (10%). Indeed almost half (46%) of all Level 3 patients were in the short-term hospital group. This is not surprising, however, given that Level 3 includes all patients who fail to gain assignment to Levels 1 or 2 solely on the basis of Detained legal status - and as has already been noted, the STH group contained a relatively larger number of patients who were detained under current mental health legislation.

The admission/short-term treatment, chronic psychiatric and rehabilitation care groups were all relatively well represented in the short-term hospital group, while the elderly and multiply handicapped care groups were correspondingly under-represented. A significantly greater number attended the ATC department in the hospital, with fewer at the unit specifically for profoundly handicapped patients.

General nursing, general medicine and chiropody were all recorded as being relatively less frequently required by the STH group, whereas social work and psychology were noted to be in particular demand.

3.3.4 Placement Category Subgroups: Concluding Comments

The major similarities and differences between the three placement category subgroups are summarized overleaf, in Table 30. The long-term hospital group was essentially older than the other two, of medium ability in terms of communication, toileting and self-help skills (ie requiring some degree of assistance only), and with a higher prevalence of severe behaviour problems and major psychiatric illness.

The short-term hospital group was both the brightest and the youngest of the three, with a significant number on detention orders. Communication, toileting and self-help skills were advanced, and overall physical status was also better. Severe psychiatric illness and behaviour problems (particularly delinquent behaviour) were common.

The community group appeared to be made up of two separate subgroups of patients. Some were fairly able and relatively independent, although a much bigger proportion than in any of the other placement categories was profoundly mentally handicapped. They tended to have been in hospital for relatively longer, and their communication, toileting and self-help skills were particularly deficient. Behaviour problems and/or psychiatric illnesses were relatively rare.

	<u>Community Group</u>	<u>Short-Term Hospital Group</u>	<u>Long-Term Hospital Group</u>
Age, IQ and Legal Status	More profoundly handicapped	Younger and brighter; tend to be detained	Generally older
Communication, Toileting and Self-Help Skills	Poor or absent	Good	Medium (ie some help generally required)
Behaviour Problems	No (or mild only)	Yes (especially delinquent behaviour)	Severe (though not so much delinquent behaviour)
Psychiatric Illness	None	Yes (especially psychoses)	Yes (all major forms)
Major DTMH Levels	1; 2; 4A; 4C	3; 4B	4B
Major Care Groups	Multiply handicapped	Admission/short-term treatment; rehabilitation; chronic psychiatric	Disturbed; elderly; semi-secure
Major Daytime Placements	Profound unit	ATC	Behaviour Nurse Therapy Department; day centre; ward-based
Major Specialist Services Provided/ Required	Social work	Psychology; social work	Psychiatry; general nursing; general and specialist medicine; chiropody

TABLE 30: Summary of major similarities and differences between the three placement categories

The distribution of patients within each placement category across the various wards in the hospital is presented in Table 31. No ward

	<u>Community Group</u>	<u>Short-Term Hospital Group</u>	<u>Long-Term Hospital Group</u>	<u>Total</u>
Erne	3 (12%)	0 (0%)	21 (88%)	24 (100%)
Ennis	7 (32%)	3 (14%)	12 (54%)	22 (100%)
Firgrove	3 (43%)	0 (0%)	4 (57%)	7 (100%)
Greenan	8 (23%)	6 (17%)	21 (60%)	35 (100%)
Finglass	11 (31%)	5 (14%)	20 (56%)	36 (100%)
Moyola	16 (44%)	3 (8%)	17 (47%)	36 (100%)
Rathmore	20 (80%)	1 (4%)	4 (16%)	25 (100%)
Rathmullan	13 (43%)	7 (23%)	10 (33%)	30 (100%)
Cloonshee	22 (73%)	4 (13%)	4 (13%)	30 (100%)
Conicar	8 (35%)	5 (22%)	10 (43%)	23 (100%)
Movilla B	1 (6%)	7 (39%)	10 (56%)	18 (100%)
Fintona South	4 (29%)	5 (36%)	5 (36%)	14 (100%)
Movilla A	3 (18%)	5 (29%)	9 (53%)	17 (100%)
Fintona North	0 (0%)	7 (41%)	10 (59%)	17 (100%)
Cushendall	8 (28%)	9 (31%)	12 (41%)	29 (100%)
Cushendun	9 (28%)	8 (25%)	15 (47%)	32 (100%)
Moylena	1 (4%)	1 (4%)	24 (92%)	26 (100%)
Foybeg	7 (25%)	4 (14%)	17 (61%)	28 (100%)
Fennor	3 (11%)	4 (14%)	21 (75%)	28 (100%)
Mallow	11 (46%)	6 (25%)	7 (29%)	24 (100%)
Moyle	6 (25%)	5 (21%)	13 (54%)	24 (100%)
Birchill	2 (20%)	8 (80%)	0 (0%)	10 (100%)
Hillcrest	10 (46%)	9 (41%)	3 (14%)	22 (100%)
<u>Total:</u>	176 (32%)	112 (20%)	269 (48%)	557 (100%)

TABLE 31: Distribution of the placement categories, by ward

was catering for patients from a single category, and indeed the vast majority of wards (19) had patients from all three subgroups. Six wards did have over 70% of their population from a single placement category, however.

If a worthwhile and realistic core hospital of the future is indeed to be effected, based on the notion of a "centre of excellence" in the provision of mental handicap services, then clearly the question of rationalization of current provision within wards will need to be addressed directly, and throughout the entire hospital site.

One aspect of a core hospital is already clear, however: the overall dependency level in the future is bound to be higher than at present. This is readily discernible from Table 32, which shows the percentages of patients in each dependency level throughout the three placement categories separately, as well as for the hospital population as a whole.

DTMH Level	Community Group	Short-Term Hospital Group	Long-Term Hospital Group	Total Population
Level 1	2%	0%	0%	1%
Level 2	23%	11%	7%	13%
Level 3	5%	10%	2%	4%
Level 4A	30%	13%	21%	22%
Level 4B	13%	56%	64%	46%
Level 4C	27%	10%	6%	14%
<u>Total:</u>	100%	100%	100%	100%

TABLE 32: Relationship between placement category and dependency level

By comparing the percentages at each dependency level in the long-term hospital group with the corresponding figures for the population as a whole (ie the two columns at the right of the table), it is clear that there is likely to be a drop in the overall proportion of every dependency level bar one over the course of the next few years. The exception is for Level 4B individuals (severe behavioural problems), where the expectation is rather for a considerable rise in overall proportion, from the current level of less than half (46%) to almost two-thirds (64%) of the population. The future core hospital is not only likely to be smaller than the present establishment, therefore, but also to have a significantly increased proportion of behaviourally disturbed individuals. Indeed even since April 1991, the percentage of Level 4 patients in the hospital has risen by a full 2% (from 44 to 46%).

All of this depends on patients from the community and the short-term hospital groups being successfully resettled, of course. Table 32 shows that just under a third (30%) of patients in the community group were in DTMH Levels 1, 2 or 3. The remaining two-thirds, however (70%), were in Level 4 - indicating quite a substantial degree of dependence on others. These individuals are clearly going to require a very specialized form of community accommodation indeed if a realistic discharge from the hospital is to be effected for them. Certainly appropriate community placements for such a large number of highly-dependent people are not available at present, and until they do become so a significant reduction in the number of hospital patients - even among those already identified as not requiring hospital care - will simply not be possible.

The Community Units of Management throughout the Northern and Eastern Boards have obviously an extremely important role to play in the whole process of resettling patients from Muckamore Abbey. The following chapter of this report looks at the level of community contacts within the hospital population, and at the issue of identifying a relevant and appropriate Community Unit for every individual.

Chapter 4 : Community Contacts and Affiliation4.1 Contacts with Next-of-Kin and Others

Information concerning the next-of-kin (NOK) of the patients was collected in terms of both the legal NOK and the "practical" NOK (with the latter defined as the person - who may or may not be the legal NOK as well - who is most directly and practically concerned with the patients' affairs). Only 16 residents (3% of the total) had no NOK who was known to the hospital, while the legal and practical NOK were recorded as different individuals in the case of some 66 patients (12%) altogether. In only 43 of these cases, however (ie 8% of the total), were the legal and practical NOK actually living at different addresses.

Parents, as can be seen from Table 33, were the most frequently reported NOK, representing well over half the population in terms of both legal (63%) and practical (58%) NOK. The difference in these

<u>Relationship</u>	<u>Frequency</u>	
	<u>Legal NOK</u>	<u>Practical NOK</u>
Spouse	4 (1%)	3 (1%)
Parent	349 (63%)	322 (58%)
Child	1 (0%)	1 (0%)
Sibling	137 (25%)	156 (28%)
Other	50 (9%)	59 (11%)
None	16 (3%)	16 (3%)
<u>Total:</u>	557 (100%)	557 (100%)

TABLE 33: Relationship of next-of-kin (NOK)

two frequencies no doubt reflects the age and increasing frailty of a number of the patients' relatives: they are simply no longer able to keep in regular contact with their son or daughter, and have to rely on someone else (a sibling of the patient, very often) to maintain that contact for them. Siblings were recorded as the legal NOK in 25% of cases and as the practical NOK in 28%. Only one individual was recorded as having a child as NOK, and only four as being married.

Table 34 summarizes the extent of contact between the patients and their NOK, in terms of both "overnight contacts" (ie involving at least one overnight stay away from Muckamore Abbey) and "daytime contacts" (visits inside or outside the hospital, but not actually involving any overnight leave). This was recorded for the legal and practical NOK separately.

	Overnight Contacts		Daytime Contacts	
	Legal NOK	Practical NOK	Legal NOK	Practical NOK
Weekly/fortnightly	27 (5%)	28 (5%)	169 (30%)	178 (32%)
Monthly/quarterly	29 (5%)	30 (5%)	153 (28%)	162 (29%)
Half-yearly	13 (2%)	13 (2%)	35 (6%)	36 (7%)
Yearly	16 (3%)	16 (3%)	55 (10%)	52 (9%)
Less than yearly/never	472 (85%)	470 (84%)	145 (26%)	129 (23%)
<u>Total:</u>	557 (100%)	557 (100%)	557 (100%)	557 (100%)

TABLE 34: Frequency of contact with next-of-kin (NOK)

The vast majority of patients (around 85%) had either no or virtually no overnight contact with their NOK, although a significant number (approximately 5%) did have such contact on at least a fortnightly basis. Interestingly, the frequency of overnight contact with the practical NOK was only marginally higher than that for the legal NOK - suggesting that where a practical NOK is involved, his/her contact is restricted to daytime visits and outings only.

As expected, the level of daytime contacts was considerably higher than for overnight contacts, and for both legal and practical NOK. Around 30% of the population had at least a fortnightly visit from their NOK, with a comparable number receiving at least a three-monthly visit. Just under a quarter of the total either never or only very rarely indeed (ie less than annually) received a daytime visit from their NOK.

All told, therefore, in view of the ages of the residents, of the fact that the hospital has traditionally served a very wide catchment area indeed, and, perhaps particularly, of the length of time that a good many of the patients had been in hospital (see above, Table 6, for details) the level of NOK contact in Muckamore Abbey must be considered as extremely high indeed.

Not all NOK would be favourably disposed to plans for their relatives to be discharged from the hospital, however. This is clear from Table 35, which summarizes the NOK attitudes to a possible discharge (in general terms only, and as based on nursing or social work staff reports on individuals' perceptions, in the main). It also gives an indication of how the patients themselves were reported to view such a possibility.

<u>Attitude to Possible Discharge</u>	<u>Legal NOK</u>	<u>Practical NOK</u>	<u>Patient</u>
Highly favourable	41 (7%)	40 (7%)	64 (12%)
Favourable, but with some reservations	99 (18%)	101 (18%)	45 (8%)
Indifferent	18 (3%)	18 (3%)	217 (39%)
Against	140 (25%)	139 (25%)	39 (7%)
Not known	259 (47%)	259 (47%)	192 (34%)
<u>Total:</u>	557 (100%)	557 (100%)	557 (100%)

TABLE 35: Next-of-kin and patient attitudes to possible discharge from hospital

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Given that in approximately 90% of cases the legal and practical NOK were recorded as being the same individual (or at least as husband and wife), it is not surprising that the attitudes to discharge of the two categories of NOK were highly similar. A quarter of the population were known to have NOK who would be favourable to the possibility of discharge from Muckamore (albeit, in the majority of such cases, with some degree of reservation). A further 3% were known to be indifferent about such a prospect, while the opinions of almost half the NOK were simply not known. A substantial minority, however (25% of the population) were known to be against the whole idea of discharge from the hospital.

As far as the patients themselves were concerned, only 7% were recorded as being definitely against a possible discharge, with a further 20% being either favourably or highly favourably disposed to such a suggestion. Almost three-quarters of the population (73%) were recorded as either "indifferent" or "not known", which is no doubt at least partly a reflection of the very poor cognitive abilities (and in particular, communication skills) of a sizeable number of the patients.

In general, though, the patients themselves would tend to view resettlement in the community in a somewhat more positive vein than would their NOK. Even so, there remains a substantial amount of work to be done, with both patients and NOK alike, if the number of discharges projected above (in Chapter 3) is to be realised in a wholly satisfactory and agreed manner.

One thing which might help in this respect would be an increased use of community placements on a temporary basis by hospital residents, so as to present them with alternatives to institutional living and thereby to remove what is no doubt one of the greatest obstacles to their acceptance of the notion of discharge: a total ignorance (in practical terms) of any alternatives. Only 15% of the population (ie 87 patients) were recorded as having had at least some contact - usually involving overnight stays - with one or more community residential facilities either immediately prior or subsequent to admission to hospital.

Contacts other than with the named NOK were also recorded. Some 6% (34) of the population were noted to have significant contacts with other (non-patient) individuals, while slightly fewer than that number (5%, 26) were reported to have equally significant relationships with other residents - ie to the extent that plans for the possible discharge of one individual would need to be taken only in conjunction with similar plans for the other. These figures represent the extent of more than simply casual acquaintances, therefore.

4.2 "Owning" Community Units of Management

As was mentioned in the opening chapter of this report, one of the main aims of the survey has been to identify the currently most appropriate and meaningful Community Unit for every resident. Erstwhile affiliation had been on the basis of either home address or source of current admission - although clearly, in view of the very long time indeed that many of the population have been in Muckamore Abbey, the original Unit may no longer be the most appropriate one to target in terms of a possible discharge, etc.

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The multidisciplinary team involved with each case made a suggestion (based on the present address of the NOK in the main, but also on the extent of contact with the NOK and on the home address at time of admission, etc.) as to which particular Community Unit should be approached with a view to accepting "ownership" of the patient. Only a very small number of the multidisciplinary teams' suggestions were queried, and it was possible to quite quickly reach agreement with the appropriate Community Units throughout the Eastern and Northern Boards (ie the traditional catchment population of the hospital) in respect of each of their charges. (The WHSSB and SHSSB have to date not been involved in that process - the figures that follow for each of those two Boards, therefore, are as yet unconfirmed.) Patients for whom no single Community Unit could be readily identified were accepted by Bannside Unit if there was an affinity with the NHSSB in general, or else by North and West Belfast Community Unit.

The breakdown of the population by Community Unit/Area Board is presented in Table 36. Almost two-thirds of the population (65%) had been "owned" by Units in the EHSSB, with a further 29% by the NHSSB.

<u>Community Unit/Area Board</u>	<u>Frequency</u>
North and West Belfast	108 (19%)
North Down and Ards	68 (12%)
South and East Belfast	131 (24%)
Down and Lisburn	56 (10%)
Bannside	55 (10%)
Causeway	41 (7%)
Loughside	64 (12%)
SHSSB	17 (3%)
WHSSB	17 (3%)
<u>Total:</u>	557 (100%)

TABLE 36: Breakdown of the population by community unit/area board

The Southern and Western Boards each had 17 patients (3%) only. The Unit with the largest percentage of patients was South and East Belfast (24%) closely followed by North and West Belfast (19%). The remaining Units in both the Northern and Eastern Boards had between 12% and 7% of the population each.

Not only did the multidisciplinary teams recommend a particular Unit for each resident, they also indicated the degree of "relevance" of that Unit for the individuals concerned. In terms of a possible discharge specifically to the "owning" Community Unit, therefore, this was rated on a four-point scale from being "important" to actively "to be avoided". The relevant data are summarized in Table 37, which shows that the link between the patients and their "owning" Unit was considered as important in almost half the cases (49%) and as at least desirable in a further 29%. It did not seem to be particularly important either way in about a fifth of cases (19%) and it was actively to be avoided in the remaining 3% of patients only.

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<u>Relevance of Community Unit</u>	<u>Frequency</u>
Important	273 (49%)
Desirable	159 (29%)
Not at all important	106 (19%)
To be avoided	19 (3%)
<u>Total:</u>	557 (100%)

TABLE 37: Relevance of "owning" community units

All told, almost 80% of the population were recorded as still having at least a reasonably strong link with an identified Community Unit. Given that a large number of the patients had been in Muckamore Abbey for a very long period of time (see Table 6 for details), this can only be considered as an extremely high figure indeed. It also underlines the necessity to take possible links with Community Units of Management fully into account when discussing patients' suitability for resettlement, etc.

Table 38 presents details of the numbers of residents considered likely/not likely to be discharged from the hospital to each of the "owning" Community Units separately. The breakdown is in terms of the three placement categories identified above, in Chapter 3. Please note that the percentages refer to the numbers in each placement category within each Unit/Area Board individually.

<u>Community Unit/ Area Board</u>	<u>Community Group</u>	<u>Short-Term Hospital Group</u>	<u>Long-Term Hospital Group</u>	<u>Total</u>
North and West Belfast	31 (29%)	36 (33%)	41 (38%)	108 (100%)
North Down and Ards	24 (35%)	12 (18%)	32 (47%)	68 (100%)
South and East Belfast	50 (38%)	20 (15%)	61 (47%)	131 (100%)
Down and Lisburn	17 (30%)	11 (20%)	28 (50%)	56 (100%)
Bannside	20 (36%)	11 (20%)	24 (44%)	55 (100%)
Causeway	7 (17%)	9 (22%)	25 (61%)	41 (100%)
Loughside	18 (28%)	11 (17%)	35 (55%)	64 (100%)
SHSSB	5 (29%)	0 (0%)	12 (71%)	17 (100%)
WHSSB	4 (24%)	2 (12%)	11 (65%)	17 (100%)
<u>Total:</u>	176 (32%)	112 (20%)	269 (48%)	557 (100%)

TABLE 38: Distribution of placement categories, by community unit/area board

The overall percentages of patients considered as suitable for resettlement over the next 18 months or so is 47% for the three NHSSB Units and 55% for the four Units in the EHSSB - figures which reflect the greater discharge rate over recent years of Northern Board than of Eastern Board residents. The Causeway Unit is particularly advanced in this respect, with only 16 patients (39% of their total) still to be resettled.

Within the Eastern Board, the Down and Lisburn Unit has the smallest proportion of its population yet to be discharged (50%) while the North and West Belfast Unit has the highest proportion (62%). North and West Belfast did accept "ownership" of those patients for whom no other appropriate Unit could be identified, however, which has perhaps artificially increased their proportion of the overall population somewhat.

Only about a third of residents from both the Southern (29%) and the Western (36%) areas are likely to be discharged in the foreseeable future. This is not surprising, however, since the patients at present in hospital from those two Boards have been admitted in the main because of extremely problematic behaviour, and as such are likely to require hospital care on an on-going basis.

Overall, the picture that emerges from the Survey is one of a continued need for community residential provision throughout the province, and particularly in the area managed by the Eastern Health and Social Services Board. A considerable number of patients have been identified as not requiring long-term hospital care. Obviously they cannot be successfully resettled, however, until appropriate community facilities are made available. Continued cooperation between the hospital and community sectors is clearly vital.

Chapter 5 : Summary and ConclusionsChapter 1 : The Survey

This report provides details on the establishment of an information database in Muckamore Abbey Hospital and presents important basic information on every patient who had been in the hospital for longer than three complete months on 9 September 1991. The data had been checked and ratified by multidisciplinary ward review teams and included both standard assessment measures and clinical recommendations. It fell into three main categories: basic demographic, dependency and clinical details; needs for care, including requirements for hospital or community accommodation and specialist support services; and clarification of links with Community Units of Management, with a view to identifying an appropriate "owning" Community Unit for every patient.

Chapter 2 : Profile of the Hospital Population

- 2.1.1 There were more males than females and the majority of the patients (78%) were under the age of 50 years. 56% were under 40 years of age. Moderate, severe and profound levels of mental handicap (IQ <50) accounted for almost 80% of the total.
- 2.1.2 Bed occupancy in the 23 wards was very high. If one ward due for imminent closure is excluded, it stood at over 98%. More than half the population had been admitted before the age of 20, and almost half had been in hospital for over 20 years. Some 90% were Voluntary patients, with the majority of the remainder detained under Part II of the Northern Ireland Mental Health Order. A small yet significant minority (thirteen individuals) were detained under Part III of the Order.
- 2.2.1 Sensory handicap can be difficult to assess in the mentally handicapped, but 20% of the population were reported as having at least one problem and 3% had serious problems in both vision and hearing.
- 2.2.2 Regarding mobility, only 60% of the population could manage stairs independently, although a further 18% could manage single-storey accommodation on their own, either on foot or in a wheelchair. 18% needed human help even on the flat, and 4% were totally bedfast or chairbound.
- 2.3.1 Epilepsy was very common, with 32% having seizures. 12% had relatively severe epilepsy, with seizures more often than monthly.
- 2.3.2 Psychiatric disorders were also common, affecting 47% of the population at some time and being predominantly "major" in type.
- 2.3.3 Medication was used frequently for both general health (61%) and for psychiatric or behavioural difficulties (60%). 41% were on anti-epileptic medication, and only 12% were receiving no medication at all.

- 2.4.1 Some 50% of the population used speech, but more than 20% had no effective communication at all. The remainder used either gestures or some other communication system (eg, Makaton). At least a basic level of comprehension was believed to be present in over 90% of cases, however.
 - 2.4.2 Continence was a major problem. Approximately 50% had some degree of difficulty in this area, of whom the majority (around a third) had a severe problem.
 - 2.4.3 Whereas some 51% were proficient in feeding skills, significantly fewer were proficient in dressing (27%) or in washing (18%). These figures reflect a considerable degree of dependence on others, with 48% of the population needing at least some degree of help in all three areas.
 - 2.5 Half of the population had severe behaviour problems, and of those the majority (almost 30%) had problems in two or more areas. All categories of problem behaviour were represented, but the brighter patients tended to have particular difficulties in noncompliant, delinquent, disruptive-hyperactive and aggressive-destructive behaviour, while the less able were more likely to have problems in offensive habits and self-injury. A past history of behaviour problems was even more common in the population (79%).
 - 2.6.1 A range of daytime placements was available. The majority of patients had some sessions off-ward, although not as yet all who might benefit. Deficit areas identified included provision for the elderly and more places for the most profoundly mentally handicapped.
 - 2.6.2 The most frequently utilized specialist services were psychiatry (49%) and general medicine (44%), followed by physiotherapy (28%), social work (27%), chiropody (25%) and general nursing (21%). Some services identified as required were not provided on-site, ie occupational therapy (15%) and dietetics (19%). Two others had sizable waiting lists for assessment, which indicates relative under-provision of those services: social work (16%) and psychology (12%).
- Of those patients considered likely to leave hospital in the future, the vast majority were recorded as likely to require the continuing services of a Community Mental Handicap Team.

Chapter 3 : Population Subgroups

Three different approaches to measuring care needs were utilized: a practical, "care groups" approach, devised within the hospital itself; an objective approach using a well-known classification system used by the Development Team for the Mentally Handicapped (which was incorporated directly into the present survey); and an approach employing "placement categories", recommended by the multidisciplinary ward review teams and indicating whether individuals' needs were best met in hospital or in a community setting.

- 3.1 The multiply handicapped constituted the biggest single care group (28%), with the behaviourally disturbed (24%), the rehabilitation/pre-discharge (19%) and the elderly (12%) all constituting sizable care groups as well. Some 8% had psychiatric illness as their major

presenting difficulty. A group requiring semi-secure provision accounted for 3% of the population, which although small in percentage terms is nevertheless the equivalent of a ward of 17 patients. Only 2% fell into the adolescent care group, reflecting the hospital's current admission policy towards children.

Wards generally accommodated patients predominantly from one particular care group, and six represented no more than two groups altogether. Most wards, however, were caring for patients from a variety of care groups.

- 3.2 The Development Team for the Mentally Handicapped (DTMH) dependency levels were used to give some indication of the degree of supervision required by individual patients. 18% of the population fell into Levels 1, 2 or 3 (ie the three least dependent subgroups). The vast majority, however, fell into Level 4A (indicating severe problems in mobility), Level 4B (severe behaviour problems), or Level 4C (incontinence difficulties): 22%, 46% and 14% respectively. Severe behaviour problems were clearly predominant, therefore.

Those with severe problems in mobility or continence (ie DTMH Levels 4A or 4C) tended to be the more severely or profoundly mentally handicapped, while those in DTMH Levels 1, 2, 3 or 4B tended to be more moderately or mildly handicapped.

- 3.3 Just over two-thirds of the population (68%) were recorded as likely to require hospital care now, but significantly fewer (48%) on a long-term basis. The majority (ie well over 80%) of those considered suitable for community care were recorded as requiring a maximum degree of supervision.

Three placement category subgroups were identified: a long-term hospital group (requiring hospital care on a continuing basis, 48%); a community group (suitable for immediate discharge from hospital, 32%); and a short-term hospital group (suitable for discharge after a further period of treatment and/or training inside hospital, 20%).

- 3.3.1 The long-term hospital group tended to be older, of medium dependency in terms of personal care and communication skills, and with a higher prevalence of severe behaviour disorder and major psychiatric illness.
- 3.3.2 The community group was made up of two separate subgroups of patients. A number were fairly able and relatively independent, although a much bigger proportion than in either of the other two placement categories was profoundly mentally handicapped. They tended to have been in hospital for relatively longer, and their communication, toileting and self-help skills were particularly deficient. Behaviour problems and psychiatric illness were relatively rare, however.
- 3.3.3 The short-term hospital group was both the youngest and the brightest, with a significant number on detention orders. Communication and personal care skills were advanced, and overall physical status was also better. Severe psychiatric illness and behaviour problems (particularly delinquent behaviour) were common.
- 3.3.4 The long-term hospital group had proportionally far more patients in DTMH Level 4B than had the population as a whole (64%, as opposed to 46%). This suggests that the hospital of the future will have a significantly increased proportion of patients who are behaviourally disturbed.

Chapter 4 : Community Contacts and Affiliation

- 4.1 Only 3% of the population had no known next-of-kin (NOK). Approximately 30% had contact with their NOK at least fortnightly, with a similar number at least quarterly. Only about 25% had little or no contact at all with their NOK. Given the wide catchment area of Muckamore Abbey, as well as the considerable length of time that a good many of its patients have been in hospital, this represents a significant degree of family involvement, and one which should obviously be taken into account in resettlement plans, etc.

NOK and patients' attitudes to leaving hospital were recorded, if known. In fact, almost half the NOKs' attitudes were not known, and 25% of them were definitely against the possibility of their relatives being discharged from hospital. Patients, on the other hand, were less likely to be against the notion of discharge.

A small number of patients had significant relationships with other residents (5%), or with other individuals in general (6%).

- 4.2 Virtually two-thirds of the population (65%) were identified as belonging to the EHSSB, 29% to the NHSSB, and 3% each to the Southern and Western Boards. Attachment to particular Community Units was considered "important" in 49% of cases, and as at least "desirable" in a further 29%.

Community Units have been given an indication of how many of their patients fell into each of the three placement category subgroups. This will allow immediate plans to be made for those in the community group, and will give some indication of likely future requirements for community placements (ie for the short-term hospital group).

Conclusions

The "Hospital Survey", initiated at the end of 1989 and still ongoing, has now become an active database, with essential information relating both to the resettlement process and to the care requirements of the hospital population.

It is used to inform the planning process for both community and hospital services, and it allows for hospital-wide equality and uniformity in the selection of individuals who might be considered for community placements. In so doing, it enables consideration to be given to dependency levels, care needs and specialist services required, while at the same time respecting family and other important relationships.

Within the hospital, the Survey provides a means of monitoring changes in dependency levels, of highlighting particular subgroups of patients requiring similar forms of care, and of targeting available resources where needs have been identified for further treatment and/or training.

The Survey represents an unprecedented degree of cooperation between the hospital and community sectors. Continuation of that cooperation is clearly indicated.

Appendix I: The Information Collected on Each Resident

Basic Background Data:

Hospital File Number	IQ (<20, 20-49, 50-69, 70+)
Surname and Forenames	Ward and Hospital Consultant
Date of Birth, Sex, Religion	Legal Status (voluntary, detained)

Date and address when Registered as Mentally Handicapped
 Date, Home Address and Source of Original Admission to Muckamore Abbey
 Date, Home Address and Source of Current Admission to Muckamore Abbey

Number of Previous Admissions to Muckamore Abbey
 Date of Most Recent Discharge from Muckamore Abbey
 Address Most Recent Discharge was To

"Contact" Information:

(Note: Information regarding the next-of-kin, NOK, was collected in terms of both the legal NOK and the "practical" NOK, with the latter defined as the person - who may or may not be the legal NOK as well - who is most directly and practically concerned with the patient's affairs)

Relationship of NOK (mother, father, etc.)
 Name, address and telephone number of NOK

Frequency of NOK Contact Involving Overnight Stays Away from Muckamore Abbey

Frequency of NOK Contact Not Involving Overnight Stays Away from Muckamore Abbey

Attitude of NOK to Potential Discharge from Muckamore Abbey]	(highly favourable, some reservations,
Attitude of Client Himself to Potential Discharge from Muckamore Abbey]	indifferent, against, not known)

Short Summary of Visits To Other Residential Facilities
 Short Summary of Significant Contacts with Other Hospital Residents
 Short Summary of Significant Contacts with Other Individuals (ie non-residents)

Skills Data:

Vision (normal, poor, blind/almost blind)

Hearing (normal, poor, deaf/almost deaf)

Mobility (whether walks, uses wheelchair or needs to be carried; whether requires human help even on the flat, upstairs only or not at all)

Dexterity (whether no, some or most daily activities limited)

Aids/Appliances (eg helmet, splint, brace, hearing aid, catheter)

Daytime Wetting Episodes]

Nighttime Wetting Episodes] (whether 0, 1 or 2, or 3+ per week)

Soiling Episodes]

Toileting Habits (whether goes by himself, indicates a need, or requires to be taken/reminded to use the toilet)

Comprehension] (whether relatively advanced ability, concerning
Expression] basic needs only, or no real ability at all)

Major Method of Expression (speech, gestures, Makaton, etc.)

Feeding]

Washing]

Dressing] (whether proficient, requiring some
Shaving] help or requiring total help)

Menstruation]

Aggressive-Destructive Behaviour]

Disruptive-Hyperactive Behaviour] (whether presenting - over

Noncompliant Behaviour] the past two years only -

Offensive Habits] a severe, a mild or no

Self-Injurious Behaviour] management problem at all)

Delinquent Behaviour]

Medical Data:

Frequency of Epilepsy

Major Physical Illnesses/Disabilities (past as well as current)

Physical Limitations (whether no, some or most daily activities limited,
due to physical condition - including epilepsy)

Psychiatric Diagnoses (past as well as current)

Current Medication (whether requiring medication for a psychiatric/
psychological problem, for epilepsy, for a health
problem, or for some other reason)

"Placement" and Other Information:

Present Daytime Placement]	(school, Behaviour Nurse Therapy Department,
Potential Daytime Placement]	profound unit, ATC/SEC, day centre, work,
]	college/other, or ward-based)

Proposed Residential Placement Now]	(whether in hospital or in community
Proposed Residential Placement in]	facility, with an indication of
6-18 months approximately]	the degree of supervision required)

Community Unit of Management]	(whether important, desirable, not
Relevance of Community Unit]	important or to be avoided)

Involvement of Specialist Services (eg speech therapy, psychiatry, orthotics)

Likely Requirement, on Discharge,]	
for Involvement of Community]	(Yes, No)
Mental Handicap Team]	

Major Care-Grouping (elderly, multiply handicapped, disturbed, etc.)

DTMH (Development Team for the Mentally Handicapped) Dependency Level (1-4)

Date Reviewed

Appendix II: Characteristics of the DTMH Dependency Levels

(from the Development Team for the Mentally Handicapped)

- Level 1: Residents who are mobile, who are generally continent, who are competent in all areas of self-help, and who have no behaviour problems.
- Level 2: Residents who are ambulant (or at least partly ambulant), who have no more than mild problems only in behaviour or in continence (but not in both), and who have at least reasonable ability in self-help.
- Level 3: Residents who are ambulant (or at least partly ambulant), and who have no more than mild problems only in behaviour and in continence. (Level 3 also includes individuals excluded from Levels 1 or 2 solely because of marked epilepsy, detained status or extremely limited self-help skills).
- Level 4A: Residents who are non-mobile (including any who are also severely behaviourally disturbed and/or severely incontinent).
- Level 4B: Residents who are severely behaviourally disturbed (including any who are also severely incontinent, but excluding those in Level 4A).
- Level 4C: Residents who are severely incontinent (but excluding those in Levels 4A or 4B).

(Note: Levels 2 and 3 may be further subdivided if desired. For the sake of brevity, however, no such subdivisions are discussed in the current report.)

Appendix III: Summary of X^2 Tests Involving Placement Categories

The following pages summarize the X^2 tests which were conducted separately between placement category and all other appropriate variables, in an attempt at identifying the distinguishing features of each subgroup.

The three subgroups have been abbreviated throughout this appendix as follows:

COM = the "community group" (ie suitable for immediate discharge).

LTH = the "long-term hospital" group (ie requiring continuing hospital care).

STH = the "short-term hospital" group (ie suitable for discharge, although only after a further period of treatment/training inside hospital).

Variables are identified down the left-hand side of each page, followed by the categories into which they were grouped for the purposes of the present tests. These were usually the categories discussed throughout Chapter 2 of this report. In a few instances, however, some categories have had to be combined so as not to violate the essential requirements of the X^2 test (ie fewer than 20% of cells with expected frequencies of under 5, and no cell with an expected frequency of under 1). Combined categories are separated by commas in the appendix, those as actually used in the tests by slashes.

The outcomes of tests which produced significant X^2 values ($p < 0.05$) are detailed next. These are followed, as appropriate, by brief comments as to which of the subgroups deviated appreciably from the overall population distribution (ie as already discussed in detail, in Chapter 2).

<u>Variable</u>	<u>Categories</u>	<u>Results of X² Test</u>	<u>Main Variations from Overall Pattern</u>
Sex	Male/Female	(Not significant)	
IQ	<20/20-49/50-69/70+	X ² =28 df=6 p<0.001	COM : Relatively more profoundly handicapped (IQ <20); fewer with IQ 50+ STH : Relatively more with IQ 50+; fewer with IQ <20
Current Age	<20/20-29/30-39/40-49/ 50-59/60-69/70-79/80+	X ² =45 df=14 p<0.001	STH : Relatively fewer over the age of 40 years LTH : Relatively more over the age of 40 years
Age at Current Admission	<5/5-9/10-19/20-29/ 30-39/40-49/50+	X ² =39 df=12 p<0.001	COM : Relatively more admitted before the age of 10 years STH : Relatively more admitted in their 20s; fewer before the age of 10 years LTH : Relatively fewer admitted before the age of 10 years
Length of Current Stay in Hospital	<1/1-4/5-9/10-19/20+	X ² =66 df=8 p<0.001	COM : Relatively more have been in hospital for over 20 years; fewer for under 10 years STH : Relatively fewer have been in hospital for more than 10 years; more for under 5 years LTH : Relatively fewer have been in hospital for under 1 year
Number of Previous Admissions	0/1/2/3/4+	(Not significant)	
Legal Status	Voluntary/Guardianship, Detained:part II/ Detained:part III	X ² =45 df=4 p<0.001	STH : Relatively fewer Voluntary; more Detained:part II

<u>Variable</u>	<u>Categories</u>	<u>Results of X² Test</u>	<u>Main Variations from Overall Pattern</u>
Vision	Normal/Poor/Blind (or almost)	(Not significant)	
Hearing	Normal/Poor/Deaf (or almost)	(Not significant)	
Mobility	Fully Ambulant/Walks unaided on flat/Walks with help/Chair unaided on flat/Chair with help/ Bedfast or chairbound	X ² =37 df=10 p<0.001	COM : Relatively fewer fully ambulant; more in virtually every other category STH : Relatively more fully ambulant
Dexterity	No/Some/Many (daily activities limited)	X ² =21 df=4 p<0.001	COM : Relatively more for whom some or many daily activities are limited STH : Relatively more for whom no daily activities are limited
Use of Aids/ Appliances	Yes/No	(Not significant)	
Physical Illnesses/ Disabilities (excluding epilepsy)	Yes/No	X ² =6 df=2 p<0.05	COM : Relatively more with a recorded physical illness/ disability STH : Relatively fewer with a recorded physical illness/ disability
Epilepsy Frequency	Monthly/<Monthly/Never	(Not significant)	
Physical Limitat- ions (on daily activities)	No/Some/Many (daily activities limited)	X ² =23 df=4 p<0.001	COM : Relatively more for whom some or many daily activities are limited STH : Relatively more for whom no daily activities are limited

<u>Variable</u>	<u>Categories</u>	<u>Results of X² Test</u>	<u>Main Variations from Overall Pattern</u>
Medication for Any Purpose	Yes/No	X ² =21 df=2 p<0.001	COM <u>and</u> STH : Relatively more on no medication at all LTH : Relatively more on some form of medication
Medication for Epilepsy	Yes/No	(Not significant)	
Medication for Health Reason	Yes/No	X ² =22 df=2 p<0.001	STH : Relatively fewer on medication for health reason LTH : Relatively more on medication for health reason
Medication for Psychiatric/ Psychological Reason	Yes/No	X ² =45 df=2 p<0.001	COM : Relatively fewer on medication for psychiatric/ psychological problem LTH : Relatively more on medication for psychiatric/ psychological problem
Medication for Other Reason	Yes/No	X ² =18 df=2 p<0.001	COM : Relatively fewer on medication for other reason LTH : Relatively more on medication for other reason
Psychiatric Status	None/Past/Autism/ Psychotic/Organic/ Dementia/Personality Disorder/Neurotic	X ² =57 df=14 p<0.001	COM : Relatively more with no psychiatric record at all; fewer with a psychotic condition STH : Relatively more with a psychotic illness LTH : Relatively more with a psychotic or organic condition, or with dementia; fewer with no psychiatric diagnosis at all (Note: "Psychotic" includes schizophrenia, depression and manic-depression; "Dementia" includes senile and presenile dementia)

<u>Variable</u>	<u>Categories</u>	<u>Results of X² Test</u>	<u>Main Variations from Overall Pattern</u>
Language Comprehension	None/Basic level/ More than basic level	X ² =21 df=4 p<0.001	COM : Relatively more with no comprehension ability at all STH : Relatively more able to understand at an advanced level LTH : Relatively fewer with no understanding at all
Language Expression	None/Basic level/ More than basic level	X ² =33 df=4 p<0.001	COM : Relatively more with no expressive ability at all STH : Relatively more with advanced expressive ability LTH : Relatively fewer with no expressive ability at all
Main Method of Expression	Speech/Gestures/Other/ None	X ² =34 df=6 p<0.001	COM : Relatively fewer use speech; more have no main method of communication at all STH <u>and</u> LTH : Relatively more use speech; fewer have no method of communication
Daytime Enuresis	0/1,2/3+ episodes per week	X ² =13 df=4 p<0.01	COM : Relatively fewer with no episodes at all, or with under 3 episodes per week STH : Relatively fewer with more than 2 episodes per week
Nighttime Enuresis	0/1,2/3+ episodes per week	X ² =13 df=4 p<0.02	COM : Relatively fewer with no epsides at all STH : Relatively fewer with more than 2 episodes per week
Encopresis	0/1,2/3+ episodes per week	X ² =20 df=4 p<0.001	COM : Relatively fewer with none or under 2 episodes per week STH : Relatively more with no episodes at all
Toileting Habits	Independent/Indicates a need/Needs to be taken	X ² =25 df=4 p<0.001	COM : Relatively fewer independent; more require to be taken to the toilet STH : Relatively fewer require to be taken; more are independent in use of the toilet

<u>Variable</u>	<u>Categories</u>	<u>Results of X² Test</u>	<u>Main Variations from Overall Pattern</u>
Feeding Skills	Proficient/Help required/No real ability at all	X ² =41 df=4 p<0.001	COM : Relatively more with no ability at all STH : Relatively more proficient LTH : Relatively more needing help) (Note: The analysis of shaving/menstruation skills involved only those 481 individuals for whom it was appropriate/relevant
Washing Skills		X ² =56 df=4 p<0.001	
Dressing Skills		X ² =45 df=4 p<0.001	
Shaving/ Menstruation Skills		X ² =45 df=4 p<0.001	
Aggressive- Destructive Behaviour		X ² =73 df=4 p<0.001	COM : Relatively more with no problem at all; fewer with a severe problem LTH : Relatively more with a severe problem; fewer with no problem at all
Disruptive- Hyperactive Behaviour		X ² =69 df=4 p<0.001	COM : Relatively more with no problem at all; fewer with a severe problem STH : Relatively more with a mild problem only; fewer with no problem at all LTH : Relatively more with a severe problem; fewer with no or only a mild problem
Noncompliant Behaviour		X ² =66 df=4 p<0.001	COM : Relatively more with no problem at all; fewer with a severe problem STH : Relatively fewer with no problem at all LTH : Relatively more with a severe problem; fewer with no or only a mild problem
Offensive Habits		X ² =62 df=4 p<0.001	COM : Relatively more with no problem at all; fewer with a severe problem LTH : Relatively more with a severe problem; fewer with no problem at all
Self-Injurious Behaviour		X ² =50 df=4 p<0.001	COM : Relatively more with no problem at all; fewer with a severe problem LTH : Relatively more with a severe problem; fewer with no problem at all
Delinquent Behaviour		X ² =18 df=4 p<0.01	COM : Relatively more with no problem at all; fewer with a severe problem STH : Relatively fewer with no problem; more with a mild or a severe problem

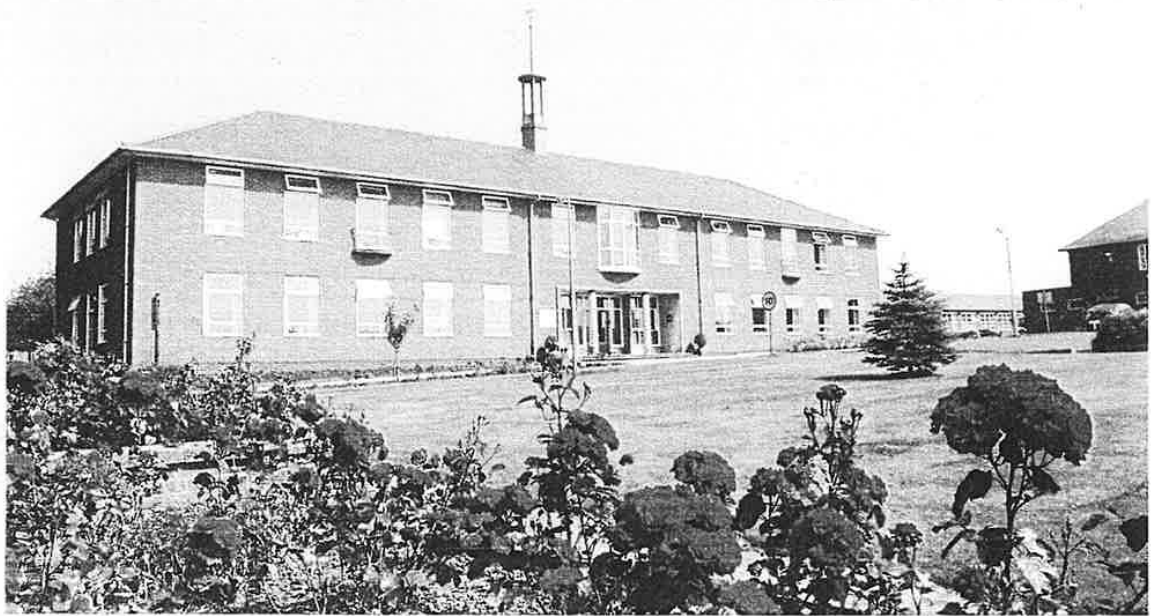
<u>Variable</u>	<u>Categories</u>	<u>Results of X² Test</u>	<u>Main Variations from Overall Pattern</u>
Behaviour Problems Prior to the Past Two Years	Yes/No	X ² =45 df=2 p<0.001	COM : Relatively fewer with past behaviour problems STH and LTH : Relatively more with past behaviour problems
Present Daytime Placement	ATC/Profound Unit/Behaviour Nurse Therapy Department/Other (work, school, college)/Ward-based	X ² =51 df=8 p<0.001	COM : Relatively more in the profound unit; fewer in the Behaviour Nurse Therapy Department, the ATC or ward-based STH : Relatively more in the ATC; fewer in the profound unit or ward-based LTH : Relatively more ward-based; fewer in the profound unit or the "other" category
Potential Daytime Placement	ATC/Profound Unit/Behaviour Nurse Therapy Department/Day Centre/Other (work, school, college)/Ward-based	X ² =115 df=10 p<0.001	COM : Relatively more in the profound unit; fewer in the Behaviour Nurse Therapy Department, "other" category or ward-based STH : Relatively more in the ATC or in the "other" category; fewer in the profound unit LTH : Relatively more in the Behaviour Nurse Therapy Department, the day centre or ward-based; fewer in the ATC, the profound unit or "other" category
Care Groups	Elderly/Multiply Handicapped/Adolescent/Admission/Semi-secure/Disturbed/Chronic Psychiatric/Rehabilitation	X ² =240 df=14 p<0.001	COM : Relatively more multiply handicapped and rehabilitation; fewer semi-secure, disturbed or chronic psychiatric STH : Relatively more admission, rehabilitation and chronic psychiatric; fewer elderly or multiply handicapped LTH : Relatively more elderly, semi-secure and disturbed; fewer rehabilitation or multiply handicapped
DTMH Level	1,2/3/4A/4B/4C	X ² =145 df=8 p<0.001	COM : Relatively fewer 4B; more 1, 2, 4A and 4C STH : Relatively more 3 and 4B; fewer 4A and 4C LTH : Relatively more 4B; fewer 1, 2, 3 and 4C

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2018



Muckamore Abbey Hospital



ON Information Resettlement QUALITY IN ACTION

NOVEMBER
1 9 9 1



INFORMATION BOOKLET

MUCKAMORE ABBEY HOSPITAL - A CHANGING HOSPITAL INTRODUCTION BY R.G. BLACK UNIT GENERAL MANAGER

The work of Resettlement in Muckamore Abbey Hospital has been ongoing for a number of years. As patients leave the hospital to take up opportunities to live in the community there are inevitable changes in the hospital. Patients who remain in hospital may have to move wards and staff will have natural anxiety about the future of their jobs and careers. The reality of course for many patients in Muckamore Abbey Hospital is that if appropriate accommodation had been provided in their local communities they would never come into hospital in the first place. In order to ensure that the task of returning these people to the community is properly co-ordinated and dealt with in a sensitive manner, I have appointed a small group of people called the Project Group for Resettlement and comprising:-

Mrs Norma Hetherington	—	Assistant Unit General Manager
Dr Maria McGinnity	—	Consultant Psychiatrist
Dr Ivan Bankhead	—	Principal Clinical Psychologist
Mr Oliver McMullan	—	Site Director
Mr Michael May	—	Principal Social Worker
		Representative from N H S S B

The Project Group take the lead role in securing new placements in the community and monitoring the work of resettlement. I have made a commitment to keeping staff, patients and families informed about resettlement and the work of the Group generally. To date, we have run three Information Days - August 1990, March 1991 and May 1991. One of these was to inform Community Units in both the N.H.S.S.B. and E.H.S.S.B. and, two of them directed towards keeping hospital staff in touch with the wider issues around resettlement. Later this year we intend to run another for Voluntary Groups, Parents and Carers.

At the last Information Day (May 1991), I gave a commitment to prepare a package of the information so that people could read and digest it at their leisure. Most people on the day found the facts and figures overwhelming to say the least. I appreciate that staff have the central role in successful resettlement and need to be kept informed. As we move to a specialist hospital, staff also need to be informed so that they can make important decisions about their future role in caring for people with a mental handicap. Clearly the people for whom we now provide care will continue to need care both in the community and in the specialist hospital. In recognition of this, we are committed to looking at staff needs for information, personal development and training.



THE PROGRESS OF RESETTLEMENT

1987 - 1991 DR MARIA MCGINNITY - CONSULTANT PSYCHIATRIST

The hospital has seen major changes in both the scale and quality of resettlement in the past four years.

When the D.H.S.S. Regional Strategy recommended a reduction of 20% in long stay hospital beds in 1986, this appeared to be an unrealistic expectation, given that for the previous ten years an average of only twelve successful placements were made outside of hospital annually. Very few of the 800 patients in the hospital were seen as suitable for the few new hostel beds which became available, and some 25% of those tried were returned after unsuccessful attempts. There were therefore not only very few opportunities for resettlement but a very limited range of residential placements in this "Service" led model.

The changes which have taken place have been as a result of the combination of a number of factors both outside and inside the hospital. The increase in potential places to suit hospital residents began when nursing homes for people with a mental handicap opened in 1986. Since then both nursing homes and residential homes have developed, varying in size and character and catering for a wide range of residents. At the same time, there has been continued pressure from within the hospital to reduce over-crowding (thereby improving conditions) and more recently (1990) for hospital retraction by reducing bed numbers. The effect of these resettlement discharges can be seen on the following graphs, showing firstly the reducing overall hospital population (Table 1) and then by ward, showing the substantial reduction achieved in overcrowding and the four retraction exercises - Moyle/Monard (24 beds) Maine (29 beds) Cappog (24 beds) and Firgrove (24 beds). (Table 2).

As the numbers being resettled has increased the hospital has had to make a number of changes - for example to respond to the demands for information regarding patients' suitability for particular facilities, to ensure that there was equity for all patients in consideration for Resettlement places, and increasingly to recognise patients' rights to be resettled.

The Hospital Survey is the culmination of a great deal of work prompted largely by the need for more information to ensure that all who should have the opportunity for resettlement could be considered when likely places arise, and that the information needed to facilitate placements is readily available.

It provides information which allows Community Units to plan facilities which will meet the needs of their hospital patients, who could be discharged to community care if suitable facilities are available.

To ensure the selection of appropriate patients for community placements, especially in new homes, a Resettlement Process has been in operation for some 18 months to guide the staff involved. This has been extended and modified to include a system of inspecting new homes, as well as making sure that all staff and relatives who should be included in the consultation are, and that they are informed of progress so that the patient can be best supported in his/her move from hospital.

Once staff could see the benefits of resettlement for individual patients, it became necessary to have an explicit policy statement to provide guidance on priorities and set quality standards. At all stages the patients' needs must be put first. The Hospital, Policy on Resettlement has now been fully discussed, amended and accepted (1991) (Table 3). We also have seen the necessity to recognise the rights of those patients who have to be moved within the hospital as a consequence of retraction and resettlement - hence the Policy Statement on Relocation (1991), issued at the same time.

The results of the Resettlement Programme to date are shown in Tables 4, 5, 6, 7. More than 200 patients have been successfully resettled since 1 January 1987 (Table 4). The majority of these have been in the Private Sector with a sizeable proportion in the Statutory, and only a smaller proportion in the Voluntary Sector (Table 5). All patients have a trial period of at least three months and up until the end of December 1990, six people have returned during this trial period; two had returned after the trial period indicating a breakdown of what was considered to be a successful placement. In both these instances new behaviours had arisen, which were unacceptable in the Unit.

A small number have also returned for short-term treatment - three patients within the trial period, and it is anticipated that the need for this support and treatment will increase as more dependant patients are resettled. A small number of deaths (6) have taken place since resettlement, and these we believe are not connected in any way to the process. As an indicator of the age of the patients resettled Table 6 shows that the majority have been between the ages of 20 and 60, but indeed a sizeable number are 60+. Many of these people have been in hospital for a very long time, in some cases over 30 years, and it is becoming clear that neither age nor length of stay in hospital are barriers to successful resettlement (Table 7).

We have therefore moved from the situation described in 1986 with very limited opportunities for resettlement into statutory homes, to the present situation where a range of accommodation exists and has been taken up on behalf of a large number of residents. The systems to ensure that this is a "needs led" resettlement are all in place and the emphasis now is on developing further the range of opportunity for multiply handicapped people and following up and supporting those already discharged. The task of staff in the hospital is to continue to offer choice about community living to patients and their families and ensure that if appropriate placements are available, we access them on behalf of our patients, in a way that meets our own quality standards.

'THE HOSPITAL SURVEY'

DR IVAN BANKHEAD - PRINCIPAL CLINICAL PSYCHOLOGIST

The major multi-disciplinary survey of our hospital residents, which has been on-going since 1 January 1990, was completed some time ago. It is intended, though, to regularly update the information we have gathered, and to add all future both medium and long term admissions to the database as well. There follows information extracted from the full report of the hospital survey made available to staff in November 1991.

Information has been collected so far on some 674 individuals. The present report, however, is concerned only with those 557 who were still in the hospital on 9 September 1991. (This represents a shortfall of some 38 on the total bed complement at present. It must be remembered, however, that the survey is concerned only with admissions of greater than three months' duration, and has always excluded any admission - including all "respite" admissions - of shorter than that period. The figures that follow, therefore, are all based only on those individuals who were resident here in September 1991, and who had been so for at least a full three-month period beforehand). Table 1 gives a breakdown of the population by age and by sex:

Table 1: Breakdown of the Population by Age and Sex:

Age (Years)	Male	Female	Total
<20	10	7	17 (3%)
20-34	131	79	210 (38%)
35-49	120	87	207 (37%)
50-64	31	40	71 (13%)
65+	23	29	52 (9%)
TOTAL:	315 (57%)	242 (43%)	557 (100%)

One of the major aims of the survey has been to identify the most appropriate "Community Units" for each of our residents. This has now been done, and formal agreements with the appropriate units throughout both the Eastern and the Northern Board areas have been agreed for every case. Perhaps surprisingly, in view of the very long time indeed that some of our patients have been in hospital, the link with a Community Unit has been identified as being "important" in almost 50% of cases, and as being at least "desirable" for a further 29% of patients.

Another major aim of the survey has focused on identifying three discrete subgroups of patients in the hospital: those who do not require hospital care at all (and who could therefore be discharged to "appropriate" community accommodation immediately – those who require a further period of treatment and/or training inside hospital, but who could hopefully be considered for discharge to community accommodation after that time; and those who will probably require hospital care on a long-term basis. The number of patients who fall into each of these categories is set out below:

Suitable for immediate Discharge	176 (32%)
Requiring Additional Treatment/Training	112 (20%)
Requiring Long-Term Hospital Care	269 (48%)
TOTAL:	557 (100%)

The Development Team for the Mentally Handicapped (D.T.M.H.) have devised a simple method for gauging the dependency-level of mentally handicapped hospital patients, based largely on measures of mobility, incontinence and behavioural disturbance. A four-level system is employed, and brief descriptions of each level (with Level 4 being further subdivided) is presented below:

Level 1: Residents who are mobile, who are generally continent, who are competent in all areas of self-help and who have no behaviour problems.

Level 2: Residents who are ambulant (or at least partly ambulant), who have only mild problems in behaviour or in continence (but not in both), and who have at least reasonable ability in self-help.

Level 3: Residents who are ambulant (or at least partly ambulant), and (Level 3 also includes individuals excluded from Levels 1 or 2 solely because of marked epilepsy, detained legal status or extremely limited self-help skills).

Level 4A: Residents who are non-mobile (including any who are also severely behaviourally disturbed and/or are severely incontinent).

Level 4B: Residents who are severely behaviourally disturbed (including any who are also severely incontinent), but excluding those in Level 4A.

Level 4C: Residents who are severely incontinent, but excluding those in Levels 4A or 4B.

The information provided by our own hospital survey allows us to assign a D.T.M.H. dependency-level to each of our residents. Bearing in mind that it is by no means a perfect measure of dependency, the breakdown of the population in terms of D.T.M.H. level does nevertheless throw up a couple of very important points. The figures are presented in Table 2.

Do remember as you look at this table, however, that the figures are in percentages - separately for each of the three subgroups of patients already discussed in terms of appropriate hospital/community placement, and then for the total present population of the hospital.

Table 2: Breakdown of the Population by D.T.M.H. Dependency-Level

D.T.M.H. Level	Suitable for Immediate Discharge	Requiring Further Treatment/Training	Requiring Long-Term Hospital Care	Total Present Population
1	2%	0%	0%	1%
2	23%	11%	7%	13%
3	5%	10%	2%	4%
4A	30%	13%	21%	22%
4B	13%	56%	64%	46%
4C	27%	10%	6%	14%
TOTAL:	100%	100%	100%	100%

Thirty percent of those individuals considered as not requiring hospital care fall into D.T.M.H. levels 1 to 3. The remaining 70%, however, are in level 4 - indicating a quite marked degree of dependency. These individuals are clearly going to require a very specialised form of community accommodation indeed, if a realistic discharge from the hospital is to be effected for them. Certainly "appropriate" community placements for such a large number of highly - dependent people are not available at present, and until they do become so, a significant reduction in the number of hospital patients -even among those who have already been identified as not requiring hospital care - will simply not be possible.

Let's assume for a moment, however, that it does prove possible to secure appropriate community accommodation for all but the "long-term hospital" group, ie, that everyone in each of the first two categories of patients is indeed discharged over the course of the next few years. That being the case, then the composition of the Muckamore Abbey Hospital of the future, in terms of the dependency-levels of its patients, is going to be at least pretty much as represented in the column headed "Requiring Long-Term Hospital Care". When that particular column is compared with the one on the far-right of the table (ie, representing the total population at present), it is clear that there will be a reduction (in percentage terms) in the numbers of patients in every D.T.M.H. dependency-level bar one - and that there will be a considerable increase in fact (from 46% to 64%) in the proportion of patients with severe behavioural disturbance.

Muckamore Abbey is likely, therefore, to find itself increasingly catering for patients with behavioural problems. Clearly that will have ramifications for the entire service that we are providing now, and that we will be expected to provide in the future.

THE HOSPITAL OF THE FUTURE

MRS NORMA HETHERINGTON - ASSISTANT UNIT GENERAL MANAGER
DR McGINNITY - CONSULTANT PSYCHIATRIST

Background – The Need for Specialist Care

There is increasing awareness of the prevalence of special problems in the care of people with a mental handicap and the need for specialist services. Depending on where surveys are done and the definitions they use for diagnosis, we find differing figures, but all show a high prevalence of behaviour disorder and psychiatric illness. People with mental handicap, we know, have a much higher prevalence of physical and sensory handicaps, and up to 30% have epilepsy, so there is complicated medical care in many cases too. With increasing handicap there are increasing difficulties in communication, and special skills are required to diagnose as well as care for these medical, psychiatric and behavioural problems. The principle of normalisation, while working towards enabling people with a mental handicap to use ordinary services, does not preclude special services to make sure that their maximum potential can be reached. The function of the hospital will be to assess, diagnose, treat and rehabilitate to appropriate community settings. Whilst accepting that in some instances the treatment period will be prolonged, the hospital would only in the most exceptional circumstances become a permanent residence. It is clear that this is one end of the continuum of care which is required if all the needs of people with mental handicap are to be met, and this hospital-type care is required to support community services.

Developing Specialist Services

If we examine what has been happening in Muckamore Abbey over the last five years, we can see that the hospital has been beginning to respond to the need to provide supporting service for community care, as well as to look after the existing population and re-examine how best this population might be cared for. On the one hand we have been clarifying what we have been doing at Muckamore Abbey while trying to work towards the basis of a specialist service.

Since 1985 we have had an Admission Policy which states that we only accept people who have a need for specific hospital care. However there still appeared to be a great need for social admissions and the respite care system with designated beds and prior booking was introduced in 1987. The embryo of a specialist hospital has been evolving from designated admissions units in the Movilla and Fintona complexes, the recent separation of the semi-secure function from admission and assessment, the development of the Rehabilitation Unit since 1987 and the specialist Day Care and Behaviour Nurse Therapy Services.

Changes in Patterns of Care

To allow us to concentrate more on those people who need hospital care, both short and longer term, we have been taking opportunities to resettle people who have no specific requirement for hospital care. In this way scarce funding might be spent on those who really need specialist services while at the same time recognising the rights of these people to have as good a quality of life as is possible to offer them outside of hospital. We have an increasing number of admissions for assessment and treatment, rising from 88 in 1989 to 105 in 1990. These admissions for assessment will increase as more dependent people are discharged through resettlement and require to come back in for short-term treatment. Indeed we are already seeing this happening.

Future Demands

So while we have been shaping some of the services which a specialist hospital might provide, we have been learning at the same time what the potential demand is for admissions for assessment and treatment from a community based service. We are also beginning to get some indication of who might constitute a new future long stay hospital population.

We know that not all of our patients who are admitted for assessment and treatment can be discharged out again and a small number continue to need hospital care, approximately 20 per year.

We are therefore in a position to estimate not only the likely functions of, but also the numbers of beds required in the future specialist hospital. By adding the number of beds needed for assessment and treatment to the numbers from the long-stay hospital group identified in the hospital survey, and taking account of the new long-stay group, we arrive at approximately 400 beds.

The hospital of the future will, we think, have three main elements:

1 Active Treatment Function for

- Specialist admission
- Short Term Treatment
- Semi-Secure Unit
- Adolescent/Autistic Service
- Behaviour Therapy Department
- Rehabilitation
- Day Care

2 Continuing Care/Treatment Function for

- Elderly (with and without Dementia)
- Multiply handicapped
- Disturbed Behaviour
- Chronic Psychiatric Illness

3 Therapeutic Support Services Including

- Psychology
- Professions Allied to Medicine, (Speech Therapy, Physiotherapy, Occupational Therapy, Chiropody, Orthotics, Dietetics)
- Pharmacy
- Dentistry
- Social Work

There are clear principles which should underly a core hospital.

- Centre of Excellence
- Specialist Treatment and Care
- Highly Trained Staff
- Explicit Admissions and Discharge policy
- Explicit operational Policies
- Dynamic Management Approach



What Have We Done So Far

While there has been an obvious increase in resettlement and discharges, already detailed, there has also been work going on in tandem to prepare us for the specialist hospital of the future.

- Ongoing investment in plant and equipment
- Rehabilitation Review and relocation in Birch Hill and Hillcrest
- Day Care Review and introduction of a single day care structure
- Plans for the Semi-Secure Unit upgrading
- Plans for Admissions Facilities
- Site Development Planning Group
- Major Submission to Area Board re baseline funding

Clearly Muckamore Abbey Hospital will continue to care for its current in-patients unless they move to a more appropriate home in the community. The size and exact nature of the hospital depends on the development of appropriate facilities in the community and on the trends in new long stay and treatment admissions in the future. But experience in this hospital and elsewhere leads us to believe that we should plan our services on the foregoing basis as an essential part of the continuance of care for people with a mental handicap.

Resettlement-Manpower Implications

MR. EAMONN MOLLOY - DIRECTOR OF PERSONNEL

The process of resettlement has obvious consequences for staff in the hospital not only in terms of the number of staff required to care for a reducing patient population but more importantly the skills and expertise that will be needed to effectively provide high quality care for a more dependent patient population.

The existing staff in the hospital are highly skilled and are totally committed to the specialist work that they do. It is important therefore to recognise their continuing contribution and co-operation in the resettlement process.

To manage this process effectively it is of paramount importance to develop and maintain appropriate methods of communication to ensure that all staff are aware of progress in resettlement. To this end, regular staff information days are held and department based briefing sessions are actively encouraged.

Resettlement and its consequences precipitated the need for a reappraisal of present and future manpower requirements.

Firstly to create a detailed manpower profile in terms of their age range, gradings, skill levels and specialist knowledge.

Secondly, to retain the existing high calibre workforce in sufficient numbers by identifying the future patient population and their associated levels of dependency and cross matching the skills that will be required of the staff to care for them. In addition, it is important to gauge the relationship between the hospital workforce and the community.

Thirdly, to identify the potential requirement to retrain or re-skill the existing staff to enable them to respond to future patient demands by exploring educational courses and familiarisation attachments in community settings. This has necessitated a closer working relationship with educational establishments in terms of course design and the securing of course nominations.

The Unit also has developed a sophisticated manpower strategy which has focused on the demand and supply of manpower, more effective utilisation of the existing staffing by highlighting the need to examine skill mix and developmental requirements. To address these issues the Unit has embarked on a nursing skill mix study in conjunction with the Nuffield Institute of the University of Leeds to enable the Unit to provide an agreed skill mix baseline for wards and associated departments. It should be noted that such a study has never before been undertaken in the specialism of Mental Handicap nursing. The Unit is therefore delighted to be chosen as the first national pilot site for this study.

The Unit General Manager has also commissioned the University of Ulster to examine in detail, the staff development and training requirements of nursing staff in the Hospital to address any potential skill or experience deficiency which may arise as a consequence of the resettlement process. This study will essentially focus on four key development areas namely:-

- Organisational**
- Educational**
- Policy Issues**
- Care and Practice Issues**

The Manpower Strategy has also attempted to address the impact of national initiatives such as the recent changes in nurse education associated with Project 2000 and the national Curriculum for Vocational Qualifications.

The policy of the Unit to maintain a high level of communication has enabled the staff to be reassured about the future and hopefully has allayed fears and apprehension about the consequences of resettlement. Additionally, the Unit's commitment to controlling manpower levels including closely monitoring turnover of staff has facilitated internal movement of staff within the Hospital to more effectively address the needs of the patients and minimise the risk of redundancy.

The Unit will continue to promote its philosophy of providing high quality care for patients by ensuring that staff are fully equipped and developed to meet existing patient needs and the demands of the future.

Striking the Balances

The Development of a Specialist Practitioner Role for People With Mental Handicap at Muckamore Abbey Hospital

DR DAVID SINES- (SENIOR LECTURER MENTAL HANDICAP)

DEPARTMENT OF NURSING AND HEALTH VISITING-(UNIVERSITY OF ULSTER)

This paper describes the ways in which mental handicap nurses may wish to apply their skills within the context of the mixed economy of care provision following the enactment of the National Health Service and Community Care Order (1991). These changes herald a range of opportunities for professional careers and support staff.

Some have described this the era of the mixed economy of care as one within which the franchise for providing such services will no longer rest with the National Health Service (or indeed with the Social Services in many instances) and we will soon witness the proliferation of a number of "not for profit", independent sector and consortia developments which will be involved in providing direct care provision for a variety of people under contract to Health and Social Service Boards.

In the future nursing skills may be provided and deployed in a totally different way which will be determined by the skills and competencies that nurses are able to demonstrate in response to client need rather than one on the facilities within which they have provided their skills on the past. Such an approach is therefore 'facility independent'.

In May 1990 the four Chief Nursing Officers of the United Kingdom commissioned a working group to consider the most effective and efficient way that mental handicap nurses could deploy their skills to meet the needs of people with mental handicap and their families within a multi-agency context of care. Their Report has now completed its consultation phase with the profession and will be published shortly.

The Chief nursing Officers stated in their terms of reference that the skills of mental handicap nurses should respond directly to the needs of people with mental handicap. In so doing they recommended the introduction of a care management approach to identify needs. Care management is an holistic approach to matching people's needs to a range of available resources in a given locality and thereafter ensuring that these needs are responded to in the way in which consumers would wish. Emphasis will therefore be placed on greater individual choice in the context of a client centred approach.

In this model, demand for skilled mental handicap nursing intervention will be determined as part of the care management process and mental handicap nurses will need to define the unique

contribution that they are able to make within the context of a mixed economy of care and will demand that they market their "product" within a potentially competitive culture.

A significant number of persons currently living in mental handicap hospitals and in other N.H.S. managed community accommodation may not require intensive nursing support and through application of care management and through the provision of a wider range of choice, it may be that Boards begin to rationalise the ways in which they offer intensive support services to people with mental handicap.

The National health Service will continue to have a specific role to play in the provision of such services but will begin to restrict its provision of residential accommodation to those persons who require intensive nursing support. Specialist mental handicap nursing care may therefore be offered to those persons with mental handicap who have associated mental health needs, behaviours that seriously challenge the skills of staff, additional sensory and physical handicaps which require medical and nursing support and to those elderly persons who by virtue of frailty and dependence require 24 hour care from skilled nurse practitioners.

It is my belief that the future shape of National Health Service provision will therefore move towards striking a balance between the provision of residential care at Muckamore Abbey Hospital and its associated outreach and support services and community care models. The formula which underpins this model is the flexible deployment of mental handicap nurses across traditional agency boundaries in order to ensure that all persons with mental handicap have access to the skills of these practitioners wherever they live for specific periods of time during their lives.

What then will the N.H.S. offer in the future?

- Assistance in preparing and facilitating people with mental handicap to access and use ordinary services in the community;
- The provision of services in support of Social Services, the Voluntary and Private Sector by assisting in the assessment of need and through the provision of responsive services to enable people to stay in their own homes;
- Specialist provision for those people who continue to challenge our skills and services by reason of behavioural presentation or a mental health need and for whom special assessment and treatment facilities may be necessary in hospital and in the community.
- Whilst the majority of people will be able to live in integrated settings in the community there may be a significant number of people whose needs can best be met effectively within a N.H.S. context and where the necessary specialist skills are concentrated (eg, people with physical, sensory, behavioural or psychiatric needs).

The challenge for nurse education will be to produce qualified practitioners who have the ability and confidence to adopt a professional approach to their work, making their own decisions about practice and accepting responsibility for those decisions in whatever agency they are working. Qualified practitioners will require access to opportunities for continuing education which will assist the practitioner to acquire professional maturity and expertise in areas of their choice in response to individual client needs. Consequently each nurse will require an individual personal package and training profile which identifies his/her needs, strengths and weaknesses. In response nurses will need to feel confident that they have a developing and emergent career structure and their skills are valued within multi-disciplinary and multi-agency teams.

We may soon be witnessing the emergence of "advanced practitioners" practising in the speciality. The P.R.E.P.P. proposals published by the U.K.C.C. provides a sensitive framework for individual nurse preparation for specialist practice and such a model is advocated within the context of this paper.

Examples of specialist practitioners are:

- **Co-ordinators of 'challenging behaviour';**
- **Interpersonal skills counsellors;**
- **Community mental handicap nurses acting as consultant nurses;**
- **Behaviour therapists;**
- **Care managers;**
- **Monitors and evaluators of service quality;**
- **Advanced practitioners in the care of people with sensory and multiple handicaps (eg, 'alternative therapies').**

In support of the notion of the advanced practitioner, nursing must also generate its own body of knowledge and research. The emergence of new practice centres or development units within the mental handicap nursing field may soon be witnessed. Such centres of excellence may provide opportunities for the acquisition of the advanced skills referred to in this paper and introduce a new breed of nurse practitioner for those persons who have specific health related needs.

Mental handicap Nurses will also require responsive and effective management and new systems will need to be devised to ensure they receive personal supervision from their managers. Nurses will also need to learn how to accept personal responsibility and accountability for their work practice in dispersed services and as such they will move from the concept of corporate responsibility to one of individual accountability as partners with clients.

What of Muckamore Abbey Hospital?

Steady progress is being made to relocate many people who currently live in hospital and if local circumstances and resources permit more people will find new homes in the community during the next few years. However, it is most unlikely that everybody who can will move to the community for at least a decade or so. Consequently health boards have a continuing responsibility to care for all people living in hospital accommodation. They will need to aim to ensure that the quality of care people receive is constantly evaluated and improved. It is apparent that nurses will continue to be most important agents in realising this objective. Their role and contribution is therefore valued and acknowledged.

It is on the basis of this analysis that I believe that nurses working with the Eastern Health and Social Services Board will be offered opportunities to deliver their skills and competences. If the workforce rises to this challenge that I believe that we will soon be witnessing the reemergence of a specialist nurse practitioner for people with mental handicap.

**BED COMPLEMENT –
MUCKAMORE ABBEY
1987 - 1991**

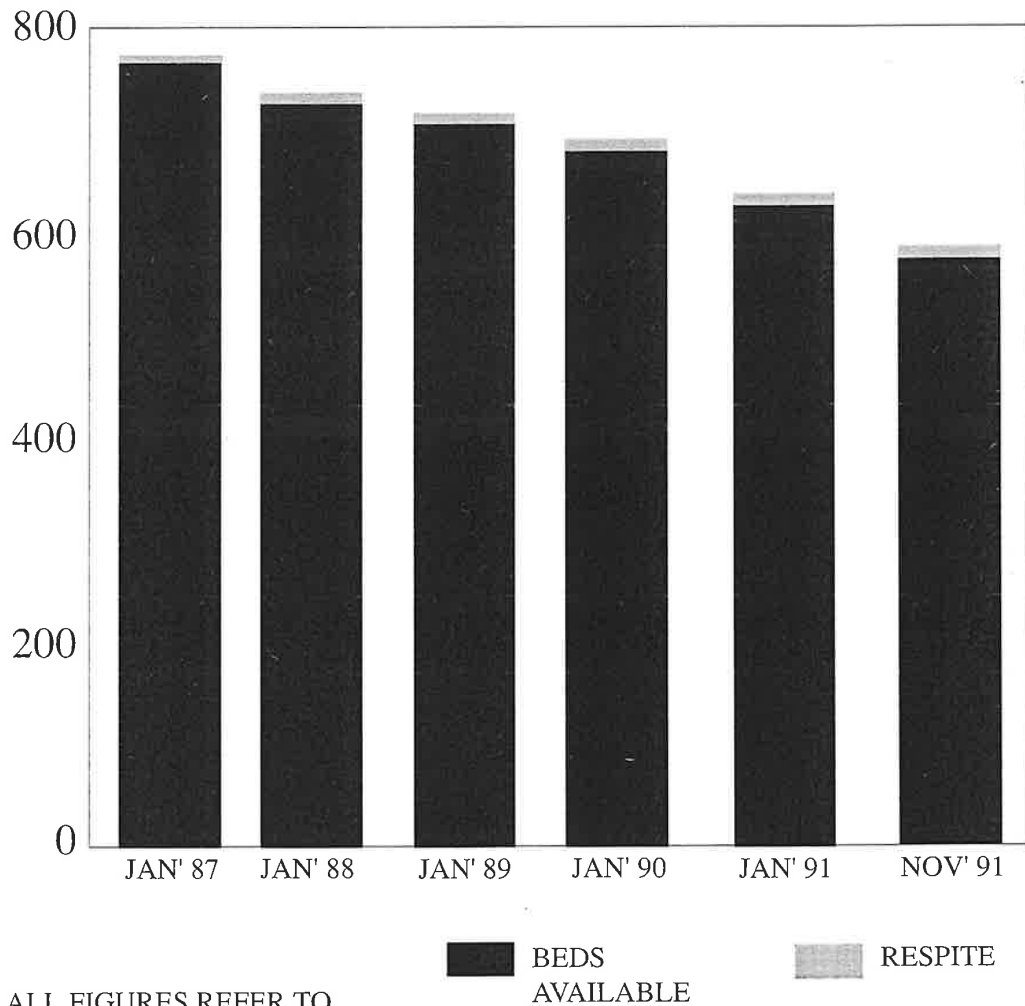


Table I.

THE NUMBER OF HOSPITAL BEDS BY WARD: JAN' 87 AND SEPT' 91

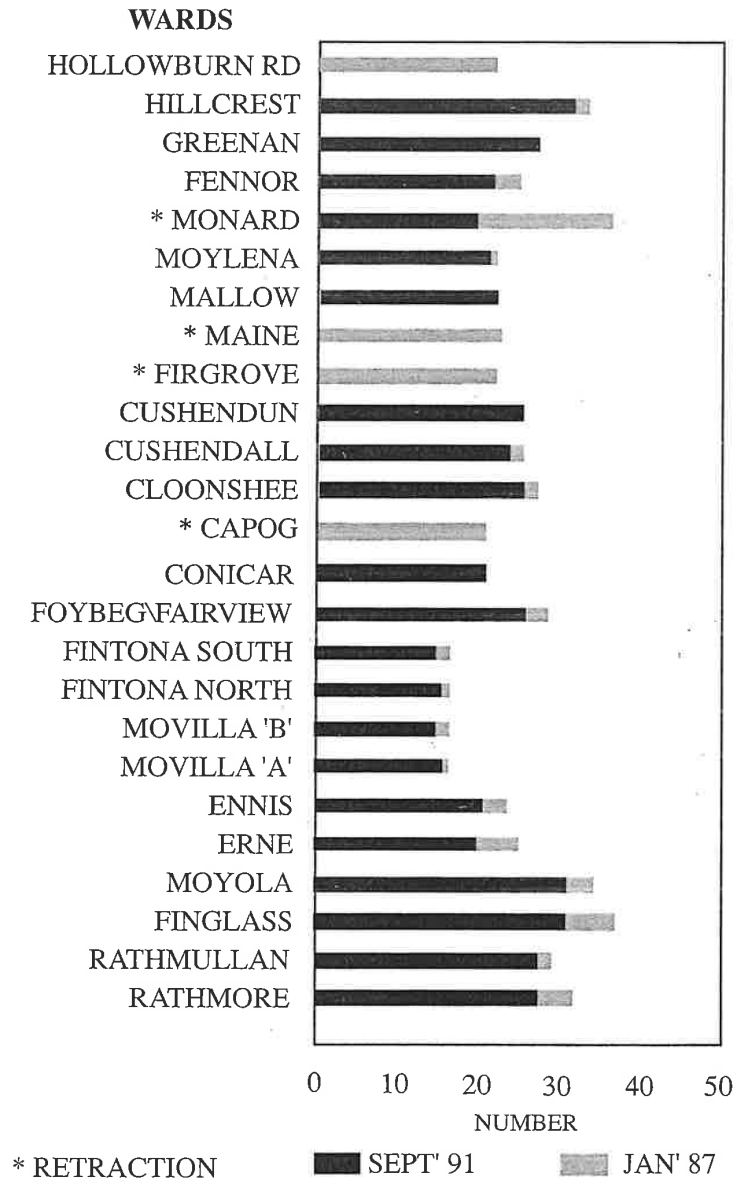


Table 2.

RESETTLEMENT PRINCIPLES

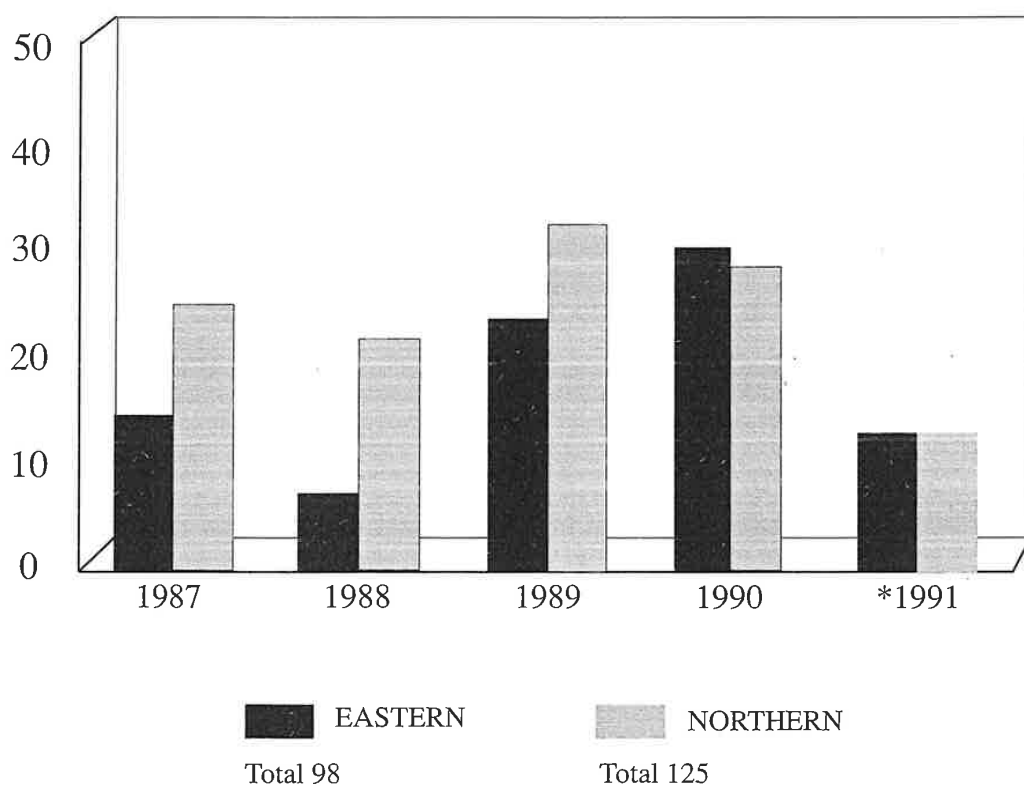
Resettlement is the process whereby discharge of long stay patients into a community setting are effected in a planned and co-ordinated manner, to meet individual needs.

- Persons not requiring hospital care should be enabled to reside in a suitable community setting.
- All aspects of resettlement should be based on a multi disciplinary assessment of patients' needs.
- Every person determined as suitable for resettlement has a right to be resettled regardless of level of disability.
- The person should have involvement at all stages in plans being made and his/her choice enabled and respected.
- Relationships important to the person, whether with family members, staff or other hospital patients, should be respected throughout the Resettlement process.
- The alternative setting should meet the person's need for care (including specialist needs) providing opportunities for personal and spiritual development, community involvement, and participation, to the extent that his/her experience is dignified.
- Resettlement placement considers all aspects of the person's life, including daytime activities, occupation and leisure.
- In decisions about resettlement, the views of family members and other significant contacts will be sought and considered, in conjunction with those of the individual concerned, and the advice of hospital personnel for him/her.
- Standards of care will be set, evaluated, and monitored to ensure that any move into the community represents an improvement in the quality of life for the individual.
- Management will take account of the impact of hospital resettlement on the receiving community.

Table 3.

RESETTLEMENT FROM MUCKAMORE ABBEY 1987 - 1991

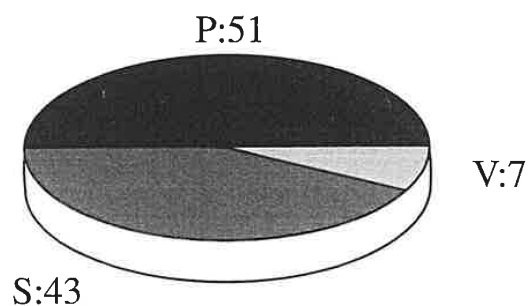
PATIENTS



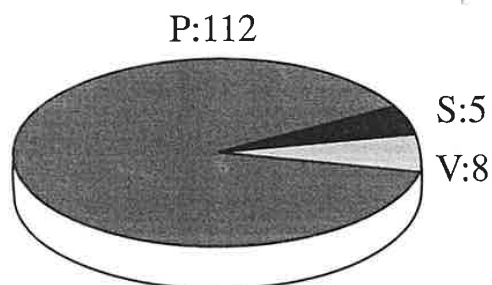
*Jan - Sept 91'

Table 4.

**RESETTLEMENT: MUCKAMORE ABBEY
TYPE OF ACCOMODATION USED
(JAN' 87 - SEPT' 91)**



EASTERN



NORTHERN

V = VOLUNTARY
P = PRIVATE
S = STATUTORY

Table 5.

RESETTLEMENT DISCHARGES BY AGE

Number of Patients

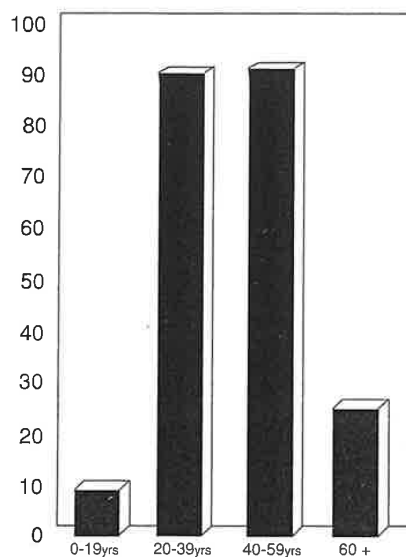
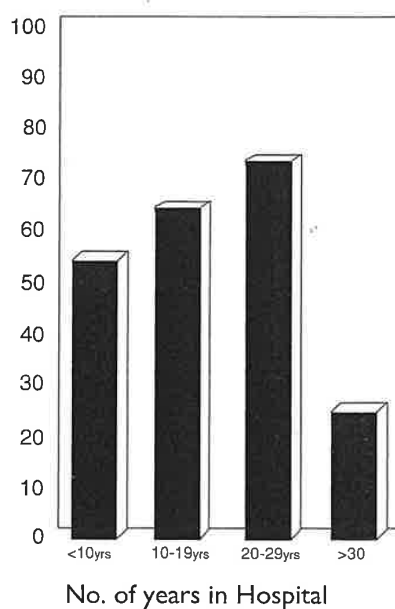


Table 6.

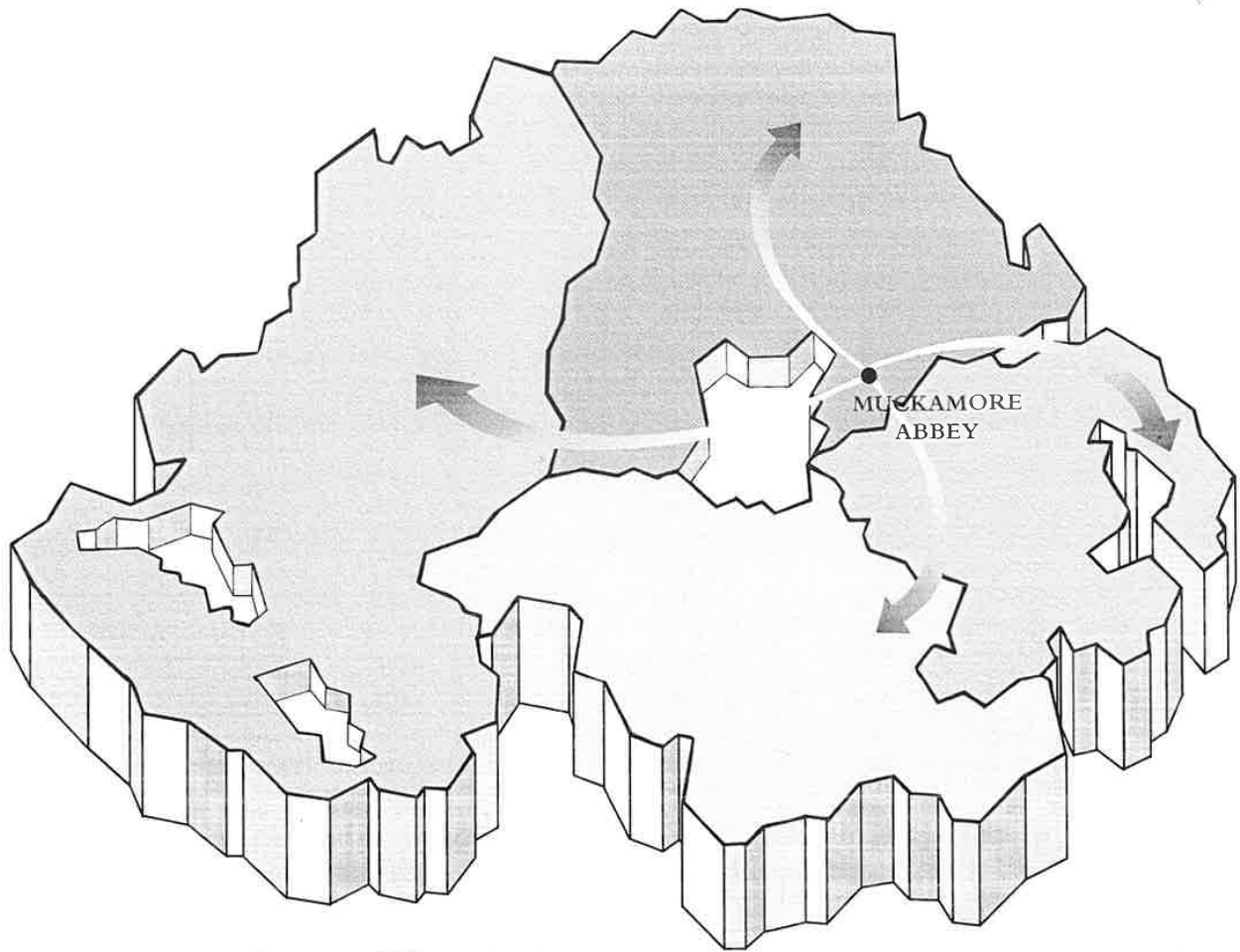
RESETTLEMENT DISCHARGES BY LENGTH OF STAY

Number of Patients



No. of years in Hospital

Table 7.



Muckamore Abbey Hospital is part of The North and West Belfast Community Unit of the Eastern Health and Social Services Board.

The strategy of the Unit is to actively pursue the resettlement of people with mental handicap to appropriate settings throughout the Province, while continuing to provide high quality hospital services for those who require specialised care.

Muckamore Abbey Hospital offers –

Province Wide – A service with specialist facilities and expertise in the treatment of serious behavioural disorder in people with a mental handicap, including offenders.

Services include –

- comprehensive assessment and treatment for those suffering from:
 - psychiatric illness and behavioural disorder
 - medical aspects of multiple and complex handicaps

A full range of specialist therapeutic and support services is available, including Day Care.

Any comments in relation to this document should be forwarded in writing to the **Unit General Manager** at the Unit headquarters.

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*Produced by Frank Murtagh Associates.
Printed by Watermark Press Ltd.*

00511

Independent Inquiry into Inequalities in Health Report

Chairman: Sir Donald Acheson

£19.50



published by The Stationery Office
as ISBN 0 11 322173 8

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Inquiry Into
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Independent Inquiry into Inequalities in Health

The Inquiry was chaired by:

Sir Donald Acheson, Chairman of the International Centre for Health and Society at University College, London.

Scientific Advisory Group

The Inquiry was overseen by a Scientific Advisory Group.
The members of the Group were:

Professor David Barker FRS,
Director of the Medical Research Council's Environmental Epidemiology Unit,
University of Southampton

Dr Jacky Chambers,
Director of Public Health, Birmingham Health Authority

Professor Hilary Graham,
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Statistical Adviser:
Frances Drever, seconded from the Office for National Statistics

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Terms of Reference

Terms of Reference

1. To moderate a Department of Health review of the latest available information on inequalities of health, using data from the Office for National Statistics, the Department of Health and elsewhere. The data review would summarise the evidence of inequalities of health and expectation of life in England and identify trends.
2. In the light of that evidence, to conduct - within the broad framework of the Government's overall financial strategy - an independent review to identify priority areas for future policy development, which scientific and expert evidence indicates are likely to offer opportunities for Government to develop beneficial, cost effective and affordable interventions to reduce health inequalities.
3. The review will report to the Secretary of State for Health. The report will be published and its conclusions, based on evidence, will contribute to the development of a new strategy for health.

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Independent Inquiry into Inequalities in Health Report

Preface

Preface

This Report addresses an issue which is fundamentally a matter of social justice; namely that although the last 20 years have brought a marked increase in prosperity and substantial reductions in mortality to the people of this country as a whole, the gap in health between those at the top and bottom of the social scale has widened. Yet there is convincing evidence that, provided an appropriate agenda of policies can be defined and given priority, many of these inequalities are remediable. The same is true for those that exist between the various ethnic groups and between the sexes.

In July 1997, I was invited by the Secretary of State for Health to review and summarise inequalities in health in England and to identify priority areas for the development of policies to reduce them. To accomplish this task, I have been aided by a small group of scientists. This Report is the result of our work together.

In this work, we have consulted widely and drawn on the expertise of a range of colleagues whose names are acknowledged in the Report. We also acknowledge and have built on the work of those who have gone before us. We mention in particular Sir Douglas Black's ground breaking report "Inequalities in Health". We have also found inspiration in the work of the World Health Organisation which, in its European "Health for All" Policy, gives precedence above all other objectives to the promotion of equity in health within and between countries.

There have been many relevant developments between the appointment of the Inquiry and our submission of this Report to Ministers. From its earliest days in office, the Government has expressed its concern about inequalities in health and in February 1998 translated this concern into a central premiss of its consultation paper "Our Healthier Nation". This has been followed not only by the 1998 Budget but by a succession of consultation documents and White Papers relevant to our inquiry.

As our work developed, it has become clear that the range of factors influencing inequalities in health extends far beyond the remit of the Department of Health and that a response by the Government as a whole will be needed to deal with them.

We believe that the policies and areas for policy development which we have identified from the available evidence, comprise an effective agenda. Its components are congruent and mutually reinforcing. We are convinced that if this agenda is implemented it will make a major beneficial impact on inequalities in health. We hope that it will also provide a sound basis for policy development well into the next millennium.

At this point, the scientific work of the Inquiry is done. We commend the Report to the elected Government as a significant contribution to social equity worthy of urgent consideration. It is now for the Government to decide the rate of implementation and the affordability of our recommendations.

Sir Donald Acheson
September 1998

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Independent Inquiry into Inequalities in Health Report

Synopsis

Synopsis

Our task has been to review the evidence on inequalities in health in England, including time trends, and, as a contribution to the development of the Government's strategy for health, to identify areas for policy development likely to reduce these inequalities. We carried out our task over the last 12 months, drawing on scientific and expert evidence, and peer review.

Although average mortality has fallen over the past 50 years, unacceptable inequalities in health persist. For many measures of health, inequalities have either remained the same or have widened in recent decades.

These inequalities affect the whole of society and they can be identified at all stages of the life course from pregnancy to old age.

The weight of scientific evidence supports a socioeconomic explanation of health inequalities. This traces the roots of ill health to such determinants as income, education and employment as well as to the material environment and lifestyle. It follows that our recommendations have implications across a broad front and reach far beyond the remit of the Department of Health. Some relate to the whole Government while others relate to particular Departments.

We have identified a range of areas for future policy development, judged on the scale of their potential impact on health inequalities, and the weight of evidence. These areas include: poverty, income, tax and benefits; education; employment; housing and environment; mobility, transport and pollution; and nutrition. Areas are also identified by the stages of the life course - mothers, children and families; young people and adults of working age; and older people - and by focusing on ethnic and gender inequalities. We identify possible steps within the National Health Service to reduce inequalities. In our view, these areas offer opportunities over time to improve the health of the less well off.

There are three areas which we regard as crucial:

- all policies likely to have an impact on health should be evaluated in terms of their impact on health inequalities;
- a high priority should be given to the health of families with children;
- further steps should be taken to reduce income inequalities and improve the living standards of poor households.

These areas form the basis of our first three recommendations.

We hope our report will provide a sound basis for policy development well into the next millennium.

Donald Acheson
David Barker
Jacky Chambers
Hilary Graham
Michael Marmot
Margaret Whitehead

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Independent Inquiry into Inequalities in Health Report

Part 1

Part 1**Introduction****Our Task**

Our task is set out in the terms of reference and the commissioning letter from the Minister for Public Health (annex A). It consists of two parts. The first is to review the latest available information on health inequalities and *"summarise the evidence of inequalities of health and the expectation of life in England and identify trends"*. This review would be based on data from the Office for National Statistics (ONS), the Department of Health (DH) and elsewhere.

The second is to identify, in the light of the review, *"priority areas for future policy development . . . likely to offer opportunities for Government to develop beneficial, cost effective and affordable interventions to reduce health inequalities"*. These policy proposals are to be based on *"scientific and expert evidence"* and *"within the broad framework of the Government's financial strategy"*.

Bearing in mind the commissioning letter and terms of reference, we have considered the work of the Inquiry to be scientific. We have limited our recommendations to those based on scientific and expert evidence.

The short timescale of the Inquiry, combined with the broad nature of inequalities in health and their determinants, prohibited a very detailed and comprehensive review. We acknowledge at the outset of this report that there are areas which, given a longer period of time for our work, we would have reviewed in more detail. Other areas of work were omitted because they were not included in our terms of reference. So, although we recognise that the setting of targets concerned with reducing inequalities in health is an important area for policy development, we were advised that consideration of this issue was not within the Inquiry's remit. We do, however, welcome the setting up of the Chief Medical Officer's working group which will consider targets, including those which address inequalities in health, as part of the work on "Our Healthier Nation"¹. In addition, we decided at an early stage not to consider recommendations for research and development, although the need for further research and development is implicit in many sections of the report.

A key objective of our report is to contribute to the development of the Government's strategy for health and an agenda for action on inequalities in the longer term. The publication on the 5 February 1998 of the consultation paper "Our Healthier Nation; a Contract for Health"¹ was an important landmark. It identified the need *"to improve the health of the worst off in society and to narrow the health gap"* as an overriding principle. This principle also underpins consultation papers on public health from Scotland, Wales and Northern Ireland²⁻⁴.

Our report takes account of the main features of "Our Healthier Nation" as they affect inequalities. We discuss tackling inequalities in the settings of schools, the workplace and neighbourhoods. Our section on the NHS includes an element on the reduction of inequalities through local partnerships taking account of plans for Health Improvement Programmes and Health Action Zones. It also takes into account the changes outlined in the White Paper *"The New NHS: Modern and Dependable"*⁵.

Structure of the report

Our report is divided into two sections. Part 1 sets out the approach which we adopted

in considering the causes of inequalities in health, and some of the principles which have guided our work. This is followed by a summary of our review of data on inequalities in health, "The Current Position". Part 2 is our review of the evidence from which we identified areas for future policy development, and contains our recommendations. This section also adds to, and amplifies, some of the data presented in Part 1. In each of the identified areas for future policy development, we have summarised the inequalities that exist, the evidence that indicates areas for policy development, and the benefit which might result from such development. A complete list of our recommendations, including cross references, is given at the end of Part 2.

Our approach

Historical context

Our report needs to be seen in its historical context, as an extension of scientific and policy development in this country over more than a century. There is a long tradition in Britain of analysing national statistics to shed light on the nature and causes of social inequalities in health⁶. This goes back at least to William Farr in 1837, when the General Register Office was set up. Farr, as the first Superintendent of Statistics, clearly believed that it was the responsibility of the national office not just to record deaths, but to uncover underlying linkages which might help to prevent disease and suffering in the future⁷.

Firm foundations were set at that time which have allowed the documentation and monitoring of health inequalities over the past 150 years to a much finer degree than in many other countries. Social and public health reformers since then - from Chadwick in the 1840s to Rowntree at the turn of the century and Titmuss and colleagues in the Depression and post-war period - have carried on the tradition, bringing the evidence into the light of day for public debate and action.

Evidence on social inequalities and of inadequate access to health care in Britain also played a key role in pressure to set up the welfare state in the post-war period, with the landmark Beveridge Report of 1942 setting out a national programme of policies and services to combat the "five giants of Want, Disease, Ignorance, Squalor and Idleness"⁸.

It was an assessment in the mid-1970s that Britain was slipping behind some other countries in health improvement, despite 30 years of the welfare state, and speculation that persisting health inequalities were to blame, that led to the setting up by the Government of the Research Working Group on Inequalities in Health in 1977, chaired by Sir Douglas Black. The resulting Black Report⁹ presented in 1980, shortly after a new Government took office, was a rare example, perhaps the first anywhere in the world, of an attempt authorised by Government to explain trends in inequalities in health and relate these to policies intended to promote as well as restore health¹⁰.

The thrust of the recommendations in that seminal report were concerned with improving the material conditions of life of poorer groups, especially children and people with disabilities, coupled with a re-orientation of health and personal social services. Although there was little sign that the report's recommendations were given any official priority in Britain throughout the 1980s, ripples from the report spread out far and wide, to be influential in research and public health debates in many countries. For example, the Black Report played a part in influencing the decision of the member states (including the UK) of the European Region of the World Health Organisation to agree a common health strategy in 1985, with equity in health as a theme running right through it, and reduction in inequities as the subject of the first of 38 targets to be achieved by the year 2000¹¹. This in itself has proved a significant development on the international front. In 1987, an update of the evidence in the Black Report was commissioned and published under the title of "The Health Divide"¹². This stimulated widespread debate and led to renewed calls for greater priority to be given to the issue of inequalities in health¹⁰.

It was not until the 1990s, however, that significant movement on the issue was perceptible. The Chief Medical Officer for England set up a sub-group under the auspices of "The Health of the Nation" national health strategy, to look into what the Department of Health and the NHS could do to reduce variations in health¹³. The report of the sub-group was published in 1995, and in the same year, the King's Fund published an independent analysis of the wider policy options for tackling inequalities in health in relation to housing, family poverty, and smoking as well as the NHS¹⁴. These initiatives, together with a growing body of evidence from a great many in the public health field, were influential in convincing the new Government in 1997 of the need to set up the current Independent Inquiry.

Socioeconomic model of health

We have adopted a socioeconomic model of health and its inequalities. This is in line with the weight of scientific evidence. Figure 1 shows the main determinants of health as layers of influence, one over another^{15,16}. At the centre are individuals, endowed with age, sex and constitutional factors which undoubtedly influence their health potential, but which are fixed. Surrounding the individuals are layers of influence that, in theory, could be modified. The innermost layer represents the personal behaviour and way of life adopted by individuals, containing factors such as smoking habits and physical activity, with the potential to promote or damage health. But individuals do not exist in a vacuum: they interact with friends, relatives and their immediate community, and come under the social and community influences represented in the next layer. Mutual support within a community can sustain the health of its members in otherwise unfavourable conditions. The wider influences on a person's ability to maintain health (shown in the third layer) include their living and working conditions, food supplies and access to essential goods and services. Overall there are the economic, cultural and environmental conditions prevalent in society as a whole, represented in the outermost layer.

The model emphasises interactions between these different layers. For example, individual lifestyles are embedded in social and community networks and in living and working conditions, which in turn are related to the wider cultural and socioeconomic environment.

Socioeconomic inequalities in health reflect differential exposure - from before birth and across the life span - to risks associated with socioeconomic position. These differential exposures are also important in explaining health inequalities which exist by ethnicity and gender. One model of how these risks interconnect is shown in figure 2.

This model has been used to guide research. The research task is to trace the paths from social structure, represented by socioeconomic status, through to inequalities in health. This can be done in stages, for example showing that work is related to pathophysiological changes such as raised blood pressure or biochemical disturbances which are in turn related to disease risk; or showing that the social environment in which people live is related to their health behaviour, such as patterns of eating, drinking, smoking and physical activity.

The model also illustrates various intervention points. Medical care, for example, might intervene at the level of morbidity to prevent progression to death, or earlier, at the level of pathophysiological changes to interrupt transition to morbidity. Preventive approaches might act at the level of attempting to change individual risk, by encouraging people to give up smoking or change diet. Interventions in the workplace or the social environment might encourage a climate which promotes healthy behaviour or improved psychological conditions. Interventions at the level of social structure would reduce social and economic inequalities.

Our approach is shared by the Government which, in "Our Healthier Nation", has expressed its determination to tackle "the root causes of health". The Prime Minister

emphasised this approach in his answer to a Parliamentary Question on low income, inequality and health (11th June 1997).

"... It is for that reason that the Secretary of State for Health has asked Sir Donald Acheson to conduct a further review into inequality and the link between health and wealth These inequalities do matter and there is no doubt that the published statistics show a link between income, inequality and poor health. It is important to address that issue, and we are doing so. The purpose of the windfall tax is to address that matter on behalf of young people and the long-term unemployed. We are also addressing the issue by introducing the minimum wage, which will help those on low incomes, and with welfare measures, particularly those designed to get single parents back to work"¹⁷.

Need to intervene on a broad front

The socioeconomic model also dictates the breadth of our review. A broad front approach reflects scientific evidence that health inequalities are the outcome of causal chains which run back into and from the basic structure of society. Such an approach is also necessary because many of the factors are interrelated. It is likely to be less effective to focus solely on one point if complementary action is not in place which influences a linked factor in another policy area. Policies need to be both "upstream" and "downstream".

For instance, a policy which reduces inequalities in income and improves the income of the less well off, and one which provides pre-school education for all four year olds are examples of "upstream" policies which are likely to have a wide range of consequences, including benefits to health. Policies such as providing nicotine replacement therapy on prescription, or making available better facilities for taking physical exercise, are "downstream" interventions which have a narrower range of benefits.

We have, therefore, recommended both "upstream" and "downstream" policies - those which deal with wider influences on health inequalities such as income distribution, education, public safety, housing, work environment, employment, social networks, transport and pollution, as well as those which have narrower impacts, such as on healthy behaviours. We describe the impact of these on health at the various stages of the life course, by ethnicity and by gender.

Absolute and relative inequalities

The health gap between socioeconomic groups can be considered in both relative and absolute terms. An example of a relative measure would be the ratio of the death rate in the lowest social class to that in the highest class. Death rates could be, for example, twice as high in the lowest as in the highest social class. The equivalent absolute measure would subtract the death rate in one group from that in another to give the rate difference. This could be expressed as, for example, the death rate in the lowest social class is 50 deaths per 100,000 population greater than the rate in the highest social class.

Both relative and absolute measures have important implications. However, it may be argued that absolute measures are the most critical, particularly with respect to identifying the major problems which need to be addressed. This is because an absolute measure is determined not only by how much more common the health problem is in one group than another, but also how common the underlying problem - for example the death rate in a particular population - actually is. A doubling in social class V of the rate of occurrence of a rare disease is not as significant as a doubling in the rate of occurrence of a common disease. Major gains in attacking health inequalities are most likely to derive from addressing those health problems which occur reasonably frequently, even if less common diseases may in relative terms demonstrate a steep gradient, occurring, say, ten or twenty times more often in social

class V than I. Relative measures are particularly useful for assessing the relative importance of different causal factors, and are important tools in aetiological enquiry.

The penalties of inequalities in health affect the whole social hierarchy and usually increase from the top to the bottom. Thus, although the least well off may properly be given priority, if policies only address those at the bottom of the social hierarchy, inequalities will still exist. Accordingly, our approach addresses the socioeconomic determinants of health as they affect the whole social spectrum.

Social environment, social support and health

The economic and social benefits of greater equality seem to go hand in hand. The quality of the social environment is worst where financial deprivation is greatest, such as the inner cities. Recent research suggests that, in addition to the ill effects due to absolute poverty, societies in which there is a wide gap between the rich and the poor suffer additional social problems, for instance, through high rates of violence and crime, and truancy¹⁸. It has also been suggested that people with good social networks live longer, are at reduced risk of coronary heart disease, are less likely to report being depressed, or to suffer a recurrence of cancer and are less susceptible to infectious illness than those with poor networks¹⁹.

This work opens up a range of policy options. Policies to reduce social inequalities and to promote social networks are part of a strategy to reduce inequalities in health in just the same way as action on economic inequalities or improvements in the material environment of disadvantaged communities. These include, for instance, policies which reduce unemployment in areas of social need, those which improve the availability of social housing for families close to their social networks, and the provision of family support services which help parents protect their children from the effects of disadvantage. Freedom from prejudice or discrimination, a respect for individual worth and a sense of belonging to society will help to reduce the manifestations of exclusion, such as crime, violence, self-harm and isolation.

Priority for parents and children

While remediable risk factors affecting health occur throughout the life course, childhood is a critical and vulnerable stage where poor socioeconomic circumstances have lasting effects. Follow up through life of successive samples of births has pointed to the crucial influence of early life on subsequent mental and physical health and development²⁰. The fact that the adverse outcomes, for example, mental illness, short stature, obesity, delinquency and unemployment, cover a wide range, carries an important message. It suggests that policies which reduce such early adverse influences may result in multiple benefits, not only throughout the life course of that child but to the next generation.

Another line of research, which concentrates on the effects of a mother's nutrition on her child's later health, has shown that small size or thinness at birth are associated with coronary heart disease, diabetes and hypertension in later life. As two principal determinants of a baby's weight at birth are the mother's pre-pregnant weight and her own birthweight, the need for policies to improve the health of (future) mothers and their children is obvious²¹. It also follows that, among migrants who move from a poorly nourished to a well nourished community, there will be implications for fetal growth and adult health for more than one generation.

Taking into account these findings and the view expressed in "Our Healthier Nation" that *"good health is the supreme gift parents can give their children"*, we take the view that, while there are many potentially beneficial interventions to reduce inequalities in health in adults of working age and older people, many of those with the best chance of reducing future inequalities in mental and physical health relate to parents, particularly present and future mothers, and children.

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Independent Inquiry into Inequalities in Health Report

Part 1 continued

Inequalities in Health: The Current Position

Socioeconomic inequalities in health and expectation of life have been found in many contemporary and past societies. In England although information based on an occupational definition of social class has only been available since 1921, other data identifying differences in longevity by position in society have been available for at least two hundred years. These differences have persisted despite the dramatic fall in mortality rates over the last century⁶.

Inequalities in health exist, whether measured in terms of mortality, life expectancy or health status; whether categorised by socioeconomic measures or by ethnic group or gender. Recent efforts to compare the level and nature of health inequalities in international terms indicate that Britain is generally around the middle of comparable western countries, depending on the socioeconomic and inequality indicators used²². Although in general disadvantage is associated with worse health, the patterns of inequalities vary by place, gender, age, year of birth and other factors, and differ according to which measure of health is used²³.

General trends in health

Death rates in England have been falling over the last century, from a crude death rate of 18 per thousand people in 1896 to 11 per thousand in 1996^{24,25}. Over the last 25 years, there have been falls in death rates from a number of important causes of death, for example lung cancer (for men only), coronary heart disease and stroke²⁵.

Life expectancy has risen over the last century²⁶, but not all life is lived in good health. Healthy life expectancy - the measure of average length of life free from ill health and disability - has not been rising; the added years of life have been years with a chronic illness or disability²⁷.

The proportion of people reporting a limiting long standing illness has risen from 15 per cent to 22 per cent since 1975. The proportion reporting illness in the two weeks previous to interview has nearly doubled from 9 per cent to 16 per cent. There is a slight increase in the proportion of people consulting the NHS²⁸.

Measuring socioeconomic position

A number of different measures can be used to indicate socioeconomic position. These include occupation, amount and type of education, access to or ownership of various assets, and indices based on residential area characteristics. There has been much debate as to what each indicator actually measures, and how choice of indicator influences the pattern of inequalities observed. For example, measures based on occupation may reflect different facets of life for men compared to women, and for people of working age compared to older people or children.

Choice of measure is often dictated by what is available. In Britain occupational social class is frequently used, especially for data collected nationally. Table 1 shows examples of the occupations in each social class group.

Mortality

Over the last twenty years, death rates have fallen among both men and women and across all social groups^{25,29}. However, the difference in rates between those at the top and bottom of the social scale has widened.

For example, in the early 1970s, the mortality rate among men of working age was almost twice as high for those in class V (unskilled) as for those in class I (professional). By the early 1990s, it was almost three times higher (table 2). This increasing differential is because, although rates fell overall, they fell more among the

high social classes than the low social classes. Between the early 1970s and the early 1990s, rates fell by about 40 per cent for classes I and II, about 30 per cent for classes IIN, IIIM and IV, but by only 10 per cent for class V. So not only did the differential between the top and the bottom increase, the increase happened across the whole spectrum of social classes²⁹.

Both class I and class V cover only a small proportion of the population at the extremes of the social scale. Combining class I with class II and class IV with class V allows comparisons of larger sections of the population. Among both men and women aged 35 to 64, overall death rates fell for each group between 1976-81 and 1986-92 (table 3). At the same time, the gap between classes I and II and classes IV and V increased. In the late 1970s, death rates were 53 per cent higher among men in classes IV and V compared with those in classes I and II. In the late 1980s, they were 68 per cent higher. Among women, the differential increased from 50 per cent to 55 per cent³⁰.

These growing differences across the social spectrum were apparent for many of the major causes of death, including coronary heart disease, stroke, lung cancer and suicides among men, and respiratory disease and lung cancer among women^{29,30}.

Death rates can be summarised into average life expectancy at birth. For men in classes I and II combined, life expectancy increased by 2 years between the late 1970s and the late 1980s. For those in classes IV and V combined, the increase was smaller, 1.4 years. The difference between those at the top and bottom of the social class scale in the late 1980s was 5 years, 75 years compared with 70 years. For women, the differential was smaller, 80 years compared with 77 years. Improvements in life expectancy have been greater over the period from the late 1970s to the late 1980s for women in classes I and II than for those in classes IV and V, two years compared to one year³¹.

A good measure of inequality among older people is life expectancy at age 65. Again, in the late 1980s, this was considerably higher among those in higher social classes, and the differential increased over the period from the late 1970s to the late 1980s, particularly for women³¹.

Years of life lost

Premature mortality, that is death before age 65, is higher among people who are unskilled. Table 4 illustrates this with an analysis of deaths in men aged 20 to 64 years. If all men in this age group had the same death rates as those in classes I and II, it is estimated that there would have been over 17,000 fewer deaths each year from 1991 to 1993. Deaths from accidents and suicide occur at relatively young ages and each contribute nearly as much to overall years of working life lost as coronary heart disease. Death rates from all three causes are higher among those in the lower social classes, and markedly so among those in class V^{32,33}.

These major differences in death rates and life expectancy between social classes do not just apply to those people already well into adulthood. Infant mortality rates are also lower among babies born to those of higher social classes. In 1994-96, nearly 5 out of every thousand babies born to parents in class I and II died in their first year. For those babies born in to families in classes IV and V, the infant mortality rate was over 7 per thousand babies. As with mortality at other ages, infant mortality rates in each class have been decreasing over the last twenty years. However, there is no evidence that the class differential in infant mortality has decreased over this period³⁴.

Morbidity

Although death rates have fallen and life expectancy increased, there is little evidence that the population is experiencing less morbidity or disability than 10 or 20 years ago. There has been a slight increase in self-reported long standing illness and limiting long standing illness, and socioeconomic differences are substantial. For example, in

1996 among the 45 to 64 age group, 17 per cent of professional men reported a limiting long standing illness compared to 48 per cent of unskilled men. Among women, 25 per cent of professional women and 45 per cent of unskilled women reported such a condition. These patterns were similar among younger adults, older men and among children²⁸.

In adulthood, being overweight is a measure of possible ill health, with obesity a risk factor for many chronic diseases. There is a marked social class gradient in obesity which is greater among women than among men³⁵⁻³⁷. In 1996, 25 per cent of women in class V were classified as obese compared to 14 per cent of women in class I. For men, there was no clear difference in the proportions reported as obese except that men in class I had lower rates of obesity, 11 per cent, compared to about 18 per cent in other groups. Overall, rates of obesity are rising. For men, 13 per cent were classified as obese in 1993 compared to 16 per cent in 1996. For women, the rise was from 16 per cent to 18 per cent³⁷.

Another indicator of poor health is raised blood pressure. There is a clear social class differential among women, with those in higher classes being less likely than those in the manual classes to have hypertension. In 1996, 17 per cent of women in class I and 24 per cent in class V had hypertension. There was no such difference for men where the comparable proportions were 20 per cent and 21 per cent respectively³⁷.

Among men, major accidents are more common in the manual classes for those aged under 55. Between 55 and 64, the non-manual classes have higher major accident rates (*figure 3*). For women, there are no differences in accident rates until after the age of 75 when those women in the non-manual group have higher rates of major accidents³⁷.

Mental health also varies markedly by social class. In 1993/4, all neurotic disorders, such as anxiety, depression and phobias, were more common among women in class IV and V than those in classes I and II - 24 per cent and 15 per cent respectively³⁸. This difference was not seen among men. However, there were striking gradients for alcohol and drug dependence among men, but not women. For example, 10 per cent of men in classes IV and V were dependent on alcohol compared to 5 per cent in classes I and II, (*figure 4*)³⁸.

Trends in socioeconomic determinants of health

Income distribution

Over the last twenty years, household disposable income per head of population has grown both in actual and in real terms. Between 1961 and 1994, average household disposable income (in real terms) rose by 72 per cent³⁹. However, this was not experienced to the same extent across the whole of the income distribution.

The median real household disposable income, before housing costs, rose over the period 1961 to 1994 from £136 per week, to £234 per week (*figure 5*). The top decile point more than doubled, from £233 per week to £473 per week. The bottom decile point rose by 62 per cent from £74 per week to £119 per week.

Households below average income

The proportion of people whose income is below average has been at about 60 per cent for the last 35 years (*figure 6*). However, the proportion of people below half of the average income (the European Union definition of poverty) has grown over this period from 10 per cent in 1961 to 20 per cent in 1991. It has decreased since then and was at 17 per cent in 1995⁴⁰.

Education

Since the early 1970s, the proportion of children aged 3 or 4 who attend school has trebled from 20 per cent to nearly 60 per cent⁴⁰. The proportion who attend school (as opposed to playgroups) varies from 84 per cent in the North East to 43 per cent in the

South West⁴¹.

Educational attainment - as measured by the proportion of children gaining 5 or more GCSEs at grades A star to C - has risen from less than 25 per cent in 1975/76 to about 45 per cent in 1995/96^{40,42}. This measure of attainment varies not only by gender, but also by geographical area and by measures of deprivation.

As well as looking at the future workforce and their qualifications, it is useful to look at the educational attainment of those presently of working age⁴⁰. In 1997, 16 per cent of men and 21 per cent of women of working age had no qualifications. There were also large differences between ethnic groups (figure 7).

Employment

The seasonally adjusted unemployment rate for those aged 16 and over stood at 6.2 per cent in summer 1998, almost three times the level of 30 years ago⁴³. Although rates have been falling since 1993, there have been changes in the patterns of unemployment over the last thirty years, well beyond what might have been expected from seasonal and cyclical variations (figure 8). Youth unemployment is still at higher rates now than it was in 1991 and unemployment rates are four times higher among unskilled workers than among professional groups⁴⁴.

Across different ethnic groups, there are very different rates of unemployment (table 5). Those from minority ethnic groups have higher rates than the white population. Black men have particularly high unemployment rates as do Pakistani and Bangladeshi women⁴⁵.

Housing

Over the last sixty years, the number of dwellings has doubled from 10.6 million in 1938 to 20.7 million in 1997^{46,47}. Housing tenure has also changed dramatically over this period with a doubling of the proportion of owner-occupied dwellings^{46,47} and a dramatic fall in the proportion of privately rented dwellings (table 6).

There has also been a growth in the number of one-person households over the last ten years from 4.4 million in 1984 to 5.5 million in 1995/96⁴⁸. The proportion of all households which had only one person rose from 25 per cent to 28 per cent over this period. In 1984, 46 per cent of one-person households were owner occupied. By 1995/96, this had grown to 54 per cent (table 7).

Between 1991 and 2016, the number of households is expected to rise from 19.2 million to 23.6 million - a rise of 4.4 million households⁴⁹.

Conditions of the housing stock vary considerably. In 1996 about 14 per cent of all households were living in poor conditions. About 8 per cent of dwellings in England were unfit, and about 7 per cent of households were living in unfit dwellings. The proportions of households in unfit dwellings varied with the type of tenure, from 4 per cent in the Registered Social Landlord sector to 18 per cent of households who rented from private landlords. In urban areas, 8 per cent of dwellings were deemed unfit whereas in rural areas, 5 per cent were deemed unfit⁵⁰.

Homelessness

Between 1982 and 1992, there was a steep increase in the number of households accepted by Local Authorities as homeless. Since then, there has been a decrease of about a quarter. Of the 166,000 households classified as homeless in 1997, over 103,000 were accepted by local authorities to be unintentionally homeless and in priority need. Over half of households accepted by local authorities as homeless had dependent children and a further tenth had a pregnant household member⁵¹.

Public safety

The crime rate has nearly trebled since 1971. In 1996, the crime rate in England was nearly one crime for every ten people⁴⁰. Crime rates were highest in areas with large

conurbations - the North East, Yorkshire/Humberside and London⁴¹. There were also different crime rates in different types of areas - lowest in affluent suburban and rural areas and highest in council estates and low income areas (table 8).

Different areas of the country have very different rates of particular types of crime. London has the highest rate of fraud and forgery, robbery and sexual offences. The North East has the highest rate of criminal damage and the lowest rate of sexual offences. Yorkshire and the Humber has the highest burglary rate. The East has the lowest overall crime rate⁴¹.

Transport

Access to private means of transport has increased in recent years. In 1996, 70 per cent of households had access to a car or a van. This compared with just over half of households in 1972. About a quarter of households had access to two or more cars and vans compared to only 9 per cent in 1972 (figure 9)^{28,52,53}.

Those with access to two or more cars or vans were not only more likely to be economically active, but also tended to be in the higher socioeconomic groups. Only seven per cent of households had access to two or more vehicles when the head of household was economically inactive compared to 36 per cent of households with an economically active head²⁸. In 1991, those who lived in the social rented sector had the highest proportion with no access to a car, 68 per cent, while those in the owner occupied sector had the smallest proportion with no access, 19 per cent⁵².

How people travel to work differs depending on whether the areas in which they live are urban or rural⁵⁴. In England in 1991, 60 per cent of people travelled to work by car in urban areas and 69 per cent in rural areas. Rail and bus accounted for 17 per cent of journeys to work for those in urban areas but only for five per cent for rural areas. A higher proportion of people work at home in rural areas, 12 per cent compared to four per cent in urban areas (table 9).

Health related behaviour

Over the last twenty years, the proportion of people who report that they smoke cigarettes has fallen. In 1974, roughly a half of men and two fifths of women smoked cigarettes, compared with less than 30 per cent of men and women in 1996. The trends in drinking alcohol are broadly unchanged over this period. However, the proportion of women who drank more than 14 units of alcohol a week rose from 9 per cent in 1984 to 14 per cent in 1996²⁸.

There is a clear social class gradient for both men and women in the proportion who smoke. In 1996, this ranged from 12 per cent of professional men to 41 per cent of men in unskilled manual occupations and from 11 per cent to 36 per cent for women²⁸. In spite of the major class differences in dependence on alcohol in men³⁸, there are very small differences in the reported quantities consumed. This is not the case among women where higher consumption is related to higher social class²⁸.

Among women, there are no differences in levels of physical activity across the social classes. Among men, higher proportions in the manual classes have a high level of physical activity than in the non-manual classes. However, some of this difference is due to work related physical activity. Men in non-manual occupations have higher rates of leisure time physical activity³⁵.

People in lower socioeconomic groups tend to eat less fruit and vegetables, and less food which is rich in dietary fibre. As a consequence, they have lower intakes of anti-oxidant and other vitamins, and some minerals, than those in higher socioeconomic groups^{35,55-58}.

One aspect of dietary behaviour that affects the health of infants is the incidence of breastfeeding. Six weeks after birth, almost three quarters of babies in class I households are still breastfed. This declines with class to less than one quarter of

babies in class V. The differences between classes in rates of breastfeeding at six weeks has narrowed slightly between 1985 and 1995⁵⁹.

Trends in health differences between minority ethnic groups

There are many indications of poorer health among the minority ethnic groups in England. For example, people in Black (Caribbean, African and other) groups and Indians have higher rates of limiting long standing illness than white people. Those of Pakistani or Bangladeshi origin have the highest rates. In contrast, the Chinese and "other Asians" have rates lower than the white population⁶⁰.

Although in analysing mortality rates we have to use country of birth as a proxy for ethnicity, a similar pattern emerges⁶¹. There is excess mortality among men and women born in Africa and men born on the Indian sub-continent and men and women born in Scotland or Ireland (table 10).

Many women from minority ethnic groups giving birth in the 1990s were born in the United Kingdom. Because country of birth of the mother, and not ethnicity, is recorded at birth registration, it is not possible to estimate infant mortality rates by minority ethnic group. However, among mothers who were born in countries outside the UK, those from the Caribbean and Pakistan have infant mortality rates about double the national average. Perinatal mortality rates have also been consistently higher for babies of mothers born outside the UK. The differences between groups have not decreased over the last twenty years³⁴.

Trends in health differences between the sexes

Death rates have been falling for both males and for females (figure 10). Since 1971, these have decreased by 29 per cent for males and by 25 per cent for females, narrowing the differential in death rates very slightly. Cancers and coronary heart disease account for 55 per cent of the deaths of men and 42 per cent of the deaths of women²⁵.

At each age in childhood, and on into adulthood, the age-specific mortality rates for boys is higher than for girls (figure 11)⁶². For the under 5s, nearly half of the difference is due to external causes, in particular accidental drowning and submersion. For children aged 5 to 14, external causes, chiefly motor vehicle traffic accidents, account for nearly 70 per cent of the difference²⁵.

Although the life expectancy gap between males and females is decreasing²⁶, this is not the case for healthy life expectancy. Healthy life expectancy of females is only two to three years more than that of males²⁷. Overall, there is little difference in the proportions of males and females reporting a limiting long standing illness⁵³. Women report more illness of many different types than men during the reproductive years⁵³.

For both children and adults of working ages, males have higher major accident rates than females (figure 12). At older ages, women have higher major accident rates than men³⁷.

The proportion of smokers is higher among girls than boys⁶³. By adulthood, the proportions of men and women smoking are about the same (29 and 28 per cent), compared with 51 per cent of men and 41 per cent of women in 1974⁵³. For both children and adults, males are more likely to drink alcohol heavily than females⁵³.

Conclusion

Inequalities by socioeconomic group, ethnic group and gender can be demonstrated across a wide range of measures of health and the determinants of health. Analysis of these patterns and trends in inequalities has informed the development of areas for future policy development, which are considered in Part 2.

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Prepared 26 November 1998

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Part 2

Reducing Inequalities in Health

Introduction: assessing the evidence

We have sought to ensure that our recommendations are based on scientific and expert evidence. To this end, we have consulted with a wide range of experts and incorporated a process of peer review. In summary, we commissioned a series of input papers from experts broadly to match the sections of the report. Most of these experts consulted widely amongst other researchers in their field. For each of these commissioned papers, we obtained an independent scientific commentary. We also sought and received a considerable volume of material from institutions and individuals with expertise or experience relevant to inequalities in health, including scientific reviews and papers. A separate Evaluation Group was convened to consider the commissioned papers with associated commentaries and asked to report on the quality of the evidence on which the recommendations in the papers were based, and to identify gaps⁶⁴. A more detailed description of the process is given in annex B.

All this material was considered and discussed within the Scientific Advisory Group. The material reflected a wealth of descriptive data documenting inequalities in health and a growing quantity of research exploring mechanisms. However, controlled intervention studies are rare. Indeed, the more a potential intervention relates to the wider determinants of inequalities in health (ie "upstream" policies), the less the possibility of using the methodology of a controlled trial to evaluate it. We have, therefore evaluated many different types of evidence in forming our judgement. The following sections incorporate our assessment of the full spectrum of evidence which we reviewed.

Cross-Government Issues

If future inequalities in health are to be reduced, it will be essential to carry out a wide range of policies to achieve both a general improvement in health and a greater impact on the less well off. By this we mean those who in terms of socioeconomic status, gender or ethnicity are less well off than average in terms of health or its principal determinants - such as income, education, employment or the material environment.

The impact of policies designed to improve health may have different consequences for different groups of people which are not always appreciated. Some policies will both improve health and reduce health inequalities. The introduction of the NHS benefited the health of all sections of the population, particularly women and children, many of whom were excluded from previous arrangements under the National Insurance Act.

A well intended policy which improves average health may have no effect on inequalities. It may even widen them by having a greater impact on the better off. Classic examples include policies aimed at preventing illness, if they resulted in uptake favouring the better off. This has happened in some initiatives concerned with immunisation and cervical screening, as well as in some campaigns to discourage smoking or to promote breastfeeding. More recently, the Government's welcome decision to provide a pre-school place for every child aged four in the country is likely to benefit health on average but could have the unintended effect of increasing inequalities. This would happen if the children of the better off made more effective use of the service.

These examples highlight the need for extra attention to the needs of the less well off. This could be accommodated both by policies directed at the least well off and by an

approach which would require the need for inequalities to be addressed wherever universal services are provided, such as publicly funded education and the National Health Service, and where other policies are likely to have an impact on health.

A broader approach of this kind which explicitly addresses inequalities could provide a new direction for public policy. It is our view that, in general, reductions in inequalities are most likely to be achieved if policies are formulated with the reduction of inequalities in mind.

1. We RECOMMEND that as part of health impact assessment, all policies likely to have a direct or indirect effect on health should be evaluated in terms of their impact on health inequalities, and should be formulated in such a way that by favouring the less well off they will, wherever possible, reduce such inequalities.

This proposal for a systematic impact assessment of policy on health inequalities is a significant extension to the steps already taken by Government to apply impact assessments to its policies¹, and to ensure better coordination across Whitehall.

We suggest that this proposal needs to be supported by a small and effective unit with a pan-Government view. Such a lead by Government would allow action on inequalities to be both reviewed and promoted. It would also serve to further encourage the steps being taken to strengthen coordination at both central and local level.

1.1 We recommend establishing mechanisms to monitor inequalities in health and to evaluate the effectiveness of measures taken to reduce them.

The effects of future policies will need to be monitored at regular intervals. For this purpose, the Government will require authoritative statistics on inequalities in health and the factors influencing them at national and local level. These will also be needed in order to set targets for reduction of health inequalities. A number of concerns about the presently available data have been raised with us. These include the scope for monitoring inequalities among older people, when many data sources have an effective cut-off point of age 64. There are continuing inconsistencies in the treatment of males and females in the census and at death registration, where married women are still mainly classified by the social class of their husband. There is also a need for greater consistency between data from the census, from vital registration and from other sources.

1.2 We recommend a review of data needs to improve the capacity to monitor inequalities in health and their determinants at a national and local level.

We have emphasised the priority we will be giving to parents and children in the report as the best way of reducing future inequalities in physical and mental health. This issue is relevant across Government.

2. We RECOMMEND a high priority is given to policies aimed at improving health and reducing health inequalities in women of childbearing age, expectant mothers and young children.

Areas for Future Policy Development

1. Poverty, Income, Tax and Benefits

Poverty and income

Inequality

Inequalities in health are of long standing and their determinants are deeply ingrained in our social structure. Since 1980, although health and expectation of life have generally improved, the social gradients of many indicators of health have deteriorated

or at best remained unchanged. Although this period was also marked by substantial economic growth, income differentials widened to a degree not seen since the Second World War. It also saw the reversal in the trend to greater equality seen in the 1960s and 1970s. Average incomes grew in real terms by about 40 per cent between 1979 and 1994/5, but this growth was far greater (60-68 per cent) amongst the richest tenth of the population. For the poorest tenth average income increased by only 10 per cent (before housing costs) or fell by 8 per cent (after them). There has been some improvement in the relative position of the poorest groups in the period since 1992 but income inequality is still pronounced and is worse than in many other developed countries⁶⁵.

The differences in incomes between those on means-tested benefits and those with other sources of income are a major determinant of income inequality in the United Kingdom. Among the poorest fifth of the population, the majority have incomes set by the level of means-tested benefit⁶⁵. People on low income, defined as below half average income, are more likely to be unemployed, lone parents and their children, people with disabilities or pensioners and to live in social housing. Some minority ethnic groups, especially Pakistanis and Bangladeshis, are over-represented in the poorest fifth of the income distribution⁶⁵⁻⁶⁹.

A similar picture emerges if poverty is defined as the receipt of Income Support. Almost a quarter of all households include at least one person receiving Income Support⁷⁰. Measured over a two year period, this figure rises to more than a third. The number of people receiving Income Support has risen from just over 4 million in 1979 to 9.6 million in 1996⁷¹. Comparisons over time are difficult but recent work has shown that the proportion of the population with below half average income has more than doubled since 1979, to reach 18 per cent in the mid 1990s⁷².

Many studies and analyses have demonstrated the association of increasingly poor health with increasing material disadvantage. For instance, all cause mortality is correlated with Townsend deprivation score, an index which combines indicators of unemployment, lack of car, not being an owner occupier and overcrowding. The highest mortality rates for both men and women are found among those who live in areas with the highest scores (most deprived), and the lowest in those from areas which are least deprived⁷³. People living in households with incomes of £350 or more per week have significantly lower rates of self-reported long standing illness than those living in households with an income of £200 per week or less⁷⁴. However, available evidence is insufficient to confirm or deny a causal relationship between changes in income distribution and the parallel deterioration in inequalities in some areas of ill health. Nevertheless, we take the view that these changes are likely to be related. In addition to being responsible for part of the burden of morbidity and mortality, they probably contribute to the persistence of the steep, unfavourable socioeconomic gradients in smoking and in the consumption of important nutrients such as antioxidants. Perhaps even more important is the damage persistent family and childhood poverty does to the health of future generations.

We welcome the Government's declared intention to redress income inequalities through the establishment of a national minimum wage, "Welfare to Work" and other measures. This approach should be accompanied by efforts to redistribute resources, in cash or kind, to those who, for reasons such as age or disability, are unable to work, and to those families for whom work is not available or appropriate. We consider that without a shift of resources to the less well off, both in and out of work, little will be accomplished in terms of a reduction of health inequalities by interventions addressing particular "downstream" influences.

Tax and Benefits

A fairer tax system will help the less well-off who are in work. It can boost the incomes of those in low paid work, neutralise the poverty trap for those able to work

and reduce inequalities. Recent changes, such as "Welfare to Work" and the announcement of the Working Families Tax Credit Scheme in the 1998 Budget, explicitly recognise the link between tax and benefits for working families. It is too early to assess the effects of these changes and they will need to be kept under review. It is our view that more may need to be done. Over the last 20 years a greater proportion of total taxation has been raised by indirect taxes⁷⁵, notably through VAT but also through excise duties. We note the Government's pledge not to extend VAT to food, children's clothes and public transport fares, and the action it has taken to reduce VAT on domestic fuels in a direct effort to help poorer and older people. Shifting the tax burden from regressive to more progressive forms of taxation and fiscal policies which take account of the combined impact of direct and indirect taxation on the living standards of lower income groups, would help mitigate the effects of income inequalities.

For the least well-off members of society, however, it is the benefit system which is the principal determinant of living standards. A comprehensive review of the social security system and its implications for health are beyond the capacity and competence of the Inquiry. Welfare reform is, however, on the Government's agenda. We believe it is important that, over time, benefit and pensions levels are set at a level sufficient to pay for items and services necessary for health and for participation in society.

We have decided to focus on two groups where we believe the current system fosters major inequalities in health and which will not reap the full benefits of the Government's recent, work-related reforms. These groups are families with children and pensioners.

Evidence

Poverty falls disproportionately on children. In the mid 1990s, around one in four of the total population in Britain were living in poverty (below 50% of average income after housing costs). Among children, the proportion was one in three⁷⁶. In 1996, 2.2 million children were in a family receiving Income Support⁷⁷.

A child, and additional children, has a much greater impact on the standard of living of poorer than better-off households⁷⁸. Yet current levels of benefits are not generous, either relative to average incomes or to levels found in much of continental Europe⁷⁹. Income Support falls significantly short of the level that independent experts determine to be the modern minimum. In 1992/3, the income of a single pensioner, owner occupier on Income Support fell £8 per week short of the standard; a couple with two children needed £34 more benefit to reach the standard^{80,81}. Depending on age, Income Support rates meet between 67 per cent and 90 per cent of minimum needs of children, as assessed by a representative cross-section of parents⁸². Another study found that Income Support levels are insufficient to meet the costs of an adequate diet for expectant mothers, particularly single women under the age of 25⁸³. Studies of the cost of meeting the basic needs of children of different ages suggest not only that the income provided by Income Support is insufficient but that the personal allowances for children understate the costs of younger children (especially those under 2 years) relative to older children^{65,84}. Independent and expert assessment of basic needs also indicates that the personal allowances paid to one- and two-parent families underestimate the relative cost of providing a basic standard of living for one-parent families^{78,84,85}. It is estimated that a lone parent with two children would need 93% of the amount required by a couple with two children to achieve the same "modest but adequate" standard of living⁸⁵. The 1998 Budget with above inflation increases in the benefit rates for younger children, childcare tax credit for working parents and the working families tax credit will contribute to the narrowing of these discrepancies. Substantial improvement will require sustained action but this is an important start which goes some way to narrowing these discrepancies but will not eliminate them.

The switch to link benefits to prices rather than earnings in the early 1980s has meant a relative deterioration in the position of groups who rely on benefits, including pensioners (figure 13)⁶⁵. The poorest pensioners are those wholly dependent on the State Retirement pension and although this is designed to be supplemented by Income Support, some one million - or around one in four of state retirement pensioners - do not claim support to which they are entitled^{86,87}. A number of factors may operate, including lack of knowledge of entitlement, a perception of being stigmatised by the receipt of benefit and physical or other difficulties in the processes of claiming. Possible ways of overcoming some of these problems are the establishment of new organisations or agencies: a pensioner's agency as a way of achieving "one-stop" provision of welfare⁸⁸; a citizen's bank⁸⁸; or a welfare "counsellor" in primary care centres in disadvantaged areas^{89,90}. A further suggestion to the Inquiry has been that an Income Support "top-up" could be paid automatically to bring the poorest pensioners up to Income Support levels.

There is a lack of experimental evidence that increasing financial resources results in measurable health gain. A rare exception is a randomised controlled trial carried out in Gary, Indiana, USA between 1970 and 1974. The intervention group received an expanded income support plan which guaranteed a minimum income to a group of mothers with low income. Mothers at high risk of adverse pregnancy outcome had heavier babies if they had received the income support plan⁹¹. However a review, which is being carried out under the auspices of the Cochrane Collaboration, has not been able to identify other evaluations of financial support interventions which include health outcomes, meeting review quality criteria⁶⁴.

Thus the bulk of the empirical evidence comes from research demonstrating that people living on low incomes, including those whose income consists entirely of state benefits, have insufficient money to buy items and services necessary for good health. Studies of the budgeting arrangements of poor families show that the money for food is often used as the reserve to iron out fluctuations in income and meet emergencies⁹². Mothers often shop alone to curtail expenditure and shop frequently to prevent food being available at home and therefore at risk of being consumed before it is essential. Spending is much reduced in the second week of the benefit cycle. Families can and do go short of food during this time because of shortage of money and, more often than not, it is the mother who goes without⁹³⁻⁹⁵. Some mothers have nutritionally deficient diets, although they are usually successful in protecting the diets of their children⁹⁴. Older people are particularly at risk of "fuel poverty" and may under-heat their homes because they cannot afford to buy fuel^{96,97}. Poverty may also act as a barrier for older people to services and care and to an adequate diet.

Benefit

Policies which increase the income of the poorest are likely to improve their living standards, such as nutrition and heating and so lead to improvements in health. This can be done by improving social security benefits, specifically for families with young children and pensioners, by increasing employment opportunities and through changes in the tax system. We have already noted that what is affordable in this area is a matter for the Government rather than the Inquiry.

At a population level, improvements in income and living standards are clearly associated with improvements in health and life expectancy⁹⁸. As the effects of such interventions on individual health have not been tested, any possible harmful side effects are unknown, if unlikely.

3. We RECOMMEND policies which will further reduce income inequalities, and improve the living standards of households in receipt of social security benefits. Specifically:

3.1 we recommend further reductions in poverty in women of childbearing age, expectant mothers, young children and older people should be made by

increasing benefits in cash or in kind to them.

3.2 We recommend uprating of benefits and pensions according to principles which protect and, where possible, improve the standard of living of those who depend on them, and which narrow the gap between their standard of living and average living standards.

3.3 We recommend measures to increase the uptake of benefits in entitled groups.

We recommend further steps to increase employment opportunities (recommendation 8.1).

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Prepared 26 November 1998

Independent Inquiry into Inequalities in Health Report

Part 2 continued

2. Education

Education plays a number of roles in influencing inequalities in health. If health is viewed in its widest sense. Firstly, it has an important role in influencing inequalities in socioeconomic position. Educational qualifications are a determinant of an individual's labour market position, which in turn influences income, housing and other material resources. These are related to health and health inequalities. As a consequence, education is a traditional route out of poverty for those living in disadvantage.

Secondly, education has a role in preparing children for life, in particular in ensuring that they have the practical, social and emotional knowledge and skills to achieve a full and healthy life. These include knowledge of the wider determinants of health, not just health related behaviour, skills in developing relationships and dealing with conflict, and practical skills such as budgeting and cooking.

Thirdly, education has a social role in preparing children to participate fully in society. This includes making children aware of their democratic rights and responsibilities, educating them about using services, co-operation and working together and enhancing greater understanding of other groups in society. The role of the school as part of the local community is an important component in achieving these outcomes.

Fourthly, the education system should protect and promote the current health of children, by providing an environment and culture which is safe, healthy and conducive to learning⁹⁹⁻¹⁰¹.

We recognise that a group of children at particular disadvantage are those who are excluded from school or who are frequent truants. These children and young people include disproportionate numbers with special educational needs, from minority ethnic groups, and who are looked-after by local authorities. School exclusion and truancy are associated with increased involvement in crime, as victims and perpetrators, substance misuse and other dangerous activities. In the long term, school exclusion and truancy are associated with unemployment, imprisonment, homelessness and teenage pregnancy. Measures to enable local education authorities to reduce truancy and exclusion are essential if the educational opportunities of this vulnerable group of children are to be protected. We note the recent report from the Government's Social Exclusion Unit on this topic. In view of its special recommendations to education and other authorities, we have not made recommendations in this area. We believe that the policy areas we recommend in this report which support parents and children at home and school will address the "upstream" factors which lead to exclusion and truancy. These policy areas should complement those recommended in the Social Exclusion Unit's report¹⁰².

This section is based on the recognition of the roles of education in reducing inequalities in health. Our recommendations in this area relate to increasing the resources for schools serving the less well off, further development of pre-school education and health promoting schools and improving nutrition at school.

Increasing resources for schools serving the less well off**Inequality**

The roles of education set out above imply a range of outcomes which are not readily measurable. However, inequality is observed when looking at educational achievement. Children from disadvantaged backgrounds, as measured by being in receipt of free school meals, have lower educational achievement than other children.

Local education authorities (LEAs) with a high percentage of pupils eligible for free school meals (an indicator of poverty) have a low percentage of pupils with 5 or more passes at GCSE levels A star to C (figure 14). Higher proportions of pupils in the south of England gain 5 or more passes at GCSE grades A star to C than in the north-east⁴¹. Higher proportions of girls than boys achieve 5 or more passes at these levels (49 per cent for girls, 40 per cent for boys)⁴⁰. Examination results of pupils attending special schools are significantly worse than for pupils in "mainstream" schools¹⁰³.

Evidence

Cohort studies show that those with low levels of educational achievement have poor adult health^{104,105}. There are a number of interpretations of this relationship, which are not mutually exclusive. Level of education may act as a marker for other influences such as socioeconomic status, occupational level or lifestyle¹⁰⁶. Educational attainment may be the route through which there are differential opportunities for income and employment, with their consequences on health¹⁰⁷. Education may have a direct influence on health related behaviour: children who do well in education tend to report healthier behaviour in adult life in relation to diet, smoking and exercise¹⁰⁸. In summary, although the extent to which education has an independent effect on health status, and the mechanisms by which it does so are not fully understood, it does appear to have an important influence. This influence may be seen as both potentiating, providing the trigger for healthier lifestyles and behaviour, and protective, providing access to employment opportunities and life chances that can protect individuals from disadvantage later in life.

However, those living in disadvantaged circumstances, who are most in need of the benefits of education, may be least able to gain access to them. Analyses suggest that inequalities in resource allocation to schools and provision for the renewal of school buildings have widened over the last two decades¹⁰⁹. Schools in disadvantaged areas are more likely to be restricted in space and have the environment degraded by litter, graffiti, and acts of vandalism. This contributes to more stressful working conditions for staff and pupils. Children coming to school hungry or stressed as a result of their social and economic environment will be unable to take full advantage of learning opportunities. And stress, depression and social exclusion may reduce parents' capacity to participate in their children's education.

Whilst we recognise the constraints on what education can achieve due to unfavourable influences outside school, we are convinced that the education sector has important opportunities within its grasp to reduce inequalities in health. Furthermore, recent research has shown that there is marked variation in the effectiveness of secondary schools, as measured by educational attainment, even when measures of disadvantage amongst pupils have been taken into account¹¹⁰. Logic and equity argue that children most in need should receive increased resources for their education. Arrangements already exist through the Revenue Support Grant Formula to take account of deprivation. We consider that the effectiveness of the current resource allocation mechanisms should be reviewed and the distribution of educational resources should be more finely calibrated to the levels of disadvantage in the school.

Benefit

Enhanced education is likely to lead to health gains both directly, for instance through the adoption of health promoting behaviours and indirectly, for instance through a greater likelihood of employment.

4. We RECOMMEND the provision of additional resources for schools serving children from less well off groups to enhance their educational achievement. The Revenue Support Grant formula and other funding mechanisms should be more strongly weighted to reflect need and socioeconomic disadvantage.

Developing pre-school education

Out-of-home day care and pre-school education are two services which overlap in providing learning and care for those below current statutory school age. There is no clear and logical dividing line between them, as both must secure and promote children's healthy physical, emotional and intellectual development. The evidence which supports the effectiveness of out-of-home day care and pre-school education in promoting children's health and development also overlaps. It is presented in full here and summarised at recommendation 21.1 (on day care).

Inequality

Currently the provision of out-of-home day care and pre-school education services varies by area. Often the services are only available for those who can pay the full or subsidised fees¹¹¹. A 1990 survey carried out by the Department of Health found that over 40 per cent of mothers of three and four year olds not attending day nursery would like their children to do so¹¹².

Evidence

Assessment of the most rigorous evaluations is found in a systematic review of randomised controlled trials of non-parental out-of-home day care before the age of 5 years¹¹³. This assessed 8 trials, all conducted in the USA. In total over two thousand children were randomly allocated to a group who received day care or to a group who did not. In 4 studies the day care started when the children were infants. Length of follow up ranged from 6 months to 27 years. Most of the studies targeted families of lower socioeconomic status, and nearly all included an element of home visiting and targeted parental training. The formal educational component varied, although all were concerned with the attainment of cognitive concepts. The review was not able to determine the effects of different parts of the programmes.

Although all studies showed that IQ was increased by participation in day care, this effect did not persist much after the end of this care. However, measures of educational performance tended to be persistently higher in the groups who received day care. Furthermore, there were no adverse effects of day care on behaviour. Other advantages included better educational, employment and financial achievement amongst mothers whose children received day care shown in some but not all of the studies. In one of the studies, the Perry Project (later called Highscope), follow up to 27 years of age showed that the people from the day care group were more likely to have advantageous social outcomes such as high school graduation, employment, fewer arrests, higher earnings, fewer teenage pregnancies and owning their own home. Furthermore, investment in pre-school provision in this project was associated with financial gain to society in the long term. Few outcomes measured health directly. Although the results of observational studies or cross-country comparisons have not always been consistent with those from experimental trials, weaknesses in design and evaluation have led to some of the apparently contradictory findings¹¹¹.

Overall the evidence suggests that pre-school education or day care may be especially effective in improving the achievement and health of the most disadvantaged children, although this will not necessarily bring them up to the level of their more advantaged contemporaries. The content and quality of the programmes are crucial. Social and emotional, as well as cognitive, objectives should be included, and high quality, including in the educator's own training, must be assured. Pre-school education may be a particularly good opportunity to involve parents in their children's education and to develop their own, particularly in enhancing parenting skills^{114,115}.

Benefit

Greater provision of high quality out-of-home day care and pre-school education should increase choice to use these services. Benefits include improved educational and social achievement in the children and perhaps for parents.

5. We RECOMMEND the further development of high quality pre-school education so that it meets, in particular, the needs of disadvantaged families. We

also recommend that the benefits of pre-school education to disadvantaged families are evaluated and, if necessary, additional resources are made available to support further development (*see also recommendation 21.1*).

Developing health promoting schools

In the next two sections, we focus more specifically on the role of the education sector in protecting and promoting the current health of children and preparing them for life. We adopt a concept of the health promoting school in line with that of the World Health Organisation/Commission of the European Communities and Council of Europe initiative:

"The health promoting school aims at achieving healthy lifestyles for the total school population by developing supporting environments conducive to the promotion of health. It offers opportunities for, and requires commitments to, the provision of a safe and health-enhancing environment"¹⁰¹.

The three main components encompass:

- enhanced education for health through the formal curriculum,
- improvements in the physical and social environment for pupils and staff to work in, including paying attention to how the organisation of the school encourages or inhibits healthy living,
- expansion of school/wider community links⁹⁹.

Inequality

As already outlined, schools in more disadvantaged areas are more likely to have a poor physical environment for both pupils and staff and resource allocation may not be matched adequately to their greater need. The capacity of schools to provide a supportive environment for children, particularly those experiencing disadvantage, has been eroded over the past 15 years, through such measures as the deregulation of school meals of a minimum standard and subsidised price, reduction of entitlement to free school meals¹¹⁶ and the reduction of access to playing fields, as school land has been sold off for housing development¹⁰⁹.

Cigarette smoking by school-aged children may be used as an indicator of health-promoting behaviour, although it is imperfect for this purpose. There is little social class gradient in the proportion of children who have ever smoked, although the average consumption of cigarettes is higher in lower socioeconomic groups¹¹⁷. However cigarette smoking in adolescence may be a marker of socioeconomic trajectory i.e. of where young people are going (class of destination) rather than where they have come from (class of origin)¹¹⁸. Thus there is a strong link between educational disadvantage and smoking status, with those leaving school at the minimum statutory age and without qualifications having higher rates of smoking in adolescence and early adulthood than their educationally advantaged peers. The association remains after parental socioeconomic status and parental smoking status are taken into account^{118,119}. Drinking alcohol over the adult safe limit is reported more often by children in lower socioeconomic groups, although they are actually less likely to be regular or occasional drinkers than those in higher socioeconomic groups¹¹⁷.

Evidence

With the important exception of children who are excluded or who truant, schools are one of the few contexts in which health promotion interventions can reach most children and young people.

A recent evaluation of health promoting schools found that this approach to health promotion can lead to gains in pupils' knowledge, attitudes, self-esteem and health behaviours, particularly in primary schools¹²⁰. However, there is no evidence yet that these approaches differentially improve health in disadvantaged pupils or are

particularly effective in disadvantaged areas.

Reviews of health promotion have tended to be topic-based. Although this approach is limited, the evidence of such reviews may be used to illustrate more general principles for implementation. Three examples are considered here. They are the promotion of life management skills, the prevention of substance misuse, and sex education.

The promotion of life management skills: emotional development and mental health may be enhanced by programmes which aim to increase competence in various areas, including problem-solving, communication, decision-making, and coping with emotions. An example is the "Life Skills" approach promoted by the World Health Organisation¹²¹. Such programmes have been associated with improved behaviour and social relationships^{122,123}. Despite the importance of parenting in protecting and enhancing the health of families, many young people leave school without acquiring the knowledge and skills which enable them to plan and achieve becoming a successful parent. Parenthood education should be started at school and be based on the values of caring for children and the importance of relationships¹²⁴. For life management skills in general, interventions with a number of components and within the context of a well-run and supportive school are more effective than single interventions^{125,126}.

Substance misuse: a recent review of interventions to prevent substance misuse among young people found that there were few rigorously evaluated interventions. However, the evidence reviewed did permit some broad conclusions which are relevant to school based health promotion programmes. These conclusions were, firstly, that programmes should recognise the specific needs of individuals and groups of individuals, and the differing social and cultural contexts in which substance misuse is engendered, initiated and maintained. Secondly, programme intensity should be high, 15 hours or more, with "booster" sessions to reinforce gains. Thirdly, the content of the programmes should include normative education which seeks to reduce perceptions of prevalence and acceptability of use. Fourthly, programmes should have a mix of elements which could include social influence and skills training. Of relevance to the approach of health promoting schools, the review found that programmes needed to have consistency of approach and context¹²⁷. In addition, early programmes, delivered in primary schools, may be successful in the prevention of substance misuse¹²⁸.

Sex education: Features associated with successful education programmes include: timing, which should precede the onset of sexual activity; a combined approach to education and information about the provision of contraception; integration with psychological approaches and with other life management skills; context, emphasising responsible and caring relationships and a recognition of social influences and pressures; a focus on specific aims, such as delayed intercourse and safe intercourse; and the tailoring of the programmes to the needs of the group they are intended to serve^{129,130}.

These examples illustrate some principles of successful health promotion in schools. These include: early education; taking account of wider influences on health-related behaviour; and a supportive school setting. Some of these principles of successful interventions could be achieved by strengthening Personal, Health and Social Education (PHSE) within primary and secondary schools. In particular, the need for sex education to start before the onset of sexual activity indicates that it needs to start in primary schools.

Benefit

Successful health promotion at school should increase "life skills" with resultant improvements in many aspects of physical, mental and social health. Health promoting schools could also provide a supportive environment and be a context for building social cohesion and for community development. For health promotion in

school settings to decrease inequalities in health, there must be attention to the particular needs of children experiencing disadvantage. Children who are excluded, or exclude themselves, from school are at high risk of adverse health outcomes and may be least able to benefit from school-based health promotion interventions.

6. We RECOMMEND the further development of "health promoting schools", initially focused on, but not limited to, disadvantaged communities.

Improving nutrition at school

Inequality

Compared with those from non-manual backgrounds, the diet of children aged 11/2 to 41/2 years from manual backgrounds has less emphasis on fruit juice, fruit and fresh vegetables (especially vegetables) and whole grain cereals and more emphasis on sweet foods and confectionery¹³¹. Comparable recent data are not available for school aged children.

Evidence

Children in families on Income Support or on income-based Job Seekers Allowance are entitled to free school lunch. About 15 per cent of pupils in England receive a free lunch and about a further 27 per cent pay for it¹³². School lunch is thus an important component of the diet of children from disadvantaged families. For this reason, and for nutrition education purposes, school lunches should reach reasonable nutritional standards. These should attempt to redress inequalities in the diet, such as fruit and vegetable consumption¹³¹. There is evidence that some members of poorer families go without food because of lack of money, although this is much more likely to be mothers than children^{93,94}. The characteristics and extent of those at risk of such "food poverty" have not been fully determined. When they are, there may be a case for extending provision of free school lunches to include children from poor families who are not currently entitled, in order to relieve overall pressure on the family food budget, and improve the nutrition of other family members. Breakfast clubs are another promising innovation, but they have not been systematically introduced or evaluated. They may be linked with out of school activities and day care as well as being a vehicle for improving nutrition in deprived areas. Their use for the latter purpose needs to be evaluated.

Nutrition education is not only about the nutritional value of food, but about budgeting for food, and choosing, preparing and cooking it. These elements should be included in the curriculum. Nutrition provided at school and nutrition education are likely to be enhanced if there is a school food policy set in the context of a health promoting school^{99,101,120}. Such a policy might, for instance, support the provision of healthy eating choices by avoiding the use of confectionery vending machines. The provision of free school fruit to reduce socioeconomic inequalities in fruit consumption has not been evaluated. Successful schemes may rely as much on the restriction of alternatives as on the provision of fruit per se¹³³. The practicality of widespread application of such schemes is also unknown. School fruit might have as much a role in forming attitudes to future fruit consumption as in present consumption.

Benefit

Improvements in the nutrition of school-children should result in decreased levels of obesity and nutritional deficiencies, and in healthier eating patterns in adult life. In turn, this may decrease the risk of some chronic degenerative and other diseases of adult life, without increasing the risk of other conditions.

7. We RECOMMEND further measures to improve the nutrition provided at school, including: the promotion of school food policies; the development of budgeting and cooking skills; the preservation of free school meals entitlement; the provision of free school fruit, and the restriction of less healthy food.



We welcome your comments on this site.

Prepared 26 November 1998

3. Employment

Employment plays a fundamental role in our society. People are often defined, and define themselves, through what they do for a living. Sociological studies emphasise that not only is employment a primary source of status in industrialised countries like Britain, but it is also significant in providing purpose, income, social support, structure to life and a means of participating in society¹³⁴. It has been called "the glue that keeps our society together"¹³⁵. In such a context unemployment and stressful or hazardous working environments are potentially major risks to health for the population of working age and their families.

There are four main policy areas to address employment and health issues, which form the basis for our recommendations:

- ameliorating the health damage among people who experience unemployment, through ensuring adequate income levels for unemployed people and their families, for example; and matching services to the greater need related to unemployment;
- increasing training and education opportunities for population groups at greatest risk, to help prevent unemployment in the future;
- removing barriers to employment through, for example, the provision of adequate child care, family-friendly employment policies and employment generation;
- improving the employment conditions and health-enhancing quality of the work environment for people in employment.

Reducing unemployment and its effects on health

Inequality

By the International Labour Office (ILO) definition, two million people were unemployed in the UK in 1997, about 7 per cent of the economically active population of working age. Around half of all unemployed men and just under a third of unemployed women had been unemployed for one year or more⁴⁰. The risk of being unemployed is much higher for young adults, people from minority ethnic groups, disabled people and for people in less skilled occupations and with fewer qualifications^{40,45}. For example, unemployment rates are four times higher among unskilled workers than among professional groups⁴⁴, and three times higher for disabled than non-disabled people¹³⁶. In addition to those recorded officially as unemployed, there are nearly 8 million people of working age in the UK who are classed as economically inactive because of long term sickness, for instance, or because they are looking after a family or have become discouraged in their search for work. A third of these report that they would like a job⁴⁰. Many of the jobless households contain children, who share the consequences and living standards of their parents not being in employment. For example, of a total of 13.3 million dependent children in the UK in 1994-95, 4.1 million lived in households with no full-time worker, three quarters of whom were living in poverty (in a household below half of average income, after housing costs)⁷².

Evidence

For a small minority, unemployment appears to lead to an improvement in health. But for the majority it tends to have a significant adverse effect on both physical and mental health. Unemployment is an important determinant of inequalities in the health of adults of working age in Britain, with people lower down the social scale being hardest hit¹³⁷⁻¹³⁹. Unemployed people are found to have lower levels of psychological well-being, ranging from symptoms of depression and anxiety to self-harm and suicide^{140,141}. In relation to physical health, unemployment carries a higher risk of morbidity and premature mortality. In the latest analysis from the Longitudinal Study covering England and Wales, for example, mortality from all

major causes was consistently higher than average among unemployed men. Among younger men, mortality from injuries and poisoning, including suicide, was particularly high. Unemployed women had high mortality from coronary heart disease and injuries and poisonings, including suicide¹⁴². The wives of unemployed men have been found to have an excess risk of death¹⁴³. Even after taking account of the more disadvantaged circumstances of unemployed people, an excess risk of death of more than 20 per cent remains¹⁴².

Explanations for how unemployment leads to poorer health centre on four main mechanisms: through increased poverty and hardship; through social exclusion (isolation, stigma); through changing health related behaviour; and through disrupting future work careers (people who experience a spell of unemployment are at greater risk of becoming unemployed again within the next two years)¹⁴⁴. In relation to hardship, the financial consequences of unemployment are often instant and dramatic. Cohort studies of people entering unemployment show that, for many, their income was cut by half as they switched from wages to social security benefits^{145,146}. The largest British cohort study in the 1980s showed that two thirds of unemployed people had a week's notice or even less, and only 1 in 10 received any form of redundancy payment. Two thirds were under 35, and most came from manual or lower service occupations, at the lower end of the pay scale and with low or no educational or technical qualifications¹⁴⁴. Families with an unemployed head are at the highest risk of poverty¹⁴⁷. Studies of the adequacy of state benefits identify unemployed households with dependent children as being particularly badly off¹⁴⁸⁻¹⁵¹.

Some of the excess morbidity and mortality associated with unemployment may be a result of people in poorer health being more likely to become unemployed, rather than vice versa. The evidence suggests that selection of unhealthy people into unemployment does indeed occur, but it is not the dominant factor explaining the observed relationship between unemployment and excess risk of ill-health. It does, however, illustrate the double disadvantage that people with chronic sickness or disability may face: their ill-health puts them at greater risk of unemployment, and the experience of unemployment in turn may damage their health still further.

Unemployment is associated with lower levels of educational attainment¹⁵² and other skills. The lack of such skills may prove a barrier to obtaining employment¹⁵³ reinforcing earlier or other disadvantage. For example, Labour Force Survey Data indicate that 41 per cent of disabled people of working age have no educational qualifications, compared with 18 per cent of non-disabled people¹⁵⁴. Unemployment is particularly high amongst young people. The rates of unemployment among people up to the age of 25 years are about twice as high as for all adult workers¹⁵⁵. Schemes to raise levels of skills amongst people without a job, particularly young people, have been important components of Government policies over the last 20 years or so. Evaluations of policies that have aimed to increase levels of skills among young people have reached differing conclusions. Some have concluded that such training increases likelihood of "a good job", whilst others have found that such success is very limited¹⁵⁶⁻¹⁶⁰. In particular, such schemes may fail the most disadvantaged by not addressing other problems, such as homelessness or lack of social support, which may present greater barriers to employment than lack of skills¹⁶¹. "Foyer" schemes are an example of a broader approach to disadvantage amongst unemployed young people. They consider the need for housing and social support as well as training and employment, but have yet to be thoroughly evaluated^{162,163}.

Many jobless households contain children, the majority living in poverty. Parents, especially lone parents, who wish to take up work may face several barriers. These include a lack of affordable child care, limited flexibility in parental leave and leave to care for sick children, and excessive and unsociable working hours. By comparison with many other member states of the European Union, the United Kingdom's policies in this area are limited. For instance, the UK has no provision for parental leave or leave to care for sick children, whereas half the (mainly European) 20 countries in a

recent study had arrangements for leave to care for sick children¹⁶⁴. The Inquiry welcomes the publication of the Government's white paper "Fairness at Work"¹⁶⁵, issued in May 1998, with its commitment to "family-friendly policies". We consider that this is an important, if modest, step in the right direction, and commend the further development of such policies. Consequently, with the exception of day care for children, we have not made a specific recommendation in this area.

But the removal of barriers to work for parents with dependent children, and higher levels of skills and additional training will achieve little unless there are jobs available. Indeed, lack of availability of employment may increase the sense of exclusion of people who are unable to gain employment despite adequate levels of skills¹⁶¹. It is outside the scope of the Inquiry to recommend specific policies on employment creation. However, we consider that increasing employment opportunities is crucial to reducing inequalities in health.

Benefit

Improved financial support during unemployment should improve material living conditions and resources needed for health, including access to food, heating, and shelter. It may also improve the ability of unemployed people to take part in the life of their communities - reducing social exclusion.

Policies aimed at the creation of employment opportunities, improved levels of education and training for young unemployed people, and removal of barriers to work for parents with dependent children should increase the chances of health enhancing employment in addition to other beneficial effects on health and its determinants, for example, income.

8. We RECOMMEND policies which improve the opportunities for work and which ameliorate the health consequences of unemployment. Specifically:

8.1 we recommend further steps to increase employment opportunities.

8.2 We recommend further investment in high quality training for young and long term unemployed people.

We recommend policies which will further reduce income inequalities, and improve the living standards of households in receipt of social security benefits (recommendation 3).

We recommend an integrated policy for the provision of affordable, high quality day care and pre-school education with extra resources for disadvantaged communities (recommendation 21.1).

Improving the quality of jobs

Inequality

For those in paid employment, there have been major changes in the nature of work over the past two decades. Along with greater labour market flexibility and deregulation of employment contracts has come greater job insecurity. Indeed, it could be considered that the concept of a secure "job for life" is now obsolete. While all sections of the workforce have been affected by these trends, less skilled manual workers at the lower end of the labour market have been affected the most, in terms of greater exposure to low paid, temporary and insecure employment¹⁶⁶⁻¹⁶⁹.

There is also a growing recognition of the impact of stressful working conditions on health. Popular opinion tends to equate stress at work with pressure of work. Surveys which ask about self-perceived pressure of work have found that people in higher socioeconomic groups report such pressure more frequently¹⁷⁰. However, evidence of health related harm is associated more with specific psychosocial factors such as imbalance between psychological demands and control, and lack of control at

work¹⁷¹. Exposure to high demand and low control is more common among lower socioeconomic groups¹⁷².

Evidence

A number of studies from the UK and elsewhere in Europe and from the USA show that an imbalance between psychological demands and control, and lack of control at work are associated with increased risk of coronary heart disease, musculoskeletal disorders, mental illness, and sickness absence¹⁷¹⁻¹⁷⁶. As these psychosocial factors are related to the organisation of work, there are opportunities for change.

A recent review of international case studies on improving psychosocial health in the workplace found that it was possible to make improvements by tailoring changes to specific workplaces¹⁷⁷. Examples included increasing the variety and understanding of the different tasks in a production process, workforce participation in identification of problems and their solutions, and altering shift patterns to make them less tiring and disruptive to workers' personal lives. Furthermore, some changes in workplace organisation resulted in improved productivity. Although effective changes were likely to be specific to particular workplaces, successful interventions had some common features¹⁷⁷. They were: appropriate commitment and effort from management; support by management and the workforce; participation of the workforce in planning and implementation; and the creation of trust. Conversely, aspects which inhibited the success of policies included: schemes which directed attention away from difficult working conditions and attempted to treat the symptoms only; technical solutions alone, imposed from the top; and cases where management retained control over the dialogue.

Successful interventions follow principles of good management practice¹⁷⁸. Current Health and Safety Executive (HSE) Guidance endorses this¹⁷⁹. The enhancement of management skills in the current and future workforce is likely to bring about both a culture and practice which is amenable to health-promoting work organisation and practices. Good management practice may be engendered during school years, particularly in the acquisition of "life skills"¹²¹ as a component of Personal, Health and Social Education, and within the context of health promoting schools. Enhancing the management skills of the current workforce, particularly in relation to the promotion of psychosocial health, may be aided by further guidance and development work by the HSE, such as extending the current "Good health is good business" campaign to include psychosocial health¹⁸⁰. It has been suggested that good practice might also be encouraged by extending psychosocial health and safety issues to award schemes, such as "Investors in People". Other options include extending existing HSE regulations to encompass psychosocial health.

Evidence from Scandinavia suggests that good practice may also be promoted by explicit commitment and leadership from the national level^{177,181}. In this respect, we welcome the Government's white paper "Fairness at Work", which has the stated aim of "putting a very minimum infrastructure of decency and fairness around people in the workplace"¹⁶⁵. In pointing out that Britain now has the most lightly regulated labour market of any leading economy in the world, it explicitly acknowledges the unfairness of this situation - denying British citizens basic employment rights that are a matter of course elsewhere. Some of the measures proposed in the white paper have the potential to influence health related psychosocial conditions at work, in particular in relation to job security. Assessing the impact on health of existing and proposed employment policies, such as these and the Welfare to Work scheme, will be crucially important to inform future policy-making.

Benefit

Improved work practices, together with complementary employment policies, should decrease psychosocial ill health and its consequences, and may have other gains, including economic gains for the individual and society.

9. We **RECOMMEND** policies to improve the quality of jobs, and reduce psychosocial work hazards. Specifically;

9.1 we recommend employers, unions and relevant agencies take further measures to improve health through good management practices which lead to an increased level of control, variety and appropriate use of skills in the workforce;

9.2 We recommend assessing the impact of employment policies on health and inequalities in health (see also recommendation 1).

4. Housing and Environment

Shelter is a pre-requisite for health. However, people who are disadvantaged suffer both from a lack of housing and from poor quality housing. Furthermore, the fear of crime compounds the social exclusion of people living in disadvantaged areas. This section sets out inequalities in housing and the environment and health and summarises the evidence which we have concluded indicates areas for future policy development. These areas are improving the availability of housing, improving its quality and increasing the safety of the environment in which people live. The section also summarises the benefits which might result from such policies.

Improving the availability of housing

Inequality

As a result of housing policy in the 1980s and early 1990s, social rented housing - local authority and housing association homes - has increasingly become a housing sector for low income groups. People moving into social housing have tended to be families with children on the lowest incomes while those moving out have been older, with higher incomes and fewer children¹⁸². The result is an over-concentration and separation of households with high levels of need in areas with poor amenities.

The last 20 years have also seen a rapid increase in homelessness, with the numbers of officially homeless families peaking in the early 1990s¹⁸³. In 1997, 165,690 households were estimated to be homeless. Of these 103,340 were officially homeless, that is they met the definition of homelessness laid down in the 1977 Housing (Homeless Persons) Act. The remainder were unofficially homeless, including rough sleepers - those without any accommodation at all - and hostel users⁵¹. Because it is difficult to be accepted as officially homeless without the presence (or imminent arrival) of children, the officially homeless population contains a large number of mothers and dependent children. Fifty seven per cent of officially homeless households had dependent children, and a further 10 per cent had a pregnant household member. Seven per cent had a household member vulnerable through mental illness⁵¹. Over a third of the officially homeless are drawn from minority ethnic groups¹⁸⁴. By contrast, minority ethnic groups are not over-represented among the unofficial homeless population, which is older and predominantly male (70 per cent of hostel users and 85 per cent of rough sleepers are men)¹⁸⁴. Young people constitute a significant and high risk sub-group among the unofficially homeless population¹⁸⁵.

Rough sleepers are also drawn disproportionately from those who have been in an institution such as prison or mental hospital or have been in local authority care.

Evidence

Very high mortality rates have been recorded for homeless people, particularly for rough sleepers and hostel users¹⁸⁶. Surveys also point to high levels of health need among the homeless population. Forty five per cent of the bed and breakfast population have been found to experience psychological distress, compared to 20 per cent of the general population¹⁸⁴. Rates of self-reported depression and anxiety are three times higher among those in bed and breakfast accommodation and ten times

higher in rough sleepers. There is also an elevated prevalence of major mental disorders, most notably schizophrenia¹⁸⁴, and, among young homeless people, a high rate of attempted suicide¹⁸⁷.

In addition to their higher risk of mental health problems, people who are single and homeless have a higher prevalence of bronchitis, tuberculosis, arthritis, skin diseases, infections, problems related to alcohol and substance misuse, and higher rates of hospital admission¹⁸⁸⁻¹⁹⁰. People living in temporary accommodation of the bed and breakfast kind have high rates of some infections and skin conditions and children have high rates of accidents¹⁹¹⁻¹⁹⁵. Living in such conditions engenders stress in the parents and impairs normal child development through lack of space for safe play and exploration¹⁹². Whilst cause and effect are hard to determine, at the very least homelessness prevents the resolution of associated health problems. For example: many young people recently made homeless do not have adequate access to health care¹⁹¹; and homeless people who are heavy drinkers may have less access to health services for all their needs, including treatment of health problems related to alcohol and substance misuse¹⁹⁶⁻¹⁹⁹.

Availability of housing is related both to the quantity and quality of housing. The quality of the housing stock in Britain has steadily improved over this century but has been relatively stable since 1991. An estimated 1.5 million (7.5 per cent) homes are "unfit", a similar number to that in 1991²⁰⁰. Estimates of the additional social, rental or "affordable" housing required varies according to the factors taken into account when making predictions. For England, typical figures have been for 90,000 to 100,000 homes per year, although some estimates are lower. However, most research indicates a considerable deficit in such housing production at present^{200,201}. Taken together with the plateau in the number of homes which are unfit, it is likely that present housing conditions will not improve over the next five years, and may worsen.

Neighbourhoods and the development of new residential areas may benefit from the principle of planning to promote a mix of housing tenures, employment status, household composition and age groups. This may avoid the problems of concentration and isolation of those suffering the greatest disadvantages^{182,202-205}, and the consequent overload on services.

Benefit

Although improvements in quantity and quality of housing are not certain to improve health, it is logical that they should do so. Such benefits would be on a range of health outcomes. Reducing official and unofficial homelessness would meet a basic health need of groups already vulnerable to poverty and ill-health, including families and mentally ill young people. If improvements are made through community-led development, this may also enhance social networks, with other potential benefits to health^{206,207}.

10. We RECOMMEND policies which improve the availability of social housing for the less well off within a framework of environmental improvement, planning and design which takes into account social networks, and access to goods and services.

11. We RECOMMEND policies which improve housing provision and access to health care for both officially and unofficially homeless people.

Improving the quality of housing

Inequality

Properties in bad condition are occupied disproportionately by single older people²⁰⁸. Minority ethnic groups are generally more likely to be living in poor housing than the white majority²⁰⁹.

Forty per cent of all fatal accidents happen in the home²⁰⁸. Almost half of all

accidents to children are associated with architectural features in and around the home²¹⁰. Households in disadvantaged circumstances are likely to be the worst affected by such accidents¹⁹⁴. Those living in high rise buildings, frequently those in lower socioeconomic groups, are more prone to serious accidents, such as falls²⁰⁸. Families living in temporary accommodation are also likely to suffer accidents in the home¹⁹⁵.

Evidence

Poor quality housing is associated with poor health^{211,212}. Dampness is associated with increased prevalence of allergic and inflammatory lung diseases, such as asthma, independent of smoking and socioeconomic factors²¹²⁻²¹⁴. Unmodernised older properties have far higher heating costs than improved and modern homes²⁰⁸. A survey of older people in 1988 found that 25 per cent were using less heat than they wished, because of the cost⁹⁷. Cold housing leads directly to hypothermia and may contribute to the excess of winter deaths seen in older people^{208,215}. It also leads to "fuel poverty"⁹⁶. Whilst the hazards of such poverty could be addressed by increasing the financial resources available to older people and others living on state benefits, a more direct approach would be to improve the energy efficiency, insulation and heating systems of affected housing. Mechanisms to do this include further development of building regulations for new and existing buildings and through further development of Government schemes which subsidise improvements in existing properties. Current Government schemes, for example, the Home Energy Efficiency Scheme, may not reach homes most in need, such as the private rented sector.

Temporary accommodation tends to be ill-designed, ill-equipped and ill-maintained. Poor housing design, for instance changes in floor levels at door thresholds, contributes to seemingly minor accidents in older people, which may have grave consequences²⁰⁸. Disabled people are under-represented amongst owner occupiers, and rely heavily on local authority housing, especially for accessible dwellings. The stock of accessible housing is insufficient to meet the needs of disabled people, particularly for those using wheelchairs²¹⁶⁻²¹⁸.

Smoke alarms are effective in reducing deaths from fire²¹⁹. The use of smoke alarms, mostly battery operated, has increased in recent years but those most at risk, e.g. living in temporary accommodation, are least likely to have an alarm where they live⁵⁰. Options to promote the use of smoke alarms include placing a duty of care on landlords to install and maintain smoke alarms and including them in fitness standards for existing buildings. Removal of other accident hazards in the home might also be achieved by changes to regulations and fitness standards.

Benefit

Improvement in energy efficiency in homes is likely to improve the health of occupants, both directly and by releasing their financial resources for other uses. It also has wider benefits in conserving energy. Removal of hazards in homes is likely to lead directly to reduced death and injury from accidents. Improvements in home design might allow disabled and older people to be cared for at home, with improvements in their quality of life.

12. We RECOMMEND policies which aim to improve the quality of housing. Specifically:

12.1 we recommend policies to improve insulation and heating systems in new and existing buildings in order to further reduce the prevalence of fuel poverty.

12.2 We recommend amending housing and licensing conditions and housing regulations on space and amenity to reduce accidents in the home, including measures to promote the installation of smoke detectors in existing homes.

Reducing the fear of crime and violence

<http://www.official-documents.co.uk/document/doh/ih/part2c.htm>

Inequality

Crime and fear of crime can affect profoundly the quality of people's lives. Just over half of the 4 million incidents of contact crime - wounding, robbery and common assault - counted by the British Crime Survey in 1995 involved injury to the victim, usually bruising and scratches. Serious physical injury is rare. But anger, shock, fear and a sense of invasion of privacy are felt by many victims²²⁰.

Not everyone is at equal risk of becoming a victim of crime. Young men, as well as being the most common perpetrators of crime, are also the most likely victims of street crime, especially physical assaults. Older people, especially women, are more likely to be victims of theft from the person. Crime tends to be concentrated in areas of social deprivation. Other indicators, such as the incidence of vandalism, graffiti, nuisance and substance misuse, are associated with levels of crime and can thus be useful markers of people's experience of crime, much of which is never reported to the police²²¹. People from minority ethnic groups are at a greater risk of violent crime and of racial harassment^{66,222}.

Fear of crime can also be a cause of mental distress and social exclusion. In particular, women and older people tend to worry more about becoming victims and this may prevent them from engaging in social activities. People's fear of being a victim of crime may be well in excess of the actual risks. The British Crime Survey found that 4 per cent of men, aged over 16 years, and 18 per cent of women felt very unsafe walking in the area near their home at night. These figures increased to 8 per cent for men and 31 per cent for women if only people over the age of 60 years were considered, and were considerably higher if lesser degrees of concern about safety were included. Furthermore, 1 per cent of men and 4 per cent of women felt very unsafe in their own homes if alone and at night²²⁰.

People who suffer from poor health are more likely to be victims of crime than those in good health. However, this may be because of the association of disadvantage with both victimisation and poor health, rather than poor health causing victimisation²²⁰.

Evidence

There is increasing evidence to suggest that society level factors, and poverty and income inequality in particular, may be important underlying causes of crime^{223,224}. Studies have described how widening income inequalities in countries like Britain and the US have been accompanied by a greater spatial separation of rich and poor²⁰². This has led to a search for mechanisms which might explain the observed relationship between income inequality and its associated residential concentrations of poverty and affluence, on the one hand, and crime on the other. One hypothesis is that income inequality is related to crime via a depletion in social cohesion, as measured by high levels of mutual distrust and low levels of reciprocity between people living in the same neighbourhood, region, or society²²⁴⁻²²⁶.

Although the evidence is incomplete, the link between income inequality, social cohesion and crime has important policy implications. It suggests that crime prevention strategies which only target the perpetrators and victims of crime and the high crime areas in which both groups live, will not achieve a significant reduction in crime unless they are accompanied by measures to reduce income inequality and promote social cohesion^{224,226}.

The most effective approaches to crime prevention are likely to be those which are integrated with wider social and economic policies for reducing health inequalities. In particular, pre-school education has been shown to have a long term effect on the incidence of criminal behaviour in early adult life^{113,115}. Similarly, measures that address the welfare needs of young people are likely to have an impact on the incidence of youth crime²²⁷.

There are a number of other measures which can help to protect local communities

from high rates of crime and help people feel more secure. These measures include modifying the physical environment in such a way that crime is less likely to occur - for example, street lighting, changing the design, layout and landscaping of buildings; providing better surveillance - for instance concierge schemes, use of CCTV cameras and security alarms; and involving local police in "community policing", where officers spend more time on the beat, are proactive in identifying problems, and form partnerships with local people, businesses and other agencies. In this way, the expertise, knowledge and resources of local communities are used in helping to define, target and resolve problems²²⁸.

Benefit

It is beyond the scope of this Inquiry to recommend particular approaches to prevent or reduce crime. However, there appears to be good evidence that crime and fear of crime is felt disproportionately by disadvantaged groups and that "upstream" policies, such as pre-school education, can reduce criminal behaviour in adolescence. There is also a general consensus that crime can be prevented through targeted policing and by involving local communities which itself may promote social cohesion²²⁸. However the relative benefits of different measures, including social and economic regeneration programmes and greater provision of services for young people, are not known.

13. We RECOMMEND the development of policies to reduce the fear of crime and violence, and to create a safe environment for people to live in.

We recommend policies which will further reduce income inequalities, and improve the living standards of households in receipt of social security benefits (recommendation 3).

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Prepared 26 November 1998

5. Mobility, Transport and Pollution

The primary function of transport is in enabling access to people, goods and services²²⁹. In so doing it also promotes health indirectly through the achievement and maintenance of social networks. Some forms of transport, such as cycling and walking, promote health directly by increased physical activity and reduction of obesity. Lack of transport may damage health by denying access to people, goods and services and by diverting resources from other necessities. Furthermore, transport may damage health directly, most notably by accidental injury and air pollution.

Improving public transport

Inequality

In the 1991 Census, those living in accommodation rented from a housing association or local authority were nearly four times as likely to have no access to a car as those living in owner occupied housing (68 per cent compared to 19 per cent) and over six times less likely to have access to two or more cars (5 per cent compared to 32 per cent)⁵². In rural areas having no access to a car was less common than in urban areas (15 per cent compared to 34 per cent), and having access to two or more cars was more common (42 per cent rural areas, 22 per cent in urban areas). People living in rural areas were somewhat more likely than those living in urban areas to travel to work by car (69 per cent and 60 per cent respectively) but much less likely to use public transport if they had no car (23 per cent in rural areas, 49 per cent in urban areas)⁵⁴.

Evidence

Lack of access to transport is experienced disproportionately by women, children, disabled people, people from minority ethnic groups, older people and people with low socioeconomic status, especially those living in remote rural areas. Examples of lack of access include: people living in council housing, where poor access to transport may limit work and training opportunities^{230,231}; higher prices and a restricted range of goods available to people whose lack of access to transport denies them opportunities to shop in supermarkets²³²; limited access to health care facilities for people without a car living in rural areas²³³; and environmental barriers in access to transport experienced by people with physical disabilities²¹⁷.

Higher traffic volumes result in feelings of insecurity, especially amongst families with children, and older people²³⁴, and are associated with lower levels of non-traffic street level activity, such as walking. This can result in a community with limited potential for building or maintaining social networks²³⁵. Disadvantaged urban areas tend to be characterised by high traffic volume, leading to increased levels of air and noise pollution and higher rates of road traffic accidents without the benefits of access to private transport²²⁹.

The cost of rail and local bus fares has risen by nearly one third in real terms since 1980, whereas motoring costs have decreased by 5 per cent²³⁶. Thus the increased cost of commonly used modes of public transport has had the most impact on those with lowest incomes. Consequently, use of transport may have declined amongst the least well off. A dramatic demonstration of this occurred in South Yorkshire. Prior to bus de-regulation in April 1986, South Yorkshire had a comprehensive and cheap public transport system, with decreasing prices in real terms and increasing usage. After de-regulation, bus fares rose by 250 per cent. Unemployed people and those who had retired reduced their journeys more than those in work (62 per cent and 60 per cent respectively compared to 37 per cent), as did school children (by 48 per cent). Social support networks suffered as travel to undertake informal caring roles became

more difficult. This resulted in increased requests for statutory support services, including home helps²³⁷⁻²³⁹. Low incomes may be particularly strained in rural areas, where the lack of public transport makes car ownership a necessity²⁴⁰.

Further development of a high quality, healthy transport system for the public, which is integrated with other forms of transport, for instance walking and cycling, and is affordable to the user, is crucial to the reduction of inequalities in health. We consider that it is beyond the scope of the Inquiry to recommend the mechanisms which might be used to improve and develop such a public transport system. However, suggestions made to us include the decentralisation of funding and responsibility for local transport within an overall policy framework, and providing suitable powers for statutory partnerships to set and monitor standards of public transport.

Benefit

Improved public transport should lead to improved access to people and facilities fundamental to health, such as family and friends, shops, parks and leisure facilities, and health care. This in turn should lead to improvement in quality of life and health. If transport is made more affordable than at present, this would release resources which might be used for health promoting activities and goods. Increased use of public transport by the general population would have the result of decreasing air and noise pollution which is suffered disproportionately by people experiencing disadvantage. A decrease in the use of cars would lead to a reduction of accidents. This is likely, but not certain, to be accompanied by a reduction in inequalities in accident rates.

14. We RECOMMEND the further development of a high quality public transport system which is integrated with other forms of transport and is affordable to the user.

Encouraging walking and cycling

Inequality

Pedestrian injury death rates for children in social class V are five times higher than for those in social class I²⁴¹, and are higher for boys than girls²⁵.

Evidence

The most health promoting and equitable forms of transport, walking and cycling, are vulnerable to the disadvantages imposed by motor vehicles²²⁹. There has been a post-war decline in walking and cycling, which has come about partly because of a sense of increased danger consequent on the rise in motor vehicle traffic volume²³⁶. There is also evidence of a high level of suppressed demand for cycling. Some disadvantaged groups, for instance children from families without a car, are more likely to make journeys by foot, cross more roads than those who have access to a car, and consequently are exposed to higher risks of a pedestrian accident²⁴².

Re-allocation of road space to provide more infra-structure for pedestrian and cycle route networks has been effective in increasing the use of these modes and decreasing accidents in some cities such as York. Other examples have been found in Europe²⁴³. Smaller schemes, such as Safe Routes to School, may also be effective²⁴⁴. Such schemes need to be sensitive to local circumstances and involve the local community in decision making and implementation. This is an important feature of successful community accident prevention interventions, and indeed any community intervention^{219,245}.

Benefit

Those engaged in walking and cycling would gain from increased physical exercise and its health benefits. If overall levels of walking and cycling increased, at the expense of the use of motor vehicles, then it is likely that accident rates and levels of air pollution would fall. The burden of both falls disproportionately on people experiencing disadvantage.

15. We RECOMMEND further measures to encourage walking and cycling as forms of transport and to ensure the safe separation of pedestrians and cyclists from motor vehicles.

Reducing the use of motor vehicles

Inequality

The main cause of air pollution is emissions from motor vehicles, which include particulates and ozone²⁴⁶. About a third of households have no access to a car⁴², and these tend to be households with lower income⁵². Yet air pollution is more common close to roads and road junctions, and in inner urban areas²⁴⁷⁻²⁴⁹, places which are often characterised by other indicators of disadvantage²²⁹. Thus the burden of air pollution tends to fall on people experiencing disadvantage, who do not enjoy the benefits of the private motorised transport which causes the pollution.

Evidence

A recent report by the Department of Health's Committee on the Medical Effects of Air Pollutants (COMEAP) concluded that air pollution in urban areas, in the form of particulate matter, is responsible for bringing forward 8,100 deaths a year and bringing forward or creating an additional 10,500 hospital admissions for respiratory disease a year. In addition, in both urban and rural areas in the summer months, ozone is responsible for bringing forward 12,500 deaths and bringing forward or creating an additional 9,900 hospital admissions for respiratory disease per year. COMEAP also confirmed their previously stated view that the association between air pollution and mortality and morbidity is causal²⁵⁰.

Two options to reduce air pollution associated with motor vehicles are to decrease their use and to decrease their capacity to pollute²⁴⁶. The latter is likely to be a lesser effect, and any success in reducing emissions of pollutants will be outweighed if the use of and number of motor vehicles continues to increase. The annual increase in the amount of road traffic from 1993 to 1995 was over 2 per cent. Apart from isolated periods road traffic volume has increased steadily since the 1950s. Projections estimate that road traffic will increase between 55 per cent and 87 per cent between 1995 and 2025 (figure 15). Most of this increase will be cars^{246,251}.

Reduction of the use of motor cars appears to depend on the availability and acceptability of alternative modes of transport. These include walking, cycling and public transport. Walking and cycling may be particularly important in reducing air pollution as they could replace short car journeys under "cold-start" conditions, which cause a disproportionate amount of pollution²⁴⁶. Car journeys to school are a typical example. In order to be able to compete with the attractions of travel by car, an effective public transport system must be integrated: that is it must be a system in which people can change quickly and easily from one route to another and from one mode of transport to another. It must also be a financially attractive option, which may mean subsidising the service for all users, not just for those from disadvantaged groups.

Benefit

Reduction of the use of motor vehicles would decrease air pollution and probably also reduce road traffic accidents. The benefit of these decreases is likely to be gained most by people experiencing disadvantage, who currently bear much of the burden. Use of alternative modes of transport might also reduce inequalities in health through the benefits that a more effective public transport system would bring to those without access to private transport. Increased opportunities for walking and cycling should increase overall health, but the effect on inequalities in health is unknown and would depend on how different sections of the population took up these opportunities.

16. We RECOMMEND further steps to reduce the usage of motor vehicles to cut the mortality and morbidity associated with motor vehicle emissions.

Reducing traffic speed

Inequality

Motor vehicle traffic accidents are a major cause of preventable deaths, particularly in younger age groups. For children and for men aged 20-64 years, mortality rates for motor vehicle traffic accidents are higher in lower socioeconomic groups^{29,241}. For instance, there would be 600 fewer deaths in men aged 20-64 years from motor vehicle traffic accidents each year if all men had the same death rates as those in social classes I and II combined³². For children and adults over 65 years mortality rates from such accidents are higher in those born on the Indian sub-continent. For adults aged 15-24 and over 65 years rates are higher for those born in Ireland²⁵². There are also differences in standardised mortality rates from motor vehicle traffic accidents around the country. The standardised mortality rate in 1996 varied from 59 in London to 122 in the East Midlands²⁵³. Age standardised rates are three times higher for males than females²⁵.

Evidence

Speeding generally exacerbates risks for all road users, but particularly for pedestrians and cyclists. The chance of a pedestrian being seriously injured or killed if struck by a car is 85 per cent if the car is travelling at 40 mph, 45 per cent at 30 mph and 5 per cent at 20 mph²⁵⁴. Speeding is common, and speed limits are broken by most motorists in urban and rural areas, using all types of vehicle, whatever the time of day, day of week, or month of year²⁵⁵.

Environmental modification of existing roads or design of new roads which has the effect of "traffic calming" reduces speed of traffic and, by effectively excluding heavy goods vehicles, also reduces noise pollution²⁵⁶. Further, it provides a better environment for play and other community based street-level activities²⁵⁷. Introduction of 20 mph zones is associated with, on average, a 61 per cent drop in pedestrian casualties and a 67 per cent drop in child pedestrian and cyclist casualties²⁵⁴. As speeding is common, stricter enforcement of current limits may also be effective. For example, the use of speed cameras typically brings a casualty reduction of around 28 per cent²⁵⁴. To reduce inequalities these measures might need to be introduced preferentially in disadvantaged areas.

Benefit

A reduction in the speed of motor vehicles should reduce the risks of serious injury or death from road traffic accidents. It may also enhance the environment for other activities such as play for children, and reduce pollution.

17. We RECOMMEND further measures to reduce traffic speed, by environmental design and modification of roads, lower speed limits in built up areas, and stricter enforcement of speed limits.

Making public transport affordable for pensioners and disadvantaged groups

Inequality

Lack of access to transport is experienced disproportionately by older people and people from low income groups, especially those living in rural areas^{229,233}.

Evidence

Older and disabled people are more likely to have low incomes and to be reliant on public transport. The price of public transport is thus a critical issue in their mobility. The well documented change in use of buses in South Yorkshire illustrates the degree to which older people's use of public transport is determined by price^{238,239}.

About 10.5 million older people are eligible for concessionary fares in Great Britain, in addition to people who are disabled, registered blind and those with impaired mobility. Concessionary fare schemes vary considerably in different parts of the

country. In London, there is a statutory scheme enabling the issue of permits to older and disabled people for travel on local buses, London Underground and suburban rail. The permit is free and travel is free after the morning peak. Outside London, local authorities have discretion to decide which form of concession to offer. Options include free travel, free or purchased permits which then allow free or reduced fare travel, or fares reduced by fixed percentages. Some authorities, for instance within the West Midlands Metropolitan Area, offer similar schemes to the statutory scheme in London. A recent survey found that most authorities (97 per cent) operate a scheme, but the many different types offered means that the cost of transport to the user varies considerably from place to place. In some places concessions are quite limited²⁵⁸. Furthermore, uptake of concessions is lower in areas of low population density, and is only 39 per cent in rural areas²⁵⁹.

Benefit

Subsidised travel for older and disabled people should reduce a current barrier to health promoting opportunities.

18. We RECOMMEND concessionary fares should be available to pensioners and disadvantaged groups throughout the country, and that local schemes should emulate high quality schemes, such as those of London and the West Midlands.

6. Nutrition and the Common Agricultural Policy

By an immense programme of subsidies to agricultural production, the Common Agricultural Policy (CAP) has helped ensure the security of Europe's food supply since the end of World War II. Although this in itself has made an important contribution to health, the gain must be balanced against the consequent increased cost of food to the consumer. The range of foods affected includes cereals, meat, eggs, dairy produce, sugar, fruit and vegetables. Although the scale of the premiums varies across this range according to market conditions, and is difficult to measure, it is often substantial.

The significance of the CAP to inequalities in health is that the subsidies have maintained food prices usually at a higher level than necessary. As the poor spend a higher percentage of their income on food than the better off, the result is that the higher prices have the greatest impact on those least able to bear them. This is borne out by the reappearance of food poverty - going without food because of lack of money - in various parts of Europe including Britain^{116,261}.

The impact of CAP on the health of the less well off

Unfortunately, although the health impact of some of the individual programmes have been evaluated, there is no comprehensive review of the CAP's impact on the food budgets of the less well off, and through this on inequalities in health. We believe that this should be given a priority. CAP is by far the largest budget within the European Union - around 40 billion ecu a year (£32.5 billion)²⁶² - and is currently being reviewed as part of the Agenda 2000 programme in preparation for the next round of the World Trade Organisation talks. However, we are concerned that the health and health inequalities aspects of the CAP should be recognised and form part of this wider debate. We see an opportunity for the UK Government to build on the success of its European Union Presidency by hosting a conference to debate the implications of CAP on health and health inequalities.

The CAP's focus has been on raw food production. Its structure has meant that subsidies have led to surpluses so that half the budget provides subsidies to storage or export. The juxtaposition of "butter and meat mountains" and rising food poverty led to unfavourable publicity and the creation of a Surplus Food Scheme designed to redistribute food to the less well off. This small but significant "social policy" outcome of the CAP tends to be limited only to storable goods such as dried or frozen

foods rather than fresh foods such as fruit and vegetables. The practical problems of redistribution have so far ruled out the use of fresh fruit and vegetables on the Surplus Food Scheme²⁶³. Even within this scheme, we believe that there is scope for more effective use of subsidies to reflect nutritional and public health goals, perhaps directed at school-aged children.

From the nutritional point of view, the situation with regard to the supply of fresh fruit and vegetables is currently the most unsatisfactory aspect of the CAP. At a time when data have pointed to the protective effects of fruit and green vegetables in the prevention of cancer and coronary heart disease^{264,265}, large sums of money are being spent in the destruction of these products. This amounted to 2.5 billion kilos of fruit and vegetables at a cost of 390 million ecu in 1993-94. Notwithstanding changes which have reduced the amount of compensation paid on such produce, it is our view that this policy needs to be reviewed, taking into account estimates of the "health gain" that would be derived from the supply of these foods at subsidised prices.

19. We RECOMMEND a comprehensive review of the Common Agricultural Policy (CAP's) impact on health in general and inequalities in health.

19.1 We recommend strengthening the CAP Surplus Food Scheme to improve the nutritional position of the less well off.

Increasing the availability and accessibility of food

Inequality

Food consumption varies between different socioeconomic groups. People in lower socioeconomic groups tend to eat less fruit and vegetables, and less food which is rich in dietary fibre. These patterns tend to hold true over all age groups in which they have been examined, from birth to 64 years. As a consequence, those in lower socioeconomic groups tend to have low intakes of anti-oxidant and other vitamins, and some minerals, especially relative to intakes in higher socioeconomic groups^{35,55-58}.

Even within low income groups, there are differences in nutrient intake which are related to income. The 20 per cent of Income Support claimants with compulsory deductions for rent or fuel have very restricted spending on food, and their resulting diets are far below reference values for intakes of iron, calcium, dietary fibre and vitamin C. This is even more likely if adults in the family smoke⁹⁴. Furthermore, there is some evidence that such inequalities in nutrition, at least for some nutrients, have increased over the last 15 years⁵⁵.

There are also pronounced differences in diet by gender. Women are more likely than men to eat wholemeal bread, fruit and vegetables at least once per day and to drink semi-skimmed milk. They are less likely to drink alcohol heavily^{35,53}. However, nutrient intakes of iron, calcium, magnesium, vitamin B12 and folate are lower in women than men, especially in women from lower socioeconomic groups. Many of the differences can be accounted for by the lower total food and energy intakes of women. An adequate intake of calcium appears to be an important component of bone health, reducing the risk of osteoporosis and fracture, although the evidence is incomplete²⁶⁶⁻²⁶⁸. Vulnerable groups, such as adolescent girls and older women, should therefore avoid low calcium intakes. The main dietary sources of calcium are milk, milk products and cereal products. Vitamin D is essential for calcium absorption and utilisation. Adequate dietary intake of vitamin D is necessary if skin synthesis is likely to be sub-optimal, for instance, for older people who are housebound or those who wear concealing clothing, and for vulnerable groups, such as pregnant and lactating women²⁶⁹. The best method of achieving adequate intake through supplementation of high risk groups is currently the subject of multi-centre trials.

Women may be more likely to under-report the quantity of their diet than men, and they are also more likely to diet. The relatively low intakes in women may partly

reflect low intakes in a substantial proportion of women who are dieting at any single survey point²⁷⁰. The association between a mother's physique before and during pregnancy and cardiovascular risk in her children in later life suggests that her nutrition may have important long term effects on the health of the next generation²⁷¹⁻²⁷⁵. The prevalence of dieting in women, especially young women, is a cause for concern.

Evidence

The evidence that links diet and nutrition to health and inequalities in health is, in the main, based on research showing that nutritional risk factors for disease and higher rates of nutrition related diseases cluster in disadvantaged groups. For example, dental caries are more prevalent in children in lower socioeconomic groups, and children in these groups have higher intakes of sweet drinks and snacks between meals - risk factors for caries. Death from stomach, oropharyngeal and oesophageal cancer is more common in lower socioeconomic groups and has been linked to low intake of fruit and vegetables, also more common in lower socioeconomic groups. Cerebrovascular disease is more common in lower socioeconomic groups and is associated, possibly through the intermediate risk factor of hypertension, with consumption of salty, energy dense foods which are high in sodium and low in magnesium and with low consumption of fruit and vegetables. This pattern of diet is more common in lower socioeconomic groups²⁷⁶.

However, the effect of policies aimed at changing nutrition or single nutrients in the diet may be difficult to predict, given the sometimes complex link between diet, nutritional status and health. Thus our recommendations are based on enabling those who are disadvantaged to have the choice to purchase and consume a balanced diet²⁶⁹.

Benefit

Reductions in inequalities in nutrition should lead to reductions in diseases which have nutrition-related risk factors. These include some types of cancer, cardiovascular disease, osteoporosis, anaemia, dental disease, and obesity and hypertension, and their complications. The extent to which these will be preferentially reduced in particular groups, for instance those from lower socioeconomic groups, is unpredictable. For instance, a reduction in total fat intake is a current recommendation to the whole population, based on the premise that this will lead to a reduction in average plasma cholesterol levels, which in turn will lead to reduced coronary heart disease. As, for a given level of plasma cholesterol, people from lower social classes have higher rates of coronary heart disease than those from higher social classes, an overall reduction in average plasma cholesterol may have a greater effect in reducing coronary heart disease in lower social classes²⁷⁷.

20. We RECOMMEND policies which will increase the availability and accessibility of foodstuffs to supply an adequate and affordable diet.

Reducing food poverty and improving retail provision

Inequality

Households in the bottom tenth of the income distribution spend an average of 29 per cent of their disposable income on food (after allowance for housing costs) compared to 18 per cent for those in the top tenth²⁷⁸. People in low socioeconomic groups buy more efficiently than high income households, obtaining more grams of food of any type per pound spent. However, they also spend more on foods richer in energy and high in fat and sugar, which are cheaper per unit of energy than foods rich in protective nutrients, such as fruit and vegetables¹¹⁶. It also costs them more to shop because the physical inaccessibility of large retail food outlets necessitates expenditure on transport or the higher prices in small local shops²³². The food budget is susceptible to "squeezing" to meet other demands, partly because it is a large proportion of low income households' budgets and partly because it is not protected.

Rent and other deductions may be made compulsorily which places additional strain on the remainder of the budget⁹⁴.

Food poverty is experienced by some people in low income groups, particularly single mothers^{93-95,116}. The diets of families living on low income may also lack choice and variety, a consequence of the expense of supplying choice and the associated potential for waste of food^{93,279,280}.

Evidence

Economies of scale allow food sold in supermarkets to be cheaper and to cover a wider range than that in smaller "high street" stores²³². Furthermore, there is a paradox in that a "healthy" basket of food has been found to cost more in disadvantaged areas than in affluent areas^{232,281}. The increasing tendency to out of town supermarkets has led to the creation of "food deserts" where cheap and varied food is only accessible to those who have private transport or are able to pay the costs of public transport, if this is available. People on low income, and in particular women and older people, are less likely to be able to drive or have access to a car, and price is a significant determinant of their ability to utilise public transport^{40,282}. The cost of transport may add a considerable amount to the cost of food shopping^{283,284}. Thus access to a cheaper and wider range of food is most restricted for some of the groups who need it most.

Currently, planning authorities do not have to consider the impact on low income groups when considering the development of retail food outlets. However, some local authorities have addressed the accessibility of food retail provision in disadvantaged areas, for instance by rate concessions to encourage retailers in these areas. Town and country planning policies could be amended or emphasised to ensure that development of retail food outlets do not have an adverse effect on those most vulnerable to poor nutrition²⁸⁵.

Benefit

People on low incomes eat less healthily partly because of cost, rather than lack of concern or information^{286,287}. Therefore increased availability of affordable "healthy" food should lead to improved nutrition in the least well off.

20.1 We recommend the further development of policies which will ensure adequate retail provision of food to those who are disadvantaged.

We recommend policies which will further reduce income inequalities, and improve the living standards of households in receipt of social security benefits (recommendation 3).

We recommend the further development of a high quality public transport system which is integrated with other forms of transport and is affordable to the user (recommendation 14).

Reducing sodium in processed foods

Inequality

The best measure of salt in the diet is 24 hour urinary sodium excretion. There are scant data on the social distribution of this in Britain. The INTERSALT study showed that people of lower education, world-wide, had higher levels of sodium excretion. This was confirmed for the UK INTERSALT centres. This, together with higher rates of obesity and lower intakes of foods rich in potassium, places those from lower socioeconomic groups at higher risk of hypertension and its related risks. Average blood pressure increases as social class decreases, i.e. it is higher in lower social classes, although the gradient is not pronounced, especially in men³⁷. However, at any level of blood pressure people from lower socioeconomic groups appear to be more vulnerable to the associated diseases, as evidenced by their higher rates of coronary heart disease and stroke²⁹.

Evidence

Less than 20% of sodium intake is discretionary and added in cooking or at the table. Most of the rest is in processed food²⁶⁴. Lower income groups have higher consumption of processed foods rich in sodium, for instance white bread, meat products (such as pies) and processed vegetables, other than frozen⁵⁵. Observational studies, trials and animal studies all point to a relation between sodium intake and blood pressure. A review of this evidence led the Department of Health's Committee on Medical Aspects of Food Policy to recommend a one third reduction in sodium intake in the British diet²⁶⁴, although other reviews have been more cautious²⁸⁸. A reduction in sodium intake, combined with a reduction in obesity and heavy drinking and an increase in potassium intake, would lower mean blood pressure in the population and hence reduce cardiovascular disease.

Benefit

Reduction of sodium in processed foods should reduce average blood pressure for the whole population. This may be of greater benefit in lower socioeconomic groups because of their increased susceptibility to the complications of hypertension, coronary heart disease and stroke.

20.2 We recommend policies which reduce the sodium content of processed foods, particularly bread and cereals, and which do not incur additional cost to the consumer.

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Prepared 26 November 1998

Independent Inquiry into Inequalities in Health Report

Part 2 continued

7. Mothers, Children and Families

We recommend a high priority is given to policies aimed at improving health and reducing health inequalities in women of childbearing age, expectant mothers and young children (recommendation 2).

Reducing poverty in families

This section sets out inequalities in wealth in families, and summarises the evidence for areas of policy development and the benefits which may result from such policies. Our recommendations relate firstly to the removal of barriers to work, for parents who wish to combine work with parenting, by increasing access to day care. Secondly they relate to enabling those who wish to devote full-time to parenting to do so, by improving the living standards of households in receipt of social security benefits.

Inequality

The increased risk of poverty amongst families with young children has been documented in the text accompanying recommendation 3. Some parents find themselves in a benefit dependent poverty trap and would seek work if affordable child-care was available. However for parents in low income groups there is a shortage of affordable and appropriate child-care, both for pre-school and school-aged children²⁸⁹⁻²⁹¹. A study of 20 countries, mostly European, found that the UK had the highest child-care costs of all countries, amounting to a quarter of average earnings¹⁶⁴. At that time there were no public subsidies for child-care.

Evidence

Out-of-home day care and pre-school education are two services which overlap in providing learning and care for those below current statutory school age. There is no clear and logical dividing line between them, as both must secure and promote children's healthy physical, emotional and intellectual development. The evidence which supports the effectiveness of out-of-home day care and pre-school education in promoting children's development also overlaps. It is presented in the text supporting recommendation 5 (pre-school education) and is summarised here.

Evaluation of non-parental out-of-home day care before the age of 5 years has found that it is associated with improvement in a range of educational and social measures, some of which have been documented many years after the care. It is important to note that the best known studies are of the effect of centre-based day care, and it is not known whether the same advantages are found with care provided in other settings. All of the assessed studies contained educational components as part of the intervention programme, and nearly all an element of home visiting and/or parental training. It is not possible to assess which components of these multi-faceted programmes were effective. However it is clear that quality, including quality in training carers, is crucial: indeed poor quality care may be damaging^{113,115}. There is no evidence for an optimal age for out-of-home day care^{113,115}. The effect of early separation of parent and child on the child's social and emotional development and attachment remains a subject of controversy.

Benefit

Greater provision of high quality out-of-home day care, especially if integrated with pre-school education, should increase the availability of these services. Since it is easier to combine paid work and family responsibilities when parents have access to high quality day care, it is a potential mechanism to alleviate family poverty for parents who wish to combine work with parenting²⁹². Other benefits include improved educational and social achievement in the children, and the potential for

beneficial effects on the psychosocial health of parents and on their opportunities for education and training.

21. We RECOMMEND policies which reduce poverty in families with children by promoting the material support of parents; by removing barriers to work for parents who wish to combine work with parenting; and by enabling those who wish to devote full-time to parenting to do so. Specifically:

21.1 we recommend an integrated policy for the provision of affordable, high quality day care and pre-school education with extra resources for disadvantaged communities (see also: recommendation 5).

In making this recommendation, we commend the Government's commitment to a national Child-care Strategy as a first step in reducing inequalities in this area.

We recommend further reductions in poverty in women of childbearing age, expectant mothers, young children and older people should be made by increasing benefits in cash or in kind to them (recommendation 3.1).

We recommend measures to increase the uptake of benefits in entitled groups (recommendation 3.3).

Improving the health and nutrition of women and children

This section describes how inequalities in nutrition in women and children influence health. Our recommendations here are focused on improving the health and nutrition of women of childbearing age and their children, with priority given to the elimination of food poverty and the reduction of obesity.

Inequality

The babies of women in disadvantaged groups are more likely to have reduced growth rates in utero. Babies with fathers in social classes IV and V have a birthweight which is on average 130 grams lower than that of babies with fathers in social classes I and II³⁴. Birthweight also varies by mothers country of birth. Babies whose mothers were born on the Indian sub-continent are on average 200 grams lighter than those of mothers born in the United Kingdom³⁴.

For women, obesity is more prevalent in lower social classes. There is a gradient of decreasing obesity with increasing social class. Twenty five per cent of women in social class V are obese compared to 14 per cent in social class I³⁷.

Evidence

Reduced growth in fetal life is associated with increased mortality and morbidity in the first year of life^{293,294}, and throughout childhood²⁹⁵⁻²⁹⁷. People who had low birthweight, or who are thin or stunted at birth, are at increased risk of cardiovascular disease and the disorders related to it in later life²¹. These associations cannot be explained by confounding variables operating in adult life. Reduced fetal growth is more common in deprived areas of Britain²⁹⁸. Birthweight is determined by the weight and height of the mother, which in turn reflects her own growth in childhood. The physique of mothers is also related to later disease in their children. Children of women who are thin, having either a low body mass index (weight/length²) or thin skinfolds are at increased risk of developing non-insulin dependent diabetes and raised blood pressure in adult life²⁷¹⁻²⁷³.

The generally agreed 'healthy diet' in pregnancy may have long term benefits in reducing the baby's later risk of cardiovascular disease without greatly influencing birthweight^{271,275}. Mothers reliant on state benefits may not be able to afford a healthy diet^{83,95} and may go short of food in order to feed their children^{93,94}. In the United States guaranteeing a minimum income to pregnant women has been shown to increase birthweight⁹¹, although the mechanism is unknown.

Children of women who are overweight are also at increased risk of coronary heart disease as adults²⁷⁴. This effect is stronger among women with short stature. Short, overweight women are more common among low socioeconomic groups. Obesity is entrained during childhood and adolescence²⁹⁹. The rates of obesity in children are increasing, but there are no marked differences between social classes³⁰⁰. However, the effects of obesity on the development of coronary heart disease, non-insulin dependent diabetes and hypertension are more severe in people who had low birthweight³⁰¹⁻³⁰⁴.

Thus a baby's long term health is related to the nutrition and physique of its mother. Policies in this area should promote the avoidance of excessive thinness or obesity and a healthy diet for women of childbearing age. They should also promote avoidance of excessive weight gain in children.

Benefit

Improvement in the diet of girls and women is likely to bring improvements not only in their own health, but in the health of their children. Avoidance of obesity similarly benefits both the mother and her child. The effects of mothers' nutrition on their children's health will take more than one generation to alter. An approach which starts with both mothers and children is likely to bring the most rapid benefits.

22. We RECOMMEND policies which improve the health and nutrition of women of childbearing age and their children with priority given to the elimination of food poverty and the prevention and reduction of obesity. Specifically:

we recommend further reductions in poverty in women of childbearing age, expectant mothers, young children and older people should be made by increasing benefits in cash or in kind to them (recommendation 3.1).

We recommend further measures to improve the nutrition provided at school, including: the promotion of school food policies; the development of budgeting and cooking skills; the preservation of free school meals entitlement; the provision of free school fruit; and the restriction of less healthy food (recommendation 7).

We recommend a comprehensive review of Common Agricultural Policy's (CAP's) impact on health in general and inequalities in health (recommendation 19).

We recommend policies which will increase the availability and accessibility of foodstuffs to supply an adequate and affordable diet (recommendation 20).

Promoting breastfeeding

Inequality

Babies of fathers from social class I are more likely to be breastfed at birth than those from social class V, but this difference has decreased over the period from 1985-1995. Continued breastfeeding is much less common in lower social classes⁵⁹.

Evidence

Breastfeeding decreases the incidence and severity of many infections of infancy, and may protect from other infant and later adverse health outcomes. Breastfeeding may also protect the short and long term health of the mother³⁰⁵.

Randomised controlled trials have shown that support to mothers during pregnancy, labour, and after birth increases not only initiation of breastfeeding, but also continuation and exclusivity, in other words breastfeeding only, without bottle feeding. Prenatal interventions tested include peer counsellors and education programmes tailored to women from specific cultural backgrounds. Continuous emotional support during labour provided by a trained - professional or lay - support person has been found to promote continued breastfeeding, as well as providing other

benefits - for instance, reduced rates of Caesarean section³⁰⁶. Help with the practicalities of breastfeeding decreased early problems and increased duration of breastfeeding³⁰⁷. Some of these interventions were tested in particular disadvantaged groups (people living on low income)³⁰⁸ and women from minority ethnic groups³⁰⁹. Evidence that they are differentially effective among people experiencing disadvantage is lacking.

Other measures of encouraging breastfeeding are based on increasing the acceptance and practicability of breastfeeding, especially outside the home. Such measures might include discussion of breastfeeding issues in Personal, Health and Social Education for school-children (see recommendation 6), using media advocacy and other publicity, and encouraging the provision of facilities for breastfeeding in shops and public places.

Benefit

Increased rates of breastfeeding should decrease the incidence of infant infection. The interventions suggested which do or could provide more support to the mother should also lead to other health gains in the mother and baby. It is unknown whether such interventions can be developed to be particularly effective in disadvantaged groups.

22.1 We recommend policies which increase the prevalence of breastfeeding.

Fluoridating the water

Inequality

Overall dental health in children is improving. The mean number of teeth with any known decay in children under 5 years has fallen over the last 10 years. However, the differential in the number of decayed teeth between those in classes IV and V and those in classes I, II and III has increased, from an excess of 17 per cent in 1983 to one of 70 per cent in 1993^{310,311}. The proportion of children who have an experience of dental decay also varies by area and by age. But at each age children living in the north have more dental decay than those living in the midlands and the south³¹².

For example, at 5 years children living in the North West NHS Region show a 59 per cent excess compared with those in the South Thames NHS Region. At 12 years there is a 75 per cent excess³¹².

Evidence

Fluoridation of the public water supply has been shown to reduce dental caries, especially amongst socially deprived communities in the UK and Australia^{313,314}. Water fluoridation provides benefits for everyone but the effects are more pronounced in people in lower social classes^{313,315}, particularly in primary dentition. The Water Fluoridation Act (1985) and associated guidance from the Department of Health (HC/87/18) placed the responsibility for decisions about water fluoridation with health authorities. Following a request from a health authority, water undertakers may fluoridate the water supply. Although the Department of Health guidance indicates that the "chief concern" of water undertakers "will be the technical feasibility of water fluoridation", in practice water undertakers have interpreted the word "may" in the Act as giving them very wide discretion. Since the Water (Fluoridation) Act 1985 received Royal Assent (30 October 1985), no new fluoridation scheme has been introduced. (Those schemes implemented in the West Midlands had legally binding agreements before the Act.) To date, over 60 health authorities have completed the publicity and consultation required by the Act but cannot have their decisions on fluoridation implemented. Amendment of the Act would ensure fluoridation of the water supplies in areas where this has been recommended following the present legal processes.

Benefit

Fluoridation of water supplies should decrease inequalities in dental caries between areas, and between socioeconomic groups. Although benefit will at first be restricted to children, in time it will become evident in adults. The balance of scientific evidence

is against harmful effects on health of fluoridation.

A relatively minor change is needed to the Act. As the process for public debate and decision-making would not be changed by the proposed amendment, arguments for and against fluoridation could continue to be considered as now.

22.2 We recommend the fluoridation of the water supply.

Reducing the prevalence of smoking in pregnancy

Inequality

Over the ten years from 1985 to 1995 there has been a slight decrease in the proportion of women smoking during or before pregnancy (39 to 35 per cent). Smoking prevalence during pregnancy is higher for manual than non-manual groups. Women from households in social class V are four times more likely to smoke in pregnancy than those in social class I⁵⁹.

Evidence

Maternal smoking is associated not only with reduced birthweight, but also with an increased risk of sudden infant death syndrome³¹⁶, and adverse effects both on the mother's health, and on the health of those with whom she shares her home³¹⁷⁻³²⁰. Recent work also suggests that, over and above the effect expected by reduction of birthweight and other socioeconomic factors, educational achievement as measured at 23 years is decreased in the children of mothers who smoke³²¹. Pregnancy is seen as a prime opportunity to encourage and help women to give up smoking for the benefit of their own health as well as their children's³²² with most women receiving advice on smoking from their midwives and doctors⁵⁹.

A systematic review of randomised controlled trials found that behavioural self-help approaches to smoking cessation were more effective than advice and feedback in reducing smoking in pregnancy³²³ but no information was given on whether interventions were particularly helpful for disadvantaged women³²⁴. Cessation rates are lower in mothers from lower socioeconomic groups⁵⁹ and a survey in the West Midlands found that pregnant women on Income Support were less likely than other women to be contemplating giving up smoking³²⁵. Given these differences in likelihood of cessation, further development of both "upstream" (see, for example, recommendations 21 and 23) and "downstream" policies (see, for example, recommendations 26.2-26.4) are likely to be necessary to achieve a reduction in inequalities in smoking prevalence in pregnancy. Interventions that target individual behaviour alone may be insufficient^{326,327}.

Benefit

A decrease in prevalence in smoking during pregnancy is likely to be followed by a decrease in women who smoke after pregnancy. This should decrease smoking-related morbidity and, eventually, mortality in mothers; passive smoking-related morbidity and mortality, including sudden infant death syndrome, in those with whom she lives and works; and increased birthweight in the children of mothers who were formerly smokers, with decreases in early mortality³²⁰. The problems of giving up smoking for disadvantaged women are discussed elsewhere (see text for recommendations 26.2-26.4).

22.3 We recommend the further development of programmes to help women to give up smoking before or during pregnancy, and which are focused on the less well off.

Social and emotional support of parents

Inequality

Parents caring for children in disadvantaged circumstances are likely to need additional family support if they are to protect their children from the effects of

disadvantage. Inequality in the need for such support is evident in the socioeconomic patterns of child abuse. Although such patterns are modified by the definition of abuse³²⁸ and ascertainment bias³²⁹, there is a consistent association between low socioeconomic status and child protection registrations³³⁰. This association is demonstrated across a range of indicators of individuals and areas, including unemployment, lone parenthood, and receipt of means-tested benefits³³¹⁻³³³.

Evidence

Most parents living in disadvantaged circumstances wish to, and do, protect and promote the health of their children under the most unpromising conditions³³⁴. A general conclusion of evaluations of family support services is that parents under stress overcome family problems more easily when there is a wide range of sources of family support available in local communities³³⁵.

Family support enables parents under stress and children in need to have some respite from their disadvantaged circumstances, and to build protective social relationships. Family support services cover a wide range, and include neighbourhood family centres and projects, baby and child health clinics, supervised play space and day care and affordable after-school care. Consequently the Inquiry has taken the view that policies which promote the emotional and social support of parents living in circumstances of disadvantage should act at a number of different levels. These policies include those which address poverty, social isolation and lack of community resources as well as ones which provide enhanced individual or group-based support. However, the research evidence tends to be biased towards assessment of interventions to support individual parents or families, often within public service settings. This is partly because it is easier to design robust experimental evaluations of such interventions. The following section summarises this evidence, recognising that it also highlights principles relevant to community-based interventions.

Social and emotional support of parents, particularly mothers, may enhance their capacity to protect their children, especially when they are trying to do so in disadvantaged circumstances. The potency of even short periods of personal support is demonstrated by a review of the effects of continuous professional or social support during childbirth. In a number of settings, women who received support from a trained person had shorter labours, less analgesia and operative delivery, and their babies had improved APGAR scores (that is, were in better condition at birth)³⁰⁶. However, most studies have used longer periods of social support, aimed at reducing stress and enhancing self-esteem and confidence during pregnancy and the early part of parenthood. The effect of home visiting during pregnancy alone on birthweight and other pregnancy outcomes is inconsistent^{334,336,337}. Some studies, whilst not showing an effect on physical health, have found social and behavioural effects. For instance, a review of controlled trials of social support in pregnancy concluded that women receiving support were less likely to feel unhappy, nervous and worried during pregnancy, and were more likely to be breastfeeding after birth³³⁸.

Home visiting in the first 2 years of life has been associated with beneficial effects during childhood. A systematic review found that programmes of home visits by professional or specially trained lay care givers tended to be associated with decreased rates of childhood injury³³⁹. They may also reduce rates of child abuse, incomplete immunisations, hospital admission, and morbidity in infancy, although the evidence is not conclusive for these outcomes. The applicability of these studies to service provision in the United Kingdom is unknown. However, in the UK at least two studies have shown that appropriately trained health visitors can detect and manage postnatal depression, leading to more rapid remission of symptoms, fewer problems in the relationship between the mother and the child, and fewer child behaviour problems^{340,341}. Although postnatal depression does not show a marked gradient with socioeconomic status, the long term effect of maternal depression on the cognitive and emotional behaviour of children is more marked in the presence of socioeconomic disadvantage³⁴².

In the UK, several experiments in home-based strategies to help parents become more self-confident and skilful in their child's development have been initiated. These have used specially trained health visitors or "community mothers", training teams of volunteers^{16,343}. Early results indicate that those receiving home-based support strategies feel more positive and have higher self-esteem during early motherhood, and the children have more complete immunisations, and less early weaning onto cow's milk. Longer-term outcomes are awaited^{16,344}. A systematic review of parent-training programmes in improving the behaviour of children with a behaviour disorder between 3 and 10 years concluded that group-based programmes were the most effective, although it is not known specifically which aspects of these programmes are important³⁴⁵. Such programmes might have an application in prevention as well as treatment.

Few studies have yet included long term outcomes. However, in a 15 year follow up of an American randomised controlled trial, mothers who had received home visits during pregnancy and the first 2 years after birth were less likely to have been identified as perpetrators of child abuse. Amongst those who were socioeconomically disadvantaged, those who had received home visits had fewer subsequent births, increased birth interval, received income support for a shorter period, had fewer behavioural problems associated with the use of alcohol and other drugs, and had fewer arrests³⁴⁶. A seven year follow-up in the UK has found improved health in children and mothers who had midwife-provided social support in pregnancy³⁴⁷.

A number of methodological issues arise in the best way of providing parental support. The most systematically evaluated studies are the randomised controlled trials. However, these tend to be conducted in particular settings and especially in health service settings. It is not clear whether the beneficial effects observed are the consequence of a particular type of support or would be seen with the provision of any support which met the needs of parents and children even if different in content - for example, child-care or financial support - or context - for example, community-based and parent-led. In addition, the quality of support offered in an experimental setting may not be reproducible in service. Thus the nature of support, who should offer it, when, and for how long is still under debate. Secondly, the applicability to the UK of the results of studies conducted outside this country is uncertain. Thirdly, the effect on some outcomes has only been tested in single trials, and must be regarded with caution. Fourthly, the identification of those most likely to benefit from support needs to be refined. The trials have mostly been conducted amongst high-risk populations. Lastly, the best way of translating research findings based on parental empowerment into service provision which does not patronise or stigmatise users needs to be addressed¹⁶.

Despite these issues, we have concluded that the strength of the evidence appears sufficient to recommend enhancing support for parents. Such support should be provided through policies acting at a number of different levels, including the relief of poverty (recommendation 21). Policies should be based in the community, should be family-centred and should meet the needs of families living in disadvantaged circumstances. In the spirit of the Children Act (1989), they should include further development of services provided on the basis of partnership with parents and between agencies^{328,348}.

Health visitors already aim to provide social and emotional support to parents and are acceptable to mothers in disadvantaged settings^{349,350}. We consider that an enhancement of their role and capacity to provide social and emotional support of disadvantaged parents is needed, as part of the range of neighbourhood services to support parents.

Benefit

Increased social and emotional support of parents should reduce the impact of disadvantage and enhance parenting skills, with consequent social and behavioural

gains in health for their children. It should also enhance self-esteem in parents. A range of other physical, social and mental health gains are possible in both parents and children. None of the evidence points to harm from support of parents, but this pre-supposes that services are delivered in an enabling and non-stigmatising manner.

23. We RECOMMEND policies that promote the social and emotional support for parents and children. Specifically:

23.1 we recommend the further development of the role and capacity of health visitors to provide social and emotional support to expectant parents, and parents with young children.

Promoting the health of looked-after children

Our recommendations on the support of families are aimed at promoting child and parental health and at the prevention of child abuse and family dysfunction. We recognise the necessity of recommending policies which will address the health needs of children who are "looked-after" by local authorities.

There were about 89,000 children looked-after by social service departments in England at any time during the year ending in March 1997, with about 65 per cent in foster placements³³⁰. Looked-after children are at particular risk of both early life and later disadvantage³³³. More than 75 per cent of looked-after children leave care with no educational qualifications and between 50 per cent and 80 per cent of care-leavers are unemployed³⁵¹. It is estimated that 30 per cent of young single homeless people have been in care. High rates of alcohol use and cigarette smoking are also reported among care-leavers and it is estimated that one in seven young women leaving care are either pregnant or already mothers³⁵². Children with an experience of public care are also vulnerable to substance misuse and mental health problems in adult life^{353,354}.

This cluster of socioeconomic and health disadvantage means that looked-after children are a key target group for policies related to education, employment and housing, and to health related behaviour, recommended earlier in our report. However, they are further disadvantaged in their access to health care, both preventative and therapeutic. Their increased mobility may result in fragmentation of, and delay in, service delivery, including assessment of, and provision for, their educational and health needs, including health promotion.

Looked-after children lack a professional advocate for their health. We recommend that looked-after children have a designated medical adviser to identify their physical and psychological health needs, and negotiate service delivery. However, this alone is unlikely to be sufficient. Looked-after children tend not to respond to health information and effective ways of providing them with appropriate information need to be further developed³⁵⁵.

23.2 We recommend local authorities identify and address the physical and psychological health needs of looked-after children.

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Prepared 26 November 1998

Independent Inquiry into Inequalities in Health Report

Part 2 continued

8. Young People and Adults of Working Age

This section sets out inequalities in the health of young people and adults of working age. It summarises the evidence which we have concluded indicates areas for future policy development, and the benefits which may result from such policies. Many recommendations given already will apply to this group. In particular, work is an important determinant of health inequalities at this stage of the life course.

We recommend policies which improve the opportunities for work and which ameliorate the health consequences of unemployment (recommendation 8).

We recommend policies to improve the quality of jobs, and reduce psychosocial work hazards (recommendation 9).

Our additional recommendations relate to preventing suicide, particularly in young men and people who are known to be mentally ill, and promoting the adoption of healthy lifestyles.

Preventing suicide

Inequality

Suicide is more common in men than in women, and in lower socioeconomic groups. In 1996 the rates were three times higher for males than females. The highest rates are for men aged 25-44 and those over 75 years²⁵. In 1991-1993 (the most recent data available by social class) in England and Wales, mortality from suicide for men was 4 times greater in social class V than in social class I²⁹. The international literature consistently shows higher rates of suicide in young south Asian women, whilst lower rates are found in African Americans and African Caribbeans³⁵⁶. The overall age-standardised mortality rate for suicide has fallen by nearly a half in women over the last 20 years, but has hardly changed for men. This hides the information that over the same period, for men under 44, there has been a rise of 20-30 per cent whereas for men aged 45 and over there has been a fall of about the same magnitude³².

Evidence

Suicide is associated with unemployment, alcohol and substance misuse, imprisonment, and mental disorder³⁵⁷. Up to half of all people who commit suicide have a history of self-harm, and up to 1 per cent of people who self-harm go on to kill themselves³⁵⁸⁻³⁶⁰. People who deliberately self-harm are also likely to have problems with a relationship, employment, education, alcohol, substance misuse, and/or finances³⁶¹.

Policies to prevent suicide include those aimed at the causes of social exclusion which may lead to suicide. These include: social support for parents (recommendation 23); pre-school education (recommendation 5); the development of "life skills" and the prevention of alcohol and substance misuse (recommendation 6); provision of adequate housing (recommendation 10, 11 and 12); the relief of poverty and reduction of unemployment (recommendation 8); the promotion of healthy workplaces (recommendation 9); and policies which promote social cohesion.

The association of suicide with existing mental illness suggests that policies for the care of young people with mental illness also provide opportunities for the prevention of suicide. About a quarter of those who kill themselves have been in contact with specialist mental health services in the year before their deaths³⁶². A recent review on the promotion of mental health in high-risk groups reinforces the role of the primary health-care team both in identifying and co-ordinating the management of people at high risk³⁶³. Community mental health teams may be more effective than non-team

standard care in preventing suicide in those who are already severely mentally ill³⁶⁴. Both types of team, which may have considerable overlap, need to ensure effective working between different disciplines and agencies³⁶³. An important component of the work of such teams is to address all the needs of the patient, including employment, housing and social support. Furthermore, particular strategies may be required to meet the needs of young people who either cannot or do not choose to access current services. These include people who default from follow up, absent themselves from school, or are in prison or young offenders' institutions.

Benefit

Most policies recommended here are aimed at the improvement of socioeconomic and living conditions, and social cohesion. They will have many benefits in addition to their contribution to the prevention of suicide.

24. We RECOMMEND measures to prevent suicide among young people, especially among young men and seriously mentally ill people.

Promoting healthier lifestyles

Health related behaviour is an important determinant of health and inequalities in health. However, the reasons why individuals adopt one form of behaviour rather than another are complex. They include the influence of earlier experience, including that as a very young child, the social and economic environment, work or school, and the cultural milieu, as well as characteristics specific to the individual. Furthermore the effects of health related behaviour or its consequences differ between individuals and between groups, depending on their susceptibility to these influences. For example the effect of a high body mass index in adult life on blood pressure is greater in people who were of lower birthweight³⁰¹.

Thus, policies designed to change health related behaviour need to act at different levels, and to accept that behaviour change, for instance in the changing of children's dietary habits, may take some time to become apparent. The Inquiry considers that, as with inequalities in health in general, inequalities in health related behaviours need to be approached on a broad front considering both "upstream" and "downstream" policies, and policies which cover both short and longer-term benefits. This section sets out inequalities in health related behaviour and the evidence which we have concluded indicates areas for future policy development. Many of the more "upstream" policies in this area have been considered earlier in this report, and are cross-referenced. However, we wish to emphasise that these "upstream" policies are of crucial importance in reducing inequalities in health related behaviour. Furthermore, we consider that policies aimed at changing health related behaviour should avoid attaching blame or stigma to individuals or groups. Thus our recommendations are based on the principles of increasing information and choice to individuals and communities, and enabling them to make healthy choices³⁶⁵.

Promoting sexual health

Inequality

Men and women from manual households have a median age at first intercourse about 2 years lower than for those from social class I households. Black young people are more likely to have first intercourse under the age of 16 than white or Asian young people. The proportions with first intercourse under the age of 16 are 26 per cent for Black men, and 10 per cent for Black women, compared to 19 per cent and 8 per cent for young white people and 11 per cent and 1 per cent for young Asian people³⁶⁶.

Under-age conception rates for places within Britain are highly correlated with indices of deprivation, with high rates in areas which are deprived²⁶⁰. However, the relatively small number of events makes further analysis difficult. There is a fourfold difference between the health authorities with the highest and lowest rates, and large differences between one time period and another.

Evidence

For many young women, pregnancy and motherhood are positive and welcomed experiences without long term negative outcomes. However, compared to women aged 20 to 35 years, teenage mothers and their children are at higher risk of experiencing adverse health, educational, social and economic outcomes¹³⁰. Approximately half of the pregnancies in under 16 year olds and a third of those in 16-19 year olds are terminated²⁶⁰. These terminations, along with miscarriages, can also have an adverse effect on the health of teenagers.

The risk of teenage pregnancy is increased in association with a number of social, socioeconomic and individual factors, many of which are more common in people experiencing disadvantage - for example, low educational attainment, poor housing. Particularly at risk are the daughters of teenage mothers, young people "looked-after" by the local authority or leaving care, school non-attendees - due to truancy or exclusion - and homeless or runaway teenagers. Although it is difficult to establish cause and effect, it is possible that reducing inequalities in some of these socioeconomic risk factors - for example, poverty or educational attainment - would reduce inequalities in unwanted teenage pregnancy¹³⁰.

More specific interventions to promote sexual health focus on education and provision of appropriate and sensitive contraceptive services¹³⁰. Features associated with successful sex education programmes include: timing, which should precede the onset of sexual activity; a combined approach to education and information about the provision of contraception; integration with psychological approaches, and with other life management skills; context, emphasising responsible and caring relationships and a recognition of social influences and pressures; a focus on specific aims, such as delayed intercourse and safe intercourse; and the tailoring of the programmes to the needs of the group they are intended to serve^{129,130}.

Most of the evaluated programmes have focused on addressing individual factors associated with teenage pregnancy, rather than the associated social and economic factors. No studies have specifically focused on reduction of inequalities in risk of outcomes. The role of sex education is discussed earlier in the text supporting recommendation 6 on the development of health promoting schools.

The role of parents in sex education also needs to be recognised. Under the age of about 16 years young people generally report that their parents should be the main source of information about sex but in practice this is often not the case. Appropriate means to help parents increase their skills and confidence in sex education need to be developed. The media also have an important role to play in providing information and influencing the climate of opinion³⁶⁷.

Provision of contraceptive services to teenagers is highly cost effective, saving £377 and £466 per unwanted pregnancy avoided for clinic and general practice provision respectively, even if only the resource consequences for the NHS of pregnancy are taken into account. The savings are much greater if the longer term health gains are considered¹³⁰. However, teenagers may lack information about contraceptive use or availability. A recent review of the literature found a lack of UK evidence on the effectiveness or cost effectiveness of different approaches to the delivery of contraceptive services to young people. Descriptive studies suggest that services should be based on a local needs assessment and ensure accessibility and confidentiality. Clinic-based settings may be used more than those in primary care. Because of the nature of teenagers' sexual activity, which can be unplanned and sporadic, provision of emergency contraception is important. However, there is widespread public and professional misunderstanding of the use of emergency contraception, which may merit particular health education action¹³⁰.

Interventions have not evaluated whether policies will preferentially promote sexual health and reduce unwanted teenage pregnancy rates in people experiencing

disadvantage. Targeting of education on contraceptive provision - for example, by individual characteristics or by area - might be a way of reducing inequalities. Over half of teenage pregnancies continue to delivery. Policies and evidence on preventing the adverse health and social outcomes of teenage pregnancy are presented under recommendations 21 and 23.

Benefit

For more "upstream" policies, promotion of sexual health and prevention of unwanted pregnancy might be only some of many benefits. In general, sex education programmes have not been associated with increased sexual activity or its complications and some have been associated with delayed onset of sexual activity^{129,130}. Sex education and appropriate contraceptive use are likely to decrease rates of sexually transmitted diseases and promote other aspects of sexual health. Prevention of unwanted teenage pregnancy will reduce the risks to the physical, mental and social health of the potential mother.

25. We RECOMMEND policies which promote sexual health in young people and reduce unwanted teenage pregnancy, including access to appropriate contraceptive services.

Encouraging physical exercise

Inequality

Levels of physical activity in men show a complex pattern with social class, with more men in lower social classes reporting physical activity as part of their occupation and more men in higher social classes reporting moderate or vigorous walking and leisure activity. In women there are similar gradients in walking and leisure activity and no clear pattern with occupational activity. People in lower socioeconomic groups walk more than those in higher groups but are less likely to describe their walking pace as brisk or fast. Inactivity, which may be a better predictor of obesity, is more common in lower social classes for both men and women³⁵.

The proportion of men who are obese has risen from 13 per cent in 1993 to 16 per cent in 1996. For women the equivalent figures are 16 per cent and 18 per cent. Obesity is higher in the lower social classes in women, with 25 per cent in class V being classified as obese compared to 14 per cent in social class I and with intermediate proportions in the classes between I and V. In men, there are lower rates of obesity in social class I (11 per cent) but the higher rates in social class V (18 per cent) are similar to those in the remaining classes³⁷. Rates of obesity and mean body mass index appear to be increasing for school-aged children³⁶⁸.

Evidence

Increased physical activity of moderate intensity is associated with lower overall mortality rates and decreased risks of mortality from cardiovascular disease, colon cancer and non-insulin dependent diabetes mellitus. Regular physical activity prevents or delays the development of hypertension, and reduces blood pressure in those with hypertension. These effects may be, in part, mediated by the fact that physical activity prevents weight gain and obesity. Physical activity also relieves the symptoms of depression and anxiety and is important in the prevention of osteoporosis. As these are common conditions, relatively small reductions in risk of them would result in significant gains in public health³⁶⁹⁻³⁷².

Recommendations to promote moderate intensity exercise most commonly cite brisk walking as the mode of physical activity³⁷³. Walking is the most common form of physical activity across all socioeconomic groups, although both the number of journeys undertaken on foot and the annual average distance walked are decreasing^{236,259}. Interventions where the mode of exercise being promoted is walking appear to be more effective than those that depend on attending a special facility to practice games or sports³⁷⁴. Walking should also be more accessible to

those in lower socioeconomic groups, as it does not require costly equipment or training. In addition it can, theoretically, be incorporated into everyday routines, although in deprived areas, improved access to a safe and pleasant environment would be a necessary pre-condition. The provision of low-cost keep fit classes in existing local facilities, such as community centres or schools is one option.

Most interventions have been tested on white, middle-aged, well-educated men and women, and it is not known whether interventions would differentially benefit those in lower socioeconomic groups. The relative effectiveness of different types of intervention is largely unknown.

The evidence on encouraging walking and cycling and the safe separation of pedestrians and cyclists from motor vehicles is given in the text for recommendation 15. These policies may be particularly important in promoting exercise in children. Fear of accidents and harm is an important component in the increasing use of transport of children in cars, particularly to and from school. The promotion of physical activity, over and above participation in formal physical education, is one of the roles of health promotion within schools (see recommendation 6).

Benefit

Decreased levels of inactivity and increased physical activity should reduce and prevent obesity, cardiovascular disease and non-insulin dependent diabetes mellitus. As well as these health benefits, opportunities afforded by exercise might also lead to wider social networks and increased social cohesion.

Reducing tobacco smoking

Inequality

There is a higher prevalence of cigarette smoking in lower socioeconomic groups. In 1996, 29 per cent of men and 28 per cent of women smoked but this ranged from 2 per cent of men (11% of women) in professional occupations to 41 per cent men (36 per cent of women) in unskilled manual occupations. Amongst smokers, men and women in professional occupations smoke fewer cigarettes per week than those in unskilled manual occupations²⁸. Furthermore, nicotine dependence is higher in people experiencing disadvantage, with higher plasma cotinine levels even after adjusting for the number of cigarettes smoked^{35,37}. Not only do men and women in the lower groups have higher prevalence rates, they also have lower cessation rates. Since 1973 rates of cessation have more than doubled in the most advantaged groups, from 25 per cent to over 50 per cent. In the least well off groups, there has been a very limited increase in cessation rates from 8 to 9 per cent cessation in 1973 to 10 to 13 per cent in 1996³⁷⁵.

Evidence

Smoking is an important component of differences in mortality between social classes³⁷⁶. In the United Kingdom, more cancer deaths can be attributed to smoking tobacco than to any other single risk factor. In 1995, smoking was estimated to account for more than 30,000 deaths from lung cancer, and a further 16,000 deaths from cancer of other sites, notably the oesophagus, bladder, stomach, mouth and throat, contributing to approximately one third of the mortality of cancer as a whole³⁷⁷. Smoking is also an important cause of chronic obstructive lung disease, coronary heart disease, stroke and aortic aneurysm. Furthermore, smoking damages the health of non-smokers. A recent review concluded that passive smoking causes lung cancer and coronary heart disease in adult non-smokers, and respiratory disease, sudden infant death syndrome, middle ear disease and asthmatic attacks in children³²⁰.

For the population as a whole, tobacco consumption falls when the real price of tobacco rises³⁷⁸⁻³⁸⁰. The price elasticity of cigarettes is higher among young people. Studies in the United States and Canada indicate that young people's intention to

smoke and their uptake of smoking are highly price-sensitive³⁸¹⁻³⁸⁶. An important factor in explaining the greater effect of price on young people is that most are not habitual, nicotine dependent, smokers. Price rises can therefore be an effective way of preventing the onset of regular smoking in adolescence. With very few smokers taking up regular smoking after the age of 20, price can clearly have a longer-term impact on the prevalence of smoking and thus on inequalities in smoking-related disease.

However the real price of tobacco has a disproportionate effect on the living standards of Britain's poorest households, for whom expenditure on tobacco is a larger proportion of disposable income³⁸⁷. Households in the lowest tenth of income spend 6 times as much of their income on tobacco as households in the highest tenth²⁷⁸. Over 70 per cent of two-parent households on Income Support buy cigarettes, spending about 15 per cent of their disposable income on tobacco³⁸⁸. Approximately 55 per cent of lone mothers on Income Support smoke, smoking on average 5 packets of cigarettes per week³²⁷. Studies of the cost of meeting basic needs, which explicitly exclude spending on tobacco, indicate that Income Support levels are insufficient to secure a basic but adequate standard of living, especially if the households contain children^{65,78,81,84,85}. Not surprisingly, therefore, low income households where the parents smoke are much more likely to be lacking basic amenities, including food, shoes and coats than non-smoking parents on Income Support³⁸⁸.

Although smoking prevalence has decreased overall, despite increases in the real price of tobacco, it has remained stable amongst people who are most disadvantaged³⁷⁵. A recent longitudinal survey of lone mothers found that living in severe hardship was the primary deterrent to quitting. This makes it unlikely that increasing the price of tobacco, and so decreasing disposable income and increasing hardship, will increase cessation rates in disadvantaged households³²⁷.

Advertising bans in Canada and New Zealand have reduced tobacco consumption. We note that the European Union Council of Ministers formally adopted the Directive to ban tobacco advertising and sponsorship in May 1998. Media advocacy and creation of unpaid publicity may not result directly in cessation but form the basis of public opinion on which other measures rest. Restrictions on smoking in public places or the workplace probably reduce consumption but the effects on cessation are undetermined. However, they may reduce the effects of passive smoking. Overall, evidence does not indicate which policies are the most effective in reducing inequalities^{320,380}. The relatively stable rate of cessation in disadvantaged groups over the last 20 years suggests that simply intensifying current approaches is unlikely to be sufficient.

The cultural and environmental barriers that disadvantaged people face in quitting smoking will take time to change. In the shorter term, a complementary strategy is to reduce nicotine dependence, which is likely to be stronger in disadvantaged smokers than amongst the affluent^{35,37}.

Nicotine replacement therapy (NRT) has been shown to be an effective treatment aid, approximately doubling success rates from both brief and intensive treatments, and with evidence that its efficacy is maintained in real world settings³⁸⁹⁻³⁹³. It is not known whether it is preferentially effective in helping those who are disadvantaged to quit. Trials have found that NRT is effective in helping nicotine-dependent smokers to stop smoking^{390,393}. Because there is a socioeconomic gradient in nicotine dependence, NRT may therefore have a differentially beneficial effect in smokers in lower socioeconomic groups. However, as it is currently sold at commercial rates over the counter, its price could prohibit its use amongst people on low incomes³⁹⁴. Preliminary evidence suggests better compliance and outcome when the smoker does not have to pay³⁹⁵. NRT could be made available on prescription or through other mechanisms which make it free to those who are least able to afford it^{394,396}. NRT on prescription would also have the benefit of involving general practitioners in smoking cessation. Brief advice from a general practitioner is a highly cost effective

method of promoting cessation of smoking, with cessation rates equivalent to rates achieved as a result of mass media campaigns, up to 5 per cent³⁸⁰. Community-based interventions and specialised smoking clinics are also effective settings in which to provide NRT³⁹⁰.

Benefit

Reduction in smoking would decrease the risk of smoking related diseases over a period of time and decrease the risks of passive smoking to companions in various settings. The relative differences in mortality by socioeconomic group are similar in smokers and non-smokers. However, given the higher mortality rate in smokers and the increased rates of smoking in lower socioeconomic groups, reduction in smoking in all socioeconomic groups will decrease the absolute difference in mortality rates between socioeconomic groups²⁷⁷.

Reducing alcohol-related harm

Inequality

Deaths from diseases caused by alcohol show a clear gradient with socioeconomic position, with an almost fourfold higher rate in unskilled working men compared to those from professional groups. In addition, alcohol is a contributory factor to deaths from accidents, which also show a pronounced socioeconomic gradient³⁹⁷.

Amongst people under the age of 30 years, there is little variation in consumption of alcohol by socioeconomic group. However problem drinking is twice as common in the poorest as in the most affluent, 17 per cent versus 8 per cent for men and 6 per cent versus 3 per cent for women. In older adults, a similar pattern exists for men. In older women consumption is greater in the affluent, but there is no socioeconomic gradient in problem drinking, and poor women are more likely than the affluent to report being drunk³⁵. Higher levels of consumption of alcohol have been consistently observed in some deprived groups, such as unemployed people³⁹⁸⁻⁴⁰⁰ and those who are homeless^{401,402}. These observations suggest that the pattern of drinking influences alcohol-related health inequalities. Problem drinking is associated with delinquency, criminality and violence, including domestic violence and child abuse. The degree to which health-damaging drinking patterns in young people persist into later life is unclear. Deprivation may contribute to the probability of continuing to drink in a hazardous fashion, and may also inhibit opportunities for positive changes in behaviour. Heavy drinking in people in higher socioeconomic groups may be less harmful than in lower socioeconomic groups because they are protected from harmful effects by better diet, housing, health care and other factors⁴⁰³.

Evidence

At a population level, there is a positive correlation between mean consumption and the prevalence of heavy drinking. This suggests that one mechanism to reduce problem drinking and thus alcohol-related harm, is to reduce mean consumption⁴⁰⁴. Overall population consumption is affected by price⁴⁰⁵⁻⁴⁰⁷. Increasing the price of alcohol may decrease consumption amongst low income problem drinkers but the effect of price elasticity on different groups has been little studied^{408,409}.

Problem drinking in young people may be influenced by wider measures which support them and enhance their chances of employment and improved living conditions. Sensible drinking habits may be engendered in childhood and so be affected by interventions at school (see recommendation 6).

A reduction in the permitted level of blood alcohol concentration for driving from 80 to 50 mg/100 ml has been associated with reduced rates of alcohol-related accidents and risk behaviour in some countries⁴¹⁰. The introduction of random breath testing is another option which may be a significant deterrent to drinking and driving^{410,411}. The provision of adequate and affordable transport would assist in reducing the perceived need to drive after drinking.

People with alcohol-related problems who are disadvantaged in other ways, through having limited financial or social resources or being homeless, may have less access to appropriate treatment services for all their needs, including treatment of their alcohol-related health problems¹⁹⁶⁻¹⁹⁹. Recommendation 11 addresses this inequity.

Benefit

A decrease in problem drinking should reduce alcohol-related disease and accidents, as well as some types of anti-social behaviour.

26. We RECOMMEND policies which promote the adoption of healthier lifestyles, particularly in respect of factors which show a strong social gradient in prevalence or consequences. Specifically:

26.1 we recommend policies which promote moderate intensity exercise including: further provision of cycling and walking routes to school, and other environmental modifications aimed at the safe separation of pedestrians and cyclists from motor vehicles; and safer opportunities for leisure.

26.2 We recommend policies to reduce tobacco smoking including: restricting smoking in public places; abolishing tobacco advertising and promotion; and community, mass media and educational initiatives.

26.3 We recommend increases in the real price of tobacco to discourage young people from becoming habitual smokers and to encourage adult smokers to quit. These increases should be introduced in tandem with policies to improve the living standards of low income households and policies to help smokers in these households become and remain ex-smokers.

26.4 We recommend making nicotine replacement therapy available on prescription.

26.5 We recommend policies which reduce alcohol-related ill health, accidents and violence, including measures which at least maintain the real cost of alcohol.

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Prepared 26 November 1998

9. Older people

In this section, older people are defined as those aged 65 years or over, unless stated otherwise.

Inequality

Mortality data by social class are limited in older people, because occupation is not recorded at all on the death certificates of men or women over the age of 75 years and is recorded for married women only if the woman has been in paid work for the majority of her life. Thus, alternative measures of social classification, such as housing tenure, are needed to describe socioeconomic differences in mortality in older people. Compared to the national average, the mortality rates in people aged 60 to 74 who had been living in local authority rented accommodation showed a 16 per cent excess, whereas rates for people who had been living in owner occupied accommodation showed a 13-14 per cent deficit⁴¹². Although data are available on fewer specific causes of death than in younger cohorts, patterns seem to be similar after the age of 65 years. The most pronounced differences between socioeconomic groups are for lung cancer and respiratory disease, coronary heart disease and stroke, all of which show higher rates as disadvantage increases ^{30,412,413}. Life expectancy at age 65 years is 2.6 years greater in men (2 years greater in women) from social classes I and II compared to men from classes IV and V³¹.

Prevention of morbidity and disability rather than mortality may be a more relevant focus in older people. Available data, which are fewer than those for younger age groups, suggest that older people experiencing disadvantage tend to have poor health. Respiratory function is lower and blood pressure higher in people from lower socioeconomic groups³⁷. Older people from lower socioeconomic groups have higher rates of total tooth loss than those from higher socioeconomic groups⁴¹⁴. Long standing illness prevalence is greater in unskilled manual groups of men over the age of 65 years than in men from professional groups, 72 per cent and 53 per cent respectively. However, there is no corresponding difference for women²⁸.

The following sections set out specific inequalities in the health and socioeconomic determinants of health in older people, and summarise the evidence which we have concluded indicates areas for future policy development to reduce these inequalities. These areas are: promoting the material well-being of older people; improving the quality of their homes; promoting the maintenance of mobility, independence and social contacts; and improving health and social services. The sections on each also indicate the benefit which may result from such policies. The inequalities, evidence and benefit in relation to most of these policies have been discussed in earlier parts of this report. They are raised again in brief here, with particular regard to their relevance for older people. As the majority of older people are women, and the ratio of women to men increases with age, some areas are discussed again in the section on gender.

Promoting material well-being

Inequality

Older people are more likely to be living in poverty, whether this is defined as below half-average income or the receipt of means-tested benefits⁶⁵. This is particularly true for older women. There are three times as many female as male recipients of Income Support⁷⁷.

Evidence

The poorest pensioners, who rely most on benefit, have experienced a relative deterioration in their income. This is the result of cutting the link between increases in

earnings and annual rises in pensions and benefits in the 1980s. Current levels of pensions are not generous compared to other European Union countries⁷⁹. Older people are at risk of fuel poverty^{96,97}, and may face extra costs in purchasing social and health care. Disabled pensioner households are more likely to be reliant on state benefits than non-disabled pensioner households⁴¹⁵.

Around one million state retirement pensioners do not take up the means-tested benefits to which they are entitled, losing on average £16 per week^{86,87}. A number of factors may operate, including lack of knowledge of entitlement, a perception of being stigmatised by the receipt of benefit, and physical or other difficulties in the processes of claiming. Possible ways of overcoming some of these problems are the establishment of new organisations or agencies: a separate pensioners' agency⁸⁸; a citizens' bank⁸⁸; or a welfare counsellor in primary care⁸⁹. Schemes such as welfare counselling in primary care could also raise awareness of other entitlements, for instance free dentures. Fear of cost is thought to deter some poor older people from seeking services and aids which would, in fact, be free to them⁴¹⁶⁻⁴¹⁹.

Benefit

Measures which increase the income of poor older people are likely to improve their living standards, such as promoting better nutrition and heating, and so lead to improvements in health.

27. We RECOMMEND policies which will promote the material well being of older people. Specifically:

we recommend policies which will further reduce income inequalities, and improve the living standards of households in receipt of social security benefits (recommendation 3).

We recommend uprating of benefits and pensions according to principles which protect and, where possible, improve the standard of living of those who depend on them and which narrow the gap between their standard of living and average living standards (recommendation 3.2).

We recommend measures to increase the uptake of benefits among entitled groups (recommendation 3.3).

Improving the quality of homes

Inequality

Properties in poor condition are disproportionately occupied by single older people, and tend to be older, privately rented properties²⁰⁹. Older women are particularly likely to live alone^{420,421}.

Evidence

Unmodernised homes have high heating costs. Cold housing leads directly to hypothermia and may contribute to the excess of winter deaths seen in older people^{208,215}. It also leads to fuel poverty^{96,97}. Schemes which aim to improve insulation and heating efficiency are the most direct way of addressing this problem. Poor housing design contributes to major accidents in older people and seemingly minor accidents which may have grave consequences²⁰⁸. Home visits for the assessment and modification of hazards can reduce falls in older people⁴²².

Benefit

Removal of hazards in the home is likely to lead to reduced death and injury from accidents. Improvements in home design may allow older disabled people to be cared for at home, with improvements in their quality of life.

28. We RECOMMEND the quality of homes in which older people live be improved. Specifically:

we recommend policies to improve insulation and heating systems in new and existing buildings in order to further reduce the prevalence of fuel poverty (recommendation 12.1).

We recommend amending housing and licensing conditions and housing regulations on space and amenity to reduce accidents in the home, including measures to promote the installation of smoke detectors in existing homes (recommendation 12.2).

Promoting the maintenance of mobility, independence, and social contacts

Inequality

Lack of access to transport is experienced disproportionately by older people²²⁹, limiting their access to goods, services, opportunities and social contacts^{423,424}. This is particularly a problem for older women^{40,282} and older people who are disabled⁴²⁵. Older people are more likely to fear becoming victims of crime than younger people. This restricts their opportunities to leave their homes, particularly at night²²⁰.

Evidence

High traffic volumes result in feelings of insecurity²³⁴ and decrease walking as well as the use of other transport^{426,427}. The use of public transport is partly determined by price^{238,239}. There are over 10 million older people who are eligible for concessionary fares. Concessionary fare schemes vary from place to place²⁵⁸ and in places are very limited. Furthermore, uptake of concessions is lower in areas of low population density, and only 39 per cent in rural areas²⁵⁹.

Benefit

Greater opportunity for travel through the availability of affordable and effective public transport should remove a barrier to health-promoting opportunities. For example improved access to community based leisure facilities, which might include the facilities of health promoting schools, should allow increased opportunity for older people to enjoy physical and social activity. Increased exercise is important in preserving muscle tone. This decreases the risk of falling and thus injury, and reduces the disability caused by osteoarthritis.

29. We RECOMMEND policies which will promote the maintenance of mobility, independence, and social contacts. Specifically:

we recommend the development of policies to reduce the fear of crime and violence, and to create a safe environment for people to live in (recommendation 13).

We recommend the further development of a high quality public transport system which is integrated with other forms of transport and is affordable to the user (recommendation 14).

We recommend concessionary fares should be available to pensioners and disadvantaged groups throughout the country, and that local schemes should emulate high quality schemes, such as those of London and the West Midlands (recommendation 18).

Improving services

Inequality

Poor older people may be less likely to receive some health care services^{428,429}, or may have poorer health outcome after receiving these services⁴²⁸. For instance severe visual problems are more likely to remain unrecognised and untreated in older people from low socioeconomic groups^{430,431}.

Evidence

Functional capacity relies on sight, hearing, mobility and continence. Older people

from low socioeconomic groups have higher rates of ill health and disability than those from more affluent groups. Health and social services can ameliorate the experience of poor health and disability in old age, and should be accessible and distributed on the basis of need. However, levels of domiciliary support are insufficient to counter an increasing trend for more older people to enter residential care⁴²⁵.

Although data are sparse, user fees - for instance for sight tests or dentures - may deter poor older people from seeking services⁴¹⁶⁻⁴¹⁹. Where demand for services exceeds supply, such as for social services support - home cleaning, shopping, bathing and meals - user fees may disadvantage those below average income, even if the poorest groups are protected through means-testing. Furthermore, poorer older people are less able to bear the additional costs of disability, such as the additional laundry costs associated with incontinence. Whenever a significant private sector exists, for instance in chiropody, poorer older people are likely to have decreased access⁴²⁸.

There has been considerable discussion on whether "ageism" exists within health services^{428,432}. Ageism in this context means the withholding of beneficial care, on the basis of the person's age. The Inquiry has not considered inequalities in health (or health care) by age group to be within its terms of reference. However, we consider that services should be provided on the basis of need, and that age alone should not be a reason for withholding a service.

Benefit

By definition, services distributed in relation to need will result in health gain, which will be greatest in those most in need.

30. We RECOMMEND the further development of health and social services for older people, so that these services are accessible and distributed according to need.

Monitoring inequalities

Inequalities in health that are demonstrable earlier in life persist throughout the lifespan into old age⁴²⁸. However, there is a lack of routinely collected reliable data on social class or other markers of socioeconomic status in people after the age of retirement. This leads to particular problems in monitoring inequalities in health and its determinants in older people.

We recommend a review of data needs to improve the capacity to monitor inequalities in health and their determinants at a national and local level (recommendation 1.2).

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10. Ethnicity

Ethnicity is difficult to define, but most definitions reflect self-identification with cultural traditions that provide both a meaningful social identity and boundaries between groups⁴³³. In this section we have considered evidence which uses various definitions of ethnicity. However, in the main these definitions are those which people apply to themselves. Thus ethnicity as used here includes cultural identity, place of origin and skin colour, and so includes white and non-white groups. Because country of birth rather than ethnic group is recorded on death certificates, mortality data are restricted to migrants only.

In the 1991 Census just over 3 million people, 5.5 per cent of the population, identified themselves as belonging to one of the non-white minority ethnic groups. Almost half had been born in the United Kingdom⁴³⁴. White minority ethnic groups were not counted on Census night. However recent estimates show that the Irish form the largest minority ethnic group, comprising 4.6 per cent of the population⁴³⁵. Data collected at the 1991 Census show that people from minority ethnic groups are more likely to live in South East England (especially London), the West Midlands, West Yorkshire and Greater Manchester. These places are home to 75 per cent of the minority ethnic population compared to only 25 per cent of the majority population^{434,436}.

The age and gender distribution of minority ethnic groups is different from the majority population. Some minority ethnic groups have more men than women, and all are relatively young⁴³⁷. African Caribbean and South Asian communities have a higher proportion of households with children than the white population. Around 3 in 10 households with a white head of household contain children under the age of 16 years. Comparable figures for minority ethnic groups are over 4 in 10 for African Caribbean households, 5 in 10 for Indian households and 8 in 10 for Bangladeshi and Pakistani households. Pakistani and Bangladeshi families also have more children than families in the majority white population, whilst African Caribbean, Indian and Chinese families have similar numbers of children. Pakistani and Bangladeshi households are also larger because they are more likely to have 3 or more adults, whilst African Caribbean households are more likely to be headed by a lone parent^{66,438}.

Inequality

Country of birth rather than ethnic group is recorded on death certificates. Thus mortality data presented below are restricted to migrants, but include migrants from Scotland, Northern Ireland and the Republic of Ireland.

Mortality

In 1989-92 mortality ratios for deaths, including perinatal mortality, from all causes for nearly all migrant groups were higher than average. However, those born in the Caribbean had a lower than average mortality ratio. For each group, except women born in Scotland, mortality from all causes fell between 1971 and 1991⁶¹. Cause and age specific mortality varies by country of birth. For instance, mortality from coronary heart disease is higher than average for people born in South Asia, Ireland and Scotland and lower than average for those born in the Caribbean and men born in West Africa. Mortality ratios for cerebrovascular disease are significantly higher than the average for all migrant groups except those born in East Africa. By contrast, mortality ratios for lung cancer are low in migrant groups born in the Caribbean, Asia and Africa and high in people born in Scotland or Ireland, whereas cervical cancer mortality is high for women born in the Caribbean^{61,439,440}. Mortality from suicide is also unusually high in young South Asian women born in India³⁵⁶. Mortality ratios

for accidents in people under the age of 15 years and over the age of 65 years are greater in migrants from Ireland and the Indian sub-continent than those born in England and Wales²⁵².

Morbidity

This section uses self identified ethnic group as the basis of analysis. Due to lack of data, unless stated otherwise white minority groups are included in "whites".

Overall people from minority ethnic groups are more likely to describe their health as "fair" or "poor" than the ethnic majority, although this difference comes from the poorer self-reported health of Pakistani and Bangladeshi people, and, to a lesser extent, African Caribbean people⁴⁴¹. Chinese people consult less with their general practitioner (GP) than whites and African Asians are as likely to have consulted with their GP as whites. All other groups consult more⁴⁴¹.

A variety of conditions show differences between ethnic groups. For example, South Asians have a tendency to central obesity and insulin resistance which may pre-dispose them to diabetes and coronary heart disease⁴⁴². On the other hand, African Caribbean people have low death rates from coronary heart disease despite their high prevalence of diabetes and hypertension⁶¹. Depression appears to be more common in African Caribbeans than in whites⁴⁴¹. Tuberculosis is more common in Pakistanis, Bangladeshis and Black Africans than in whites, and the incidence of tuberculosis in these groups is rising⁴⁴³.

There are limited data on morbidity in white minority ethnic groups, and they were included with the white majority in the Fourth National Survey of Ethnic Minorities, the source of much of the recent data on the health of minority ethnic groups. However available data support the view that Irish people have higher rates of morbidity as well as mortality. Analysis of the long standing illness question in the Census, for example, shows rates are higher for those born in Ireland⁴⁴⁴. Rates of hospital admission for psychiatric disorder are also high in Irish people⁴⁴⁵.

Smoking is more common in African Caribbean and Bangladeshi men where the rates of smoking (42 per cent and 49 per cent) exceed those in white men (34 per cent). Indian and African Asian men report the lowest rates (19 per cent and 22 per cent). By contrast, in women rates of smoking are low (5 per cent or less) for all groups, except African Caribbean women, where the rates (31 per cent) are similar to those in white women (37 per cent). Alcohol consumption tends to be lower in all minority ethnic groups for both men and women compared to that in the white population. Comparable information is lacking for Scots and Irish people living in England and Wales. Total abstinence is common amongst Muslim groups, predominantly within the Pakistani and Bangladeshi communities⁴⁴¹.

In a survey of reported physical activity fewer men and women aged 16 to 74 years from minority ethnic groups than from the general population reported levels of activity which would benefit their health (defined as at least 30 minutes of moderate intensity physical activity on at least five days per week). For instance, amongst South Asian men aged 16 to 74 years, 67 per cent of Indians, 72 per cent of Pakistanis, and 75 per cent of Bangladeshis reported that they did not take part in enough physical activity to benefit their health, compared with 59 per cent of men in the general population. For South Asian women, the corresponding figures were 83, 86 and 82 per cent compared with 68 per cent of women in the general population. Furthermore, men and women from minority ethnic groups were more likely to report being sedentary than men and women from the general population⁴⁴⁶.

Socioeconomic status

(Due to lack of data, unless stated otherwise white minority groups are included in "whites".)

There are important differences between ethnic groups in factors which are associated

with health, and which the Inquiry has taken the view are determinants of health. Firstly, socioeconomic status is different between ethnic groups. Compared to the majority white population (unemployment rate 6.5 per cent), Labour Force Survey estimates of rates of male unemployment are slightly higher in Indians (7.4 per cent), and considerably higher in African Caribbean (20.5 per cent), and Pakistani and Bangladeshi groups (15.9 per cent)⁴⁵. The sample size is too small for reliable estimates of rates in Chinese people. Surveys of minority ethnic groups have higher absolute percentages of people out of work, but the same pattern of differences between groups^{66,441}. Part of these differences is due to the relatively young average age of these minority ethnic groups, and the associated high rates of unemployment in young age groups in general.

Social class distribution shows similar patterns, with Pakistani and Bangladeshi groups showing a more disadvantaged profile. Perhaps most striking is the number of people from all minority ethnic groups who are living in poverty, as defined by less than half the average income. Just under a third of white households have incomes below this level, compared to a third of Chinese, two-fifths of African Caribbean and Indian households and four-fifths of Pakistani and Bangladeshi households⁶⁶. Minority ethnic groups are also much more likely to be reliant on Income Support⁶⁷. Although the 1991 Census showed a worse socioeconomic profile amongst Irish people, a recent survey shows that there are differences within the Irish, with men born in the Republic of Ireland being more likely to be in social class V than any other group. Men born in Northern Ireland, however, were more likely to be in social class I than men born in England, and as likely to be in social class II⁴³⁵. Another recent survey found relatively high proportions of Irish people amongst those earning more than £30,000 or with a university degree. Thus there may be some polarisation within the Irish group to different parts of the socioeconomic spectrum.

About four fifths of Indian and Pakistani households are owner occupied, compared with about two-thirds of white households and half of African Caribbean, Bangladeshi and Chinese households. Overcrowding is relatively common in minority ethnic households - one in ten African Caribbean and Indian households, and more than one in three Pakistani and Bangladeshi households compared with roughly one in fifty white households. Housing quality also varies. About a third of Pakistani and Bangladeshi people live in households which lack a basic amenity, for example, exclusive use of an inside toilet^{66,441}.

Evidence

The contribution of socioeconomic inequalities to inequalities in health both within and between ethnic groups has been much debated over the last twenty years. In an examination of migrant mortality data from the 1970s, there was no socioeconomic gradient for those born on the Indian sub-continent, and an association between higher socioeconomic status and higher mortality for those born in the Caribbean. Differences in socioeconomic status did not account for differences in mortality between migrant groups⁴⁴⁷. However, analysis of more recent data (1991-93) on migrant mortality has shown a relationship between socioeconomic status and health for some migrant groups⁴³⁹.

All cause mortality was higher in men from manual classes than those from non-manual classes for all migrant groups, except those from West or South Africa, where the difference was present but smaller. In general this pattern was similar for the major causes of death, with the exception of coronary heart disease in men born in the Caribbean. Similar gradients have been found for self-reported health in a recent survey of minority ethnic groups⁴⁴¹. Thus within minority ethnic groups in Britain, lower socioeconomic status is associated with higher rates of both mortality and morbidity.

However, it is not clear to what extent socioeconomic status accounts for differences in health between ethnic groups. The most recent analysis of migrant mortality

suggests that socioeconomic differences, as measured by social class, do not explain the different rates of mortality between groups born in different countries⁴³⁹. However coding of socioeconomic status using occupation, as in social class, may be a particularly inappropriate proxy in migrants because of the high proportion of young people and women amongst them who have never worked. Within any band of social class, minority ethnic groups tend to be less advantaged than the majority white population. For example, mean income for Pakistanis and Bangladeshis is about half that found for whites in the same social class category⁴⁴¹.

The Fourth National Survey of Ethnic Minorities used an alternative index, standard of living, which took into account material deprivation, measured by housing problems, and ownership of cars and consumer durables. Socioeconomic status as measured by this index did account for some of the differences in reported health between most ethnic groups, whilst occupational class did not⁴⁴¹. Thus socioeconomic inequalities contribute to the inequalities in health within ethnic groups, and may contribute to the inequalities in health between ethnic groups.

The diversity of experience of health between different ethnic groups may reflect different causes of poor health; differential susceptibility to these causes; differential access to factors which ameliorate cause or susceptibility, for example, preventive health care services; or a combination of these. The Inquiry has decided to make recommendations in two general areas. Firstly, there are recommendations aimed at reducing the inequalities across ethnic groups in the socioeconomic determinants of health, given the clear evidence that these are important determinants of health in people from minority ethnic groups as they are for the ethnic majority. Secondly, there are recommendations addressed at considering the needs of people from minority ethnic groups in using services, particularly health services, which will ameliorate their experience of ill-health.

The main examples of recommendations to address differences in health across ethnic groups are considered here with a summary of their relevance to inequalities across ethnic groups, in addition to their earlier consideration in appropriate parts of the preceding text. Other recommendations may have relevance to inequalities across ethnic groups to some degree.

Benefit

In general, the benefits from policies considered here would be expected to decrease inequalities in health within ethnic groups. The benefit of such policies should be relatively wide, and be felt by those within each group who are least well off. Because minority ethnic communities typically contain a higher proportion of households with children than the white population, these communities should benefit from policies targeted at mothers, children and families (recommendations 2 and 21-23) and those related to education (recommendation 4-7). The extent to which such policies will decrease differences between ethnic groups is unknown. But the balance of evidence would favour a reduction in inequalities between groups.

Considering the needs of people in different minority ethnic groups

Although separate mechanisms might be set up to consider policies which affect inequalities in health amongst minority ethnic groups, this risks marginalising minority ethnic issues. It also implies that the health problems in minority ethnic groups are, in the main, different from those in the ethnic majority, with different causes and different solutions, whereas in fact the similarities are greater than the differences^{448,449}. However, failure to make specific consideration of minority ethnic issues risks increasing ethnic inequalities by unintentionally favouring policies that benefit the ethnic majority. Thus policies to consider inequalities in health should include consideration of the application of these policies to minority ethnic groups as a matter of course, including ways of ensuring that racial prejudice and harassment are overcome. This requires that the structures and processes of policy-making are

sensitive to the position and needs of people from minority ethnic groups. One way of achieving this is to ensure that minority ethnic groups are represented on appropriate decision-making and advisory bodies, and that other opportunities are taken to seek their views. As well as the direct effect of such representation, the visibility of people from minority ethnic groups in such positions may reduce the sense of exclusion felt by some group members.

31. We RECOMMEND that the needs of minority ethnic groups are specifically considered in the development and implementation of policies aimed at reducing socioeconomic inequalities.

Reducing poverty

People from minority ethnic groups have higher than average rates of unemployment^{40,45}. Within minority ethnic groups, there is a clear association between material disadvantage and poor health. Very high proportions of people from some minority ethnic groups are living on low levels of income, and are dependent on state benefits. There are a number of ways in which members of minority ethnic groups may be disadvantaged by the social security system. Some of the potential problems are related to the structure of the system and its assumptions. The State pension, for example, is based increasingly on the assumption that retired people should have built up occupational or other personal provisions over their working lives, but this would be impossible for people who migrated to Britain well into their working lives. Other problems are due to a failure to consider the specific needs of members of minority ethnic groups, for instance for translated or additional information⁴⁵⁰⁻⁴⁵². Lack of these may lead to under-claiming of benefits. The younger demographic structure of many minority ethnic groups means that policies which improve the welfare of women of childbearing age, expectant mothers and children are of particular importance.

We recommend policies which will further reduce income inequalities, and improve the living standards of households in receipt of social security benefits (recommendation 3).

We recommend policies which improve the opportunities for work and which ameliorate the health consequences of unemployment (recommendation 8).

Improving housing, safety and the material environment

Although owner occupation is quite high in some minority ethnic groups, housing quality is often poor, regardless of tenure⁴⁴¹. Overcrowding and lack of basic amenities is more common in some minority ethnic groups. Furthermore, current housing policy supports construction of homes for relatively small households, whereas for some minority ethnic groups, including Bangladeshis and Pakistanis, requests for housing are to accommodate extended family households. In addition, some minority ethnic groups find that their choice of area of residence is restricted by fear of crime and harassment⁴⁵³.

We recommend policies which improve the availability of social housing for the less well off within a framework of environmental improvement, planning and design which takes into account social networks, and access to goods and services (recommendation 10).

We recommend policies which aim to improve the quality of housing (recommendation 12).

Responses to the Fourth National Survey on Ethnic Minorities suggested that more than one in eight people from minority ethnic groups had experienced some form of racial harassment in the past year⁶⁶. Although most of these comprised racial insults, many respondents reported repeated victimisation and a quarter of all respondents

reported being fearful of racial harassment. The British Crime Surveys have shown that South Asians and African Caribbeans are at greater risk of being victims of crime than whites. Although much of the difference in relation to African Caribbeans was explained by social and demographic factors, these did not explain the greater risk of victimisation for South Asians²²².

We recommend the development of policies to reduce the fear of crime and violence, and to create a safe environment for people to live in (recommendation 13).

The use and effects of transport on ethnic minorities has been little researched, partly because of a lack of relevant data^{454,455}. Areas, particularly inner urban areas, with high proportions of minority ethnic residents are often characterised by markers of disadvantage^{434,436}. These include on-street parking, higher traffic volumes and lack of areas for play, and are associated with a high rate of traffic accidents amongst children from some minority ethnic groups⁴⁵⁶.

We recommend the further development of a high quality public transport system which is integrated with other forms of transport and is affordable to the user (recommendation 14).

We recommend further measures to encourage walking and cycling as forms of transport and to ensure the safe separation of pedestrians and cyclists from motor vehicles (recommendation 15).

We recommend further steps to reduce the usage of motor cars to cut the mortality and morbidity associated with motor vehicle emissions (recommendation 16).

We recommend further measures to reduce traffic speed, by environmental design and modification of roads, lower speed limits in built up areas, and stricter enforcement of speed limits (recommendation 17).

We recommend concessionary fares should be available to pensioners and disadvantaged groups throughout the country, and that local schemes should emulate high quality schemes, such as those of London and the West Midlands (recommendation 18).

Improving services

A number of studies have suggested that people from minority ethnic groups do not receive the same quality of care as the ethnic majority. Overall use of primary care is similar or greater amongst minority ethnic groups to the ethnic majority but people from minority ethnic groups are more likely than whites to: find physical access to their general practitioner (GP) difficult; have longer waiting times in the surgery; feel that the time spent with them was inadequate; and be less satisfied with the outcome of the consultation^{441,457}. They may also be less likely to be referred to secondary and tertiary care^{441,458-460}. Part of these differences may be related to problems with communication. A significant number of people from minority ethnic groups, particularly South Asian women and Chinese people, find it difficult to communicate with their GP^{441,457}. There may also be cultural differences in the expression of symptoms, making the use of Western diagnostic approaches inappropriate for some groups, especially for mental illness⁴⁶¹. Women from some minority ethnic groups, notably Pakistanis and Bangladeshis, prefer to consult with female doctors and in order to overcome communication difficulties, female doctors with the same minority ethnic background as themselves⁴⁴¹. Given the younger demographic structure of many minority ethnic groups, the provision of sensitive maternal and child health services is of particular importance.

An illustrative example is ethnic differences in cervical screening. A national survey carried out recently found that South Asian women, especially Pakistani and Bangladeshi women, were less likely to have had a cervical smear in the past five

years. About half of the Pakistani and Bangladeshi non-attenders lacked basic information about cervical screening, that is reported that they had not received an appointment or did not know what the test was⁴⁵⁷. Yet in a qualitative study carried out in the same period in East London, women from minority ethnic groups were enthusiastic about cervical cytology screening once they understood the purpose of the test and its procedures. Administrative and language barriers were important factors in participation in the screening programme, as were the adequacy of surgery premises⁴⁶².

One solution is to train health workers in "cultural competency". This involves acquiring the skills to understand and be sensitive to cultural differences in the presentation of illness and treatment, and other dimensions of health⁴⁶³. Bilingual link workers can act as translators and advocates for people from minority ethnic groups who experience communication problems with health care professionals. Support for health professionals such as general practitioners and health visitors who are themselves from minority ethnic groups is a further strategy to increase the quality of services to people from minority ethnic groups.

People from minority ethnic groups tend to congregate in specific geographical locations, which are frequently areas of multiple disadvantage^{434,436}. Place as well as individual disadvantage may affect health^{464,465}. However, the concentration of people from minority ethnic groups in particular areas may also be protective of health, by preserving levels of social support and a sense of community⁴⁶⁶⁻⁴⁶⁸. The advantages and disadvantages are likely to be conditional upon the place, and the minority ethnic group living there, making local consideration of policies to reduce inequalities essential.

32. We RECOMMEND the further development of services which are sensitive to the needs of minority ethnic people and which promote greater awareness of their health risks.

33. We RECOMMEND the needs of minority ethnic groups are specifically considered in needs assessment, resource allocation, health care planning and provision.

There are limitations on data currently collected to assess inequalities in health across ethnic groups. Death registration collects only country of birth, and so only mortality of migrants can be considered. Yet almost half of those who identified themselves as belonging to a minority ethnic group on Census night in 1991 had been born in the United Kingdom. The high proportions of young people and women who have never held a job, and the downward social mobility that may accompany immigration, mean that classification based on occupation is inappropriate as a measure of socioeconomic status in minority ethnic groups, particularly in comparison to the ethnic majority⁴⁴¹. Grouping of minority ethnic people, such as Black or South Asian, may be inappropriate, merging together people who have different cultures, religion, migration history, socioeconomic status and geographical location.

We recommend a review of data needs to improve the capacity to monitor inequalities in health and their determinants at a national and local level (recommendation 1.2).

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Prepared 26 November 1998

Independent Inquiry into Inequalities in Health Report

Part 2 continued

11. Gender

Introduction

Gender, like socioeconomic status, shapes individual opportunities and experiences across the life course. While many experiences of childhood are similar for boys and girls, they are exposed to different risks. Men and women occupy different positions in the labour market and in the home, which again bring different health risks.

Inequality**Mortality and life expectancy**

Mortality is greater in males at all ages. In childhood, from 1 to 14 years, the higher mortality rates in boys are because they are more likely to die from poisoning and injury, including motor vehicle accidents, fire and flames, accidental drowning and submersion. The gender difference in mortality rates widens in the teenage years so that by the age of 15 years boys have 65 per cent higher mortality than girls. Over the last 20 years, the difference in childhood mortality rates between boys and girls has remained constant, despite falls in overall mortality⁶².

In adult life, mortality is also greater in men. This is most pronounced in youth and early adulthood. For instance, the mortality rate is 2.8 times higher for men than for women aged 20-24 years. In youth and early adult life, the cause of the differences in mortality rates is the higher rates of male death from motor vehicle accidents, other accidents and suicide. Furthermore, mortality rates for women aged 25-40 have declined over the last 20 years, whereas those for men of the same age have increased^{469,470}.

Across the whole of adult life, mortality rates are higher for men than women for all the major causes of death. These include cancers and cardiovascular disease. However, the specific cancers vary between the sexes. In women, breast cancer is the most common neoplasm to cause death (lung cancer is the second most common), whereas in men it is lung cancer (prostate cancer is the second most common). The overall fall in mortality rates since 1971 has been accompanied by a slight reduction in the differential death rates between men and women. In 1971 males had a 64 per cent higher mortality rate than women. By 1996 this had reduced to a 55 per cent higher rate in men²⁵.

Life expectancy is 5 years longer in women than in men. Overall life expectancy has increased for both sexes throughout this century²⁶. Recently, the increases have been slightly greater for men than women, reversing an earlier slight trend in the opposite direction. However, for healthy life expectancy, that is years of life free of disability or chronic illness, there is a smaller gender difference. Women have a 2 to 3 year greater expectancy of healthy life than men. Overall healthy life expectancy has changed little over the last 10 years and the difference between men and women has also remained constant²⁷.

The choice of measure of socioeconomic status may influence the pattern of health inequalities observed. For example, measures based on occupation may reflect different facets of life for men compared to women, but the extent to which this affects observed patterns of health between and within sexes is unknown. Using the Townsend index as a measure of deprivation, the different effects of socioeconomic status and gender are such that the least well off women still have lower mortality rates than the most well off men (figure 16)⁷³. In general, gender differences in mortality are smaller in areas of relative affluence and greater in the most

economically deprived areas^{471,472}.

Furthermore, there are differences between the genders in the magnitude of the socioeconomic gradient in mortality. Analyses have shown that, for all-cause mortality, the gradient is steeper in men than in women, and that this is also the case for the major causes of death, with the exception of cardiovascular disease^{471,472}. These differences between and within genders have important policy implications.

They suggest that policies which decrease socioeconomic inequalities will have a differential effect by decreasing male mortality, and particularly mortality in more disadvantaged men. They also suggest the need for gender specific policies to reduce inequalities, because the causes of inequalities may be different for men and women.

Morbidity

A traditional view of gender differences in morbidity has been to highlight an apparent paradox: that males have higher mortality rates but females have higher rates of morbidity^{473,474}. However, in more detailed analysis, this generalisation often does not hold true. For example, in adults, gender differences in global measures of health and well-being are relatively modest⁴⁷⁵. In people over 60 years of age, for instance, the difference in proportions of men and women in 5 year age bands who reported that they were in good health seldom varied by more than 5 per cent⁴⁷⁴. Furthermore, broad assumptions that females experience more ill-health than males conceal specific gender differences in both directions.

For children, boys are more likely to report long standing illness, 18 per cent for boys and 15 per cent for girls, although the difference is only 1 per cent greater in boys for limiting long standing illness. Boys are 30 to 40 per cent more likely than girls to have consulted at a general practice for serious conditions, but about 10 per cent less likely to have done so for minor conditions. Hospital admissions are higher for boys, although the difference from rates for girls has decreased somewhat²⁸. A review of the interaction of gender and age during childhood concluded that while boys had higher rates of chronic physical illness in childhood, this pattern was reversed in early to mid- adolescence, when there were higher rates for girls. This pattern was repeated for psychological disorders, mostly neurotic, where an excess in young boys was replaced by an excess in girls by mid-adolescence⁴⁷⁶. One possibility is that the increased levels of physical complaints in adolescent girls arise, at least in part, as a result of the lowering of their psychological well-being at this age⁴⁷⁶.

Women have more morbidity from poor mental health, particularly those related to anxiety and depressive disorders³⁸. Furthermore, psychosocial health in women is strongly influenced by socioeconomic status. For example, a recent analysis of the socioeconomic patterning of women's health found that psychosocial well-being displayed the steepest socioeconomic gradient. Lone mothers had particularly poor psychosocial health, even after controlling for household income, employment status and occupation⁴⁷⁷. On the other hand, men have higher rates of alcohol and drug dependence³⁸.

Osteoporosis deserves special mention as it is a disabling condition which is more common in women. The lifetime risk from the age of 50 years of fracture of the hip, spine or distal forearm - for which osteoporosis is a major determinant - is 14 per cent, 11 per cent and 13 per cent respectively for women compared to 3 per cent, 2 per cent and 2 per cent for men. The causes of the differences in fracture rates between men and women are not fully understood, but differences in bone density, size and architecture, together with a gender difference in falling, are likely to be major contributors⁴⁷⁸.

Women have much higher rates of disability than men, especially at older ages⁴⁷⁹. Data from the 1994 General Household Survey showed that older women were more likely to experience restrictions of mobility, self-care and ability to perform household

tasks than older men⁴⁸⁰. For instance, under a fifth of men over the age of 85 years were unable to go out and walk down the road, compared with nearly half of women. When measures of functional impairment are combined - ability to get up and down stairs, walking outside, getting around the house, ability to bathe or wash oneself, to cut toenails and to get in and out of bed - 14 per cent of women over the age of 65 years suffer from functional impairments sufficient to require help on a daily basis to remain living in the community, compared to only 7 per cent of men. By the age of 85 and over, these figures have risen to nearly 40 per cent for women and 21 per cent for men⁴⁷⁴. As a consequence, the 1991 Census showed that twice as many women as men over the age of 65 years lived in a communal establishment, 6.4 per cent of women compared to 3 per cent of men⁴⁸¹.

Health related behaviour

The proportion of both men and women who smoke has decreased over the last 20 years, but this decrease has been proportionately more in men so that there is now no differential in rates between men and women smoking. About 6 to 7 per cent of men drink alcohol very heavily, based on the (now discontinued) definition of more than 50 units per week. This compares to 2 per cent of women, drinking more than 35 units per week. These proportions, and the proportions who drink heavily, have changed little over the past 10 years. Women are more likely than men to eat wholemeal bread, fruit and vegetables at least once per day, and to drink semi-skimmed milk³⁵. They are also more likely to diet²⁷⁰. Levels of physical activity are higher in men than women, but this is mainly due to men's higher levels of occupational activity³⁵.

In children and adolescents, the patterns are slightly different, and may herald differences in future gender patterns of adult health related behaviour. Secondary school-aged girls have higher rates of regular smoking than boys, although boys who are regular smokers smoke more tobacco⁶³. Higher smoking prevalence among girls has been reported since regular national surveys of school children were first conducted in 1982. If these gender differences were carried forward into adulthood, there should now be evidence of higher rates of smoking among women than men in the 16-24 age group, and to a lesser extent, in the 25-34 age group. Since these trends are not in evidence, it appears that the gender difference in smoking observed among school children is transient⁴⁸². Boys tend to drink alcohol more often than girls and to consume more when they do drink⁶³. But girls are more likely to have been offered illegal drugs¹¹⁷. Girls tend to eat fruit and vegetables more often than boys, but also eat more less "healthy" foods, such as cakes and chips, and tend to go without breakfast. By year 11 of secondary school, 23 per cent of girls are dieting and only about half are happy with their weight¹¹⁷. Girls spend less of their free time playing games or sport^{483,484}.

Socioeconomic determinants

There are important gender differences in factors which are associated with health, and which the Inquiry has taken the view are determinants of health. Despite women's increased participation in paid employment over the past 30 years, women and men occupy very different positions in and outside the labour market. Nearly 30 per cent of women of working age are economically inactive, and only 35 per cent work full-time; among men, 16 per cent are economically inactive and nearly 60 per cent work full-time⁴². Over half the female labour force is employed in the clerical, personal and retail sectors as secretaries, waitresses, hairdressers, checkout operators etc., sectors characterised by low paid work^{485,486}. Among men, less than one fifth work in these services⁴⁸⁵. Outside the labour market, it is women rather than men who take primary responsibility for keeping the home and family going: doing the shopping, cooking and housework and caring for children and other relatives⁴⁸⁷. Forty per cent of women spend over 50 hours a week caring for someone living with them⁴⁸⁸.

Gender differences in educational qualifications vary by age and measure. In 1997, 23 per cent of women of working age had no qualifications compared with 16 per cent of

men⁴⁵. By contrast girls are more likely to gain 5 or more GCSEs at grades A star to C than boys⁴¹.

Women's different positions in the labour market and in the home means that they live more home-based and community-based lives, where they provide for the health needs of vulnerable groups, including children and adults with long term needs for care. Their different occupational and domestic positions also make women more vulnerable to poverty than men, both during their reproductive and working lives and in old age. It has been estimated that two thirds of adults in the poorest households are women, and women make up 60 per cent of adults in households dependent on Income Support⁷⁶. Because women are more likely to have breaks in employment and to work part-time in low paying jobs, they are less likely to be eligible for and in receipt of contributory benefits than men and more likely to be on means-tested benefits, both before and after retirement age^{77,489}. Among those aged 65 or over, for example, there are three times as many female as male recipients of Income Support⁷⁷. Social isolation is also more likely in women than men. Women are less likely to be able to drive or to have access to a car^{40,282}. Older women are more likely than older men to be widowed and to live alone^{420,421}.

In summary, despite their more favourable position with respect to socioeconomic determinants of health, males have higher mortality rates. Gender differences in morbidity vary according to the age group under consideration, the type of morbidity being measured and the measure used.

Evidence

The Inquiry has considered the evidence on gender inequalities in three ways. Firstly, there are obvious differences in the health of males and females which relate to their different biology. Such differences include, for instance, the differences between the sexes in specific diseases of the reproductive organs, and the ill health that may be associated with childbearing. The Inquiry has sought to identify determinants of or solutions to gender-specific health states which are amenable to policy intervention. An example is policies to prevent unwanted teenage pregnancy. Unwanted teenage pregnancy is more common in girls from disadvantaged backgrounds and is associated with a range of adverse health outcomes. Gender inequalities of this type have been considered at appropriate points in the preceding text and are not considered again in this section.

Secondly, there are gender differences in health that do not appear to be predicated on inevitable differences in biology. An example is the higher rate of accidental death in young adult males. Accidental death is associated with lower socioeconomic status, yet low socioeconomic status (as measured by employment status) is more common amongst young women than young men⁴⁹⁰. This suggests that the gender difference in death rates from accidents reflects social and cultural influences which have a differential impact on men and women. These types of inequalities are likely to be amenable to policy interventions. They have been considered in the appropriate sections of the preceding text and the main examples are re-considered in this section with a summary of their relevance to gender differences. Other recommendations may also have some relevance to gender inequalities.

Thirdly, there are differences between genders in wider aspects of health, particularly mental and social health. An example is the existence of food poverty amongst lone mothers living on state benefits^{93,94}. This is likely to be less common amongst men of the same age because they are less likely to be living in these circumstances. Going without food because of lack of money might not be within the definition of morbidity but it can hardly be described as a healthy state. Similarly, cultural expectations of male and female roles may mean that the frustrations, hopelessness and loss of self-esteem associated with unemployment are felt more keenly by the male partner of an unemployed couple, even if both are seeking work. Again, such feelings are not compatible with good mental health, although they would not be described as

psychiatric morbidity. In addition to their earlier consideration in appropriate parts of the preceding text, the main examples of recommendations to address gender differences in these wider aspects of health are considered specifically here, with a summary of their relevance to gender inequalities. Again, other recommendations, not reconsidered here, may have relevance to such gender inequalities to some degree.

We have focused our recommendations in three areas: reducing death in young men; improving health is disadvantaged women with young children; and reducing disability in older women.

Benefit

In general, the benefits from policies considered here will decrease gender inequalities by decreasing disadvantage to either males or females. The benefit of such policies should therefore be relatively wide, and be felt by those males or females who are least well off. However, the mechanisms which link social and cultural influences to differences in male and female health are not well understood. Partly as a consequence, the differential effect on male and female health of policies is often unknown.

Finally, it should be noted that policies which improve the health of women of childbearing age may, in addition, improve the health of the next generation²¹. This may itself have implications for gender differences in health, as males may be more susceptible to some adverse events in utero and early life than females²¹. For example, boys are more susceptible than girls to the long term effects of postnatal depression in their mothers³⁴².

Reducing death in young men

Our policies in this area aim to reduce deaths from accidents and suicide. Mortality from road traffic accidents is higher in males of all ages²⁵. The policies which we recommend may have a differential effect on males, particularly those in lower socioeconomic groups, because they are aimed at reducing the opportunity for, or enforcing limits on, risk-taking behaviour as a pedestrian or motor vehicle user.

In England and Wales in 1996, the age-standardised mortality rate for suicide was three times higher in males than in females - 137 and 44 per million respectively²⁹. The overall rate has fallen by nearly a half in women over the last 20 years, but there has been little change in men. For men under the age of 44 years, however, there has been a rise of 20-30 per cent, compared to a fall of about the same magnitude in men over this age³². There is a steep social class gradient in deaths from suicide. In 1991-1993, rates for men were 4 times higher in social class V than in social class I. Our policies aim to reduce the causes of social exclusion which lead to despair and to improve mental health services for people who are already mentally ill. Detailed evidence in support of these recommendations is given at appropriate points in the preceding text.

34. We RECOMMEND policies which reduce the excess mortality from accidents and suicide in young men. Specifically:

we recommend policies which improve the opportunities for work and which ameliorate the health consequences of unemployment (recommendation 8).

We recommend policies which improve housing provision and access to health care for both officially and unofficially homeless people (recommendation 11).

We recommend further measures to encourage walking and cycling as forms of transport and to ensure the safe separation of pedestrians and cyclists from motor vehicles (recommendation 15).

We recommend further steps to reduce the usage of motor cars to cut the mortality

and morbidity associated with motor vehicle emissions (recommendation 16).

We recommend further measures to reduce traffic speed, by environmental design and modification of roads, lower speed limits in built up areas, and stricter enforcement of speed limits (recommendation 17).

We recommend policies to prevent suicide among young people, especially among young men and seriously mentally ill people (recommendation 24).

We recommend policies which reduce alcohol-related ill health, accidents and violence, including measures which at least maintain the real cost of alcohol (recommendation 26.5).

Improving health in disadvantaged women with young children

Women are more likely than men to take primary responsibility for caring for children and other relatives⁴⁸⁷. Forty per cent of women spend over 50 hours per week caring for someone living with them⁴⁸⁸. Improving the conditions - financial, social and environmental - in which women in poorer circumstances care for their families is likely to be an essential part of any strategy to reduce socioeconomic inequalities in health. People on low incomes or reliant on state benefits are more likely to be lone parents, most of whom are women⁶⁵. Furthermore, current levels of benefit fall short of the level which independent experts determine to be the modern minimum^{78,80,81,84,85}. Lone mothers may go without food because of lack of money, and some have nutritionally deficient diets^{93-95,116}.

Caring for young children in disadvantaged circumstances, particularly as a lone mother, carries with it an increased risk of poor mental health. In the Health and Lifestyle Survey, the most important factor associated with the mental health of married women aged under 45 years, was the age of their youngest child. Women with children under the age of 5 were most likely to show signs of psychological disturbance. The age of youngest child had no association with physical health⁴⁹¹. In a survey of 11,000 mothers 8 months after birth (the Avon Longitudinal Study of Pregnancy and Childhood), material disadvantage was more strongly related to stress-related conditions such as depression, anxiety and headache/migraine, than to conditions like backache, haemorrhoids and cough/cold. For the former conditions, higher levels of self-reported morbidity and general practitioner consultation were associated with a cluster of social disadvantages - living in rented housing, non-employment, younger age, lower educational status. Having more than one child was associated with higher self-reported morbidity for both depression and anxiety⁴⁹².

Women of all ages are more likely than men to be reliant on public transport, especially buses. Fewer women than men can drive, and fewer women than men own or have access to a car^{40,282}. Surveys in a number of UK cities have found that around two thirds of women are afraid to go out alone at night, and that significant numbers will not use public transport because of fears for personal safety⁴⁹³. This combination of lack of access to transport and fear for safety is likely to decrease opportunities for access to family and friends, facilities and services.

Policies aimed at the material, social and emotional support of women who are pregnant or who have young children should lead to improved psychosocial health in the mother and related improvements in the health of their children. These improvements should be felt in many aspects of health and its determinants, and be apparent in the short and long term. Detailed evidence in support of these recommendations is given at the appropriate points in the preceding text.

35. We RECOMMEND policies which reduce psychosocial ill health in young women in disadvantaged circumstances, particularly those caring for young children. Specifically:

we recommend further reductions in poverty in women of childbearing age, expectant mothers, young children and older people should be made by increasing benefits in cash or in kind to them (recommendation 3.1).

We recommend uprating of benefits and pensions according to principles which protect and, where possible, improve the standard of living of those who depend on them, and which narrow the gap between their standard of living and average living standards (recommendation 3.2).

We recommend measures to increase the uptake of benefits in entitled groups (recommendation 3.3).

We recommend policies which improve the availability of social housing for the less well off within a framework of environmental improvement, planning and design which takes into account social networks, and access to goods and services (recommendation 10).

We recommend the further development of a high quality public transport system which is integrated with other forms of transport and is affordable to the user (recommendation 14).

We recommend policies which will increase the availability and accessibility of foodstuffs to supply an adequate and affordable diet (recommendation 20).

We recommend policies which reduce poverty in families with children by promoting the material support of parents; by removing barriers to work for parents who wish to combine work with parenting; and enabling those who wish to devote full-time to parenting to do so (recommendation 21).

We recommend an integrated policy for the provision of affordable, high quality day care and pre-school education with extra resources for disadvantaged communities (recommendation 21.1).

We recommend policies which improve the health and nutrition of women of childbearing age and their children with priority given to the elimination of food poverty and the prevention and reduction of obesity (recommendation 22).

We recommend policies which promote the social and emotional support for parents and children (recommendation 23).

We recommend the further development of the role and capacity of health visitors to provide social and emotional support to expectant parents, and parents with young children (recommendation 23.1).

We recommend policies which promote sexual health in young people and reduce unwanted teenage pregnancy, including access to appropriate contraceptive services (recommendation 25).

Reducing disability in older women

People on low incomes or reliant on state benefits are more likely to be lone parents, especially women, or pensioners, the majority of whom are women. Only a quarter of older women have an occupational or personal pension compared to two thirds of older men⁴⁹⁴. Low income decreases their chances of maintaining autonomy and independence by rendering them unable to pay for transport, social care and aids or adaptations to compensate for functional disability⁴⁷⁴.

Properties in poor condition are occupied disproportionately by single older people, the majority of whom are women²⁰⁹. These homes have higher heating costs. The combination of living alone, and on a low income, puts older women at high risk of

fuel poverty^{96,97,474}.

Women of all ages are more likely than men to be reliant on public transport, especially buses. Fewer women than men can drive, and fewer women than men own or have access to a car. This gender difference is most pronounced for older women^{40,282}. Surveys in a number of UK cities have found that around two thirds of women are afraid to go out alone at night, and that significant numbers will not use public transport because of fears for personal safety^{220,493}. Fear for personal safety is greater in older women than those of younger ages. Older women are more likely to live alone than older men^{420,421}, and thus need to go out in order to access social networks.

Older women are more likely than older men to suffer from functional impairments sufficient to require help on a daily basis to remain living in the community⁴⁷⁴. Changes in community care policies in the early 1990s made it more difficult for older people to obtain local authority residential or home care. Such policies have had a greater effect on older women. Older men are more likely than older women to have the financial resources to pay for such care, and are more likely to be living with a wife, who can contribute to care^{420,421}. Older disabled women are twice as likely as men with a comparable level of disability to live alone⁴⁷⁴.

Our recommendations are aimed at the reduction of disability in older women, by improving the material support to them, the environment in which they live, and access to the services which they need. Detailed evidence in support of these recommendations is given at appropriate points in the preceding text.

36. We RECOMMEND policies which reduce disability and ameliorate its consequences in older women, particularly those living alone. Specifically:

we recommend further reductions in poverty in women of childbearing age, expectant mothers, young children and older people should be made by increasing benefits in cash or in kind to them (recommendation 3.1).

We recommend uprating of benefits and pensions according to principles which protect and, where possible, improve the standard of living of those who depend on them and which narrow the gap between their standard of living and average living standards (recommendation 3.2).

We recommend measures to increase the uptake of benefits in entitled groups (recommendation 3.3).

We recommend the development of policies to reduce the fear of crime and violence, and to create a safe environment for people to live in (recommendation 13).

We recommend the further development of a high quality public transport system which is integrated with other forms of transport and is affordable to the user (recommendation 14).

We recommend concessionary fares should be available to pensioners and disadvantaged groups throughout the country, and that local schemes should emulate high quality schemes, such as those of London and the West Midlands (recommendation 18).

We recommend the quality of homes in which older people live be improved (recommendation 28).

We recommend the further development of health and social services for older people, so that these services are accessible and distributed according to need (recommendation 30).

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Prepared 26 November 1998

The National Health Service

The institutional links to Government, whereby the Secretary of State for Health is responsible for the service, gives the National Health Service (NHS) a different status from the areas for policy development considered earlier in the report. For this reason, we have set out this section and our recommendations slightly differently, focusing on management and operational issues. However, as for the rest of the report, we have based our recommendations on scientific and expert evidence.

Equity

Equity was a founding principle of the NHS⁴⁹⁵ and is central to Government policy^{5,87}.

The NHS has several interlinked responsibilities in relation to health inequalities:

- to provide equity of access to effective health care
- to work in partnership with other agencies to improve health and tackle the causes of health inequalities
- to provide professional leadership and to stimulate the development of health policies beyond the boundaries of the NHS^{13,14}.

This chapter examines what is known about the relationship of socioeconomic variations in health to equity in health care and what action could be taken by the NHS in conjunction with others to reduce health inequalities.

The principle of equity includes several important elements: ensuring that health care services serving disadvantaged populations are not of poorer quality or less accessible; that the allocation and application of resources are in relation to need; and ensuring that positive efforts are made to achieve greater uptake and use of effective services by making extra efforts to reach those whose health is worse.

Equity in access to health care

Differences in access to preventive health care or treatment services do not necessarily indicate inequity in access between social groups unless these differences are adjusted for need. A recent systematic review indicated that much of the research on inequities in access to health care neither adjusted for need nor for socioeconomic factors⁴⁹⁶. Furthermore relatively little research has studied the effects of variations in health care treatments on the course of disease and the reasons for differential survival between social groups.

We have considered inequalities in relation to primary care, secondary care, including specialist care, and mental health services. Our overriding perspective has been that the NHS, should, above all, be aiming to provide equitable access to effective health care for those who need it. In the case of primary care, it is important that services are readily accessible as well as effective. For some specialist hospital services, a different balance needs to be struck between local access and securing an effective critical mass of services to achieve the best outcomes⁴⁹⁷.

Inequities in access to primary care

Access to effective primary care is influenced by several "supply" factors: the geographical distribution and availability of primary care staff, the range and quality of primary care facilities, levels of training, education and recruitment of primary care staff, cultural sensitivity, timing and organisation of services to the communities served, distance, and the availability of affordable and safe means of transport. "Demand" factors such as lay health beliefs, knowing what services are available

locally and wider socioeconomic influences, such as financial insecurity, social mobility and lack of informal carer support will also affect patterns of utilisation and access to health care.

Higher rates of general practitioner (GP) consultation are associated with greater social and economic deprivation even after adjusting for need⁴⁹⁶. However, the further away patients live from their GP, the less frequently they tend to consult. This is evident in rural areas - although the differences are not as great for serious health problems as for less severe ones⁴⁹⁸.

Communities most at risk of ill health tend to experience the least satisfactory access to the full range of preventive services, the so called "inverse prevention law". Prevention services include cancer screening programmes, health promotion and immunisation. While differences are most noticeable amongst socioeconomic groups it is likely that, for example amongst Bangladeshi women, additional inequalities in access are experienced⁴⁹⁹. Lack of access to women practitioners can be a deterrent to Asian women taking up an invitation for cervical cancer screening⁴⁶². Local studies have shown that access to female practitioners is poorest in areas with high concentrations of Asian residents⁵⁰⁰ and that practices with a female doctor or nurse are more likely to reach the cervical cytology targets set out in the GP contract⁵⁰¹. Sub-regional and small area analyses illustrate this inequity for areas such as Liverpool⁵⁰² and Birmingham where, using nine indicators of primary care services, the most deprived areas tended to be the least well served⁵⁰⁰. Within London, health promotion claims by GPs are highest in the least deprived and lowest in the most deprived areas (figure 17)⁵⁰³.

Inequities in access to secondary care

Evidence on variations in access to secondary care is often difficult to interpret, since many studies do not adjust for case mix or distinguish between emergency and elective care. Monitoring equity of access to secondary care from routine data sources is also difficult, since the collection of data about ethnicity, socioeconomic status and utilisation of the private sector is incomplete.

There is a positive relationship between levels of deprivation in an area and hospital admission rates, although there are great variations in hospital admission rates between GP practices^{504,505}. Thus deprivation is not the only factor influencing hospital admission and higher admission rates could also in part reflect poorer access to primary and community care services, as for example in the case of diabetes and asthma⁵⁰⁶.

For out-patients, attendance is either higher in disadvantaged groups or similar to the better off, after adjusting for need. For some minority ethnic groups out-patients attendance rates are lower than for the ethnic majority⁴⁹⁶. There is some evidence to suggest this may be related to GP referral beliefs and practices^{458,507}. Inequity in access to investigation and specialist cardiac services treatment has been observed in relation to socioeconomic factors, ethnic group, gender, age and geography. For example, since mortality from coronary heart disease in South Asians is 40 per cent higher than the general population, intervention rates for large Asian communities might be expected to be higher than average. The evidence shows the opposite after adjusting for socioeconomic and geographical factors⁴⁹⁶. Similarly, rates for coronary artery bypass grafts and coronary angioplasty are not generally higher in areas with the greatest need (figure 18)^{508, 509}. For many other NHS hospital treatments, there is little evidence of systematic inequities in access between deprivation groups⁵⁰⁹.

Inequities in access to mental health services

Mental health services, although specialist in nature, are both community and hospital based. Here we focus on the link between social deprivation and serious mental illness and utilisation of mental health services. The use of psychiatric - especially inpatient

hospital services - is positively correlated with high levels of deprivation and unemployment⁴⁹⁶. There is also evidence of high inpatient admission rates for schizophrenia but lower consultation rates for mental health problems among young African Caribbean men⁴⁹⁶. In contrast, women and men from South Asian populations have much lower rates of GP consultation for mental health problems than the white population^{507,510}.

There is a lack of consensus about the explanation for these different patterns of utilisation. Over-representation of young male African Caribbeans in the inpatient sector may be due to higher levels of need or, alternatively, racial discrimination within both the NHS and criminal justice systems. Equally, it is not clear whether the observed under-utilisation by Asians represents inequities in access to services or an appropriate response to lower levels of need. Whatever the explanation of these differences in access, it is clear that, given the high prevalence of severe mental illness in the local population, mental health services in inner cities have difficulty in coping with demand⁵¹¹.

The allocation of resources for mental health services should be sufficiently weighted to meet the needs of culturally diverse populations and to enable strategies to be developed which provide culturally appropriate services, and strengthen further developments of community based services within the NHS, local authority, voluntary and community sector. Such strategies need to consider other influences on mental health, such as housing and employment.

Clinical governance

Routine information systems are needed to alert clinicians and managers to changing patterns of access and health outcomes. We welcome the Government's intention to produce, after a developmental period, and make public, comparative information on clinical outcomes. We suggest that the best way of encouraging effective clinical governance is to ensure that valid, robust and user-friendly data are provided. The commitment to develop National Service Frameworks should reinforce this by setting and monitoring minimum standards.

37. We RECOMMEND that providing equitable access to effective care in relation to need should be a governing principle of all policies in the NHS. Priority should be given to the achievement of equity in the planning, implementation and delivery of services at every level of the NHS. Specifically:

37.1. we recommend extending the focus of clinical governance to give equal prominence to equity of access to effective health care.

37.2 We recommend extending the remit of the National Institute for Clinical Excellence to include equity of access to effective health care.

37.3 We recommend developing the National Service Frameworks to address inequities in access to effective primary care.

37.4 We recommend that performance management in relation to the national performance management framework is focused on achieving more equitable access, provision and targeting of effective services in relation to need in both primary and hospital sectors.

Providing equitable access to effective care should also include a process of monitoring the quality of local partnerships for health and social care, and the involvement of local people in the provision of services.

37.5 We recommend that the Department of Health and NHS Executive set out their responsibilities for furthering the principle of equity of access to effective health and social care, and that health authorities, working with Primary Care Groups and providers on local clinical governance, agree priorities and

objectives for reducing inequities in access to effective care. These should form part of the Health Improvement Programme.

Resource allocation

We welcome the progress that has been made in recent years in achieving a more equitable approach to allocating health service and related resources. However, the evidence suggests that more needs to be done^{512,513}.

Firstly, the methodology for estimating the size of underenumerated, mobile and homeless populations needs to be improved in the census and inter-censal years. This is a particular problem for the allocation of resources to Primary Care Group populations.

Secondly, there is insufficient recognition of ethnic and cultural needs in the funding arrangements, such as the costs of bilingual advocates/interpretation which have been shown to improve health outcome in disadvantaged ethnic groups⁵¹⁴. An "Ethnic Diversity Levy" and allocating it in relation to size, diversity and need identified by health authorities may provide a more effective targeting and accountability mechanism.

Primary care

An "inverse care law" is still evident in relation to the distribution of medical and nursing staff in relation to need⁵¹⁵. A number of studies have also shown that deprived areas suffer increasing difficulty in recruiting GPs⁵¹⁶. This situation has been exacerbated - especially in inner London - by the poor quality of primary care premises, large numbers of single-handed GPs, GPs approaching retirement and practices without training status⁵¹⁷⁻⁵¹⁹. This inequity extends beyond that of GPs to other primary care staff including practice nurses, health visitors and district nurses⁵²⁰.

A formulaic approach such as the allocation of GPs to health authority areas, such as operated by the Medical Practices Committee, is unlikely to be sufficient as a policy to deal with the growing shortage of GPs in deprived inner city areas. Equally, the GP deprivation payment system whereby GPs working in deprived areas receive additional payments, whilst well-intentioned, has neither been effective in attracting GPs to these areas, nor in increasing access to effective services for disadvantaged populations^{516,521}. Innovative schemes, such as the introduction of salaried GPs, have been shown to help redress some of these inequities⁵²².

Hospital and community health services (HCHS)

Despite the efforts to achieve greater equity in the allocation of HCHS services, evidence suggests that a number of issues still need to be addressed^{512,513}. One is the pace by which health authorities move towards their target resource allocations and the way in which those resources are then spent. In 1998/99, if the top 20 per cent of health authorities in England were able to move to their target allocation, this would involve a shift of over £198 million from those currently over target. Such shifts of resources are large and would need careful planning, but need to be achieved if HCHS resources are to be distributed equitably (*figure 19*)⁵²³.

Health promotion

Aside from specific health promotion payments in primary care, and ring-fenced HIV/AIDS and substance misuse funding, there is no recognition of a capitation or needs-based allocation to support health promotion services on a more comprehensive basis. The needs-based formula for targeting HIV prevention funds has achieved some success in allocating resources where they are most needed⁵²⁴, although their use needs to be targeted and monitored more effectively. The principle of ring-fencing resources with greater accountability for their use could be used both visibly and effectively in local inter-agency work to support the principles of "Our Healthier Nation"¹.

The role of the private sector

The value of privately funded acute health care provided both within and independently of the NHS was estimated at £2.35 billion in 1996 with private revenue within the NHS estimated at £252 million in 1996/7525.

A number of studies suggest that the distribution of, and access to, private health care compounds existing inequalities^{526,527}. Currently, information on levels of activity and quality of private sector services is not routinely available. This means that no complete picture exists for both public and private sectors of access, resources and the outcomes of treatment in relation to need.

We suggest that those providing private health care should be required to give the same routine information on activity and quality of services as the NHS. This is already statutorily required in the case of assisted conceptions, abortions and nursing home care and such arrangements could be extended as part of the performance assessment framework. An independent review of private practice would enable full consideration of the relationship of private practice to the NHS, and its impact on equity issues.

38. We RECOMMEND giving priority to the achievement of a more equitable allocation of NHS resources. This will require adjustments to the ways in which resources are allocated and the speed with which resource allocation targets are met. Specifically:

38.1 we recommend reviewing the "pace of change" policy to enable health authorities that are furthest from their capitation targets to move more quickly to their actual target.

38.2 We recommend extending the principle of needs-based weighting to non-cash limited General Medical Services (GMS) resources. The size and effectiveness of deprivation payments in meeting the needs and improving the health outcomes amongst the most disadvantaged populations, including ethnic minorities should be assessed.

38.3 We recommend reviewing the size and effectiveness of the Hospital and Community Health Service (HCHS) formula and deprivation payments in influencing the health care outcomes of the most disadvantaged populations, and to consider alternative methods of focusing resources for health promotion and public health care to reduce health inequalities.

38.4 We recommend establishing a review of the relationship of private practice to the NHS with particular reference to access to effective treatments, resource allocation and availability of staff.

Local partnerships to reduce health inequalities

As many of the determinants of health inequalities lie outside the health care system, it is essential for the NHS to work effectively across organisational boundaries in partnership with local authorities, the voluntary and business sectors, to involve local people in developing and providing services, and to contribute actively to social and economic regeneration.

This shared responsibility for health is central to the idea of a local Health Improvement Programme, described in "Our Healthier Nation" and "The New NHS" White Paper^{1,5}, as well as such initiatives as Healthy Living Centres. These plans will need to be properly supported by appropriate mechanisms and underpinned by local commitment if they are to successfully play their part in a concerted national programme to improve health and tackle health inequalities⁸⁷.

Birmingham and Liverpool, cities whose health and local authorities are coterminous, have undertaken detailed analyses of inequalities within their boundaries^{500, 528}. Liverpool, the first to join the World Health Organisation's Healthy Cities initiative 10 years ago, has a joint City Health Plan based on a comprehensive review of health and its social, economic and educational determinants. More recently its employment, economic and regeneration strategies have been more closely aligned to health objectives. Whilst there is little evidence of any reduction in inequalities in most health areas, there is some evidence of a shift of primary care resources into areas of greatest need with a resultant increase in immunisation uptake⁵⁰². A new index of quality of life and health has been developed to help monitor progress in implementing the plan.

Information about the supply of services and resources going into an area is not easy to obtain, but these types of "equity audit" are essential for developing a more strategic approach to addressing health and health care inequalities at a local level.

The NHS White Paper sets out five new vehicles for improving health and tackling health inequalities, as well as local Health Improvement Programmes⁵. They include Primary Care Groups, a new system of clinical governance, a duty of partnership between health and local authorities, and a new NHS performance assessment framework. The principle of equity needs to be given prominence as this framework is developed if inequalities in health are to be addressed in a co-ordinated way.

Developing the capacity for tackling health inequalities

In order to take forward a new agenda to tackle health inequalities, the skills, resources, and capacity of organisations to work together need to be strengthened. The Chief Medical Officer's interim report on strengthening the public health function identified the need for shared posts to support the creation of local health partnerships, work across organisational boundaries and involve local people in health promotion and service delivery⁵²⁹. One conclusion was that a well resourced multi-disciplinary network is required at each level of the health care system to take forward policy development, share innovation and good practice. Steps need to be taken nationally to ensure that the capacity for interagency working at local level is strengthened and that the resources and skills available for specialist health promotion, including professional and community development are protected.

National level

Health inequalities between social groups and between areas will not be reduced by local action alone. Local agencies will need the leadership and support of central Government and the European Union. This approach is relevant if new incentives and freedoms to working in partnership and sharing resources are to be created.

39. We RECOMMEND Directors of Public Health, working on behalf of health and local authorities, produce an equity profile for the population they serve, and undertake a triennial audit of progress towards achieving objectives to reduce inequalities in health.

39.1 We recommend there should be a duty of partnership between the NHS Executive and regional government to ensure that effective local partnerships are established between health, local authorities and other agencies and that joint programmes to address health inequalities are in place and monitored.

Effective working will be strengthened by better co-ordination of policies and programmes between Government Departments, non-Departmental public bodies and agencies, such as the Health Education Authority, Food Standards Agency and Environment Agency. This returns us to our first recommendation which emphasises the need for Departments to consider impact assessments on health inequalities in the formulation of policy, and to keep these developments under review.

We RECOMMEND that as part of health impact assessment, all policies likely to have

a direct or indirect impact on health should be evaluated in terms of their impact on health inequalities, and should be formulated in such a way that by favouring the less well off they will, wherever possible, reduce such inequalities (recommendation 1).

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Prepared 26 November 1998

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Part 2 continued

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Prepared 26 November 1998

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Prepared 26 November 1998

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Annex A

Annex A - Letter from the Minister for Public Health

10 July 1997

Sir Donald Acheson
 International Centre for Health & Society
 University College, London
 1-19 Torrington Place
 LONDON WC1 6BT

Review of inequalities in health

I thought it might be helpful to follow up our most useful conversation last Friday in order to confirm both where we had got to and the outstanding action on which you agreed to come back to me.

We have now agreed slightly revised terms of reference as follows:

- "1. To moderate a Department of Health review of the latest available information on inequalities of health, using data from the Office for National Statistics, the Department of Health and elsewhere. The data review would summarise the evidence of inequalities of health and expectation of life in England and identify trends.
2. In the light of that evidence, to conduct - within the broad framework of the Government's overall financial strategy - an independent review to identify priority areas for future policy development, which scientific and expert evidence indicates are likely to offer opportunities for Government to develop beneficial, cost effective and affordable interventions to reduce health inequalities.
3. The review will report to the Secretary of State for Health. The report will be published and its conclusions, based on evidence, will contribute to the development of a new strategy for health."

We discussed the timing of your report. You were very concerned that a credible and reputable piece of work covering such a broad spectrum of issues could not be completed by January 1998 as we had originally hoped. However, you undertook to produce that part of your report which related to the work of the NHS by January 1998. You will then seek to produce by the end of March 1998 such further work as you are able to do properly in the time available. Any outstanding sections would form part of the final report to be delivered by the end of June.

However, proceeding on that basis makes it all the more important that the Department, whether through the CMO or the Secretariat, are kept in very close touch with your emerging findings so that these can be taken into account in the drafting of the Health Strategy White Paper which I intend to publish in the middle of next year. As I said, I recognise the time pressure which my overall timetable imposes on you but I do think it is vital to ensure that your work is relevant to the development of my new strategy for health.

Finally, we discussed the size and composition of the group of experts who you would like to assist you. As I said, I am concerned that the current proposals would create too large and unmanageable a group and you kindly undertook to consider how to reduce its size whilst covering all the major interests. I am most grateful to you for agreeing to consider these points further and to come back to me in due course. On further reflection, given the scientific basis of the evidence you intend to produce, scientists are clearly your essential resource for further advice.

The Secretary of State and I are both delighted that you and I have now been able to

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reach agreement on the basis on which you will carry out your review and I am sure it will prove a most important contribution to the development of health and social policy. I am extremely grateful to you for agreeing to take this on and hope we can keep in touch from time to time in the months ahead.

TESSA JOWELL

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Annex B

Annex B - The Process of the Inquiry

1. Sir Donald Acheson was invited by Ministers on 10 July 1997 to undertake an independent review of inequalities of health in England. The commissioning letter from the Minister for Public Health is attached at annex A.

Terms of Reference

2. The Inquiry's terms of reference were:

- (1) To moderate a Department of Health review of the latest available information on inequalities of health, using data from the Office for National Statistics, the Department of Health and elsewhere. The data review would summarise the evidence of inequalities of health and expectation of life in England and identify trends.
- (2) In the light of that evidence, to conduct - within the broad framework of the Government's overall financial strategy - an independent review to identify priority areas for future policy development, which scientific and expert evidence indicates are likely to offer opportunities for Government to develop beneficial, cost effective and affordable interventions to reduce health inequalities.
- (3) The review will report to the Secretary of State for Health. The report will be published and its conclusions, based on evidence, will contribute to the development of a new strategy for health.

3. The purpose of the Inquiry was to inform the development of the Government's public health strategy and, in particular, to contribute to the forthcoming White Paper, "Our Healthier Nation". A two stage timescale was agreed to assist this process. It provided for confidential draft advice to be presented to Ministers in advance of the publication of the final report.

Scientific Advisory Group

4. After initial consultations on the major issues of health inequalities in the summer of 1997, the business of the Inquiry was taken forward by a Scientific Advisory Group (SAG) of experts, chaired by Sir Donald and supported by a small Secretariat. The members of the Group were:

Professor David Barker frs, Director of the Medical Research Council's Environmental Epidemiology Unit, University of Southampton

Dr Jacky Chambers, Director of Public Health, Birmingham Health Authority

Professor Hilary Graham, Director of the Economic and Social Research Council's Health Variations Programme at Lancaster University

Professor Michael Marmot, Professor of Epidemiology and Public Health, University College, London and Director of the International Centre for Health and Society.

Dr Margaret Whitehead, Visiting Fellow at the King's Fund, London

5. The SAG met on 19 occasions between August 1997 and September 1998. It oversaw the process, received the evidence submitted and developed the recommendations and the final report.

Process

6. As a first step, the Inquiry commissioned a series of topic (or "input") papers from academics and other experts in the field. The purpose of the papers was to identify and summarise key issues and to allow the SAG to consider the state of the scientific evidence and possible areas for policy development in accordance with the Inquiry's

terms of reference.

7. The Inquiry took a broad view of the causes and the impact of health inequalities on individuals and society. Accordingly, these papers explored aspects of the life course, of the economic, social and physical environments, and of the behaviours which affect individual health. Input papers on a total of 17 topics were presented to the SAG. They are listed in full in Annex D.

8. Most of the authors of the input papers consulted widely among a network of other researchers in the area. The papers were presented at SAG meetings by the author(s). Invited experts were asked to comment on the input papers as part of the SAG discussions. The main findings of the papers and results of the SAG discussions were summarised in a series of commentaries.

9. These input papers, and commentaries, together with other evidence were scrutinised by a separate Evaluation Group. This Group, chaired by Professor Sally Macintyre, Director of the MRC Medical Sociology Unit, was set up to provide a further element of peer review to the process. The members of the Group were Dr Iain Chalmers, Director of the UK Cochrane Centre, Dr Richard Horton, editor of The Lancet, Dr Richard Smith, editor of the British Medical Journal. The Group noted the lack of evidence to support many suggested policy interventions, and recommended that the Inquiry should make explicit the quality of evidence and argument used to support proposed areas for policy development. The SAG received a report from the Group and accepted its advice.

10. The SAG also received a number of presentations from other experts and from within its own ranks. These were usually less formal events, and the results were not considered by the Evaluation Group. They were, nevertheless, crucial in expanding and strengthening the evidence base of the Inquiry.

11. Written submissions were also sought from a range of bodies and individuals, and many additional contributions were received. This evidence was considered by the SAG and, as far as possible, fed into the development and review of the input papers. A full list of the presentations and submissions received is in annex D.

12. The process was also aided by a series of "chairman's briefings", usually informal discussions with experts covering issues arising from the consultation paper "Our Healthier Nation" and from the initiatives of other Government Departments.

13. The report's recommendations and supporting argument documented in this report are the result of all these processes.

14. Draft confidential advice was submitted to Ministers in July. This final report was submitted at the end of September 1998

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Annex C

Annex C - Acknowledgements

The Inquiry would like to thank the many individuals and organisations who provided valuable information and support across the wide range of our interests.

Iain Chalmers was a founding member of the Scientific Advisory Group (SAG) and resigned after the early meetings to concentrate on supporting the Evaluation Group. He was aided by Trevor Sheldon until he left the SAG. The SAG was also aided by David Blane and Cyrus Cooper who served as substitutes for Michael Marmot and David Barker in the early months of the Inquiry.

The secretariat to the Inquiry was provided by Ray Earwicker (Administrative Secretary) and Catherine Law (Scientific Secretary). Frances Drever was the Statistical Adviser to the Inquiry. Anna Donald and James Nazroo assisted with scientific aspects of the work. Scientific support was also provided by Malu Drachler, Kerry-Ann Holder and Tanja Megens. Zubeda Seedat provided administrative support for the team. Gabrielle Allnut, Gavin Larner and Imogen O'Shea provided Secretariat support in the early months of the Inquiry. Jane Kincaid was Sir Donald's personal secretary during the Inquiry. Jane Pearce provided secretarial support to Catherine Law.

Sally Macintyre chaired the Evaluation Group. The other members were Iain Chalmers, Richard Horton, and Richard Smith.

Input papers were commissioned by the Inquiry from experts in the field. They were Sara Arber, Michaela Benzeval, Richard Best, David Blane, George Davey Smith, Adrian Davis, Anna Donald, David Goldberg, Bobbie Jacobson, Kay-Tee Khaw, Catherine Law, Barbara MacGibbon, Sally Macintyre, James Nazroo, Michael Nelson, Aubrey Sheiham (together with Richard Watt), and Jane Wardle (together with Michael Farrell, Mervyn Hillsdon, Martin Jarvis, Stephen Sutton and Margaret Thorogood), Patrick West, Richard Wilkinson, Geoff Whitty (together with Peter Aggleton, Eva Gamarnikow and Paul Tyrer).

The discussion of these papers within the SAG was informed by contributions from: Mel Bartley, Raj Bhopal, Liza Catan, Sarah Curtis, Astrid Fletcher, David Gordon, Bobbie Jacobson, Michael Joffe, Suzi Leather, David Leon, Stuart Logan, Duncan MacLennan, Alan Marsh, Chris Power, Andrew Rugg Gunn, Helen Sweeting, Chris Thompson, and Sally Tomlinson.

The following individuals provided valuable assistance to the Inquiry: Phil Alderson, Eric Appleby, Jim Appleyard, John Ashton, Rasaratnam Balajaran, Sir Christopher Ball, Terri Banks, Ann Barker, Colin Barnes, John Bennett, Richard Berthoud, Roger Bibbings, Sheila Bingham, Sir Douglas Black, Mildred Blaxter, Lisa Bostock, Shaun Boyle, Michael Chan, David Coggon, Michel Coleman, Sarah Colles, June Crown, Gšran Dahlgren, Nick Day, Finn Diderichsen, Sir Richard Doll, Peter Flynn, Kamini Gadhok, Jane Gillie, John Gooderham, John Gray, Sian Griffiths, Sir John Grimley-Evans, David Hall, Chris Ham, Mike Hayes, Iona Heath, Kate Hunt, Raymond Illsley, Rachel Jenkins, Ken Judge, John Keast, Sebastian Kramer, Ramesh Kumar, Tim Lang, Gaynor Legall, David Lewis, David Lindsay, Robert Maxwell, Martin McKee, Pamela Meadows, Geof Mercer, Lynn Murray, Fraser Mustard, Julia Neuberger, Anne Parker, Marie Power, Andrew Prentice, George Radda, Hamid Rehman, Sian Robinson, Ian Roberts, Helen Roberts, Roberto Rona, Sir Michael Rutter, Alex Scott Samuel, Carol Sherriff, Anne Sofer, Tony Stanton, Carolyn Stephens, Sarah Stewart-Brown, Sir Kenneth Stowe, Peter Townsend, David Weaver,

and John Yates.

Written submissions were sought from a range of organisations and individuals, and many additional contributions were received. A list of contributors is attached at Annex D.

Officials from several different Government Departments not listed individually provided the Inquiry with information, assistance and advice.

The Inquiry was supported by the Department of Health who provided office accommodation and support staff.

The Medical Research Council provided the Scientific Secretary and support staff from its Environmental Epidemiology Unit at the University of Southampton.

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Annex D

Annex D - Papers, Submissions and Evidence to the Inquiry

Input Papers

The SAG received and discussed the following commissioned input papers, listed below.

1. Mothers/families/children

Catherine Law, MRC Environmental Epidemiology Unit, University of Southampton

2. Youth

Patrick West, MRC Medical Sociology Unit, Glasgow

3. Adults of Working Age

David Blane, Imperial College, London

4. Older People

Kay-Tee Khaw, University of Cambridge

5. Housing

Richard Best, Joseph Rowntree Foundation

6. Social Environment

Richard Wilkinson, University of Sussex

7. Poverty and Income

George Davey Smith, University of Bristol

8. National Health Service

(a) Michaela Benzeval, King's Fund and Anna Donald, University College, London

(b) Bobbie Jacobson, City and East London Health Authority

9. Nutrition

Michael Nelson, King's College, London

10. Education

Geoff Whitty, Institute of Education, London (lead author)

11. Areas

Sally Macintyre, MRC Medical Sociology Unit, Glasgow

12. Ethnicity

James Nazroo, Policy Studies Institute, London

13. Transport/Pollution/Material Environment

(a) Adrian Davies, Open University

(b) Barbara MacGibbon, MRC Institute for Environment and Health, Leicester

14. Gender

Sara Arber, University of Surrey

15. Mental Health

Sir David Goldberg, Institute of Psychiatry, London

16. Health-Related Behaviours

Jane Wardle, University College, London (lead author)

17. Oral Health

Aubrey Sheiham, University College, London (lead author)

Other Presentations

The SAG received a number of other presentations and briefings from experts in the field, apart from those provided by Departmental officials. They were:

Policies to Tackle Inequalities in Health, Margaret Whitehead, King's Fund

Socioeconomic Determinants and Ill Health, Andrew Dilnot, Institute for Fiscal Studies and Richard Wilkinson, University of Sussex

Area Inequalities, Daniel Dorling, University of Bristol, and John Hills, Centre for Analysis of Social Exclusion, London School of Economics

Life Cycle Trajectories, Diana Kuh, Chris Power, Yoav Ben-Shlomo and Mike Wadsworth, University College, London

Socioeconomic Discussion Paper, Hilary Graham, ESRC Health Variations Programme, Lancaster University, Michael Marmot, University College, London

The Role of Psychosocial Factors, The MacArthur Foundation Research Network on Socioeconomic Status and Health, Teresa Seeman, Sheldon Cohen, Shelley Taylor, Karen Mathews, and Michael Marmot

Psychosocial Stress in Childhood, Scott Montgomery, Royal Free Hospital School of Medicine, London

Intergenerational Effects on Inequalities in Health, David Barker, MRC Environmental Epidemiology Unit, University of Southampton

Stress in the Workplace, Peter Graham and Malcolm Darvill, Health Directorate, Health and Safety Executive and David Coggon, MRC Environmental Epidemiology Unit, University of Southampton

Benefits Briefing, John Hills, Centre for Analysis of Social Exclusion, London School of Economics, and Robert Walker, Centre for Social Policy Research, Loughborough University

Health Inequalities at a Local Level, Jacky Chambers, Birmingham Health Authority, Ruth Hussey, Director of Public Health, Liverpool Health Authority, Alan Chape, Deputy Chief Executive, Liverpool City Council, Bob Stewart, Newcastle Healthy Cities

Submissions

The following individuals submitted evidence to the Inquiry:

Jo Asvall, Christopher Bates, Peter Bradley, Eric Brunner, Mike Catchpole, Ben Cave, Elizabeth Dowler, Douglas Fleming, Peter Fonagy, John Godfrey, Meg Goodman, Mark Haggard, Andrew Haines, Irene Higginson, Anthony Jenner, Colwyn Jones, Brian Keeble, Azim Lakhani, Alyson Learmonth, Gerard Leavey, Michael Lennon, Donald Light, Caroline Lindsey, Paul Nicholson, John Radford, Bethan Reeves, Jane Robinson, Michael Rosen, Oliver Russell, John Shanks, Veena Soni, Raleigh, Marjorie Smith, Simon Strickland, Kathy Sylva, Jonathan Talbot, Mary Tilki, Patricia Walls, Graham Watt, Elizabeth Whitehead, Arthur Wynn, Margaret Wynn.

The following organisations submitted evidence to the Inquiry

Action on Smoking and Health (ASH), ASH Scotland, and ASH Wales

Afiya Trust
 Age Concern
 Alcohol Concern
 Association for Public Health
 Association of Charity Officers
 Association of Community Health Councils
 Association of Directors of Social Services
 Barnados
 British Medical Association
 Centre for Health Economics, University of York
 Chartered Institute of Environmental Health
 Child Accident Prevention Trust
 Child Health Advocacy Network and the National Children's Bureau
 Child Psychotherapy Trust
 Community Practitioners' and Health Visitors' Association
 Coventry City Council
 Derby City Council
 Economic and Social Research Council
 EQUAL
 Equal Opportunities Commission
 Faculty of Public Health Medicine
 Faculty of Occupational Medicine and Society of Occupational Medicine
 Family Planning Association
 Food and Drink Federation
 Friends of the Earth
 Health and Low Income Project
 Health Education Authority
 Institute of Child Health
 Inter-Authority Comparisons and Consultancy
 King's Fund
 Kirklees Health for All Women Health Policy Group
 Kirklees Metropolitan Authority
 Local Government Association
 London School of Hygiene and Tropical Medicine
 Macmillan Cancer Relief
 Medical Practitioners' Union
 Medical Research Council
 Men's Health Forum
 Men's Health Trust
 MIND
 National Energy Action
 National Food Alliance
 National Heart Forum
 National Institute for Ethnic Studies in Health and Social Policy
 National Institute for Social Work
 National Osteoporosis Society
 National Perinatal Epidemiology Unit
 NHS Confederation
 North West Public Health Association
 Nutrition Society
 Oxfam
 Peak District Rural Deprivation Forum
 Public Health Alliance
 Public Health Laboratory Service
 Royal of Pathologists
 Royal College of Ophthalmologists
 Royal College of Physicians
 Royal College of Psychiatrists

Royal College of Surgeons
Royal College of Midwives
Royal College of Nursing
Royal College of Paediatrics and Child Health
Royal College of Obstetricians and Gynaecologists
Royal College of General Practitioners
Sheffield City Council
Sheffield Health
Shelter
Socialist Health Association
Society of Health Promotion Specialists Poverty Caucus Group
Society for Social Medicine
Stroke Association
The Big Issue in the North and the Big Step Limited
Tobacco Control Alliance
UK Baby Friendly Initiative
Watson Wyatt Partners
West Kent Breastfeeding Alliance

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**North & West Belfast
Health & Social Services Trust**

Muckamore Abbey Hospital

**Consultation Document in relation to the closure of seven
Resettlement Wards and Reduction of Treatment Bed
Capacity at Muckamore Abbey Hospital.**



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**North & West Belfast
Health & Social Services Trust**

Muckamore Abbey Hospital

**Consultation Document in relation to the closure of seven
Resettlement Wards and Reduction of Treatment Bed
Capacity at Muckamore Abbey Hospital.**

June 2000

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SUMMARY

This document sets out the background to proposals to close seven wards and to reduce treatment capacity to 115 beds by 2002, in line with the objectives of the DHSS Regional Strategy (1997-2002).

It seeks views specifically on the mechanism proposed to close the seven wards and the process and order by which the wards should be closed, having regard to the best interests of the patients who will be affected.

The achievement of the target 115 beds at Muckamore will require the development of a range of community services to enable the resettlement of some 250 people currently resident in the hospital to new homes in the community.

The primary responsibility for resettlement will rest with local Trusts in the communities from which the patients originate. Each patients move will follow and be based upon the development of an individual person centred plan completed with the patient, their carer, the clinical team at the hospital and staff in the community Trust.

All views and submissions will be considered by the North & West Belfast Health & Social Services Trust in arriving at a decision on the processes to be used in closing wards and reducing treatment beds.

Responses to the document should be sent to:

The Chief Executive
North & West Belfast Health & Social Services Trust
Glendinning House
6 Murray Street
BELFAST
BT1 6DP

Further copies of the document can be obtained by writing to the Chief Executive as above or by phoning 028 90 327156 X 4214.

1.0 INTRODUCTION

- 1.1 In line with the stated commissioning intentions of the 4 Health & Personal Social Services Boards in Northern Ireland and with the Department of Health Social Services Policy (1995) and Regional Strategy (1997-2002) it is proposed to close seven resettlement wards and reduce the treatment capacity at Muckamore Abbey Hospital to 115 beds.

2.0 CONSULTATION PROPOSAL

- 2.1 There are currently (June 2000) some 360 patients in the hospital. To achieve the targets will require approximately 250 people to move to alternative provision in community settings. As far as possible and appropriate they should move to homes and be provided with the necessary services close to their families and originating home areas. The process will involve all four Commissioning Boards and all the community Trusts in Northern Ireland, who will work closely with all concerned to ensure that changes will be handled sensitively, by consent and with the patients' wishes as expressed by themselves or their advocate being carefully considered.
- 2.2 The North & West Belfast Health & Social Services Trust is committed to ensuring that all proposals, suggestions, comments and views on how best to achieve the closure of the seven wards and to reduce the treatment capacity within the timescale set down are considered. The ward closures will result in the cessation of respite care in the hospital by 2002.
- 2.3 Views are sought from service users, carers, voluntary groups, public representatives and all interested parties on how North & West Belfast Health & Social Services Trust can ensure that the changes are managed in such a way as to maximize opportunities and minimize disruption for patients who will be affected.

Proposals for childrens services do not form part of this consultation and will be dealt with separately. It is accepted that the children's assessment and treatment service should transfer from the main hospital site to a community setting.

3.0 POLICY CONTEXT

- 3.1 The Department of Health & Social Services published its document "Services for the Mentally Handicapped in Northern Ireland - Policy and Objectives" in 1978. The document reflected the worldwide movement towards "normalisation" and the provision of non-institutional care and support for people with a mental handicap. It acknowledged that there were at that time few alternatives to hospital care such as hostels or nursing homes, where care in the home was not an option.

- 3.2 The 1978 policy advocated the development of community services and the late 1970's and early 1980's saw significant increase in the provision of hostel and group home accommodation linked to improved day care services. The number of people with mental handicaps living in psychiatric and mental handicap hospitals reduced from 1699 in December 1978 to 1505 in December 1986.
- 3.3 The DHSS Regional Strategy for people with a mental handicap (1987-1992) saw a further acceleration in discharges from hospital, reducing the numbers living in hospital to 1047 by December 1992. This was in part supported by the funding arrangements for community care at that time and in part by bridging finance arrangements. Most of these patients were discharged to nursing (or residential) homes.
- 3.4 Patients continued to be admitted to hospitals for assessment and treatment, and in some cases where care arrangements in the community had broken down and no alternative was available.
- 3.5 During this period there was significant further development of alternative hostels, day care services and the improved availability of professional support such as social work, specialist community nursing services, and to a lesser extent psychology and the professions allied to medicine e.g. Physiotherapy, Speech & Language Therapy and Occupational Therapy.
- 3.6 In Northern Ireland, as in the rest of the world, the vast majority of people with a learning disability are supported outside hospital settings. Large hospitals have either closed or become much smaller with a clear focus on the provision of specialist assessment and treatment for people with a learning disability who have additional problems.
- 3.7 The basis of the current proposals is contained in the Regional Strategic Plan 1992-97 **"The Department wish to see the development of community care services in order to facilitate the discharge from hospital of people with a mental handicap and largely to eliminate the need for people to be admitted to hospital on account of a mental handicap"**
- 3.8 The target in the Regional Strategy 1992-97 was that the numbers of people in psychiatric and mental handicap hospitals should reduce from 1047 in December 1992 to less than 700 (by 1997). In 1995 the Department of Health & Social Services issued a Review of Policy for People with a Learning Disability, the review concluded that **"care in the community remains the preferred option for the long term care of all people with a Learning Disability"** **"resettlement of those in hospital should be pursued with the utmost vigour"** and that **"Purchasers and providers need to develop long term resettlement programmes designed to quicken the pace of discharge... Specialist hospitals of the future should be smaller, more accessible and less institutional than those of today, and should be reduced to the minimum level commensurate with the numbers of patients needing assessment and short-term treatment which cannot be provided elsewhere"**

4.0 THE RESPONSE OF COMMISSIONING BOARDS TO DHSS POLICY AND STRATEGY

4.1 Each Board has reviewed its service needs as follows:

- The Eastern Health & Social Services Board has indicated that it requires 70 specialist assessment and treatment beds by 2002 with a view to reducing this further to 45-50 beds by 2005.
- The Northern Health & Social Services Board has stated that they anticipate their requirement for specialist in-patient assessment and treatment would be in the region of 35 beds by 2002.
- The Western Health & Social Services Board will put in place provision for 43 assessment and short-term treatment beds and will in addition continue to require 5 beds at Muckamore Abbey Hospital.
- The Southern Health & Social Services Board will provide for 45 short-term assessment and treatment beds and will in addition continue to require 5 beds at Muckamore Abbey Hospital.

See Appendix 1 for details of consultation carried out previously by Health & Social Services Boards.

4.2 Each Board will work with its community Trusts and with North & West Belfast Health & Social Services Trust to coordinate the development of the new services which will be required to support patients who are to be resettled and to develop the community assessment and treatment services which will be needed to reduce the demand for admissions to hospital by 50%.

4.3 Person centred plans will be developed on an individual basis. However to facilitate planning Boards and Trusts have begun the process of identifying the likely services which will be required in the community and in the hospital during and after the period to 2002 and in estimating their cost. It is accepted that additional resources are required in order to achieve the objectives set out in the Regional Strategy.

5.0 THE RESPONSE BY NORTH & WEST BELFAST HEALTH & SOCIAL SERVICES TRUST

5.1 North & West Belfast Health & Social Services Trust assumed responsibility for managing Muckamore Abbey Hospital in 1994. Prior to that date it managed the hospital as a directly managed unit of the Eastern Health & Social Services Board from 1990.

The Trust has two aims in managing the hospital:

- ♦ To maintain the services and environment at Muckamore Abbey Hospital to a safe and acceptable standards for the patients receiving treatment and care at the hospital. To this end almost £7m has been invested since 1993.

- ◆ To facilitate by consensus the resettlement of patients to appropriate packages of care in the community. To this end over 250 people have successfully moved since 1990.

- 5.2 In collaboration with Commissioners the Trust has reshaped services provided at the hospital in line with Government Policy, the Regional Strategy and Commissioners intentions.

In 1995 the Trust completed a "Strategic Context Document", the first phase of its bid for capital to develop core treatment services for the future, providing 150 beds. This would have made available the full range of treatment services for the EHSSB and NHSSB with a smaller number of highly specialist beds for the WHSSB and SHSSB. Since that time Commissioners have revised the projected aggregate treatment requirement to 115 beds (See Appendix 1).

- 5.3 An active programme to resettle patients from Muckamore Abbey Hospital had begun in 1987. The process was managed by a hospital based Resettlement Team working with colleagues in receiving community units of management. Funding came from the Social Security budget initially. Later in the process bridging mechanisms were introduced together with funding arrangements linked to Trusts care management processes.

Approximately 250 patients were successfully resettled and a reduction in overcrowding (wards that had patient numbers of 30-40 people) was achieved together with the closure of eight wards.

- In 1992 the Trust published Resettlement and Relocation Principles which are the quality standards for resettlement from the hospital. See appendix 2.

6.0 THE RESETTLEMENT AND WARD CLOSURE PROCESSES 1987-98

Patients were resettled from wards across the hospital. As an increasing number of beds became vacant at the hospital the financial "bridging" arrangements necessitated the closure of a ward. A ward with a high proportion of empty beds would be selected for closure and the remaining patients relocated to other wards. By 1995, many patients had been required to move several times, contrary to good practice. The patient mix in some areas in the hospital was also becoming increasingly problematic. It became clear that a more focused and systematic approach to ward closures and resettlement was required if disruption for patients and staff were to be minimised.

7.0 THE PATIENT CENSUS

- 7.1 In 1996 following the agreement of a "service specification" with the Directors of Public Health of the EHSSB and NHSSB a census of the hospital population was carried out by the clinical teams. This placed patients into one of three categories based on their individual clinical needs at that time:

◆ **Hospital Treatment**

People with an absolute requirement for specialist hospital care

◆ **Community Treatment**

People with complex needs and a requirement for high levels of specialised support and treatment but who did not need specialist hospital care and who could derive benefit in terms of quality of life in a community setting.

◆ **Continuing Care**

People with less complex needs who did not require hospital care or high levels of specialised support and treatment but required appropriate care and support services which could be provided in a community setting.

7.2 The information gleaned from the census enabled staff to develop a comprehensive profile of patients in each category and to identify their service requirements and accommodation needs in the short and long term.

7.3 Following the completion of the census the Hospital Management Team undertook an additional exercise to establish if it would be feasible to physically separate the care of those patients identified as requiring hospital treatment from those who could be resettled following the development of an appropriate package of care.

8.0 REPROFILING

8.1 As a result of the census and the modelling work undertaken it was agreed that patients should be moved within the hospital in line with their assessed needs for treatment and care. Patients and families were fully informed about the relocation process.

8.2 The advantages of reprofiling for patients were firstly that by placing patients suitable for resettlement together, wards which would close following further resettlement were clearly identified and could be selected for closure. The requirement for relocation could be reduced if not eliminated. It should also assist in ensuring that as many patients as possible could be resettled at the same time, which would maintain relationships, take account of personal friendships and compatibility, as well as the detailed assessments of individual needs for care and services.

8.3 In July 1998 North & West Belfast H&SS Trust, the EHSSB and NHSSB held a public meeting to outline the proposals to reprofile. Families of every patient at the hospital received a letter outlining the purpose of the meeting and inviting them to attend. This meeting was attended by over 300 people. After the meeting approximately 150 families were seen at the hospital, at home, spoken to by telephone or had enquiries responded to in writing. This follow-up concentrated mostly on the impact for individual patients and their families.

8.4 A similar meeting was held for staff working in the hospital and individual queries responded to in a similar fashion.

- 8.5 Reprofitting was achieved in November 1998. It signalled an end to people being resettled from a range of wards and has allowed for the development of a phased selective programme of closing identified wards.

This approach was seen as essential if the Trust is to:

- Minimise disruption for patients, carers and staff
- Reduce the uncertainty for patients, staff and carers arising from a piecemeal resettlement programme
- Ensure available resources are used to the maximum benefit of the patients
- Facilitate better planning for the enhanced community support and treatment services required
- Bring stability to a complex situation
- Facilitate the efficient day to day running of the hospital
- Achieve the Regional Strategic Objectives

9.0 ACHIEVEMENT OF THE TARGET BED REQUIREMENT

- 9.1 A reduction in treatment capacity is required as alternatives are developed in the community (approximately 80 beds removed by 2002). North & West Belfast Health & Social Services Trust will prepare a business case to outline how treatment services will be provided after 2002. The proposed specification for the service is at appendix 3.

- 9.2 The closure of the seven wards currently caring for patients not identified in the census as requiring hospital care is proposed. These seven wards are:

- Cushendall
- Ennis
- Finglass
- Foybeg
- Moyola
- Oldstone
- Rathmullan

The clinical profile of patients in these wards indicate that they could be cared for in the community if appropriate packages of care were made available.

- 9.3 **The Trust wishes to consult specifically on the criteria to be used in selecting from within these seven wards the order in which they will close. The Trust would propose to rank order the wards using criteria related to quality of life of the people living in these wards and the potential for betterment of that generally e.g. overcrowding, physical environment, etc. The Trust would welcome suggestions for other criteria and mechanisms which might be used in order to ensure that the best interests of the people living in the wards are met so far as is possible.**

10.0 CURRENT BED STATE

Having completed the reprofiling the relocation of patients took place during November 1998 and resulted in the configuration outlined in the table below.

The current service agreements for the hospital requires 416 beds including 7 respite beds and 15 childrens treatment beds. At May 2000 bed occupancy was as follows:-

Name of Ward	Bed Complement	Number in ** Residence	
Core Treatment Wards			
Erne	24	19	Proposed to reduce to 115 beds
Fairview	22	21	
Fintona North	19	19	
Fintona South	17	18	
Greenan	34	29	
Mallow	20	18	
Movilla A	18	18	
Movilla B	17	22	
Moylena	20	20	
Sub Total	191	184	
RESETTLEMENT WARDS			
Cushendall	28	25	Proposed to relocate to the community
Ennis	22	21	
Finglass	36	32	
Foybeg	26	21	
Moyola	36	29	
Oldstone Rehab Unit	27	17	
Rathmullan	28	26	
Sub Total	203	171	
GRAND TOTAL	394	355	

Plus 7 Respite Beds

Plus 15 childrens treatment beds

TOTAL 416

**** Includes 12 reserved beds for patients on leave, leave on trial and trial resettlement**

11.0 RESETTLEMENT PROCESS

- 11.1 Community Trusts will work with staff at the hospital to assess the needs of those patients for whom they will be responsible. They will consult with next of kin about reprieve in the community and will be expected to liaise with service users and carers in developing the necessary service plans.
- 11.2 The primary responsibility to develop an appropriate package of care rests with the community Trusts but the clinical team at the hospital will be involved in all stages of the process. Each community Trust will provide a named officer to coordinate the resettlement process for its patients (See Appendix 4).
- 11.3 The process for individual resettlement will follow existing protocols agreed between North & West Belfast Health & Social Services Trust, Community Trusts and Commissioning Boards.
- 11.4 Resettlement will not be considered to have been completed until all involved are agreed that the individual has settled into their new home.
- 11.5 Resettlement will be underpinned by the principles contained in the North & West Belfast document (appendix 2) and for EHSSB Trusts the agreed standards indicated at (appendix 5).

12.0 CHOICE AND ADVOCACY

- 12.1 Patients eligible for resettlement are entitled to advice and support from staff caring for them, those who have responsibility for resettlement, organisations with service responsibilities and others. In addition some may require the services of an independent advocate to facilitate them in making an informed choice, to express their needs and choices or to make representations as to their best interests.

13.0 PROCEDURES WHERE THERE IS A PERSISTENT DISAGREEMENT

- 13.1 Each Board will consider the possibility of making available an independent mediation service when there is persistent disagreement between the parties on resettlement proposals.

14.0 BREAKDOWN IN COMMUNITY PLACEMENT

Following successful resettlement (see 11.4 above) in the event of a breakdown of the placement the owning community Trust will be responsible for resolving the problem, whether through improvement to the existing support package or by devising a more appropriate option.

Readmission to the hospital will be considered, as for all other people with a learning disability living in the community where there is a clinical indication of a requirement for in-patient assessment or treatment. Such admission will not be to a designated "resettlement" ward.

15.0 CONSULTATION PROCESS

15.1 North and West Belfast H&SS Trust is committed to consulting service users, carers and other stakeholders on how the major changes required by Departmental Policy can be achieved in the best interests of people with a learning disability and their families who will be directly affected. This consultation document will be widely circulated (see appendix 6) and its availability will be published in the local press.

15.2 Community Trusts in consultation with Commissioning Boards may communicate with service users and families from different localities and this may include the following:

- Meetings with existing service user and carer groups (with special arrangements to facilitate users with communication difficulties)
- Localised public meetings
- Focus Groups
- Meetings with local public representatives and politicians
- Meetings with local voluntary and private sector providers
- Meetings with trade unions and professional organisations

arrangements to communicate in respect of residents of North & West Belfast Health & Social Services Trust are included at appendix 7

15.3 The timetable for the consultation process is:

- | | |
|---|---|
| • Issue of Consultation Document | 1 st July 2000 |
| • Locality consultations | 1 st July – 30 th September |
| • Response deadline for document | 30 th September 2000 |
| • Collation of responses, review of consultation and preparation of Implementation plan | 30 th September – 31 st October |
| • Feedback to respondents and stakeholders | 1 st - 14 th November 2000 |
| • Implementation from | 14 th November 2000 |

16.0 CONCLUSION

This document has outlined the background to the proposal to close seven resettlement wards and to reduce treatment capacity to 115 beds by 2002.

We want to hear the views, opinions and advice of the widest possible range of current and potential service users of Muckamore Abbey Hospital on how we should select the closure of the seven resettlement wards and the process and order by which the ward closures should take place.

North & West Belfast Health & Social Services Trust is committed to hearing and taking on board the views of all who participate in this consultation and to providing feedback on the outcome of the process and how the consultation has been reflected in decisions taken and in the implementation plan.

To respond to this document please write to:-

The Chief Executive
North & West Belfast H&SS Trust
Glendinning House
6 Murray Street
BELFAST
BT1 6DP

Further copies of the document can be obtained by writing to the Chief Executive as above or by phoning 028 90 327156 X 4214.

OR

e-mail - crowhurst@nwb.n-i.nhs.uk

Copies of the document can also be obtained in other formats upon request e.g. braille, large print, tape etc.

Responses are requested by 30th September 2000.

APPENDIX 1

**RESPONSE TO REGIONAL STRATEGY AND INFORMATION ON CONSULTATION BY
EASTERN HEALTH & SOCIAL SERVICES BOARD**

At an Eastern Health & Social Services Board meeting held on 14 March 1995, an option appraisal report on the future provision of specialist treatment and care services for people with a learning disability was considered. It was decided that before the Board reached a final decision it should consult widely on the document. To facilitate this, it was agreed that a number of meetings would be held in local areas across the Board. Seventeen meetings entitled "Your Services, Your Say" were held during June 1995. The Eastern Health & Social Services Council assisted with this process and each meeting was chaired by their chief officer. One of the meetings was held in Muckamore Abbey Hospital. In addition to the open meetings people were also invited to respond in writing using a free post return.

In 1996 the DHSS issued their Regional Strategy for Health & Social Well-being, outlining its strategic intentions: **"Each Board and Trust should develop a comprehensive range of services for people with a learning disability and their carers. The overall objective is that by 2002 long term institutional care should no longer be provided in traditional specialist hospital environments. As an integral feature of the comprehensive services, specialist provision should be linked to community-based care and treatment."**

Each Board was informed and influenced by this review and responded to the remits outlined above as follows.

In September 1995 the Eastern Health & Social Services Board considered a paper concerning the future of services for people with learning disabilities. A further consultation took place in June 1996 leading to the production of "A Model of Community-based Services for People with Learning Disabilities" which outlined the vision of where the Board would like to be in 2002 and beyond, and outlined the principles which should be adopted to underpin service delivery. The document included the commissioning framework and a proposed implementation plan and indicated a requirement by 2002 of 70 treatment beds. On 11 August 1998 the Eastern Health & Social Services Board at their public Board meeting approved the service and financial strategy to underpin this model and outlined their proposed financial plan.

**RESPONSE TO REGIONAL STRATEGY AND INFORMATION ON CONSULTATION
BY NORTHERN HEALTH & SOCIAL SERVICES BOARD**

NHSSB patients use the second largest number of beds at Muckamore Abbey Hospital. During the 1990's the NHSSB had achieved the targets for resettlement laid out in the Regional Strategy. In response to the Regional Strategy 1997-2002. The Northern Health and Social Services Board outlined its commissioning intentions in "Promoting Ability - a Strategy for the Development of Care for People with a Learning Disability", which was formally endorsed by the Board in April 1998. The strategy is explicitly based on the principles outlined in the Regional Review of Policy in 1995 and the objectives contained in subsequent Regional Strategies. The approach outlined in the Board's

strategy was developed on the basis of a consultative process lasting six months which involved a wide range of statutory, voluntary and independent perspectives, carers' groups and professional representatives. The Board also engaged the services of United Response (NI) to undertake a specially tailored parallel consultation process involving service users in order to ensure that their perspective would also be taken into account. The final document was heavily influenced by the verbal and written submissions which emanated from this process.

In relation to hospital care for adults the Board stated that it would: "aim to reduce its aggregate requirement in specialist hospitals from the current figure of 140 beds by an average of 20 per annum until 2002."

It is anticipated that its requirement for specialist inpatient assessment and treatment would be in the region of 35 beds within the timescale of the strategy. The Board acknowledged the importance of working collaboratively with all relevant interests in the development of appropriate community services if this aim was to be achieved.

WESTERN HEALTH AND SOCIAL SERVICES BOARD - PURCHASING INTENTIONS AND CONSULTATION

The Western Health and Social Services Board produced a Strategy for Learning Disability Services in the West and presented this to the Western Health and Social Services Board Administration Services Committee on 26th August 1996. The service template which the Board indicated they wished to put in place was an assessment and short-term treatment provision of 48 beds. The Department subsequently approved an outline business case from Foyle Trust for 43 assessment and treatment beds. Provision will also be made for 5 rehabilitation bed places. The Western Health & Social Services Board will continue to purchase 5 beds at Muckamore Abbey Hospital.

SOUTHERN HEALTH AND SOCIAL SERVICES BOARD - PURCHASING INTENTIONS AND CONSULTATION

The Southern Health and Social Services Board Review of Learning Disability Services report was presented to their Board on 8th February 2000 and was approved for formal consultation. It has now been circulated widely with the closure date for comments 28th April 2000.

Each stage of this review process was undertaken through multidisciplinary Project Teams which included senior personnel from the Board's Programme Commissioning Group, Trusts, Consultants representing Psychiatry and Psychology and a representative from Mencap. Regular discussions also took place with a Reference Group which included Executive Directors from Trusts, a Non Executive Director from the Southern Board, a GP representative and a representative from the Health & Social Services Council. In addition, the Project Team held three consultative seminars/workshops involving a range of voluntary groups, carers and service users. To ensure further opportunity for involvement and discussion, each Trust established its own Reference Group.

The SHSSB have indicated they intend to continue to manage withdrawing long-stay hospital services through developing community-based services and will continue to provide specialist assessment and treatment in patient services for those people with the most complicated needs, linked to community-based care (Strategic and Financial Framework 1999-00/2001-02).

The preferred hospital model for the Southern Board is a hospital with 45 short-term assessment and treatment beds with the continued purchase of 5 treatment beds at Muckamore Abbey Hospital. However, further evidence-based research may impact on any final decision on bed numbers.

APPENDIX 2

NORTH & WEST BELFAST HEALTH & SOCIAL SERVICES TRUST

RESETTLEMENT PRINCIPLES

Resettlement is the process whereby discharges of long stay patients into a community setting are effected in a planned and coordinated manner, to meet individual needs.

- Persons not requiring hospital care should be enabled to reside in a suitable community setting.
- All aspects of resettlement should be based on a multi-disciplinary assessment of patients' needs.
- Every person determined as suitable for resettlement has a right to be resettled regardless of level of disability.
- The person should have involvement at all stages in plans being made and his/her choice enabled and respected.
- Relationships important to the person, whether with family members, staff or other hospital patients, should be respected throughout the Resettlement process.
- The alternative setting should meet the person's need for care (including specialist needs) providing opportunities for personal and spiritual development, community involvement, and participation, to the extent that his/her experience is dignified.
- Resettlement placement considers all aspects of the person's life, including daytime activities, occupation and leisure.
- In decisions about resettlement, the views of family members and other significant contacts will be sought and considered, in conjunction with those of the individual concerned, and the advice of hospital personnel caring for him/her.
- Standards of care will be set, evaluated, and monitored to ensure that any move into the community represents an improvement in the quality of life for the individual.
- Management will take account of the impact of hospital resettlement on the receiving community.

APPENDIX 3

PROPOSALS FOR TREATMENT SERVICES AFTER 2002

The reduction in bed capacity to 115 by 2002 will require a redefinition of the role of in-patient hospital services. It will also require significant enhancement of the capacity to treat people in the community to reduce the requirement for admission to hospital.

In October 1999 a multi-disciplinary, multi agency task group, reporting to the Regional Project Steering Group, was established, chaired by Dr David Stewart, Director of Public Health, EHSSB, to bring forward a specification for Core Hospital Services.

Within the specification the group proposed definitions of the categories of patients to be admitted to the Core Hospital are as follows:-

ASSESSMENT SERVICE

- (a) For assessment of people with Mental Disorder (Psychiatric Illness, Severe Challenging Behaviour).

Including an intensive care environment where the patients present a serious risk to themselves or others.

- (b) For assessment of people with Mental Disorder (Psychiatric Illness, Severe Challenging Behaviour) who, because of co-existing disabilities, would be inappropriately assessed with their peers due to their vulnerability. These people would generally be more profoundly handicapped and/or physically disabled.

TREATMENT SERVICES

- For people in whom a mental illness has been diagnosed.
- And who require a period of ongoing treatment and review with the objective of:-
 - (a) stabilizing their condition and
 - (b) developing a sufficiently robust treatment plan to be delivered in a secondary or other setting.

This will include people who require to be detained under Mental Health Legislation

- For people with Severe Challenging Behaviour for whom a treatment plan has been devised but who remain unpredictably unstable and who require ongoing assessment and refining of their treatment plan so that a treatment plan can be devised which is sufficiently robust to be delivered in a secondary or other setting.

- Providing a similar treatment service for those people who in addition to their presenting problems would be inappropriately placed alongside the above patients due to their vulnerability. These people would generally be more profoundly handicapped/physically disabled.

FORENSIC ASSESSMENT

Providing an assessment service for offender patients who will require nursing and supervision in a secure environment.

FORENSIC TREATMENT

For people who graduate from forensic admissions and who continue potentially to pose a significant risk either to themselves or to others such that they should/cannot be discharged. This will include those subject to the provision of Parts II and III of the Mental Health Order, but not be confined to them.

It was noted in the specification document that many patients in addition to their mental disorder or need for forensic services also present with complex epilepsy. It was also noted that many patients present with more than one of the specified conditions.

CATEGORIES OF ADMISSION

Planned Admission would be by agreement between GP, Community Learning Disability Team, Community Consultant Psychiatrist, Admitting Consultant Psychiatrist.

Emergency Admission would be by agreement between GP, Community Psychiatrist and Receiving Consultant.

The Group identified two other specific services which are required. A service for adolescents and a rehabilitation service. Discussions are ongoing and decisions in relation to their location are required.

APPENDIX 4

NOMINATED OFFICERS FROM HEALTH & SOCIAL SERVICES TRUSTS

Mr M Sweeney Ass. Director of Disability Services	Armagh & Dungannon Health & Social Services Trust St Lukes Hospital Loughall Road ARMAGH BT61 7NQ
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Mr I Sutherland Deputy Director of Disability Services	Craigavon & Banbridge Community Health & Social Services Trust Banbridge Health & Social Services Centre Scarva Street BANBRIDGE BT32 3AD
Mr F McKeating Resettlement Officer (Disability)	Down Lisburn Health & Social Services Trust Disability Resource Centre Downshire Hospital Ardglass Road DOWNPATRICK BT30 6RA Tel: 028 44616915
Mrs M Keenan OBE Programme Manager Learning Disability Services	Foyle Health & Social Services Trust Riverview Park Abercorn Road LONDONDERRY BT48 6FB Tel: 028 38831983
Mrs E Taggart Disability Services Manager	Homefirst Health & Social Services Trust Spruce House Braid Valley Site Cushendall Road BALLYMENA BT43 6HL Tel: 028 25635464

Mrs N Hetherington
Director of Hospital Services

GENERAL ENQUIRIES

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RESETTLEMENT ENQUIRIES

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APPENDIX 5

RECOMMENDED RESETTLEMENT PRINCIPLES AND STANDARDS - EASTERN HEALTH & SOCIAL SERVICE BOARD TRUSTS

1. Persons not requiring permanent residential care should be enabled to live in a suitable community setting.
2. Resettlement should represent an improvement in the person's quality of life.
3. All aspects of resettlement should be based on a multidisciplinary formal assessment of the person's needs.
4. Decisions about resettlement should take account of the long term aims for the person's care.
5. Every person has, via a formal review process, the right to be considered for resettlement regardless of the level of their disability.
6. The person should be involved in all decisions being made, unless demonstrable reasons exist why this is not possible. Any infringement of this right should be explained to the person, recorded in his/her file and the reasons regularly reviewed.
7. The person should, of right, have access to independent, objective advice about the benefits and disadvantages of any plans proposed.
8. Relationships important to this person, whether with family members, staff or peers, should be respected.
9. The alternative setting should meet the person's needs for care, with opportunities (as appropriate) for training for independence, personal development and community involvement to the extent that his/her life is enriched.
10. Resettlement considers all aspects of a person's life, including day time activities, occupational opportunities and leisure interests.
11. Information about proposals for resettlement should be shared with the person's relatives at the earliest opportunity and their views will be sought and considered in conjunction with the individual concerned together with the views of staff involved in his/her care.
12. Management should ensure that standards of care are set, monitored, evaluated, and publicised at regular intervals.
13. Management will be sensitive to the impact of resettlement on the receiving community.
14. The person being resettled and their relatives should be made aware verbally and in writing of a clear complaints procedure, which includes recourse to persons in authority and with the provider of care support.

15. All rights associated with citizenship are automatically retained by persons in residential and nursing care and homes must safeguard those rights and help people to exercise them.
16. All persons in residential care should receive a "Care Contract".
17. All patients should have access to an advocacy service.

APPENDIX 6

CIRCULATION LIST

Antrim Borough Council
 Armagh & Dungannon Health & Social Services Trust
 British Association of Occupational Therapists
 British Dietetic Association
 British Medical Association
 Carers National Association
 Causeway Health & Social Services Trust
 Challenge
 Chartered Society of Physiotherapists
 Craigavon & Banbridge Health & Social Services Trust
 Department of Health & Social Services & Public Safety
 Directors of North & West Belfast H&SS Trust
 Disability Action
 Down Lisburn Health & Social Services Trust
 Downs Syndrome Association
 Eastern Health & Social Services Board
 Eastern Health & Social Services Council
 Eastern Health & Social Services Registration & Inspection Unit
 Eastern Multifund
 Equality Commission
 Foyle Health & Social Services Trust
 Heads of Department at Muckamore Abbey Hospital
 Homefirst Health & Social Services Trust
 Human Rights Association Commission
 Institute for Counselling & Personal Development
 Law Centre (N.I.)
 Local Medical Committees - Eastern Health & Social Services Board
 Local Medical Committees - Northern Health & Social Services Board
 Local Medical Committees - Western Health & Social Services Board
 Local Medical Committees - Southern Health & Social Services Board
 Mencap
 Mental Health Commission
 Members of Local Assembly for N.I.
 Members of Parliament for N.I.
 Newry & Mourne Health & Social Services Trust
 Next of Kin - Parents at Muckamore Abbey Hospital
 NIPSA
 Northern Health & Social Services Board

Northern Health & Social Services Council
Northern Health & Social Services Registration & Inspection Unit
Northern Ireland Members of European Parliament
N.O.W.
PAPA
Programme Managers of North & West Belfast H&SS Trust
Relevant Private Sector Nursing and Residential Homes
Royal College of Nursing
Sense (N.I.)
Society of Chiropodists
Society of Parents and Friends of Muckamore Abbey Hospital
South & East Belfast Health & Social Services Trust
Southern Health & Social Services Board
Southern Health & Social Services Council
Southern Health & Social Services Registration & Inspection Unit
Speech & Language Therapists
Sperrin Lakeland Health & Social Services Trust
Ulster Community Health & Social Services Trust
Unison
United Response
University of Ulster
Western Health & Social Services Board
Western Health & Social Services Council
Western Health & Social Services Registration & Inspection Unit

APPENDIX 7**ARRANGEMENTS TO COMMUNICATE IN RESPECT OF RESIDENTS
OF N&WBHSST**

North & West Belfast Health & Social Services Trust has responsibility for 72 people currently receiving treatment and care at Muckamore Abbey Hospital. It is the intention of the Trust that all of these patients and their families will be visited or spoken to during the consultation period and the effect on them of the proposal to close seven wards and reduce treatment beds explained to them.

We will provide detailed information to patients and their families on how they will be involved in the development of a person centred plan. North & West Belfast Health & Social Services Trust currently supports 80 people in the community who are unable or choose not to live with their family. These people live in a range of services from specialist residential and nursing homes, to hostels or group homes with the majority in supported housing. Many have been successfully resettled from hospital.

The Trust has well established mechanisms to consult with service users, their carers and the community. All of these will be utilised during the consultation process.

The Trust has well established links with local politicians, MLAs, other public representatives, trade unions and professional bodies which will be utilised during the consultation process.

Professional staff within the learning disability programme of the Trust will make themselves available to attend meetings with service users and parents groups if required. The Trust will make special arrangements for service users who have special needs e.g. staff trained in the use of Makaton or other communication techniques will be available. Special transport requirements will as far as possible be facilitated.

Arrangements will be made to ensure service users and carers have opportunities to see the range of services currently available in the community so that they are better able to make informed choices.

Staff within the learning disability programme have experience in working with advocates and will cooperate fully with advocates chosen by service users or carers to represent their views.

The Trust will also consult with staff in the voluntary and independent sector to ensure effective communication with all parties with a relevant interest in the proposed service changes.

NORTH & WEST BELFAST HEALTH & SOCIAL SERVICES TRUST

MUCKAMORE ABBEY HOSPITAL

M E M O R A N D U M

FROM: Norma Hetherington TO: All Wards/Departments
Director of Hospital Services

REF: memoh16/nh/p163 REF: G338-C

18th July 2000

**RE: CONSULTATION – CLOSURE OF SEVEN RESETTLEMENT WARDS
AND REDUCTION OF TREATMENT BED CAPACITY**

Your ward or department should have received a copy of the above document. In the accompanying letter we indicated an intention to meet with staff over the consultation period to explain the content of the document and to answer questions.

It is the intention of the members of the Hospital Management Team to organise a number of meetings targeted on groups of wards or departments which may raise similar issues. It is hoped that everyone who wishes to attend will be able to attend at least one meeting. While meetings will be targeted at groups of wards or departments they are open to all staff.

A preliminary list of meetings has been arranged to commence the process and others will be arranged during September.

The list is as follows:-

Friday, 21 st July at 2.30 p.m.	Rathmullan Foybeg Finglass
Friday, 21 st July at 3.45 p.m.	Cushendall Ennis Moyola Oldstone
Tuesday, 25 th July at 7.00 p.m. AND Wednesday, 30 th August at 7.00 p.m.	Security Staff Night Duty Staff

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Tuesday, 25 th July at 2.00 p.m.	Estates
AND	Laundry
Friday, 4 th August at 2.00 p.m.	Transport
	Stores
	Non ward based Catering & Domestic staff
Tuesday, 8 th August at 2.00 p.m.	DayCare
AND	Mallow
Tuesday, 8 th August at 3.00 p.m.	Conicar
	Fintona North
	Movilla A
	Fairview
Tuesday, 8 th August at 4.00 p.m.	Erne
	Fintona South
	Movilla B
	Moylena
	Greenan
Thursday, 31 st August at 3.00 p.m.	Administration
	Medical Staff
	Senior Nurse Managers
	Professions Allied to Medicine
	All other Professional Staff

It is assumed that ward based catering and domestic staff will attend with their ward. It is intended that at least two meetings will be arranged for all wards and large departments to facilitate maximum attendance with peers. If only one is listed in the above list another will be organised during September.

All meetings will be in the Seminar Room. Should you require clarification on the proposals please contact me or any member of the Hospital Management Team.

Norah Hart

for NORMA HETHERINGTON
Director of Hospital Services

c.c. Mr R G Black, Chief Executive
Mr E Molloy, Director of HR/CA
Mr P Ryan, Director of Planning
Dr C Marriott, Director of Medical Services (Hosp)
Mr O Donnelly, Business Manager
Mrs A Campbell, Acting Nursing Services Manager



RGB/NH

28th June 2000

To: MAH Staff

Dear Colleague

RE: CHANGE PROCESS AT MUCKAMORE ABBEY HOSPITAL

I enclose a copy of the above document which is being issued for consultation with responses requested by 30th September 2000. Further copies are available from this office and from the office of the Director of Hospital Services at Muckamore Abbey Hospital.

Staff have been aware for some time of the impact of the Government's Policy of Community Care for People with a Learning Disability on services at the hospital. North & West Belfast H&SS Trust are determined that the change process will be managed in the best interests of patients and staff.

I know that Mrs Hetherington with other senior staff of the Trust have had meetings with a number of representative groups in the recent past to share information and ideas about how the change may proceed. This process will continue during the consultation period and Mrs Hetherington and the other members of the Hospital Management Team will be arranging to speak to staff groups during the consultation period. Members of the Hospital Management Team are available to speak to individuals and groups on request.

I would urge you and colleagues to read the document and respond before 30th September 2000.

Yours sincerely

R G Black
Chief Executive

enc.
Caring in Partnership

Trust Headquarters • Glendinning House • 6 Murray Street • Belfast BT1 6DP
Tel: (028) 9032 7156 • Fax: (028) 9082 1285

RG Black: Chief Executive



Awarded For Excellence
Residential & Supported
Living Services



Awarded For Excellence
Muckamore Abbey Hospital



Awarded For Excellence
Assisted Living Scheme



Moving on from Muckamore Abbey Hospital

The outcomes and lessons as perceived by people with learning disabilities; their key-workers, care managers and relatives.



Roy McConkey, Jayne McConaghie, Felice Mezza and Jennifer Wilson

School of Health Sciences, University of Ulster

December 2000



This book is to be returned on or before
the last date stamped below.

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Acknowledgements

The work of the project was greatly assisted by the advice and guidance provided by the steering group¹ and the time and effort of the managers and staff of residential services in EHSSB area; the care-managers and social workers but above all by the people with learning disabilities and their relatives who so willingly allowed us to enquire into their lives. Our thanks to Sonee Bhurgri and Joanne McCullough for assistance with data analysis. This research was funded by the University of Ulster.

© University of Ulster and E.H.S.S.B., Belfast, 2000

¹ Dr Johnston Calvert chaired the Steering Group and its members were Dr Maria McGinnity (Muckamore Abbey Hospital), Dr Michael Donnelly (QUB) Theresa Nixon (EHSSB) and Dr Damien Hughes (Muckamore Abbey Hospital).

Executive Summary

This study followed up 68 people from the Eastern Health and Social Services Board area who had been resettled from Muckamore Abbey Hospital in the period 1996 to 2000. The aims were:

- ☐ To document the settings to which people moved and the characteristics of the residents;
- ☐ To detail the changes, if any, that have taken place in relation to the resident's placement;
- ☐ To obtain the views of residents, service providers, care managers and family carers to the move and to the present placement,
- ☐ To assess the resident's needs and implications for the development of future services for them and others moving from the Hospital.

Interviews were conducted with the majority of people who had moved and information was also obtained through questionnaires and telephone interviews from their present key workers, care-managers and relatives.

The main findings were:

The resettlement population

- ☐ The most recent resettlements have tended to focus more on females than males; on people who have been in hospital for shorter times and who were under 60 years of age. Proportionately fewer people who were the responsibility of S&E Belfast Trust have been resettled.
- ☐ The median length of time people had been in Hospital was eight years (range 1 to 40 years).
- ☐ Their median age on discharge was 37 years (range 19 to 62 years).
- ☐ Most resettlements took place in 1997 and 1998 with only one occurring in 2000.

Where people moved to

- ☐ Nearly three-quarters of people moved from the Hospital to residential homes and a further 15% to nursing homes. Only eight persons moved to ordinary housing.
- ☐ Nearly all residents had their own bedroom in a facility solely for people with learning disabilities.
- ☐ Three-fifths of the places were in Co. Down.
- ☐ Nine out of ten continue to live in the place to which they moved.
- ☐ Nearly all had ongoing contact with psychiatrists and social workers and some with community nurses. Four of the 68 were presently back in hospital with a further ten people having had one or more treatment admission. The latter tended to be people with mental health and behaviour problems living in community settings.

Present characteristics of the people who had been resettled

- ☐ One third of the resettled population were rated as low dependency²; another third as high dependency³ and a third had a mixed profile. As a group they appear to be less able than previous resettlement populations studied in N. Ireland.
- ☐ Residential homes served the widest range of clients in terms of dependency whereas nursing homes had more dependent people and community houses less dependent people.
- ☐ Epilepsy was the most common additional disability with nearly one third of persons affected by it. A few people were rated as immobile; severely visually impaired and hearing impaired.
- ☐ Around half the people were rated by staff as having challenging behaviours that were rated moderately serious or severe. These were mainly aggression to others and to self.
- ☐ Two in five people (40%) were reported to have a mental health problem of which depression was the most common.
- ☐ For 21 people, staff considered that their behaviour problem had improved since the move.
- ☐ All were registered with local GPs and most had a Healthcheck in the past 12 months. The most commonly occurring health problems were constipation and persistent skin trouble.
- ☐ The majority of residents were reported to have seen their GP, a dentist, social worker, psychiatrist and optician in the past 12 months.
- ☐ Over three-quarters took regular medications with a mean of four drugs prescribed for each person.

The views of people who had been resettled

- ☐ People mentioned more things that they liked about their present residence than they named about the Hospital and had fewer dislikes than for the Hospital.
- ☐ Nearly all were happy to have moved. Only one person said they had not wanted to move from the hospital and another wished they could move back there.
- ☐ Nearly all the people had some form of day activity programme and most reported a variety of evening and weekend activities both in and outside of the residence.
- ☐ Half the people interviewed reported having friends with one quarter having friends from outside the residence.
- ☐ Nearly all reported as being in good health.

The views of relatives

- ☐ Although a majority of families welcomed the move from the Hospital; a significant minority (26%) had been unhappy at the prospect of the move.

² Typically they are able to communicate through speech and to understand instructions; able to look after their personal care needs and with basic reading, writing and numerical skills.

³ Typically poor communication skills; dependent on others for their self-care and unable to read and write with little or no understanding of numbers.

- ☐ After the move all families felt the residence was at least equivalent to the Hospital with over four out of five families rating it as much better than the Hospital.
- ☐ Only one third of families reported that they had been offered an alternative to the present placement.
- ☐ The features families liked best about the present residence were the staff; the homely atmosphere; the buildings and their relative having their own room.
- ☐ The aspects they felt required improvement were more activities for the residents; better communication with staff; having more staff available and less staff turn-over.

The views of key-workers

- ☐ Key-workers rated all but one of the residents as very well-suited or reasonably well suited to their present placement.
- ☐ Suggested improvements centred around smaller, community based accommodation and people having their own houses while others required increased care and support.
- ☐ Most residents appear to have choice over clothes, leisure activities and household routines with few having choice over staff or where and with whom they live.
- ☐ Two-thirds of residents had at least monthly contact with relatives but less than a quarter had contact with friends outside of the residence.
- ☐ The majority of residents made recent use of various community facilities although this was less for people resident in nursing homes.

The views of care-managers

- ☐ The present placement was chosen mainly on the basis of assessed needs and the preferences of the family and the person themselves.
- ☐ Alternative accommodation was available to only ten of the people who were resettled.
- ☐ A team of people were involved in making the decision to move. Consultant psychiatrists; hospital staff, social workers, care managers, family and clients were involved with the majority of people.
- ☐ Care managers rated the present placement as very suitable for 88% of residents and reasonably suitable for the remainder.
- ☐ Increased independence and improved family contact were the two main outcomes expected from the placement.
- ☐ The main improvements suggested by care managers to the present placement centred on improved day services and greater access to community facilities.
- ☐ Ten people (15% of total) were thought to be at risk of abuse from others or of abusing others. All but one lived in residential homes. Safeguards were in place to manage these risks.
- ☐ Care managers mentioned supported living arrangements as the main form of preferred alternative accommodation. However there are plans for only two people to move from their present placement and this will be into supported housing.

Costs

- ☐ Although the Board had allocated £2.15 million towards resettlement, 17.5% of this was spent on funding people who were already in community settings.
- ☐ There was nearly a four-fold difference between the lowest cost package (£11,000) and the most expensive (£41,500).
- ☐ The most expensive packages for the EHSSB were in private residential homes with nursing homes and statutory residential homes providing the lower cost packages. However when other sources of funding are added in, supported living packages in community settings are also among the highest in cost.
- ☐ There was no apparent relationship between the cost of the packages and the needs of the residents in terms of dependency level, challenging behaviours, mental health and physical health problems.
- ☐ There was no apparent relationship between costs and outcome measures such as amount of choice, number of leisure pursuits and social relationships. Hence the sole determinant of cost appears to be the model of accommodation chosen.

Discussion and Implications

The resettlements had resulted in improved material standards of living and increased user satisfaction. People with additional needs had been successfully resettled and most were availing of day activities and accessing health services. Although some placements of people back in hospital appear to have broken down and other people had been re-admitted to hospital for periods of time, these were no greater than reported in previous studies.

Four shortcomings were identified in the recent resettlement programme.

- ☐ The continuing reliance on congregated living settings despite the Model of Community-Based Services adopted by the Eastern Health and Social Services Board (1996) and the better outcomes that have been shown to come from supported living models.
- ☐ The failure of people to move on to more independent living arrangements despite this need being identified by both key-workers and care-managers.
- ☐ The dearth of social networks experienced by people in the various types of residential accommodation.
- ☐ The slow down in the resettlement programme from 1997 which makes it very unlikely that the Regional target will be met by 2002.

It was concluded that four issues require urgent attention if the lessons from this and previous studies in N. Ireland are to be heeded; namely

- ☐ *The relative under-funding of resettlements compared to Great Britain.* This may be especially pertinent as the patients remaining in hospital are likely to have greater needs than those in this study.
- ☐ *The development of a wider range of housing and support options.* This is particularly necessary in order to facilitate people with the competence and aspiration to move on to more independent living arrangements. They also enable other sources of funding to be accessed.

- ❑ *The need for improved community support services.* Specialist services have traditionally been located in hospitals but as patients relocate and hospital placements retract, there has to be a concomitant increase in professional resources in the community such as psychology, psychiatry and community nursing. These will also be necessary to support an aging population of people with learning disabilities who in the past may have transferred from the family home to hospital settings.
- ❑ *A focus on outcomes.* Greater attention needs to be given in future commissioning on the outcomes that residential, housing and support options produce for people with learning disabilities. This will help to ensure that best value is being obtained for the monies expended.

Background

In many Western countries long-stay hospitals for people with learning disabilities have closed or are closing. Emerson and Hatton (2000) report a 48% decrease in the English long-stay hospital population from 1994 to 1997. In the latter year, around 7,500 patients were still resident in hospitals but they constituted only 13% of all the people in some form of residential accommodation. In the United States, 15% of people living in formal, supervised residential services during 1996 were in State Institutions; some 60,000 persons in all (Braddock, 1999). Similar data has been reported for Australia (Griffen and Parmenter, 1999).

Hence the era of the long-stay hospital appears to be drawing to a close but more completely in some regions within these countries rather than in others. In the United States, nine states are no longer operating any large-scale facilities for these clients whereas 13 States have not closed any large facilities, nor do they propose to do so although they are reducing in size (Braddock, 1999). This regional variation is also evident across English Health authorities (Bailey and Cooper, 1997).

The improvement in people's quality of life on moving from hospital to community settings continues to be documented (Cooper and Picton, 2000; Srivasta and Cooke, 2000) and the findings generally confirm the conclusions of a thorough review commissioned by the English Department of Health in 1994 (Emerson and Hatton, 1994). In the main, the resettlement of patients has produced a better life for them, not least in terms of their physical surroundings but also in the opportunities it provided for the development of communication and domestic skills, increased contact with family and friends and in the use of community facilities. However some studies have reported some deterioration in people's psychological well-being with increased challenging behaviours and more depression noted (Srivasta and Cooke, 2000) whereas others have reported decreases in challenging behaviours (Cooper and Picton, 2000).

Northern Ireland Services

In N. Ireland there had been no tradition of hospital-based care for people with severe learning disabilities until the 1950s when specialist hospitals were opened. Moreover these hospitals tended to serve people with mild and borderline 'mental handicap' who had associated mental health problems or who had committed offences requiring semi-secure accommodation.

From the early 1980s long-stay patients began to be resettled into hostels and other community facilities. Three studies have monitored the resettlements of these patients. Donnelly et al (1997) reported on a random sample of 114 patients discharged from three hospitals in the period 1987 to 1990. Few of the sample had major problems with daily living skills and behavioural problems were also uncommon. Nevertheless around 70% were resettled into residential or nursing homes. Former patients were satisfied with their new homes and reported feeling happier, healthier and more independent since discharge. However social networks were poor and there was no evidence to suggest that people were undertaking new or ordinary daytime activities.

McGinnity, McVicker, Marriott et al (1990) in unpublished research followed the first 100 patients discharged from Muckamore Abbey Hospital in the period 1987 to 1992. All had been re-settled in the Northern Board area although nearly half came from other Board

areas. In all, 88% went to nursing homes provided by the private sector and only 6% to voluntary accommodation; 5% statutory provision and one person to lived independently. Over 90% of residents and 72% of relatives interviewed expressed satisfaction with the placement. However the authors note that some people could move on to more independent living arrangements but that "there are clear gaps in provision and a definite possibility of people being "trapped" into a particular level and form of care. (p.16).

Donnelly et al (1996) followed up at 12 and 24 month intervals a group of 214 patients who had been discharged in the period 1990-1992 mostly into nursing homes (60%); residential homes (22%) and hostels/group homes (12%). Only five persons (2%) went into some form of independent living. Although little or no change was found in patient's competences, certain aspects of challenging behaviour had improved after 12 months. People were also less depressed and more satisfied with their new homes. Few changes were found in their patterns of activities or social networks. The authors recommended that purchasers and providers in N. Ireland "give more attention to ways in which the principles of normalisation could be incorporated in the process of contracting and delivering of services" (p. 598).

In 1996, the Eastern Health and Social Services Board adopted a model of community based services for people with learning disabilities which emphasised person-centred planning; ordinary living principles and individual support packages. A core element was the resettlement of all long-stay patients from Muckamore Abbey Hospital who no longer required hospital treatments. This was in line with the DHSS policy guidance (1995) that stated: "*the resettlement of those in hospital should be pursued with the utmost vigour*" with "*the aim being to reduce to zero by 2002 the number of long-stay patients in hospital*" (DHSS (NI) 1995b, p. 53).

In the period January 1996 to April 2000, resettlements continued from Muckamore Abbey Hospital although not on the scale originally envisaged of 40 per year in order to meet the target of having all long-stay people resettled from the Hospital by 2002. Informal reports from service personnel suggested that these patients tended to be less able and had more additional needs than those resettled in earlier years, plus a wider range of housing and support options were now available than had been the case a decade or more ago. A review of these placements would also provide insights to guide the continuing resettlement process of upwards of 180 people remaining in the Hospital.

Hence the aims of the present project were:

- ☐ To document the settings to which people moved and the characteristics of the residents;
- ☐ To detail the changes, if any, that have taken place in relation to the resident's placement;
- ☐ To obtain the views of residents, service providers, care managers and family carers to the move and to the present placement,
- ☐ To assess the resident's needs and implications for the development of future services for them and others moving from the Hospital.

The study was retrospective and resources did not permit any comparisons to be made with other groups, such as patients continuing to live in the Hospital or those in community settings who had never been resident in the Hospital. Also limited data was

Moving on from Muckamore Abbey Hospital

10

available about the clients prior to their discharge so it was not possible to monitor changes since resettlement.

However when possible, comparisons will be drawn with the findings from other research studies. Hospitals records were accessed to obtain some information about the people continuing to live in the resettlement wards of the Hospital. Contrasts could then be drawn between those who had been recently resettled and those still in Hospital.

Resettlement Population

Overview

This section describes the people who had been resettled. This is contrasted with information about patients currently residing in resettlement wards at Muckamore Abbey Hospital. Details are also given about the locations to which people moved.

Determining the resettlement population

The EHSSB supplied the name of 83 people whom they considered to form the resettlement population for the study, namely those who had left Muckamore Abbey Hospital since January 1996 to April 2000. These names were checked against the Hospital database with the following results.

<i>Number of people:</i>	
6	No record of hospital admissions
4	Resettled prior to January 1996 (in 1976;79;93;94)
5	Admissions of less than one year or respite user only
68	Had been resident in Hospital for at least one year.

Patients presently residing in hospital.

Details were obtained from Hospital records of all the patients aged 19 years and over from the EHSSB area who were resident in resettlement wards in September 2000. This consisted of 107 persons (68% male: 34% female) in seven different wards. When describing the characteristics of patients who had been resettled, comparisons will be drawn with the patients remaining in hospital.

Characteristics of patients resettled

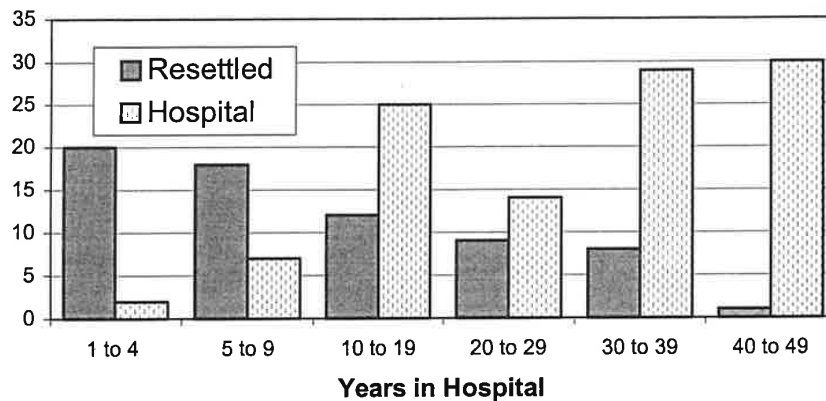
Gender

Of the 68 persons resettled; 37 (54% were male) and 31 (46%) were female. By contrast there were more males in hospital than females (68% and 32%). Hence proportionately more females than males have been resettled.

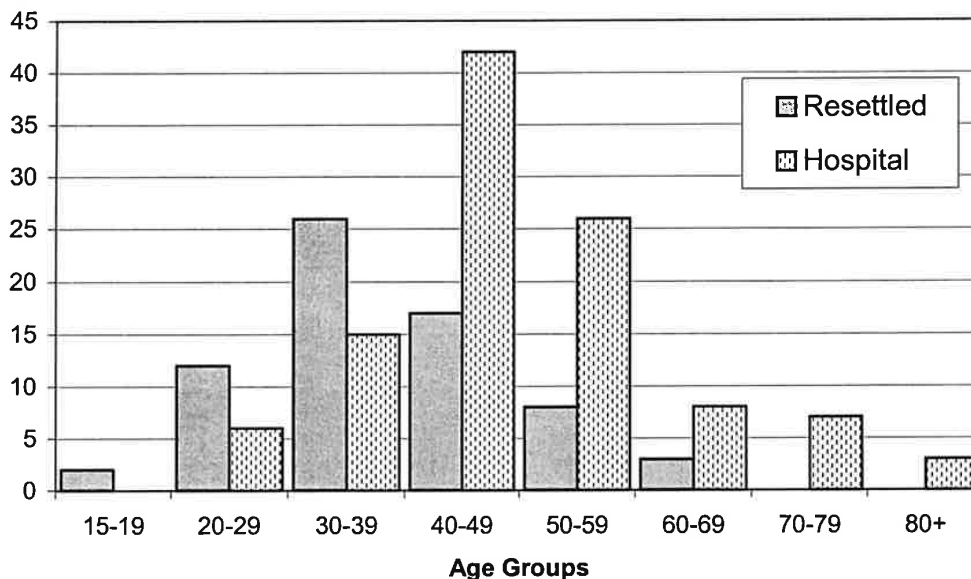
Length of stay in Hospital

For the resettled group, the median length of stay in hospital was eight years with a range from one to 40 years. For those remaining in hospital, the median length of stay was 32 years (range 3 to 49 years).

Figure 1 shows the numbers of people within the different length of stay groupings. This suggests that people who have been in hospital longest tend to stay there. For this resettlement population, their average of length of stay in Hospital prior to final discharge was some ten years less than reported in the previous N. Irish studies.

Figure 1: The length of stay in Hospital of the two groups**Age on Discharge**

The median age on discharge was 37 years (range 19 to 62 years). The median age of those remaining in hospital was also 37 years but the range was from 22 to 92 years. The numbers within each age group are shown in Figure 2. This data suggests that older people were less likely to be considered for resettlement.

Figure 2: The numbers within each age grouping**Responsible Trust**

The bulk of people resettled were reported to be the responsibility of North and West Belfast Trust (29 persons; 42% of the total); followed by Ulster Community and Hospitals Trust (16: 24%); South and East Belfast (14: 21%) and Down Lisburn (10: 15%). Nonetheless the majority of people were resettled in Co. Down (see later).

Of those in Hospital, over one third are the responsibility of North & West Belfast Trust (35%) and of South & East Belfast (34%) with Down Lisburn and Ulster Community and Hospital Trust having 16% each. These figures suggest that proportionately fewer people were resettled from S&E Belfast Trust.

Year of discharge

Of the 68 persons; 12 (18%) left the Hospital in 1996; 31 (46%) in 1997; 15 (22%) in 1998; 9 (13%) in 1999 and 1 (1%) in 2000. The rate of resettlements has slowed over the period.

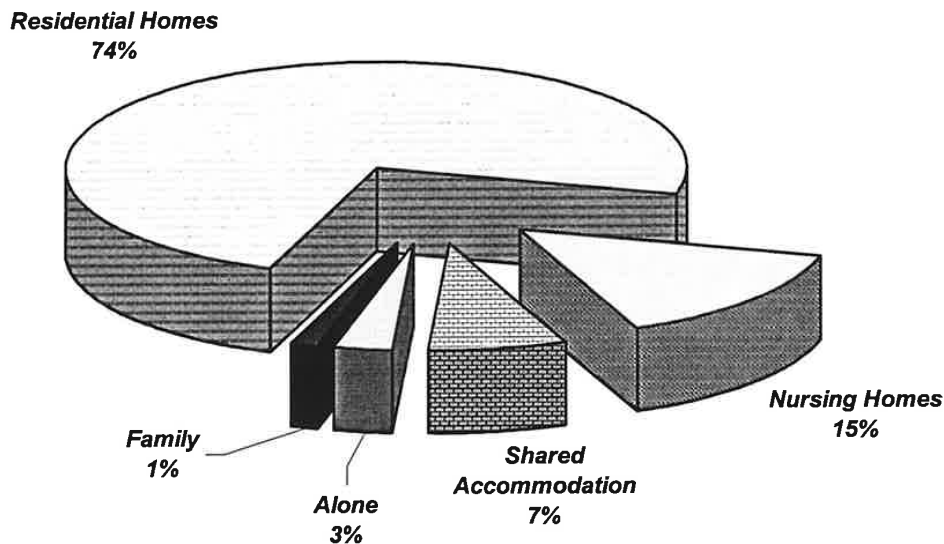
Summary

- ❑ Fifteen persons (18%) did not meet the criteria for inclusion in the project; either they had been discharged from the hospital prior to 1996; they had never been admitted there or had been in Hospital for less than one year.
- ❑ The most recent resettlements have tended to focus more on females than males; on people who have been in hospital for shorter times and who were under 60 years of age. Proportionately fewer people from S&E Belfast Trust have been resettled.
- ❑ The median length of time people had been in Hospital was eight years (range 1 to 40 years).
- ❑ Their median age on discharge was 37 years (range 19 to 62 years).
- ❑ Most discharges took place in 1997 and 1998 with only one in 2000.

Where did people move to?

Figure 3 shows the breakdown of the type of accommodation to which people were first located. In all, 60 (89%) people went to residential and nursing homes with only 8 (11%) persons moving to ordinary housing.

Figure 3: The type of accommodation to which patients moved



Of the 67 placements in residential accommodation; 35 (52%) were with the private sector; 22 (33%) in statutory provision and only 10 (15%) with the voluntary sector.

Of the 60 persons who moved to residential or nursing homes; 22 moved to one, newly built residential home and another 7 to a new facility specifically for people with autism. These two facilities account for 45% of the people relocated. Three people went to each of four different facilities; two people to a shared house managed by a voluntary organisation; two to a private residential home, two to a private nursing home; two to aHSS Trust residential home and 15 different establishments took one person each. Hence people were resettled to a total of 25 different residential and nursing homes (see listing in Appendix 1) plus two people went into a supported living service provided by a HSS Trust. One person went to live with her family.

In all 63 persons (94%) moved to accommodation that was solely for people with learning disabilities. Of the remaining four in residential accommodation, one went to a home for frail elderly; another for deaf persons with additional needs; one for persons with mental health needs and another for persons who are deaf/blind.

Table 1 summarises the size of the facilities to which people moved. The range was from single person accommodation to a home with 72 registered places for the frail elderly. Overall the median size of facility was 19 places; however nursing homes had a median of 33 places (range 18 to 72). The largest facility for people with learning disabilities had 36 places; divided into four self-contained units with 9 persons in each.

Table 1: The size of facilities to which people moved and their present placement

	<i>Number of Residents placed (N=67)</i>
Own tenancy	2 (3%)
Shared Housing (2/3)	5 (7%)
Home 6- 10 persons	3 (5%)
Home 11-19 persons	25 (34%)
Home 20 – 72	32 (49%)

In all, 59 persons (87%) had their own bedroom after the move and 9 people (13%) shared with one other person. Over two-thirds of persons in residential accommodation (N=43) had rooms on the ground floor. Upstairs rooms were thought suited to all the people in them. Although 30 residents were reported to have a wash-basin in their bedroom, only four persons had ensuite toilet and shower/bath.

Table 2 (overleaf) summarises the locations to which people moved. Just under a third of the placements (22 persons: 33%) were in Belfast with the majority in Co Down – 38 (56%) and the remainder in Co Antrim (N=7: 9%) and one in Derry City.

Re-admissions to Hospital

Of the 68 persons, 14 (21%) had been re-admitted to Hospital. Of these, 10 had been discharged again but four (6%) remain in Hospital and have been there for over 12 months. All four had been resettled in residential homes (two statutory and two private homes). It is not clear as yet whether they will return to their community placement.

Table 2: The areas to which people moved

	<i>Number (N=68)</i>	<i>Percent</i>
Antrim	1	1.5
Ballyclare	2	2.9
Ballynahinch	22	32.2
Bangor	2	2.9
Belfast	22	32.4
C'fergus	1	1.5
Derry	1	1.5
Downpatrick	10	14.7
Holywood	1	1.5
Lisburn	1	1.5
N'ards	3	4.4
Randalstown	1	1.5
Toome	1	1.5
Total	68	100.0

Of the ten treatment admissions; two persons had repeat admissions of two and three episodes respectively (both from residential homes and with mental health problems only); the remaining eight had one admission episode. Significantly more of these people came from community settings; five of the nine people living in these settings had been re-admitted compared to five of the 54 people in nursing and residential homes (Chi Sq 18.2 $p < 0.01$). Readmissions were most common for people whom key-workers reported as having both mental health problems and problems behaviours; i.e. six of the eight people who had one admission).

Of people re-admitted to the Hospital all had been seen by psychiatrists at least once and mostly on two or more occasions in the 12 month period. Likewise all had social worker involvement at least once; but often on four or more occasions. Community nurses however were involved with just over half the people re-admitted on four or more occasions. It is likely that these contacts occurred both pre and post-admission. None of the 18 people with behavioural and/or mental health problems who were seen by psychologists had been re-admitted to Hospital. (Fuller details of resident's contact with health and social services are given later)⁴.

One person had been admitted in 1997; two person in 1998; six people in 1999 and five in 2000. Readmissions were proportionately higher among those people resettled in 1996 and in 1999.

The re-admission rate of 21% is higher than the 7%-9% reported in past studies in N. Ireland (Donnelly et al., 1996; Donnelly et al., 1997) and the 8.4% readmission rate to a North of England Hospital (Seager et al, 2000). This may reflect differences in the needs of the people who had been resettled coupled with the availability of community support services.

⁴ Further information on admissions to Muckamore Abbey Hospital is available in a series of reports by Laird, McConkey and Marriott, 2000).

Changes in Accommodation

Of the 68 people, 59 (87%) continue to live in the place to which they moved. The following changes occurred:

Now back in Hospital	4
Moved to another residential home	3
Moved from residential home to own tenancy	1
Deceased*	1

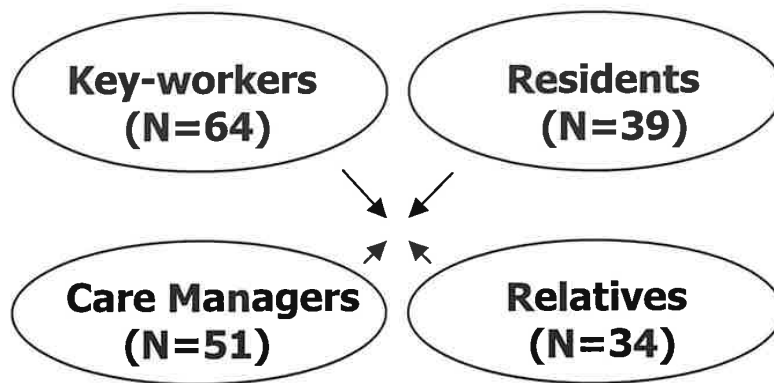
**This person died two years after moving, aged 49 years. During the data gathering phase another person died aged 64 years; two and half years after moving. The latter was included in the follow-up sample.*

Summary

- ☐ Nearly three-quarters of people moved from the Hospital to residential homes and a further 15% to nursing homes. Only eight persons moved to ordinary housing.
- ☐ Nearly all residents had their own bedroom in a facility solely for people with learning disabilities.
- ☐ Three-fifths of the places were in Co. Down.
- ☐ Nine out of ten continue to live in the place to which they moved.
- ☐ Nearly all had ongoing contact with psychiatrists and social workers and some with community nurses. Four of the 68 were presently back in hospital with a further ten people having had one or more treatment admission. The latter tended to be people with mental health and behaviour problems living in community settings.

Information Gathered at Follow-Up

All of the resettled population – bar the person who died - were followed up during 2000; a total of 67 persons. Independent researchers gathered the information either through interview or self-completion questionnaires with four groups as shown.



Resident Interviews: Of the 67 persons; 27 (40%) could **not** be interviewed due to communication problems, though on a number of occasions an interview was attempted. Another person refused to be interviewed. In all, 39 persons (58%) were interviewed.

Family Questionnaires: Care managers had been asked to forward a self-completion questionnaires to families. However this yielded only 15 replies by mid-October. Telephone interviews were then conducted with a further 17 families reported by the residential facility as having regular or frequent contact with their relative plus one face-to-face interview with a family carer who looked after her relative at home. The total of 34 relatives represents 58% of all known relatives and 69% of those relatives reported to have regular contact with the residents.

In total, information was obtained from either the person or their relatives for 56 of the 67 (84%) people in the resettlement population. Moreover proportionately more relatives of highly dependent people commented while it was clients of lower dependency who were interviewed.

Key Workers: For 66 people in some form of supported accommodation, information was obtained from key-workers for 64 persons (97%) but not for two persons presently living in Muckamore Abbey Hospital. However not all the questions were answered; hence the number of respondents may vary and this is noted in the results section.

Care Managers: All the placements of people in non-statutory services are care-managed. Self-completed questionnaires were sent out to the care-managers in the four Community trusts for 67 clients and replies were received for 51 persons (76%).

Comment

Although information was obtained from one of the four sources for everyone; there were only 14 persons (21%) for whom all four informants provided information. The ideal would have been to have the same data set for all people in the identified population but this was not possible for the reasons given. Hence some caution needs to be exercised in drawing comparisons among the four groups of respondents as they will not always reflect the same residents.

Present Characteristics of the people who moved

Overview

This section describes the people who were resettled in terms of their additional disabilities, social competence, physical health needs, mental health problems and challenging behaviours. Details are given of the day services they receive and their contacts with health and social service professionals.

(NB Information in this section is based on key-worker's or family carer's assessment of residents at present. This data was not available for three people presently living in Muckamore Abbey Hospital and the one who is deceased)

Of the 64 persons, 62 (97%) were single; one was married and another widowed.

Three people (5%) were reported to have Down Syndrome; seven (11%) had a diagnosis of autism and one (2%) had cerebral palsy.

Additional Disabilities:

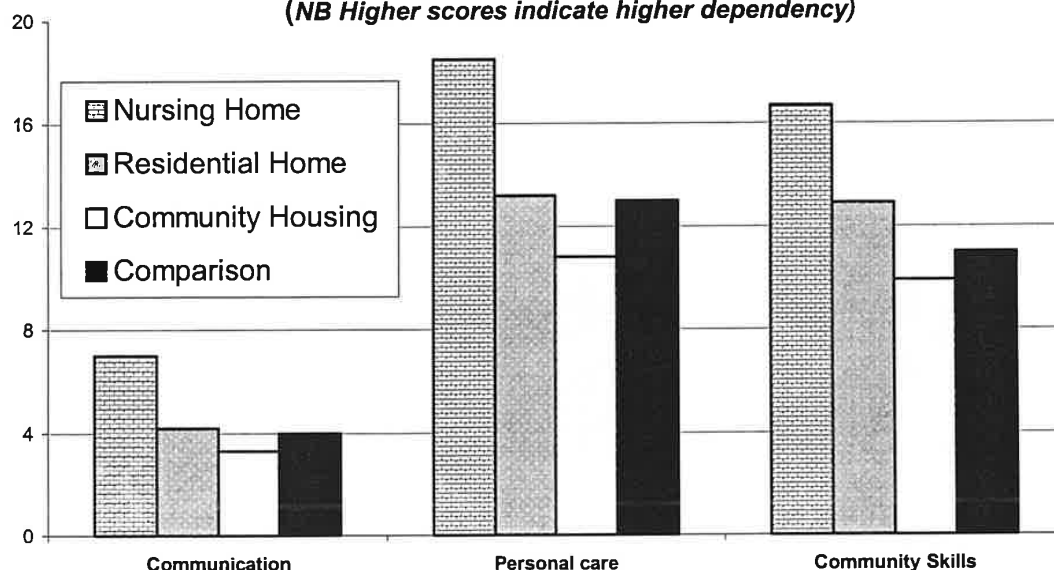
Of the 64 persons on whom information was available;

- ☐ One had partial sight and another was blind for all practical purposes.
- ☐ Four persons (6%) had partial hearing and two (3%) were deaf for all practical purposes.
- ☐ Six people (9%) were unable to walk alone.
- ☐ Seven people (11%) had difficulty using their hands.

Social Competence

The Index of Social Competence (McConkey and Walsh, 1982) was completed by key-workers for each resident. Figure 4 shows the mean dependency scores for residents in the three types of accommodation. This is done in terms of communication; their personal care skills and community skills of reading, writing, telling the time and money.

Figure 4: Mean scores on three social competence measures for residents in three types of accommodation
(NB Higher scores indicate higher dependency)



Not surprisingly those resident in nursing homes tended to be the more dependent in all three areas ($p < 0.05$). (The mean score for 260 people with learning disabilities attending day centres in Belfast is also shown.)

Residents could be grouped into those were low dependency⁵ in all three domains; those with high dependency⁶ in all three domains and those with a mixed profile, namely high dependency in some domains and low in others. Table 3 shows the distribution of these groups across the different type of accommodation. Residential homes have people of diverse abilities whereas Nursing Homes tend to have higher dependent residents and community placements, the less dependent (Chi Sq 11.3 $p < 0.05$).

Table 3: The numbers and percentages of people in the three dependency groups by types of residential accommodation.

<i>Accommodation</i>	<i>Low dependency</i>	<i>Mixed Dependency</i>	<i>High Dependency</i>
Nursing home (N=11)	0	3 (27%)	8 (73%)
Residential Home (N=44)	17 (39%)	15 (34%)	12 (27%)
Community (N=9)	5 (56%)	2 (22%)	2 (22%)
Total	22 (34%)	20 (31%)	22 (34%)

Those who were rated as high dependency had spent a significantly longer time in hospital (median 20.5 years) compared to those in the other two groups (median 7.0 years) ($F = 8.6$ $p < 0.001$).

Epilepsy

Five persons (8%) had recurring fits and a further 17 (27%) had a history of epilepsy for which medication was taken but they had no fits at present.

Health Needs

Table 4 summarises the number of residents who had experienced the health problems listed in the last 12 months. In all 20 residents did not have health problems whereas 20 people had one problem; 14 had two problems and 7 had three or more health problems. Surprisingly residents in nursing homes had no more health problems than people living in other settings nor did those who were older compared to younger people. However those people with mental health problems (see below) also tended to have more physical health problems (mean 1.5 versus 0.91: $F = 4.3$ $p < 0.05$).

In all 24 persons (37%) were considered by the key-workers to be of average weight; with 7 persons (11%) underweight, 25 persons (39%) overweight and 6 (9%) obese.

In all 13 people were reported to smoke (six people less than 10 cigarettes per day and 7 people smoking between 10 and 20 per day) and with four persons this was considered to a problem. With three persons their use of alcohol was also considered a problem.

⁵ Typically they are able to communicate through speech and to understand instructions; able to look after their personal care needs and with basic reading, writing and numerical skills.

⁶ Typically poor communication skills; dependent on others for their self-care and unable to read and write with little or no understanding of numbers.

Table 4: The number of people with different health problems

<i>Health Problem*</i>	<i>Number</i>	<i>Percent</i>
Constipation	18	28
Persistent skin trouble	17	26
Recurring stomach problems	8	12
Obesity	5	8
Persistent foot problems	3	5
Eye Problems	4	6
Piles	3	5
Bronchitis	3	5
Sciatica, Lumbago etc.	2	3
Asthma	4	6
Heart Problems	2	3
Trouble with teeth/gums	2	3
High blood pressure	1	2

* Nobody was reported to have problems with arthritis, varicose veins, diabetes or strokes.

Five persons (6%) had been admitted to a general hospital as a result of an accident or injury since coming to the residence.

Mental Health

In all 27 people (40%) were considered to have a mental health problem. Table 5 lists the types of problems reported by the key-workers. This proportion is higher than that reported in English studies (e.g. Emerson et al, 2000) and probably reflects the role that Muckamore Abbey Hospital plays in treating people with mild or borderline learning disabilities who have mental health problems (Laird et al, 2000).

Table 5: The frequency of mental health problems (N=64)

<i>Mental Health Problem</i>	<i>N (%)</i>
Depression	15 (23%)
Anxiety	7 (11%)
Schizophrenia	5 (8%)
Maniac depression	4 (6%)
Personality disorder	2 (3%)
Organic psychosis	1 (2%)
Alcohol abuse	1 (2%)

Although more people with mental health problems tended to live in community settings rather than residential and nursing homes, the differences were not significant.

Problem behaviours

In all, 32 persons (50%) were reported to engage in one or more of the behaviours listed in Table to a moderately serious or severe degree. One half of these people (16) were also reported to have mental health problems.

Proportionately more of these people tended to be resident in community settings (6 out of eight persons had problem behaviours) and residential homes (48% had problem behaviours) than in nursing homes (2 of 10 had problem behaviours).

As Table 6 shows, the most frequently occurring behaviours were aggression to others, self-injurious behaviours and depression.

In all, six persons (9%) show three of these behaviours; 15 persons (23%) show two of them and 11 persons (17%) show one of the behaviours.

Table 6: Problem behaviours that are rated as being moderately serious or severe at present (n=64)

<i>Problem behaviour</i>	<i>Number showing Behaviour (%)</i>
Aggressive to others	15 (23%)
Self-injurious behaviour	11 (17%)
Depressed/lethargic/moody	11 (17%)
Destructive of property	8 (13%)
Overactive/restless	7 (11%)
Odd/stereotyped behaviour	6 (9%)
Inappropriate sexual behaviour in public	3 (5%)

With 24 of the 32 persons reported to have moderate and severe problem behaviours; they usually take the form of brief episodes but with six persons these are sustained or prolonged episodes. (No information on intensity was given for two people).

For ten people the behavioural episodes occur one or more times a day; for 13 persons they occur once or more a week and with eight persons it is less often. (No information on frequency was given for one person).

Half of the people (16 of 32) with problem behaviours were reported to have a treatment plan to prevent or reduce the person's behaviours. These were all in residential homes. These took the form of behaviour management programmes (N=6), token/incentive awards (N=5), TEACCH (N=3) and care planning (N=2).

The most immediate response to the behaviour took the form of diversional activities (7) along with de-escalation and redirection techniques (3). However physical restraint was usually used with one person and sometimes with four others and rarely with another seven. Sedation was used with one person; sometimes with one person and rarely with five others. Arm splints were usually used with one person. All of the above were done within the context of a treatment plan.

Past behaviours

Keyworkers noted that 53 persons (83%) had shown problem behaviours in the past and for 44 persons (69%) these were rated as serious or very serious. The most commonly mentioned were physical and verbal aggression (33 persons) self-injury (18 persons) and destructive of property (8). Other problem behaviours were inappropriate sexual behaviours (6), inappropriate speech (5), hyperactivity (4) and withdrawn (3). Table 7 contrasts past and present behaviours.

Although the numbers of people showing problem behaviours has dropped, the reduction is most marked among those whose behaviours were not very serious; less with those who showed serious behaviours and least among those with very serious behaviours (Chi Sq 7.4 $p < 0.05$). Similar decreases in problems behaviours have been

reported in previous studies (e.g. Donnelly et al, 1996) although not in others (Srivasta and Cooke, 2000).

Table 7: The numbers and percentages of people who showed problem behaviours in the past and at present (N=50)

	<i>In past – not very serious behaviour</i>	<i>In past – serious behaviour problem</i>	<i>In past – very serious problem</i>
No behaviour problems at present	5 (83%)	14 (42%)	2 (17%)
One or more behaviour problems	1 (17%)	18 (58%)	10 (83%)
Total	6	32	12

Day Services

In all, 57 people (88%) were reported to attend day services. These were mainly provided by the local HSS Trust (19 persons), provided in the residence (18 persons), provided by the residence but in a separate building (8 persons) or by a voluntary agency (12 persons).

However those resident in nursing homes were most likely to attend a day service in or adjacent to their residence with only one person (9%) attending a day centre provided by the Trust. By contrast half of those in residential homes and all but one (88%) in community settings attended day services away from the residence.

Health Services

All residents were reported to be registered with a local GP and 51 (76%) persons were reported to have a health check during the past year. In addition, 36 people (55%) were reported to have had a positive health screen in the past two years.

The professionals most frequently seen by the residents in the last 12 months are noted in Table 8. Only one person had *not* seen their GP. Residents in nursing homes (45%) and residential homes (44%) were more likely to see their doctor on six or more occasions compared to none of the people in community settings (Chi Sq 27.9 p<0.01). However those with reported physical health problems were no more likely to see their GP than those with no reported health problems.

Table 8: The number of residents who had seen the professionals listed in the last 12 months (n=65)

<i>Professional</i>	<i>Not at all</i>	<i>Once</i>	<i>Two/three</i>	<i>Four and more</i>	<i>Not known</i>
Doctor	1	8	14	37	0
Dentist	4	18	29	8	6
Social Worker	7	12	10	28	8
Psychiatrist	10	10	12	22	11
Optician	29	18	3	1	14
Psychologist	33	4	5	9	14
Comm. Nurse	38	2	4	10	15

Psychiatrists and community nurses were significantly more likely to have contact with residents in community settings and in residential homes than they were with people in nursing homes. Psychologists had contact only with people living in residential homes.

People with epilepsy, mental health problems and challenging behaviours were no more likely to see any of the professionals listed; especially psychiatrists, psychologists and community nurses than those without these problems. However those with challenging behaviours tended to be seen more frequently by psychiatrists and community nurses.

In addition, certain residents saw the following professionals one or more times: dietician (5), speech and language therapist (4), occupational therapist (4), district nurse (3), physiotherapist (3), podiatrist (3) and audiologist (1).

In all 11 people had seen a medical specialist at a hospital and 7 had seen a surgical specialist.

A total of 17 people had seen a music therapist, 13 an art therapist and 5 an aromatherapist; mostly provided in the residence as part of their day activity programme.

A total of 52 persons were taking regular medications; three for hay fever; laxatives and ear drops while the remaining 49 persons had various specialised medicines including anti-convulsants, anti-depressants, hypnotics, mood stabilisers, anti-psychotic and anti-cholinergics. Others were prescribed cardiovascular and endocrine drugs. Each person was reported to have a mean of 4 drugs prescribed (range 1 to 8). Medical advisers noted that these drug regimes need to be reviewed at least annually by GPs or consultant psychiatrists; and in the case of some, every three months.

Summary

- ❑ One third of the resettled population were rated as low dependency in personal care; another third as high dependency and a third had a mixed profile. As a group they appear to be less competent in personal care than previous resettlement populations studied in N. Ireland.
- ❑ Residential homes served the widest range of clients in terms of dependency levels whereas nursing homes had more dependent people and community houses less dependent people.
- ❑ Epilepsy was the most common additional disability with nearly one third of persons affected by it. A small number were rated as immobile; visually or hearing impaired.
- ❑ Around half the people were judged as having challenging behaviours that staff rated as moderately serious or severe; mainly aggression to others and to self.
- ❑ Two in five people (40%) were reported to have a mental health problem of which depression was the most common.
- ❑ For 21 people, staff considered that their behaviour problem had improved since the move.
- ❑ All were registered with local GPs and most had a Healthcheck in the past 12 months. The most commonly occurring health problems were constipation and persistent skin trouble.
- ❑ The majority of residents were reported to have seen their GP, a dentist, social worker, psychiatrist and optician in the past 12 months.
- ❑ Over three-quarters took regular medications with a mean of four drugs prescribed for each person.

Views of people with learning disabilities

Overview

This section reports the views of people who had been resettled in terms of what they like and do not like about their present residence compared to the Hospital; their feelings about moving from hospital; their friendships and the activities they are involved in.

Sample

Interviews were undertaken with 39 persons who had been resettled; 58% of the available population. A Discriminant analysis⁷ contrasting those people who had been interviewed with those who had not, yielded only one significant discriminating variable, namely dependency level. Interviews were done with 96% of people rated by key-workers as having low dependency; with 60% of people rated as 'mixed dependency' and with 18% of those with rated as high dependency (Chi Sq 27.0 $p < 0.001$).

Present residence

Of those interviewed, 27 were living in residential homes; 5 in shared housing; 4 in nursing homes; 2 had their own tenancies and 1 lived with her family. All of the residents in the nursing homes and supported accommodation named at least one thing they liked about their present residence as did 26 of the 27 people in residential homes. These are listed in Table 9.

Table 9: What the people with learning disabilities like about their present residence and Muckamore Abbey Hospital (N=39)

(NB The same person could state more than one thing they liked)

<i>Likes about present residence</i>	<i>N</i>	<i>Likes about present residence</i>	<i>N</i>
Friends	7	Smallness	1
Outings	6	Multi-sensory room	1
Staff	4	Boyfriend nearby	1
Food	6	Family here with me	1
Like it	4	Nothing to like	1
Quietness	3		
Independence	3	<i>Liked about</i>	
Freedom	4	<i>Muckamore Abbey Hospital</i>	<i>N</i>
Community facilities	2	Friends	8
Co-residents	2	Staff	4
Own TV	2	Good/alright	3
Music	2	Disco/dances	3
Privacy	2	Picnics/BBQs	1
Surroundings	1	Plays/concerts	1
Building	1	Working in gardens	1
Clothes	1	Food	1
Downpatrick town	1	Felt better there	1
Near home	1	Quiet	1
Go to work	1	Nothing to like	16
Social skills group	1	No mentions	5

⁷ The variables entered into the analysis were age, gender, length of stay in hospital, dependency level, number of problem behaviours and mental health problems.

However eight people commented on things they did not like about their residential home; as did two people living in Nursing homes and two in supported accommodation. Their views are listed in Table 10.

People were asked in another part of the interview to state what they had liked and not liked about living in the Hospital. As the tables show, people seem to prefer their present place of abode given the diversity of comments about what they like and the fewer dislikes that are stated.

Table 10: What the people with learning disabilities do NOT like about their present residence and did NOT like Muckamore Abbey Hospital

(NB The same person could state more than one thing they disliked)

<i>Dislikes for present residence</i>	<i>N</i>	<i>Disliked about Muckamore Abbey Hospital</i>	<i>N</i>
Staff	2	Didn't like any of it	5
Noisy	1	Food	5
Afraid of another resident	1	Hassled by others	4
Afraid at night-time	1	Not getting out	4
Laundry	1	Missing family/friends	3
Bored at work	1	Shared dorms	3
Visitors in and out	1	No freedom	2
Money not good	1	Staff	2
Lonely	1	People stealing things	1
Travelling to centre	1	Room	1
Don't go to Gateway Club	1	Throwing chairs	1
<i>Nothing disliked</i>	<i>25</i>	Noisy	1
		Too big	1
		Afraid of dark	1
		Lonesome	1
		No money or cigarettes	1
		Everything about it	1
		<i>Nothing to dislike</i>	<i>5</i>
		<i>No mentions</i>	<i>7</i>

People living in residential settings (38) were asked specifically what they thought about the staff and co-residents at their present place and at the Hospital. In all, 30 persons (79%) liked the staff in their present residence with the other eight persons (21%) stating they liked some and not others. Comparable figures for the Hospital were 58% liking the staff and 11% liking some and not others. However eight persons (21%) did not like any of the Hospital staff and four persons made no comment.

A similar pattern held for co-residents. In all 71% people stated they liked the people they presently live with; three (8%) liked some and not others and two did not like any (5%) (Six people made no comment.) At the Hospital, 47% liked their co-residents; 24% liked some and not others and four people (11%) did not like any of them (seven people did not comment.)

When asked if they felt safe and secure in the two places; more answered yes for their present residence (87%) compared to the Hospital (70%). The former included all the people living in shared housing and own tenancies. Reasons for feeling not safe at

present were being scared of other residents; living in an area that is not safe and being frightened at night. Another commented that he *"used to be afraid; it took a while to get used to the new place"*.

Move from the Hospital

Around two-thirds of people reported that they had requested a move from the hospital. Of the 36 persons answering the question, 33 (92%) said they were happy to move; two people did not want to move at first but they came round to the idea and another was not really bothered. Twelve went on to give a reason; five stating they did not like the Hospital, two to get 'freedom'; two because the other residents 'get you down'; one to be nearer his sister and one felt it was 'time to move to a different place'. One person who did not want to move said it was because she was happy in the Hospital and the other commented: *"I didn't want to move at first because I was afraid but I'm glad I did make the move"*.

In all, 33 persons (85%) said they were glad they had left the hospital; 2 (5%) were not glad and 4 did not comment. However, six people (15%) said they felt like moving back to the hospital and another four persons (10%) felt like this sometimes. (However only one person expressed a wish to move back to the Hospital when asked about their wishes for the future.)

Over two-thirds (27 persons:69%) did not feel like moving back. Equally a total of 31 people (80%) reported they were happier since leaving the hospital; two (5%) were unsure and three (8%) were not happier (all three were living in residential homes).

When asked if they missed anything about the Hospital; 11 persons (28%) made no comment and 14 (36%) said 'nothing'. The remaining 14 (36%) mentioned missing friends (N=8); staff (4); activities, such as discos (3) and the grounds (3). In all, 7 persons (18%) mentioned things they did at the Hospital that they could not do now. These included going to dances; into Antrim town; ten-pin bowling; gardening and the town parade. However most people (82%) could not think anything they were not now able to do.

Finally some people commented:

If I had to go back (to the Hospital) for a while it would not bother me – I know I would be coming back to (residence)

I love living here (in new house).

I would love for my friends (at Hospital) to come and live here.

I thought I would be happier and I am not really

A lady who had been readmitted to the Hospital said:

I miss (residence) – I want to go back. I loved it there.

Present Living arrangements

All but one person reported having their own bedroom. All reported that they had their own personal possessions and 32 reported that a weekly amount was given to them for pocket money. Nearly all (34) were able to buy their own clothes; 26 reported having their own bank/post office account and 23 a choice of meals. (The proportions were higher for people in shared/supported housing than for residential homes).

Friendships

Over half the people (21) reported having friends but less than a quarter (9 people) reported having friends outside of the residence; eight of these lived in residential homes and one person in a nursing home. In addition two people living in a shared house had a befriender recruited by the service agency who took them to the cinema and similar outings. However 12 people said they had no friends and five made no comment.

Activities

All mentioned a range of activities they did during the day. Attendance at a day centre was the most commonly mentioned (23 people) but people also went to College (N=5) Vocational Training (2) and did jobs around the residence (2). One person was on work experience but no one had paid employment.

A wide range of leisure pursuits were mentioned when asked what they did at evenings and at weekends. In the evenings; watching television (25) and listening to music (15) were the most popular pursuits. In all 19 people mentioned only home-based activities. Among the out-of-home pursuits were going to the pub/cafe (7) cinema (3) walking (3) watching football (2) shopping (2) and using a health club (1).

Weekend pursuits were more varied. In all 34 people (87%) mentioned one or more activities that took them out of the house. These are listed in Table 11.

Table 11: The number of people involved in weekend leisure pursuits

<i>Activity</i>	<i>Number mentioning</i>
Going to the pub	12
Shopping	9
Visiting relatives	6
Cinema	6
Walks	5
Outings in car	4
Meals out	2
Watching football	2
Visitors to the house	2
Church	2
Visiting girlfriend/boyfriend	2
Bowling	2
Social Clubs	1

In addition 26 people (67%) reported having been on holiday during the past 12 months.

People were also asked if they had done the activities listed in Table 12. Overall the mean number was 8.4 activities with a tendency for more to be reported for people living in residential homes (mean 9.3) than for shared/supported housing (7.6) and nursing homes (4.5).

Table 12: The number of people who have engaged in the activities listed (n=39)

Activity	Number of residents
Been shopping	32
Been to a café	32
Been to a hairdresser	26
Been to the pub	23
Had trips out with family or friends	23
Been to the cinema	23
Been on the bus	21
Been to a play or concert	20
Had family or friends round for a meal	19
Been to a Social club	17
Been on an overnight stay	15
Been to their bank	16
Been to a place of religious worship	14
Been to a sports event	11
Had guests to stay	1

Their health

Most of people (91%) stated they are keeping well at the moment. However over one-third (34%) mentioned that they had been sick since moving to the home. This was mainly flu-like illnesses although one person reported having leukaemia and another had treatment for pressure sores on the feet.

Summary

Although the findings in this section were obtained from over half of the people who had been resettled; they may or may not apply to the other people who were not able or willing to express an opinion.

- ☐ People mentioned more things that they liked about their present residence than they named about the Hospital and they had fewer dislikes than for the Hospital.
- ☐ Nearly all were happy to have moved. Only one person said they had not wanted to move from the hospital and another wished they could move back there.
- ☐ Nearly all the people had some form of day activity programme and most reported a variety of evening and weekend activities both in and outside of the residence.
- ☐ Half the people interviewed reported having friends with one quarter having friends from outside the residence.
- ☐ Nearly all reported as being in good health.

Views of Relatives

Overview

Relatives were asked to comment on their reactions to the move from hospital and to give their views on their relative's present residence.

Sample

Of the 68 persons in the resettlement population; six had no known relatives or no contact with any relative. For a further three it was deemed inadvisable to make contact with the family. Care managers were asked to forward self-completion questionnaires to relatives of the 59 remaining residents.

In all 16 completed questionnaires were returned. Telephone interviews were then carried out by research staff with 17 families who were recorded as having regular or frequent contact with their relative plus research staff interviewed one family carer who was looking after their relative at home; a total of 34 informants. This represents 58% of all known relatives and 69% of relatives reported to have regular contact with the residents. The main reason for non-responses was a lack of telephone at home; wrong phone numbers; no recent addresses or a failure to respond to the questionnaire.

A Discriminant analysis⁸ was undertaken to examine possible differences among the relatives who were contacted with those we were unable to contact. This yielded only one significant discriminating variable, namely length of time the person had been in hospital. The people whose relative had been contacted had been in hospital for a significantly longer time than those whose relatives were not contacted (mean 15 years v's 9.9 years: $F=4.0$ $p<0.05$). These also tended to be people who were classed as high dependency.

Hence the information from relatives complements the interviews undertaken with the people themselves as these tended to be those with lower dependency needs.

Reactions to the move from the Hospital

In all 21 families (62%) said they were happy to consider a move from the hospital. Some commented as follows:

I realised he wasn't happy at Muckamore

Very unhappy with Muckamore

The Hospital was far away – (mother) ill travelling so much

He was not getting educated or any activities at Muckamore; used to copy bad behaviours of other patients

Nine families (26%) were unhappy with the prospect of the move.

N. was happy and settled there

I was unsure how he would adapt to move as he had been so many years at Muckamore Abbey Hospital.

⁸ The variables entered into the analysis were age, gender, present residence, length of stay in hospital, dependency level, number of problem behaviours and mental health problems.

He had been in Muckamore for so long; we felt he was too aggressive to move out.

Four relatives (12%) had no strong views either way. One mother commented:

I felt a bit torn – pleased with the Hospital but assured the move would be good for N.

All but five families (N=29: 85%) said they had been satisfied with their involvement in planning the move and one third (12: 35%) reported that they had been offered alternative placements.

Present Placement

In all 28 families (82%) felt the placement was very well suited to their relative's needs; 5 (15%) that it was reasonably well suited and one (3%) that it was not suitable and felt that the person needed to move but no reasons were given.

Also 28 families (82%) rated the service very much better than the hospital; three (9%) as much the same and no-one said it was worse. (Three families did not comment).

The things which two or more families mentioned as liking best about the present residence are listed in Table 13. Two families were unable to comment, as they did not visit their relative in the residence.

Table 13: Features of present accommodation that families liked

<i>Features liked</i>	<i>Number of mentions (N=33)</i>
Staff – friendly; efficient, more of them	19
Modern building	13
Atmosphere of place; homeliness	12
Own room	10
Day Care/activities provided	6
Relative is happier there	6
More freedom and independence	5
Close by relative's home	4
Friends and social life	4
Good food	3
Outings provided	2
Clean and hygienic	2
Treated as a person/individual attention	2

Families appear to judge the facility mainly in terms of the staff; its homeliness and standard of accommodation and their relative having a room of their own. Relatives also mentioned other things they liked; including the residence being near shops and facilities; having an all female unit and their relative being with people who could talk.

Fifteen (45%) of the 33 relatives mentioned one or more things they would like to see improved. These are listed in Table 14.

Individual relatives noted a variety of other improvements. These included more privacy on visits to the residence; relative having own room; forming a parent's group; reviews being held; medical check-ups; speech and language therapy; more socialising; relative having a job; moving to more independent living; improved personal hygiene and

appearance; receiving payment for work done in day centre and receiving training in independence.

Table 14: Improvements suggested by relatives in present residence

<i>Improvements wanted</i>	<i>Number mentioning (N=15)</i>
More activities	5
More information from staff	3
More staff	2
Less turn-over of staff	2
Closer to family home	2
More space to move around	2

Relatives were asked to rate the residence in terms of the features listed in Table 15. These seem to indicate a high level of satisfaction with the current residence. The two people reported by relatives to be unhappy with their present placement had also stated this themselves (see earlier). One lived in a statutory residential home and another in a shared house in the community.

Table 15: The number and percentage rating features of the residences

<i>Feature</i>	<i>Yes</i>	<i>Unsure</i>	<i>No</i>
We find staff there helpful	33 (97%)	1 (3%)	
We are involved in making decisions about relative	31 (91%)	2 (6%)	1 (3%)
Our relative is happy there	32 (94%)		2 (6%)
We are kept well informed about what is going on	30 (91%)	3 (9%)	
We are happy with our relative's current service	29 (88%)	3 (9%)	1 (3%)
We have contact with relative as often as we like	29 (85%)	2 (6%)	3 (9%)

Likewise relatives were asked to say whether the statements listed in Table 16 were true for their relative's current service.

Table 16: The number and percentage of relatives rating the service
(NB Some families did not answer all the questions)

<i>Feature</i>	<i>True</i>	<i>Not sure</i>	<i>Not true</i>
Seem happy and content where they are living	32 (97%)	1 (3%)	
They look well dressed and healthy	32 (97%)		1 (3%)
Relationships with relatives are maintained	27 (82%)	6 (18%)	
Regular day time activities are provided	27 (87%)	4 (13%)	
They enjoy a busy and enjoyable life	27 (87%)	4 (13%)	
They have an active and healthy lifestyle	27 (84%)	5 (16%)	
Appropriate emotional support available to them	26 (84%)	5 (17%)	
Protected from exploitation and abuse	26 (84%)	4 (13%)	1 (3%)
Residents have choice on day-to-day matters	22 (71%)	8 (26%)	1 (3%)

These results also suggest that the families have few concerns about the present residences.

Most families made further comments; a selection follows.

This home has been the best my brother has had. He seems happy, he is more talkative than when he was in Muckamore.

My relative has lived in present situation for 18 months and there has been a vast improvement in her attitude and her general well being.

When I have Susan out she always comments that she wants to go home to (residence). So she must be happy enough when she calls it her home.

In comparison to Muckamore we are very happy with the current placement but there are some aspects we would to see improved. Our daughter does seem happy. She has complex needs but the staff are very tolerant when she is going through a difficult phase

N has improved dramatically since his transferral, both physically and mentally due in part I feel to a much more caring environment. Any negative happenings have been due to a lack of staff.

Pity there is not more places like (residence). The Board was completely unhelpful about the provision of a new place that N could move to. I had to locate somewhere myself. I took on the system and won.

The weekends need to be planned to have more activities, such as exercise. The staff changeover is too high. There are too many people in the building and it is quite institutionalised.

When people go into a home the parents are sometimes not thought of. The whole family changes. Social workers get less involved once the person is admitted. Parents need more information.

Comment

Emerson et al (2000) note that parents often are very satisfied with existing services be it hospital or community-based services. However they state: "longitudinal studies have repeatedly demonstrated that, following their relative's move to community-based services, relatives rate these services highly and, in retrospect, tend to express preference for the new arrangements." (p.112).

Summary

- ☐ Although a majority of families welcomed the move from the Hospital; a significant minority (26%) had been unhappy at the prospect of the move.
- ☐ After the move all families felt the residence was at least equivalent to the Hospital with over four out of five families rating it as much better than the Hospital.
- ☐ Only one third of families reported that they had been offered an alternative to the present placement.
- ☐ The features families liked best about the present residence were the staff; the homely atmosphere; the buildings and their relative having their own room.
- ☐ The aspects they felt required improvement were more activities for the residents; better communication with staff; having more staff available and less staff turn-over.

The Views of the Key-Workers

Overview

The key-workers for each of the people resettled gave their opinion on the suitability of the present placement and they provided information on the care practices followed with the client; the choices they could make; their social contacts and the leisure pursuits they engaged in.

Sample

Information was obtained from the key-workers of 64 of the 67 people followed-up (96%) but not for two persons presently resident in Muckamore and the person living with her family.

Present residence

Key-workers rated 48 persons (80%) as being 'very well suited' to their present placement and a further 11 persons as being 'reasonably well suited'. Only one person was rated as being not suited to their present placement; a residential home. (Four key-workers did not answer this question.) However a higher proportion of people in nursing and residential homes (87%) were rated as 'very well suited' compared to those in community housing (38%) (Chi Sq 12.0 $p < 0.05$).

The reasons given for placements being well suited centred around the service meeting the client's needs; they were happy and content, and their behaviour had improved. Comments linked with 'reasonably suited' tended to mention the person being too able for the group they lived with (2) being closer to their family (2) having a more structured routine (2) and not suited to the other tenants (2).

Key-workers were asked to note what sort of placement would be needed for the person if the present arrangements were no longer available. Different arrangements were noted for 13 persons (20%). These included:

	<i>Number mentioning</i>
Smaller community based house	4
Own accommodation with support	2
Sheltered accommodation	1
Higher staffing	1
Nursing Care required	1
Challenging Behaviour Unit	1
24 care required	1
Community house with space	1

These suggestions may be indicative of changes in the person's needs since moving to their present placement or it may indicate a placement that was not available when the person left the hospital.

Care Practices

All the residents were reported to have a care plan drawn up for them and this had been reviewed during the past 12 months for all but two persons. Likewise a review had been held for the person during the past 12 months and 38 persons (59%) had attended their review. With 52 persons (81%) a weekly activity planner had been drawn up. This was more often the case for those in residential homes (91% of these residents)

compared to nursing homes (55%) and community residences (62%) (Chi Sq 10.1 $p < 0.05$).

The extent of choices that residents could make was assessed using a 24-item scale. For each choice, the key-worker selected one of four options; namely resident has the final say (unless clearly inappropriate or dangerous); regular choice given but final say does not rest with the person; occasional choice offered and no choice available.

The choices that most residents were reported to have the final say were:

	<i>Number mentioning</i>
Clothes worn each day	45
Leisure activities take part in home	45
Choice of Personal possessions	42
Haircut	40
Time go to bed	38
Time spent in bath/shower	37
Clothes purchase	35
Content of evening meal	35
Day-time activities	32

The choices they were least likely to have the final say in were:

	<i>Number mentioning</i>
Firing of unsuitable staff	0
Recruitment of staff	1
Staff performance review	1
Who they live with	7
Keeping pets	8
Where they live	9
Moving home in the future	10
Involvement with friend of opposite sex	15

There was a tendency for residents in nursing homes to have fewer choices in which they had the final say (mean 8.6 choices) compared to those in residential homes (mean 11.0) and in community settings (mean 16.6). ($F=3.36$ $p<0.05$).

When asked to give a reason for why choice might be limited for the residents; the most common reasons were:

	<i>Number mentioning</i>
Poor communication	14
Challenging behaviour	13
Resident would make inappropriate choices	5
Not motivated to make choice	3
Family make choices	3
Guardianship Order/Detained patient	2
Other residents restrict choice	1
Building restricts choice	1
Availability of staff	1
Inappropriate sexual advances	1

Social Contacts

Tables 17 and 18 list the residents' contact with family and friends outside of the residence. Over two-thirds have regular (once a month) or frequent contact (at least fortnightly) with relatives. Contact with the family takes the form mainly of visits to relative's home and overnight/weekend stays (17 people); telephone calls (11 people); relatives visiting the residence (7) and taking the person on outings from the residence (7 persons).

By contrast, contact with friends outside of the residence is very much less with only 14 people (21%) having regular or frequent contact. However this includes contact with people from the day centres. Only five people were reported to meet their friends away from the centres; through visits to the residence (4) or going out with them socially (2) or for shopping (1).

Table 17: The number and percentage of residents having contact with relatives (n=65)

<i>Frequency of contact</i>	<i>Number of residents</i>	<i>Percent</i>
Frequent contact	26	40
Regular contact	19	29
Occasional contact	11	17
Known relatives but no contact	3	5
No known relatives	3	5
No answer given	3	5

Table 18: The number and percentage of residents having contact with friends outside of the residence (n=65)

<i>Frequency of contact</i>	<i>Number</i>	<i>Percent</i>
Frequent contact	8	12
Regular contact	6	9
Occasional contact	1	2
Has friends but no contact	5	7
No known friends	39	57
No answer given	6	9

In addition, 11 people were said to have visited friends at the Hospital and 4 to have had friends from the Hospital come to visit them.

Leisure Pursuits

For each resident, the key-workers were asked to note if they had taken part in the activities listed in Table 19 within the past four weeks. Items marked with an asterisk may include services provided by the residential facility rather than in community settings.

Overall, the mean number of activities was 5.6. However people living in nursing homes had a significantly lower mean score (3.1 activities) than those in residential (mean score 5.8) or community homes (7.4 activities) ($F=6.1$ $p<0.01$). A similar pattern was reported by Emerson et al (2000) when comparing people living in residential campus settings and those living in dispersed community housing.

Table 19: The number of people who have engaged in the activities listed (n=65)

<i>Activity</i>	<i>Number of residents</i>	<i>Percent</i>
Been shopping	51	79
Been on the bus*	39	60
Been to a café	39	60
Been to a hairdresser*	38	59
Had trips out with family or friends	37	57
Been to the pub	37	57
Been on an overnight stay	16	25
Been to their bank	19	29
Been to the cinema	18	28
Been to a place of religious worship	14	22
Been to a Social club	13	20
Been to a play or concert	11	17
Had family or friends round for a meal	6	9
Been to a sports event	6	9
Had guests to stay	0	0

Keyworkers also noted for 32 people, one or more leisure pursuits that people did with their co-residents who were friends. These are summarised in Table 20. However only 14 people were noted to take part in activities outside of the home.

Table 20: The number of people who have engaged in the activities listed with friends (n=32)

<i>Activity</i>	<i>Number mentioning</i>
Chatting together	10
Going to the pub	7
Listening to music	6
Shopping	6
Outings in car/bus	7
Cinema	4
Meals out	3
Walks	3
Social outings	3
Social Clubs	3
Bowling	3
Playing games	2
Singing songs	1

In all, 27 people (42%) were reported to have had a holiday in the past 12 months.

These results largely mirror the answers given by people themselves when they were interviewed (see earlier).

Summary

- ☐ Key-workers rated all but one of the residents as very well-suited or reasonably well suited to their present placement.
- ☐ Suggested improvements centred around smaller, community based accommodation and people having their own houses while others required increased care and support.
- ☐ Most residents appear to have choice over clothes, leisure activities and household routines with few having choice over staff or where and with whom they live.
- ☐ Two-thirds of residents had at least monthly contact with relatives but less than a quarter had contact with friends outside of the residence.
- ☐ The majority of residents made recent use of various community facilities although this was less for people resident in nursing homes.

Views of Care Managers

Overview

Care managers were asked to provide information about the choice of placement for the person; the people involved in the decisions and other options available at that time. Their views were sought on the present residence in terms of what they liked about it; the expectations they had for the placement and the improvements they would like to see. Ideas for alternative placement were requested. Their perception of risks of abuse was also sought.

Sample

Care managers or social workers were sent a self-completion questionnaire for all the persons in their Trust who were in the resettlement population and had moved into some form of residential accommodation; 67 persons in all. Replies were received for 51 persons (76%). Despite repeated reminders, Down Lisburn and Ulster Community Hospital Trust submitted returns for less than half of their residents.

Of the 51 people on whom care managers reported; 36 (70%) were living in residential homes; 8 (16%) in nursing homes and 7 (14%) in community settings.

Move from the Hospital

The main reasons given by the care managers for the choice of placement are summarised in Table 21. The two main influences were the assessed needs of the person and the choice of client and/or family.

Table 21: The reasons given for choosing the placement (N=51)
(NB More than one reason could be given.)

<i>Reasons</i>	<i>Number of mentions</i>
Met assessed need	31
Choice of client and family	14
Choice of family	8
Choice of client	6
Challenging behaviour	6
Home area	4

Care managers were also asked to list the people who had been involved in making the choice of residence and the replies for 47 people are summarised in Table 22. For most people these included consultant psychiatrists, hospital staff (notably nurses), care managers and social workers. A variety of other professionals were named, probably because of the specific needs of certain individuals.

Although staff from the receiving residential unit were not often involved in the choice of placement, all persons left the hospital on a trial basis and this provided an opportunity for these staff to assess the suitability of the placement.

Table 22: The people involved in the decision about choice of residence (N=43)

<i>Person involved</i>	<i>Number of residents</i>
Consultant Psychiatrist	32
Hospital staff	31
Social worker	30
Care Manager	29
Family	28
Client	25
Day Care Staff	16
Community team	11
Receiving Unit	8
Psychologist	5
Physiotherapist	2

Other residential options were reported to have been considered for only ten (20%) of the 51 residents. In the main, these were the same type of accommodation as the one in which the person was placed, e.g. other residential homes.

Suitability of present placement

In all 45 (88%) of the 51 persons were rated as being well suited to their present placement and 6 persons as 'reasonably well suited'.

The things which the care-managers liked best about the placement are listed in Table 23. Although a variety of things were named, the availability of day care was the most commonly mentioned.

Table 23: The features which care-managers liked about the resident's current placement (N=48)

<i>Features liked</i>	<i>Number of mentions</i>
Day care available	22
Purpose-built, modern facility	15
Links with community	14
Close to family	13
Small unit, homely	12
Staff supervision and support	11
Safe and settled environment	10
Resident is happy and healthy there	7
Home area of resident	6
Specialist facility	6
Person-centred approach	4
Community based	3
Relative/friends in residence	3
Promotes independence	3
Person choose it	2

Table 24 shows the expectations of the care managers about what the person will gain from their placement. The two main themes were increased independence for the resident and more family contact.

Table 24: The expectations that care-managers hold for the placement

<i>Change expected</i>	<i>Number of residents</i>
More independence and maturity	27
More family contact	21
Safe and settled environment	15
Promote self-help skills	12
Access community facilities	7
Move on to independent living	6
More choice	5
Improved quality of life	4
Specialised approach	3
Decrease in problem behaviours	3
Remain out of hospital	3
Day activities provided	2
Risks controlled	2

Care managers were also asked to note up to three things they would like to see improved in the present placement and these are summarised in Table 25. Improved day care options and greater access to community facilities were the most commonly mentioned issues. However a range of issues were noted for individuals including more socialising, moving to a bigger unit for more company, better physical surroundings, self-help skills being promoted, person's safety improved and epilepsy better managed.

Table 25: The improvements that care-managers would like to see in the client's placement.

<i>Improvement</i>	<i>Number of mentions</i>
Day care options	13
Greater access to community facilities	10
Smaller unit	7
Single room provided	4
Move to supported independent living	4
Better and more flexible staffing	3
Accepting of staff support	2

Risk of abuse

Care managers were asked to give an assessment of the risks of abuse that they felt the resident could pose to other residents or the risk they had of being abused by others. This information was not requested from other informants as it was felt care-managers would be in the best position to provide this.

Table 26 summarises the results. Although the numbers are small and the differences could not be tested statistically, all but one of the ten people identified live in residential homes. It appears that safeguards are in place in all instances to cope with these risks.

Table 26: The number and percentage of residents thought to be at risk of abusing others or being abused

	<i>Risk to others</i>	<i>Risk of being abused</i>
Solid evidence exists	3*	0
Some reason for concern	6^	5*
Possible but no real reason for concern	13	20
Little or no risk	29	26
Total	51	51

* People in residential homes: ^ 5 of six are in residential homes

Future Accommodation

Finally, care managers were asked to state the type of service the person would require if they had to move from their present service. Table 27 summarises the replies given for 44 persons

Table 27: Alternative accommodation if present placement was no longer available (N=44)

<i>Type of accommodation</i>	<i>Number of mentions</i>
Supported Living	15
Residential home	12
Nursing Home	8
Highly supervised accommodation	5
Specialised Unit	3
Secure Hospital ward	1

However there are plans for only three persons to move in the future; from residential homes to more independent supported living arrangements.

Summary (NB Based on returns for 76% of people resettled)

- ☐ The present placement was chosen mainly on the basis of assessed needs and the preferences of the family and the person themselves.
- ☐ Alternative accommodation was available to only ten people.
- ☐ A team of people were involved in making the decision to move. Consultant psychiatrists; hospital staff, social workers, care managers, family and clients were involved with the majority of people.
- ☐ Care managers rated the present placement as very suitable for 88% of residents and reasonably suitable for the remainder.
- ☐ Increased independence and improved family contact were the two main outcomes expected from the placement.
- ☐ The main improvements suggested to the present placement centred on improved day services and greater access to community facilities.
- ☐ Ten people were thought to be at risk of abuse from others or of abusing others. All but one lived in residential homes. Safeguards were in place to cope with these risks.
- ☐ Care managers mentioned supported living arrangements as the main form of preferred alternative accommodation. However there are plans for only three people to move from their present placement and this is into supported housing.

Costs

Overview

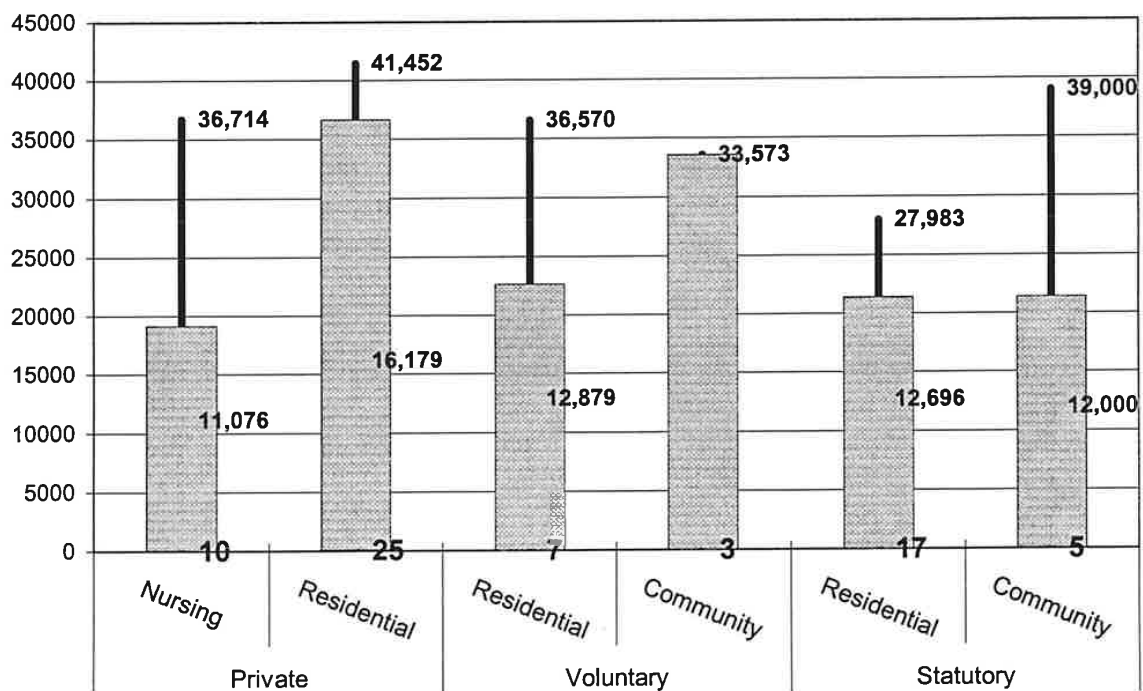
Information was supplied by the EHSSB of the costs to them of the resettlement packages. In addition other costs and sources of income were identified. Relationships between costs and type of setting; client characteristics and outcomes were explored.

EHSSB Costs

According to EHSSB figures, 83 people were considered to have been resettled at a total cost of £2.15 million. As explained earlier (see p.11), 15 people in this group did not meet the criterion for resettlement, namely resident in the hospital for at least one year and had been discharged in the period January 1996 to April 2000. The costs for this group of 15 persons amounted to £321,524; 17.5% of the total amount.

The cost of the resettlement packages for 68 people amounted to £1.833 million. This was inclusive of day service costs. A regression analysis was undertaken to determine the significant predictors of cost⁹. The only two significant predictors were the provider agency and type of accommodation.

Figure 4: The median, lowest and highest costs of residential accommodation by type and the numbers placed in each.



⁹ The variables entered into the equation were the type of accommodation (i.e. nursing home; residential and supported living) the provider agency (i.e. private, voluntary, statutory), size of the residence and owning trust. The client measures were dependency level, mental health problems, challenging behaviours and physical health problems.

As Figure 4 shows, the highest costs were in the private residential homes where 25 people had been placed. By comparison, the costs in the statutory residential homes (17 placements) were significantly lower in terms of median, minimum and maximum costs. Residential homes run by voluntary organisations had similar median and minimum costs to the statutory homes but a higher maximum cost.

The median costs of nursing home accommodation was the lowest across all the options but within this option the range of costs was high. Indeed with the exception of costs in the community houses run by voluntary organisations, there is a wide range of costs involved in all types of provision. This is highest in the community accommodation provided by the statutory sector with a more than three-fold difference from lowest to highest costs.

This variation cannot be explained in terms of the resident's characteristics at least as reported by key-workers from these homes. Thus residents with higher dependency needs, mental health problems, challenging behaviours or physical health problems do not have a higher cost allocated to them. It could be that these costs represented needs at the point of resettlement and these have subsequently changed.

The failure to find close correspondence between costs and client characteristics is a common one in past studies. Rather the main determinant of costs appears to be the model of service provided, especially in terms of staff cover. Perhaps this is not too surprising as the costs of these packages were predominantly calculated on a 'block basis' and using notional staffing ratios rather than on the assessed needs of individuals for staff support.

In past studies, costs have generally been lower in private and voluntary sector provision than in statutory homes (Beecham et al, 1997). However the present study does not include the management and administrative costs that statutory services may have absorbed.

An accurate cost of providing for these clients in hospital was not available. It is estimated that these are currently in the region of £39,000 per annum. Thus nearly all the care packages for these individuals continue to be lower than the costs of hospital placements; a finding reported also by Beecham et al (1997). By contrast the costs of English resettlements in community accommodation tend to exceed the hospital costs (Emerson and Hatton, 1996).

Breakdown of costs by Trusts

Table 28 summarises the costs of the resettlements across the four Trusts.

Table 28 : The costs of the resettlements packages by Trusts

TRUST	N	Median	Minimum	Maximum	Sum
Ulster Community	15	£33,573	£12,769	£36,647	£449,816
Down Lisburn	10	£32,171	£22,224	£41,452	£317,229
North & West Belfast	29	£21,957	£12,000	£36,746	£707,192
South & East Belfast	14	£21,407	£11,076	£39,000	£358,857
<i>Total</i>	<i>68</i>	<i>£27,696</i>	<i>£11,076</i>	<i>£41,452</i>	<i>£1,833,094</i>

The differences were not statistically significant although there was a tendency ($p < 0.09$) for the median costs to be higher in Ulster Community & Hospital Trust and Down

Lisburn Trust than in the two Belfast trusts. The earlier data suggests that these costs are influenced by the model of service chosen by these Trusts. For example Down Lisburn placed all their people in residential homes while North & West Belfast had the highest use of Nursing homes.

Cost of community services

An additional cost is the professional inputs provided to these clients by community health and social service personnel¹⁰. As described earlier (p.16) the number of contacts was greatest with GPs, dentists, social workers and psychiatrists. With the exception of the latter, these were similar across the three types of accommodation although psychiatrists tended to have more contact with residents in community and residential homes than with those in nursing homes. And although psychologists saw relatively few people, these were all living in residential homes. Likewise community nurses were involved mainly with people in community settings.

Emerson et al (2000) report these costs as averaging between £650 and £1,200 per annum which is relatively low compared to the cost of the overall care package but for the population in this study they would tend to increase the costs of placements in residential homes and community settings compared to those in nursing homes.

Other funding sources

The monies provided by the EHSSB are supplemented by additional social security payments and housing benefits. Although care managers were asked to supply these figures, they were only available at best for 34 persons. Hence it was not possible to calculate accurately the total costs per individual package. However the median costs across all types of accommodation was £8,000 although those living in homes provided by the voluntary sector and housing associations probably attracted higher housing benefits. But these may have produced costs saving for the EHSSB.

Costs and Outcomes

There is little consensus regarding the outcomes that residential services should be expected to achieve for people with learning disabilities although this is increasingly influenced by the Quality of Life themes (Felce and Perry, 1996). Four aspects in particular have featured in recent research (Emerson et al, 2000): the amount of choice the person experiences in their daily life; their social relationships with friends and family; the extent of leisure activities they experience and their physical health and well-being. Does a higher cost care package produce better outcomes on these measures?

Spearman rank correlations were therefore calculated between the cost of the packages to HPSS and the measures completed by key-workers to reflect the above outcomes. None of these correlations were statistically significant either across the total sample or within the residential homes. Hence there does not appear to be a relationship between costs and outcome measures of choice, leisure activities, social relationships and health.

¹⁰ *Although additional monies were provided by the Board to certain Trusts to augment their community services, these could not be apportioned specifically for the people who had resettled.*

Summary

- ☐ Although the Board had allocated £2.15 million towards resettlement; 17.5% of this was spent on funding people who were already in community settings.
- ☐ There was nearly a four-fold difference between the lowest cost package (£11,000) and the most expensive (\$41,500).
- ☐ The most expensive packages for the EHSSB were in private residential homes with nursing home and statutory residential homes providing the lower cost packages. However when other sources of funding are added in, supported living packages in community settings are also among the highest in cost.
- ☐ There was no apparent relationship between the cost of the packages and the needs of the residents in terms of dependency level, challenging behaviours, mental health and physical health problems.
- ☐ There was no relationship between costs and outcome measures such as amount of choice, number of leisure pursuits and social relationships. Hence the sole determinant of cost is the model of accommodation chosen.

Discussion and Implications

Overview

The main conclusions of the research findings are summarised in terms of its successes and shortcomings with comparisons made to previous research findings from N. Ireland and elsewhere. The implications and issues for future resettlement programmes are discussed.

The successes of resettlement

The findings of the study confirm the conclusions of Emerson and Hatton (1996) regarding the outcomes from previous resettlement programmes in these islands.

The move from more to less institutional environments is associated with improvements in material standards of living, increased user satisfaction, increases in adaptive behaviours, increased participation in community-based activities and increased contact with family and friends (p. 30).

"Improved material standards of living" is evident from the numbers of people having their own bedroom instead of the dormitory-style accommodation of the Hospital and they are living with smaller numbers of people. Their relatives also commented on the homeliness of the surroundings and the modern buildings.

"Increased user satisfaction" is clearly present. The residents themselves are happier; mentioning many more things they liked and fewer dislikes compared to the Hospital. Nearly all their relatives rated the present placement as better than the hospital; even those who were initially unhappy at the prospect of their relative moving.

Although the study is not able to document increases in adaptive behaviours and in contacts with the community and family; these can be inferred from comments made by residents; relatives and the care-managers; for example, most of the people have access to community facilities; many have trips out with their family and some stay overnight with them.

In addition a number of other features appear to have been successful with these resettlements.

Day activities were provided for nearly all the residents. The finance for this was included in their care packages which was possibly not the case in the past, when the dearth of day activities was noted. However it is an aspect that still needs improvement as will be discussed later.

Residents had access to health services. High levels of contact are reported with GPs. In addition residents are accessing a range of specialist and generic services as needed.

Improvements in problem behaviours Key-workers reported fewer people having problem behaviours especially of a more minor nature.

Patients with high dependency needs; challenging behaviours and mental health problems were successfully resettled. Although direct comparisons with previous

Northern Irish resettlement populations was not possible; it appears that this group included individuals with higher support needs.

The level of placement breakdowns is low Just over one in ten of the original placements did not work out; with three people moving to another residential home and four people are presently back in hospital. It is not yet clear whether or not they will be returning to their place of residence.

In sum, the resettlements have brought notable gains for the people resettled from hospital - including those with extra needs. This represents better value for the money expended. Also relative's unwillingness was overcome and access to health and social service professionals was maintained.

Shortcomings of the resettlement programme

These resettlements fall short in four main areas compared to the aspirations set out in the Eastern Board's model of community-based services.

Reliance on congregated living models

Nine out of ten people moved into residential and nursing homes ranging in size from six to 72 beds. This proportion is only marginally lower than the 98% reported by Donnelly et al (1996) who moved into similar accommodation between 1990-92. In that study a much higher proportion of people went to nursing homes compared to the present population but there were financial incentives for the doing this in the early 90s.

Supported living models have not been used to any great extent for resettlements despite being promoted by the Board in their model of services and the benefits which this model of housing and support has been shown to offer people with learning disabilities over other forms of accommodation (Emerson et al, 2000).

The continuing reliance in N. Ireland on private sector providers is also noteworthy as is the relative low usage of the voluntary sector compared to Great Britain (Emerson and Hatton, 2000) and the Republic of Ireland. This entails greater costs for health and social services as housing benefits and independent living fund monies cannot be claimed.

Failure of people to move on

Although people's needs were reported to be reviewed annually in their place of residence, there is little indication that people who need or aspire to move into other accommodation are doing so. The key-workers identified 13 people whom they thought required a different type of placement; mostly into more independent living arrangements. Like-wise this was the option most commonly mentioned by care-managers if the existing placements were no longer available. However it appears that this has happened for only one person since they moved from hospital with plans for only another two people to follow this option.

What is it that keeps people 'trapped' in inappropriate settings (McGinnity et al, 1992)? In the past, explanations revolved around the perverse incentives associated with preserved rights payments. This is not the case with these resettlements. There are a number of inter-related factors; the predisposition of professional staff to stick with 'tried and tested' models of care, the lack of immediate support for people in more independent settings and the fears of relatives and even the individuals themselves.

However these same issues probably surrounded the initial placements from hospital and were worked through then. Thus the changing needs of the residents must be reflected in regular reviews of needs and updated care-packages. This is especially crucial with the present resettled population half of whom are under 37 years of age and the youngest is 20 years old.

Social Integration

A common failing of many resettlement projects has been the failure to create social networks of acquaintances and friends for the people with learning disabilities. Although the proportions of people claiming to have friends outside of the residence is higher than that reported by Donnelly et al (1996), it is still fewer than one in four persons according to the key-workers and the residents themselves and is likely to be another person with a learning disability.

A number of factors can contribute to this. A prolonged stay in hospital; the geographical isolation of the residence from the person's home area and the inability of the person to travel independently are all possible factors. In addition the priority of commissioners of services and of Registration and Inspection Units has been on the physical well-being of residents rather than on their social inclusion. However a number of agencies have started to develop befriending schemes as a means of building up resident's involvement in community activities and extending their social networks. These and other efforts, such as reviewing the role of support staff should feature in future resettlements.

Slow down in resettlements

The highest number of people resettled was achieved in 1997 with 31 persons leaving the Hospital. Since then the numbers have declined to only one in 2000. The reasons for this slow down fall outside the scope of this study but it is now extremely unlikely if not impossible for the Board to achieve the Department's target of 'zero' people in long-stay hospitals by 2002. Consideration of the reasons for this should help identify critical elements in future resettlement programmes.

Implications for future resettlements

This study focussed on patients from the EHSSB area who had been resettled in recent years. Nonetheless it is likely that the implications extend to other parts of N. Ireland as similar issues have merged to that reported in past studies that involved resettlements in other Board areas.

Money

Although cost comparisons are difficult to make with studies done elsewhere, recent research carried out in Great Britain reports the average per annum accommodation costs (at 1997/98 levels) as ranging from £32,000 in 'village communities' to £46,000 in NHS residential campuses and dispersed housing schemes (Emerson et al, 2000). These authors also note the wide range of costs within these options from £19,000 to £90,000. In the present study the cost range was narrower with the median costs (inclusive of social security benefits) generally lower than the British figures.

However the costs in the private residential homes and voluntary community costings were higher than those in village communities but lower than for dispersed housing and NHS accommodation. However the N. Irish figures includes day service costs of up to

£5,000 per annum which are not included in the British costs. It is reasonable to conclude therefore that less money continues to be spent on resettling patients from N Irish hospitals than in Great Britain (Beecham et al, 1997). Hence there is a bigger risk here that the choice of place is cash-driven rather than on the basis of client need and quality of life outcomes.

This may also explain the lack of correspondence in this study between costs and client needs in terms of dependency level, challenging behaviours and mental health needs. Emerson et al (2000) report similar findings for NHS campus settings which are the closest to the residential homes used in N. Ireland. He found no cost differences for residents with higher dependency and challenging behaviours although those with mental health needs did have significantly higher costs. However for those in dispersed housing and supported living schemes; the costs were significantly higher for residents with higher dependency and challenging behaviours but not for those with mental health problems. Thus the Board's preferred model of ordinary living for these clients may well incur increased costs in order to meet the particular needs of certain clients. It is likely also that a higher proportion of such clients remain to be resettled from the Hospital; especially those in the 'discharge delayed' category presently in treatment wards at the Hospital.

Housing options

At the end of the 1990s most resettlements in N.Ireland are still into congregated living models. This suggests a dearth of housing and support options which is indeed the case as a study in the NHSSB identified (McConkey and Barr, 2000). Among the options that have been developed elsewhere (Simons and Watson, 1999) and which are starting to develop in N. Ireland (McConkey and McConaghie, 2001) are shared housing for 2/3 persons; single person tenancies; owner-occupancy options and adult placement schemes.

It is essential to develop such schemes for three user-groups. First, those in existing residential homes who could live more independently and thereby create places for those moving from hospital for whom these placements may be more suitable. Second, for people presently living with their family so that they can continue to live in to the local community when their carer is no longer able or available to care for them. Third, for people moving from Hospital who may find it hard to live with others.

Hence future resettlement programmes should be executed within the wider framework of expanding housing and support options within community settings rather than focusing solely on placing individuals from the Hospital.

A related issue is the geographical location of new housing developments. This study found that the majority of people were placed in Co. Down although most were the responsibility of the two Belfast trusts. In part this may be skewed by reliance on the private sector but it does call into question the Board and Trust's commitment to the provision of local services.

Furthermore all the people from one Trust were placed in the one type of residential accommodation. This may not reflect the balance of accommodation as a whole within that Trust but if it did, then there would be issues of equal access and availability to a range of service options for users across the Board area.

Community supports

Resettlement is not simply a question of finding alternative accommodation for people living in hospital. As many studies have shown, this one included, the provision of a comprehensive care package is essential to prevent placements breaking down. In this regard, the inclusion of day care activities is essential and the most recent resettlements have incorporated these. Although these are commented on favourably, nonetheless care-managers did see room for improvement as did some of the residents and relatives. Three dimensions might be worth pursuing; the use of community facilities and the development of social networks; the use of further education and vocational training opportunities; and the provision of work experience and employment opportunities. These options will also increase social inclusion.

The availability of professional supports is also important (Allan, 1999). Interestingly a higher proportion of people living in community settings were rated by key-workers as 'reasonably well-suited' rather than 'very well' suited to their placement. Moreover these were the people who were more likely to have been readmitted to hospital. People with mental health problems and/or challenging behaviours may be in need of particular specialist support. This could come from trained support workers but they in turn may need advice and guidance from professionals. The data suggests that this was available to most of the residents living in community housing from psychiatrists and social workers but fewer people were in contact with community nurses and none at all with psychologists. Hence improved access to multi-disciplinary teams may increase the suitability of this form of accommodation to people with extra needs.

Service Outcomes

Greater attention needs to be given in future commissioning on the outcomes that residential, housing and support options produce for people with learning disabilities. This will help to ensure that best value is obtained for the monies expended.

To date, the most commonly used frameworks are the five accomplishments proposed by O'Brien (1987) and expanded by Felce and Perry (1995) into a quality of life schema. These emphasise the importance of choice, social integration, day and leisure activities and physical health and well-being. There is increasing evidence that certain models of provision are more likely to produce desired outcomes than others (Felce et al, 1998: Emerson et al, 2000). Equally congregated models of care – such as those predominantly used in N. Ireland to-date – are less likely to provide favourable outcomes. Nonetheless the correspondence between costs and outcomes remain weak given the wide variations reported within the same model of provision.

In future, commissioners should specify more precisely the outcomes expected from the placement for the individual and institute monitoring procedures to ensure that these outcomes are being achieved. This study suggests that this could be built into the care-management process with clients, key-workers and relatives playing an active role in reviewing and developing the services.

Conclusions

- ☐ This follow-up of people who have been resettled from Hospital has confirmed the benefits to people of moving on from the Hospital.
- ☐ Equally it has identified four shortcomings compared with the aspirations of the Board and the outcomes of similar programmes undertaken in Great Britain; namely the continuing reliance on congregated living settings; the failure of people to move on to more independent living arrangements; the dearth of social networks experienced by people in the various types of residential accommodation and the slow down in the resettlement programme from 1997 which makes it very unlikely that the Regional target will be met by 2002.
- ☐ Four issues require urgent attention if the lessons from this and previous studies in N. Ireland are to be heeded; namely the relative under-funding of resettlements compared to Great Britain; the development of a wider range of housing and support options; the need for improved community support services and a clearer focus on outcomes expected from residential services.

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Appendix 1

Residences to which people moved

<i>Name of Residence</i>	<i>Number of people resettled (N=68)</i>	<i>Number presently living there (N=67)</i>
Residential Homes		
Beeches Ballynahinch	22	22
Ardcora	7	7
Down Residential Project	3	3
Hanna Street Hostel	3	3
Kimberley House	3	3
611 Ormeau Road	2	1
Aaron House	2	1
Mertoun Park	2	1
Bridge House	1	1
Edenvale	1	1
Hill Hall	1	1
RNID (Derry)	1	1
Shaws Avenue	1	1
Fairhaven	1	1
Rigby Close	0	1
Nursing Homes		
Somerton Road	3	3
Arches	1	1
Glencairn Clinic	1	1
Maine PNH	1	1
(Ladyhill) Mehran	1	1
Queenscourt	1	1*
Three Island PNH	1	1
Wheatfield	1	1
Shared Housing/Supported Living		
S&E Belfast Trust Supported Living	2	3
URNI – Ambleside Drive	2	2
Grays Park Court	1	1
URNI - Squires Hill	1	1
Greystone Complex	1	1
With family	1	1

** person died after information gathering started*

00002

The same as you?

A review of services
for people with
learning disabilities

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Ministerial foreword

It is over 20 years since the last policy initiative on learning disability services in Scotland. Although there has been progress in many areas since then, it has not been consistent. Overall, the pattern of services in Scotland is not as advanced as in many countries in Europe. So, I very much welcome this wide-ranging review, and the way it has been carried out. In it we meet the commitment in our Programme for Government 'Making It Work Together' to publish in 2000 our proposals for services for people with learning disabilities.



The Learning Disability Review has succeeded in involving many of those with an interest, especially those who use services and their carers, at different points in the journey. I know from meeting people how much that has been welcomed and valued. I was involved in the review-visiting projects, at one of the seminars and answering questions in a live internet session. I was very impressed by the desire for change, the reasonableness and responsibility of those pressing for it and the willingness of agencies to respond.

This review began by looking at services, especially in social and healthcare, and their relationship with education, housing, employment and other areas. However, its focus changed to include people's lifestyles. That is what matters. Services are there to support people in their daily lives.

We are committed to improving the quality of life for people with disabilities. The review reflects our wider policies including **social inclusion**, equality and fairness, and the opportunity for people to improve themselves through continuous learning. These are just as important and just as relevant to people with learning disabilities as they are to all of us.

The focus of the report is consistent with our existing policies on community care. 'Modernising Community Care' wants better results for people through quicker and better decision-making, greater emphasis on care at home and agencies working more closely together. Our desire to improve the general health of people with learning disabilities is also directly related to our aims

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in 'Towards a Healthier Scotland'. The responsibility of the Joint Future Group, which I chair, is to build on both these documents and identify and promote good practice in working with others.

People with learning disabilities should be able to lead normal lives. We want them to:

- be included, better understood and supported by the communities in which they live;
- have information about their needs and the services available, so that they can take part, more fully, in decisions about them;
- be at the centre of decision-making and have more control over their care;
- have the same opportunities as others to get a job, develop as individuals, spend time with family and friends, enjoy life and get the extra support they need to do this; and
- be able to use local services wherever possible and special services if they need them.

People with learning disabilities want to make a positive contribution to society. Communities and individuals must learn to recognise their needs and respond more positively to them. A programme to improve public awareness is part of helping them to have a better quality of life.

I particularly welcome the opportunities for people to have more say and more control over their lives. Professionals need to acknowledge their limits and the rights of others. Using **direct payments**, **brokerage** and advocacy services more will help people have more influence.

Lastly, the review recommends that for all but a few people, health and social care should be provided in their own homes or in community settings alongside the rest of the population. I know that many people will welcome this idea. However, we must put in place the appropriate services and support to allow people to live properly in the community, to allow the rest of the long-stay institutions to close.

In welcoming the vision for the future, we have to be realistic and recognise the many pressures there are for resources both nationally and locally. We want and need to make the lives of people with learning disabilities better. Over time that will need more resources but now we can make better use of the considerable funds that are available in all sectors. The review gives agencies very clear signals about the level of change needed. People with learning disabilities and their carers must see early evidence of that beginning to take shape.

A handwritten signature in black ink, appearing to read 'Iain Gray', with a long, sweeping horizontal line extending from the end of the signature.

Iain Gray MSP

Deputy Minister for Community Care

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How the review was done

- 1 We formed four main groups (see appendix 7 for details):
 - an interdepartmental steering group;
 - a multidisciplinary working group;
 - a users' and carers' group; and
 - a stakeholders' group made up of experts in the field.
- 2 We set up six smaller task groups with specific responsibilities to discuss **complex needs**, best practice, training, the **mapping of services**, best-value, and children's services.
- 3 We carried out a major consultation to get a good understanding of:
 - learning disabilities;
 - the experiences people have of services;
 - the demand for services; and
 - what the solutions to service shortfalls might be.
- 4 We used a range of methods including the following.

Written views

We wrote to over 600 people and agencies inviting their views on current services and on the shape of future services.

Website (<http://www.scotland.gov.uk/ldsr/>)

We set up an interactive website to give and receive information about the review and to generate on-going debate. Iain Gray, Deputy Minister for Community Care, held a live session on the web to hear the concerns and hopes people have. The website contains most of the material we used.

User and carer roadshows

The user and carer group held 11 roadshows across Scotland to get a national view on what people with learning disabilities and their carers need and want.

Site visits

We visited sites across Scotland to see, at first hand, good and new, creative projects.

Meetings

We met people who used services, carers, staff and representatives from professional organisations to listen to what they felt was important now and in the future.

Conferences

We held four national conferences across the country:

- explaining the reason for and scope of the review;
- examining the best use of resources;
- discussing good practice; and
- looking at the shape of future services.

Workshops

We held four smaller workshops on:

- children's issues;
- people with **complex needs**;
- staff development; and
- a brainstorming day for all the groups involved in the review.

Research, surveys and analysis

We carried out the following research and surveys.

- A survey of people with learning disabilities and their families about social and healthcare services.
- A survey of housing solutions and a review of international literature on housing options for those with learning disabilities.
- Research on the general health needs of people with learning disabilities.

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- Research on the needs of people with **profound** and **multiple disabilities**.
- Research on the needs of those with **challenging behaviour**.
- An analysis of those with learning disabilities who are held under the Mental Health (Scotland) Act 1984.
- A policy paper on public education about people with learning disabilities.
- Analysis of community care plans, health improvement plans, trust implementation plans, children's plans, Scottish Health Advisory Service reports, and relevant Social Work Services Inspectorate reports.

Adults and children

5 Our evidence and recommendations relate to services for both adults and children unless we say they are for a particular group such as older people or adolescents. Where we make recommendations relating to local authority services these should be considered by those dealing with adults *and* those dealing with children.

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2 The same as you?

1 Understanding the issues

“Disabled people, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.”

United Nations (1975) The Declaration on the Rights of Disabled Persons

1 People with learning disabilities have always been part of society. Sometimes they have been treated well, and sometimes they have been treated in ways that are unacceptable. Sometimes what seemed the best approach has, looking back, appeared lacking in understanding. More disturbingly there have been some well-documented serious instances of abuse. Always it has been a matter of how people deal with one another. There are important issues of human rights, responsibilities and **social inclusion** that we all need to look at if progress is to be made.

2 People with learning disabilities and their families are entitled to as full a life as possible. They are entitled to feel valued and to be included in society. They and their carers generally know best what support they need and they should be at the heart of decisions that affect their lives. Barriers that prevent people getting the right help quickly need to be removed and support services should be improved. We all need a better understanding of people with learning disabilities if they and their carers are to get better services and opportunities.

3 People with learning disabilities need help from a number of different agencies and professionals at different stages in their lives. Generally, people with learning disabilities want, and should be able, to use the local services that everybody else uses. These services need to adapt their approaches to meet the needs of people with learning disabilities. If local services cannot meet particular needs, specialist services should add to, not replace, ordinary services.

Who are people with learning disabilities?

4 There is a range of views about how useful definitions are, and how they apply in different settings. However, it is important to have a definition

so that people with learning disabilities get the services and support they need, and so that agencies can plan these services better. Our definition includes traditional descriptions from medicine and education along with details of the support that people need to be able to do the things they would like. We provide a more detailed discussion of definitions in Appendix 3. In the next few years the causes of learning disability are likely to be understood much better. The effects on our social, health and educational services will stay the same.

Our definition

5 People with learning disabilities have a significant, lifelong condition that started before adulthood, that affected their development and which means they need help to:

- understand information;
- learn skills; and
- cope independently.

6 People with learning disabilities should have a range of support and services to meet the following needs.

- Everyday needs

For example, a place to live, security, social and personal relationships, leisure, recreation and work opportunities.

- Extra needs because of their learning disability

For example, help to understand information, support to make decisions and plan, learn skills, help with communication, **mobility** or personal care.

- Complex needs

For example, needs arising from both learning disability and from other difficulties such as physical and **sensory impairment**, mental health problems or behavioural difficulties.

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7 For any of these needs the level of support will vary. A person with learning disabilities may need:

- occasional or short-term support;
- limited support, for example, only during periods of change or crisis;
- regular long-term support, perhaps every day; or
- constant and highly intensive support if they have complex or other needs which are related.

As one person told us:

"You need to take time to get to know us – we are all different."

8 So people with learning disabilities have a range of needs which will change during their lifetime. Professionals need to help people plan for the future. For many people with learning disabilities, particularly those with **complex needs**, organisations need to work together with the individual and their family to plan and support them.

People with learning disabilities should have the following.

- Services that promote and protect their health and welfare, help them lead lives which are as normal as possible and are best suited to their needs, whether at home, in schools, health services or other settings.
- Information, advice and help to get education, work and leisure that offers personal fulfilment, consistency and security, best meets their needs and personal preferences, and helps them to be included and accepted within local communities.
- Ordinary homes which are private, secure, comfortable and safe.

People with learning disabilities and their families should:

- have accurate and easily accessible information at the right time about what services and support are available locally and nationally, in a number of different ways;
- be involved when professionals make decisions about what help to

provide, so that they can have a real choice about what happens to them; and

- get independent advice and advocacy services when they need them.

Families and carers should have:

- a range of help to support them including training and advice to look after a person with a learning disability;
- access to professionals who take into account and find ways to meet their needs as carers (whether they are parents, brothers and sisters or other family members); and
- access to short breaks.

Communities need to:

- have greater understanding of people with learning disabilities and how they can contribute to the community; and
- be involved in supporting people with learning disabilities and their families to achieve their rights.

Employers need to:

- overcome prejudice associated with employing people with learning disabilities, and play their part in helping them to reach their potential.

How many people in Scotland have a learning disability?

9 We do not have enough detailed information about the number of people in Scotland who have learning disabilities. While there are some reported differences across the UK, studies suggest that, in Scotland:

- 20 people for every 1,000 have a mild or moderate learning disability; and
- 3 to 4 people for every 1,000 have a **profound or multiple disability**¹.

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10 On this basis, there are around 120,000 people in Scotland with learning disabilities. Using information from three local areas which appears to be reasonably thorough we estimate that only 30,000 people are in regular contact with local authorities or the health service in Scotland. Others may have occasional or short-term contacts.

11 Research suggests that 15-20,000 people need a lot of help to cope with daily living². Of these about 25% (4,000 to 5,000) are children and young people aged under 16. A further 25% (4,000 to 5,000) have **complex needs** which need a lot of support. People with learning disabilities are often not as healthy as the rest of the population. They may need more health support than primary care alone can provide³. As people's learning disability becomes more severe, so does the likelihood of complex health needs such as epilepsy, **mobility** and **sensory impairment**. People with learning disabilities may need support and services because of mental health problems⁴. Around 30% to 42% of children with learning disabilities may need help for emotional and behavioural problems⁵. Older people with learning disabilities have more mental health problems. This is particularly so for people with Down's syndrome who may get **early onset dementia**⁶.

12 The number of people with learning disabilities in the UK has increased over the last 35 years. Researchers estimate an increase of 1.2% a year between 1960 and 1995 of people with severe learning disabilities, with a significant increase in those who are older⁷.

13 This means that since 1965 the number of people with severe learning disabilities has increased by 50%. The number of people with moderate needs has probably increased in much the same way.

14 In 1965, many people with severe disabilities were cared for in hospitals, though the then increasing number in hospital in Scotland (about 7,000) included many people with mild disabilities and some who had no disability⁸. By 1998 less than 2,450 people with learning disabilities were cared for in hospitals⁹. The rest, including 90% of those with **complex needs**, were cared for in the community. These are very significant changes affecting:

- people with learning disabilities;
- their families;

- staff working in local authorities and health settings; and
- society in general.

15 Research suggests that the number of people with learning disabilities will continue to grow by over 1% a year over the next 10 years¹⁰. And, more will live longer, so the needs of people with learning disabilities will change.

Who provides support?

Families

16 By far the most support is provided by parents, brothers and sisters and other relatives. This is a lifelong commitment and it is striking that family carers are often given the responsibility for (and expected to provide) social and nursing care that many professional agencies refuse to offer. Research suggests that:

- 25% of people with learning disabilities have a carer aged 65 or over;
- 20% have two carers aged 70 or over; and
- 11% have only one aged 70 or over¹¹.

Younger and older carers tend to have different expectations. Younger carers may be looking at how best their child can develop, whereas older carers are likely to be worried about how their child will be looked after when they die.

Local authority and health services

17 Local authority and health services include:

- community care services;
- child care services;
- criminal justice services;
- primary care health services provided by doctors, health visitors and district nurses;
- pharmaceutical services;
- dental services;
- ophthalmic services;
- pre-school and school education;

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- housing;
- leisure and transport services.

Experiences differ a lot from person to person and area to area. The relationship a person has with primary care services is very important. In some areas people with learning disabilities enjoy the same services in the same way as the rest of the population. In others, professionals do not understand people's needs properly. It is all too common for people to miss out on, or be inappropriately referred to and accepted by, specialist services. We need local authority and health services to work together better to help people find their way through the system.

Voluntary organisations

18 For many years, voluntary organisations have provided a wide range of very important services and support for adults and children with learning disabilities and their families. The residential and other services they provide are often excellent, partly because of the length of their experience, but mainly because they focus on personal relationships. They are also highly-valued for being realistic and coming up with new ideas, as sources of accurate and accessible information, and for providing effective advocacy.

Specialist health and local authority services

19 Specialist health services in hospital and community settings have been focused more and more on those people with learning disabilities who have **complex needs**. Community Learning Disability Teams (CLDTs) have developed in most areas in Scotland over the last 20 years. Some are made up of nurses and psychologists, while others have social workers attached to them. Some provide services to adults, while others provide for children as well. Their links to other agencies also vary. Local authority specialist services have increased to meet the needs of the greater number of people with learning disabilities in the community. While CLDTs have provided a valuable service in many parts of the country, we need more consistent structures that make sure they are co-ordinated and reduce the chance of duplication.

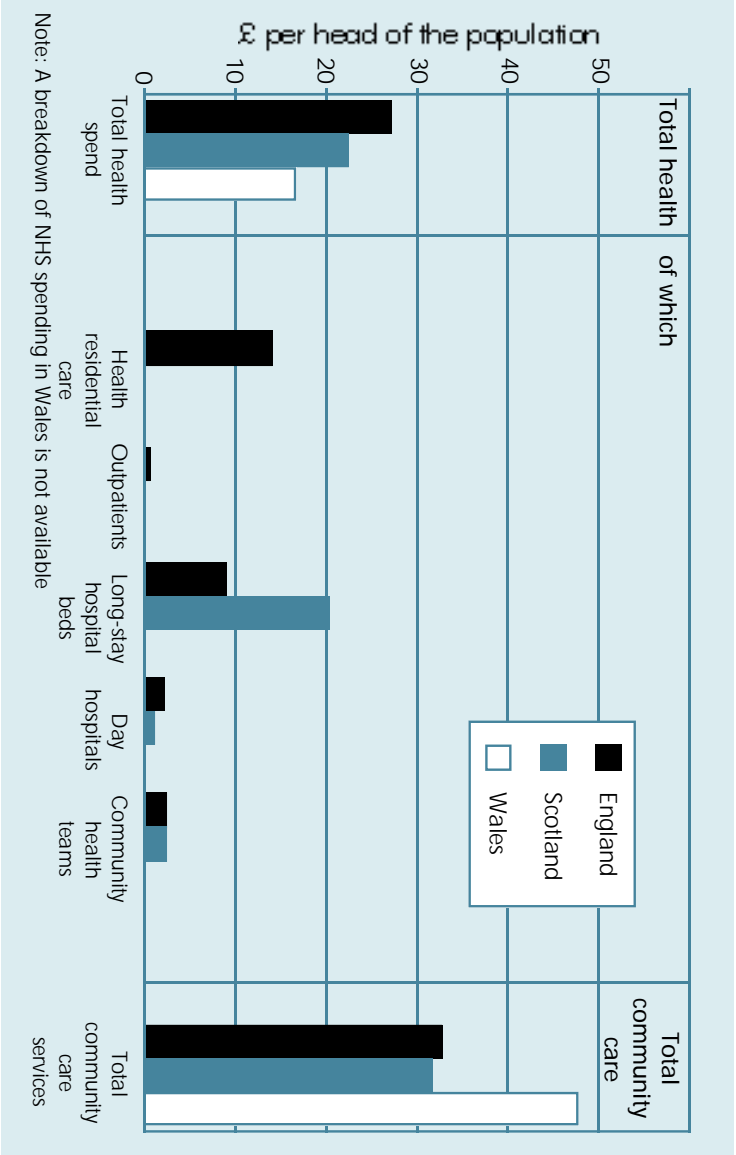
Where does the money go?

20 Local authorities and health boards spend about £275 million a year on services specifically for people with learning disabilities. About

£115 million¹² is on health services, and £160 million¹³ on social care services. Between 1980 and 1998 the number of people with learning disabilities in hospital in Scotland has fallen by nearly two-thirds from 6,500 to less than 2,450¹⁴. At the same time the number of residents in care homes for people with learning disabilities has increased from 1,000¹⁵ to 4,800¹⁶ with another 600 people living in supported accommodation. We also know of about 900 mostly older people in other homes who have some degree of learning disability. This is a significant shift, although the pace of change in Scotland has been slower than in other parts of the UK and much of Europe.

21 We can see this by comparing how resources are spent in Scotland with England and Wales. In England, health and local authorities spend £5917, 18 each year on learning disability services for every person in the population. In Wales the figure is £6319. In Scotland, the equivalent is only £5420. 21. In part this is to do with the priority given to learning disability services in England and Wales over the last 20 years. In Scotland 37% of the spend goes on hospitals, while in England only 15% is tied up in hospitals. Figure 1 below makes this clear.

Figure 1: Where the money goes England, Scotland and Wales compared



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In Wales 74% of total spending goes through local authority community care services, while in Scotland only 58% does. The result is that as well as having the lowest total spend on services for people with learning disabilities, Scotland has even less well resourced community services for people with learning disabilities, their families and carers.

22 Levels and style of service also vary a lot within Scotland. The highest-spending local authority spends seven times as much as the lowest for every person of the total population²². There are also differences in the amount health boards spend; the highest and lowest differ by 37% for every person²³. (This figure does not include the islands.) During the review, people who used services and their carers said that how well they were treated often seemed to depend on where they lived or, indeed, on the different professionals they were working with.

23 Carers said that help was often only provided when there was a crisis (when it was most expensive). They said a little support earlier might have made their lives easier and cost less.

24 Families receive very different levels and quality of service in nearby authorities or even in different areas of the same social work or health authority. The reasons behind many decisions are not clear.

Putting people first

25 Many professionals and managers agree that things need to change to help people with learning disabilities have fuller lives. But change is not easy. Many of the ways local authorities and health services organise accommodation and support for people with learning disabilities tend towards keeping things the same.

26 The review offers an opportunity to change from thinking which is led by services to thinking which is led by people's needs; from people with learning disabilities having to depend on separate care services, to their being able to use everyday services more.

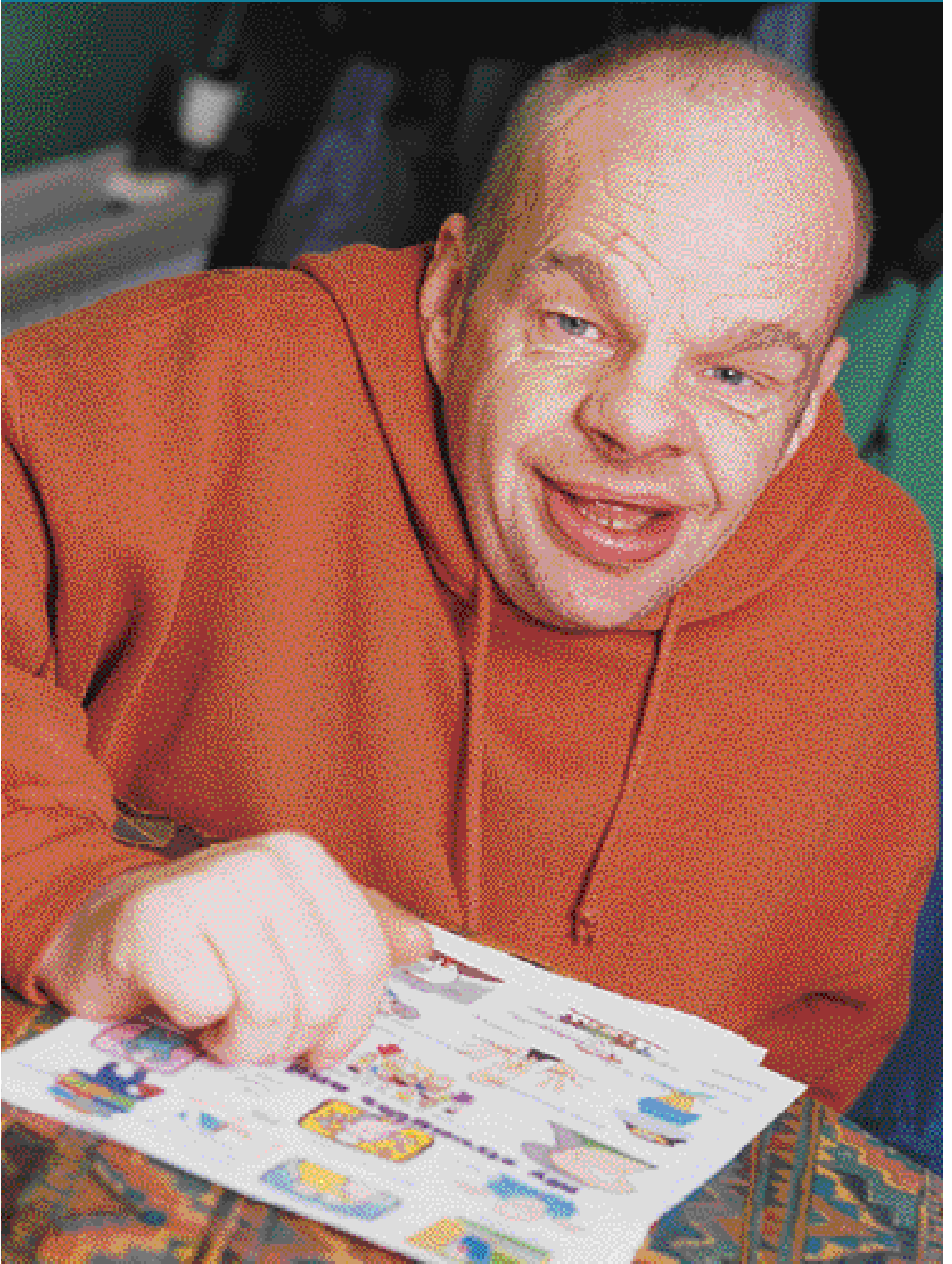
Seven principles

27 We consulted widely during the course of the review on a number of principles which we thought were central to helping people with learning

disabilities lead full and active lives. Seven principles emerged and we have taken account of these in all our considerations and recommendations.

- People with learning disabilities should be valued. They should be asked and encouraged to contribute to the community they live in. They should not be picked on or treated differently from others.
- People with learning disabilities are individual people.
- People with learning disabilities should be asked about the services they need and be involved in making choices about what they want.
- People with learning disabilities should be helped and supported to do everything they are able to.
- People with learning disabilities should be able to use the same local services as everyone else, wherever possible.
- People with learning disabilities should benefit from specialist social, health and educational services.
- People with learning disabilities should have services which take account of their age, abilities and other needs.

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2 The way ahead

1 Local authorities and health boards have made progress on joint planning across boundaries since the Community Care Act was introduced²⁴. Local authorities have lead responsibility for planning community care and for producing children's services plans. More users and carers have been involved in planning community care. 'Modernising Community Care'²⁵ promotes and strengthens joint planning and joint working at a local level. But strategies and plans have no value in themselves. Better information, communication and effective collaboration are essential to achieve our medium and longer-term aims.

2 Chapters 3 and 6 look at the need for better information, communication and working together. Chapters 4 and 5 aim to change dramatically where people stay and how they spend their days. In this chapter we recommend another seven important developments to improve the future for people with learning disabilities.

- Firstly, we need a clear focus within local authority and health planning systems on agencies working together to develop services for people with learning disabilities. This will include a requirement for them to produce 'partnership in practice' agreements. Local authorities should take responsibility for all non-health-related needs of people with learning disabilities, their families and carers. Health boards must make sure they provide an effective health service for people with learning disabilities.
- Secondly, we need to set up local area co-ordinators to improve local services.
- Thirdly, we need longer-term planning to support people with learning disabilities, and 'personal life plans' for those people with learning disabilities who want them.
- Fourthly, we need a 'change fund' to help local authorities move quickly from the present position towards our vision for people with learning disabilities.
- Fifthly, we need to strengthen people's entitlement to **direct payments**.
- Sixthly, we need to set up a Scottish centre for learning disability.
- Finally, we need to develop a Scottish service network for **autistic spectrum disorders**.

Partnership in practice

3 To make sure this happens consistently throughout Scotland we propose that local authorities, health boards and primary care trusts should prepare 'partnership in practice' (PIP) agreements for learning disability services in their areas. The Scottish Executive should see the first agreements by 1 June 2001 and these should cover services for children and adults for a three-year period. These agreements should form part of, and not be on top of, the community care, children's and health planning processes (such as health improvement plans (HIPs), trust implementation plans (TIPs), local health care co-operative plans and individual practice plans). The PIP should draw together the information that is already in existing plans to make sure all the agencies involved in planning services for adults and children with learning disabilities can come to an agreement. Part of a local PIP should be a section for promoting health linked to local and national health promotion strategies.

4 Though the areas in Scotland to be covered by each PIP should be agreed locally, we recommend that generally a PIP is developed for each local authority area or group of local authorities working together. We expect the important contribution currently made by the voluntary sector in providing services to be a central consideration and we expect these agreements to be developed by consulting users and carers. We set out a number of the main elements which should be included in the next few pages.

Assessing needs and planning

5 The agreement should include needs assessment covering children and adults with learning disabilities. The agreement should look specifically at:

- support for families and carers;
- physical disabilities and **sensory impairment**;
- mental health;
- **profound and multiple disability**;
- **challenging behaviour**;
- offending behaviour;
- **autistic spectrum disorders**;
- ethnic-minority issues;
- children who are changing schools;
- young people who plan to leave school and will need adult services;

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- ageing; and
- the needs of people with 'life-limiting conditions' and those with **palliative care** needs.

6 The agreement should outline the plans for developing and **commissioning** accommodation and social support in line with our recommendations in this review. It should map current services and include a plan for providing accommodation in the community and support for people with learning disabilities living with their families, and for their families. The first PIP agreement should include plans for setting up and maintaining a local register of adults and children with learning disabilities. We expect registers to contain details of people who:

- currently receive services;
- have been assessed; and
- may need services in the future and want to be on the register.

7 We need to have a range of services in place to meet the needs of people with learning disabilities, especially those with **complex needs**. In particular, health boards, trusts and local authorities should make sure that:

- adults and children with learning disabilities have access to the full range of general health and social services;
- adults and children with learning disabilities can benefit from specialist health and social care services, including hospital and residential services, when this is in their best interests;
- appropriate support, training and education is provided to staff working in primary care and other general health and social care settings; and
- services for people with learning disabilities are co-ordinated locally including those with **complex needs**.

8 Health boards should have health promotion strategies which look at the needs of people with learning disabilities and their families. Positive health includes many of the ideas in this review – fulfilling potential, good relationships, support for families and carers and so on.

9 Local psychiatric services and learning disability services should agree

arrangements for working with, providing advice to, and referring clients *between* services. In particular this should focus on the needs of people:

- with mild learning disabilities;
- with a **dual diagnosis**;
- who are experiencing problems in adolescence or old age; and
- who have dementia at an early age.

10 Health boards and trusts still have important responsibilities for people with learning disabilities and their families. They must make sure they provide as full a health service for people with learning disabilities as for anyone else. They should provide a small number of both assessment and treatment places for people with **complex needs** and for people who are **detained** in hospitals. There should be agreed ways of working with local authority social work departments and primary care colleagues on placing people in and releasing them from hospitals.

11 The agreement should include **advocacy** and other measures which place people who use services and carers at the centre of the decision-making process.

12 Local authorities should have the main responsibility for all non health related needs of people with learning disabilities and their families. This includes providing accommodation, education, social care and support, day services, employment, leisure and recreation, transport, information and communication.

13 Local authorities have always had responsibility in this field under their social work role. Many are now developing the broader approaches described above which help promote **social inclusion**. For long-stay patients who have left hospital, as for others, accommodation and social support should be the responsibility of local authorities.

14 Many people with learning disabilities have conditions which specialists are very familiar with, but these are all too often neglected if there is no specialist involved. To neglect special health needs is as much a failure to put services at the centre of people's lives as to neglect the need for friendships.

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15 Local authority and health boards must make sure all professionals work together, whatever agency they work in and that in future they use specialist medical, nursing, paramedical and social care professional skills to the best advantage.

Human resource strategies

16 Local authorities and health boards will need to put human resource strategies into place so plans can be put into practice effectively. Many of the developments we outline here or later, such as clarifying responsibilities, appointing local area co-ordinators and plans for closing long-stay hospitals will all affect staff. The changes which will need to be carried out as a result of this review can only be put in place properly if local authorities and health boards look at the significant training and retraining needs of front-line staff. Nurses currently working in long-stay hospitals are one priority group; support and residential care workers are another.

17 The 'partnership in practice' agreement should include a human resource strategy which builds on the principles of lifelong learning as set out in 'Learning Together – Lifelong Learning Strategy of the NHS in Scotland'. This says that staff can expect support from their employer in helping them keep up to date and get more skilled.

18 The 'partnership in practice' agreement should include an outline of:

- the human resource issues involved;
- whether any of the plans mean that the principles of **TUPE** should be used; and
- how the agencies involved plan to work together to put an effective strategy in place.

Recommendation 1 Each local authority or group of authorities and health boards should draw up a 'partnership in practice' agreement by 1 June 2001.

Co-ordinating local areas

19 We looked at the way services were developing in other countries and were particularly interested in an idea from Western Australia. This looked at

supporting people to live in their own communities. Local area co-ordination in Western Australia is an approach driven by the needs of people and is designed around each person. Local area co-ordinators provide funding directly to the customer to buy what they need, rather than using services from an agency paid for using a block grant.

20 In chapter 3 we refer to the difficulties people with learning disabilities and their carers have in getting information about what services are available. Many people also said that professionals displayed a lack of knowledge about learning disabilities. We believe that a specialist worker dedicated to working with a small number of people using services in one area would help people and their families through the current maze of systems.

21 Local area co-ordinators could have a number of different professional backgrounds. Each local area co-ordinator will support about 50 people so that they know them personally and can respond to individual needs. The precise number of people to be supported will be for local areas to decide. The co-ordinator's role is on many levels (individual, family, agency, community), and includes many areas (housing, including supported accommodation, employment, health, education, respite and so on). They will co-ordinate services and provide information, family support and funding to individuals and their families. We think the local area co-ordinators may be best placed within local health care co-operatives. In some areas they may need to work with more than one co-operative.

22 The local area co-ordinators' main task will be to make sure that other services are available which meet people's needs. They will:

- help people who use services decide what their needs are, and make plans for the future;
- with a budget, provide funding directly to people who use services, and try to get hold of new funding where there are gaps in services;
- provide information and help people get advocacy services;
- build relationships with people with disabilities and their families;
- support individuals and families to develop and maintain strong networks;
- help people who use services to co-ordinate the way support and services are provided;

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- work with other individuals and agencies to encourage people with disabilities to be included in society (for example, with the key workers to be set up by the Beattie Committee²⁶);
- make connections with members, groups and agencies from local communities;
- set joint aims for themselves, users and carers and monitor the quality and quantity of services provided to people with learning disabilities; and
- deal with complaints and any conflicts between people using services and their carers, families and professionals.

23 The co-ordinators will be responsible to a joint management committee made up of local authority, health and voluntary sector representatives as well as local users and carers. They will send regular reports to their joint management committee, who will also help to sort out any complaints. The exact nature of the responsibilities of local co-ordinators will be decided by the joint management committees of the areas they serve.

24 Local area co-ordinators have an important role in carrying out assessments and overseeing how learning disability services are co-ordinated.

25 Helping people with learning disabilities to lead full lives means better assessment of their social and healthcare needs. This should include what a person wants, what strengths, skills, problems and needs the person has, and what they need to realise their goals.

Recommendation 2 Health boards and local authorities should agree to appoint local area co-ordinators for learning disabilities from current resources used for managing care and co-ordinating services. Initial training for putting local area co-ordinators in place will begin in Autumn 2001.

A personal life plan

26 This section identifies the need for better longer-term planning for people with learning disabilities across the many services and types of support available. Any assessments for community care, health or children's services must have clear outcomes. From the point of the Future Needs Assessment

onwards and for all adults, we suggest that this takes the form of a new 'personal life plan'. This plan would be for everyone who has a learning disability and wants a life plan. The plan should describe how the person, his or her family and professionals, will work together to help that person lead a fuller life. **Brokerage services** should be part of what is offered. This is where the person with a learning disability has someone to act as a go-between for them to get what is needed. These have led to more person-centred outcomes especially for people who have not managed to get settled by using more traditional services. They can be a cost-effective way to break away from traditional methods.

27 The local area co-ordinator will be responsible for making sure that each person who wants to, has the opportunity to develop a life plan. The co-ordinator should write down the life plan and each person, their carer and their **advocate** or representative should have a copy. This plan will replace the existing community care assessment. Co-ordinators should:

- find out whether other people are visiting the person, what they are doing and whether they can use the same information to do an assessment together;
- tell the person that they are carrying out an assessment, what they will do and how long it will take;
- take account of language needs and cultural practices;
- tell the person what kinds of decisions depend on the assessment and what might happen; and
- at the end of an assessment, tell the person, and their family or carers if appropriate, what happens next.

28 The life plan will include healthcare needs including dental, ophthalmic, pharmaceutical, hearing, communication and physiotherapy needs as well as any other special support. It will set out the person's assessed care needs including:

- short breaks for the person or their carer;
- meaningful work or other opportunities during the day;
- further education;
- housing and transport needs; and
- how each of these should be met.

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29 Plans for children drawn up at the time of Future Needs Assessment must link to any other assessment or **Record of Needs**. There will be a regular review of the life plan so that the family can get more involved. Everyone who signs up for the plan will be able to ask for a review whenever it seems necessary. We suggest a yearly detailed review of the life plan for people with more **complex needs** living at home, and those in long-stay hospitals. This will allow the co-ordinator to plan future care in a non-hospital based environment.

30 Above all it is important that a person with a learning disability, their family or carer should not only feel involved in, but also own the plan. The plan will focus on the person. It will spell out their wishes and preferences. The plan must concentrate on how to build on their strengths, to develop them as individuals and to help them lead active and fulfilling lives. Wherever possible plans should spell out how the person with a learning disability can actively contribute to the community. It should look at what is in the best interests of the person with a learning disability in a very thorough way focusing on needs and what is available.

Recommendation 3 Everyone with a learning disability who wants to, should be able to have a 'personal life plan'. (Recommendation 26 builds on this.)

A change fund

31 We recognise that local authorities can do much more to improve care and support for people with learning disabilities, including where people stay and how they spend their days. They can only partly achieve this by using existing resources more effectively and they will need more money.

32 Hospitals, care homes and day care serve about 17,000 people, 2,450²⁷ in hospitals and 14,300²⁸ in social care. So, the scale of change is huge. We believe agencies will need financial help to manage this change.

33 Bridging finance is one of the methods that has been used to bring about change in the NHS. It has provided over £150 million of help towards the cost of setting up new services while running down the old ones. There are no similar facilities to support change in social care services at the moment.

34 We believe people who use services and their carers will welcome the new directions proposed but may have concerns about how the changes will affect them in the short term. Experience suggests that people who use existing services will worry about change in case they lose essential support without anything being put in its place. They may need time to see for themselves the benefits of a new and very different set of services. Changing the patterns of care will mean taking these anxieties into account.

35 Local authorities, for their own services and those they commission from (mostly) the voluntary sector, will not be able to manage and pay for old and new services at the same time. They will need help with the costs of creating new services while keeping the old ones going until it is appropriate to close them down. Funding is also needed to re-direct existing services, develop new ones and to pay for training to improve the skills of staff.

36 Alongside that we have recognised the need to invest in certain important areas such as short-term breaks or **advocacy** if people with learning disabilities are to be properly supported in the community. We see a national 'change fund' as the way of helping with this and developing services. We would want to use the 'change fund' effectively and make sure it is linked to developments outlined in 'partnership in practice' agreements.

Recommendation 4 The Scottish Executive should set up a 'change fund' to help local authorities put in place the recommendations in this review.

Direct payments

37 Since 1997, local authorities have been able to give money directly to people to buy the help they need (if they want and are able to manage the money effectively)²⁹. This arrangement is called a **direct payment**. Not many people with learning disabilities have these at the moment. Eleven social work departments have schemes - some are quite new and running as test schemes.

38 Some people and their families or carers do not want the extra responsibility of arranging, paying for and managing services directly. They feel they do not have the knowledge or skills to do that. On the other hand, many are very keen to take more control of their affairs, sometimes with help.

24 The same as you?

We think **direct payments** should be available to all those who want them. This includes people with **complex needs** who may need the support of an **advocate** to give their views.

39 Despite the small numbers so far, there are some very powerful examples of people getting better focused, more personal and newer services.

An example of good practice

Values into Action are currently promoting **direct payments** becoming more available to people with learning disabilities.

40 It is clear that **direct payments** could play a far bigger role in the future. They can be for one-off payments which would tend to be small but prevent problems by providing a short break or an aid. They could also buy longer-term care services. We need to make sure they are regularly reviewed so that they meet people's changing needs. They could deliver quicker and better outcomes for people's problems. Most importantly, they give people greater control over their care.

Recommendation 5 By 2003, anyone who wants direct payments should be able to have them, and local authorities should be included in the list of possible providers.

A Scottish centre for learning disability

41 In the next few chapters we identify the need for:

- developing advocacy services further;
- appropriate training and support to staff and agencies who work with people with learning disabilities;
- the public to be more aware of learning disabilities; and
- people with learning disabilities to be much more active in the communities in which they live.

42 We considered whether existing organisations could take forward this change alone and decided that we need to create a new organisation to support them. We call this the Scottish centre for learning disability.

43 The main purpose of the centre is to provide a Scotland-wide resource to help the general public and professional staff understand learning disabilities. The centre should support users, carers and agencies to achieve better outcomes. People with learning disabilities, their families and carers will be members of the joint management committee alongside professionals and academics.

What the centre will be responsible for

44 The centre will offer the following services.

- Consultancy, training and advice to agencies, professionals, staff and others on putting in place the recommendations of this review.
- An advisory and matching service to support local authorities, health boards and others which help those whose needs are so specialised that they cannot be met locally.
- Partnerships with large regional or national enterprises to encourage employment opportunities beyond those provided by individual local authorities.
- High-quality educational materials for:
 - people who use services and their carers to help them follow their goals;
 - academic establishments and staff to raise the overall level of awareness and understanding about learning disabilities;
 - training social care staff in agencies, who plan and provide services for those with learning disabilities; and
 - joint training to share knowledge, understanding and values.
- A programme of public involvement that encourages people in the community to get to know and help people with learning disabilities so that they, too, can enjoy being active citizens.
- Links with national and international research centres to carry out or promote joint research into services for those with learning disabilities.
- Help local services develop new and different practice based on national and international research findings.

The centre will aim to develop advocacy services in local authorities and health boards.

26 The same as you?

The centre will work with other organisations and add to other recent national initiatives such as the Scottish Accessible Information Forum (SAIF) and the Disability Rights Commission (DRC). Enable, as the national organisation representing people with learning disabilities and their families, has already developed an information and advice service. We consider it essential that the centre uses their expertise in developing their services and also consults other organisations which have an interest in this area such as People First.

45 We expect that either the centre or Enable will maintain and extend the Scottish Executive website.

Recommendation 6 The Scottish Executive should set up a new Scottish centre for learning disability. This would offer advice, training and support to agencies, professionals, people with learning disabilities and parents to bring about the changes we have recommended in this review. The centre will also support the further development of advocacy services.

Scottish service network for autistic spectrum disorders

46 Professionals do not know enough about **autism** and **Asperger's syndrome**. They do not recognise it as often as they should. Early and accurate diagnosis is essential to give people the right help and education to reduce the effect of their disability. Although many children in Scotland are diagnosed before they start school, far fewer people are diagnosed than the research suggests exists³⁰. The number of people identified varies widely in different areas as does the knowledge, skill and services. There are not enough facilities for assessing and diagnosing these conditions particularly for older children and adults and in smaller authorities and rural areas. Added to this we were also told that even when there is a diagnosis, services may not be available as no agency sees it as their responsibility to provide them.

47 Some areas have good locally-based services for children but not for adults and other areas have little access to specialist advice and support. The Yorkhill Centre for Autism provides a service for assessing and diagnosing children under 12, although they will provide advice and support to local services for older children. Health boards use this service in different ways.

48 Children of pre-school and primary-school age are usually supported in special schools and special units within **mainstream** schools and in local

services for children and adults. Many services for children and adults with learning disability are not suitable for people with **Asperger's syndrome** whose intellect may not be affected but who have great difficulty in communicating and relating to other people. Some children's services have adapted their environment, routines or staffing levels to make the service 'autism-friendly'. With the right advice and knowledge many others could follow this lead. We also need to see more specialist services for people with **autism**. Voluntary sector organisations specialising in **autism** provide informed and highly-valued support and services for people and their families.

49 To make support for people with an **autistic spectrum disorder** better, local and national priorities must be to:

- continue improving early diagnosis;
- give professionals in local services quick access to information, specialist knowledge, expertise and training;
- widen the range of local support and services available; and
- help people get specialist services quickly when they need them.

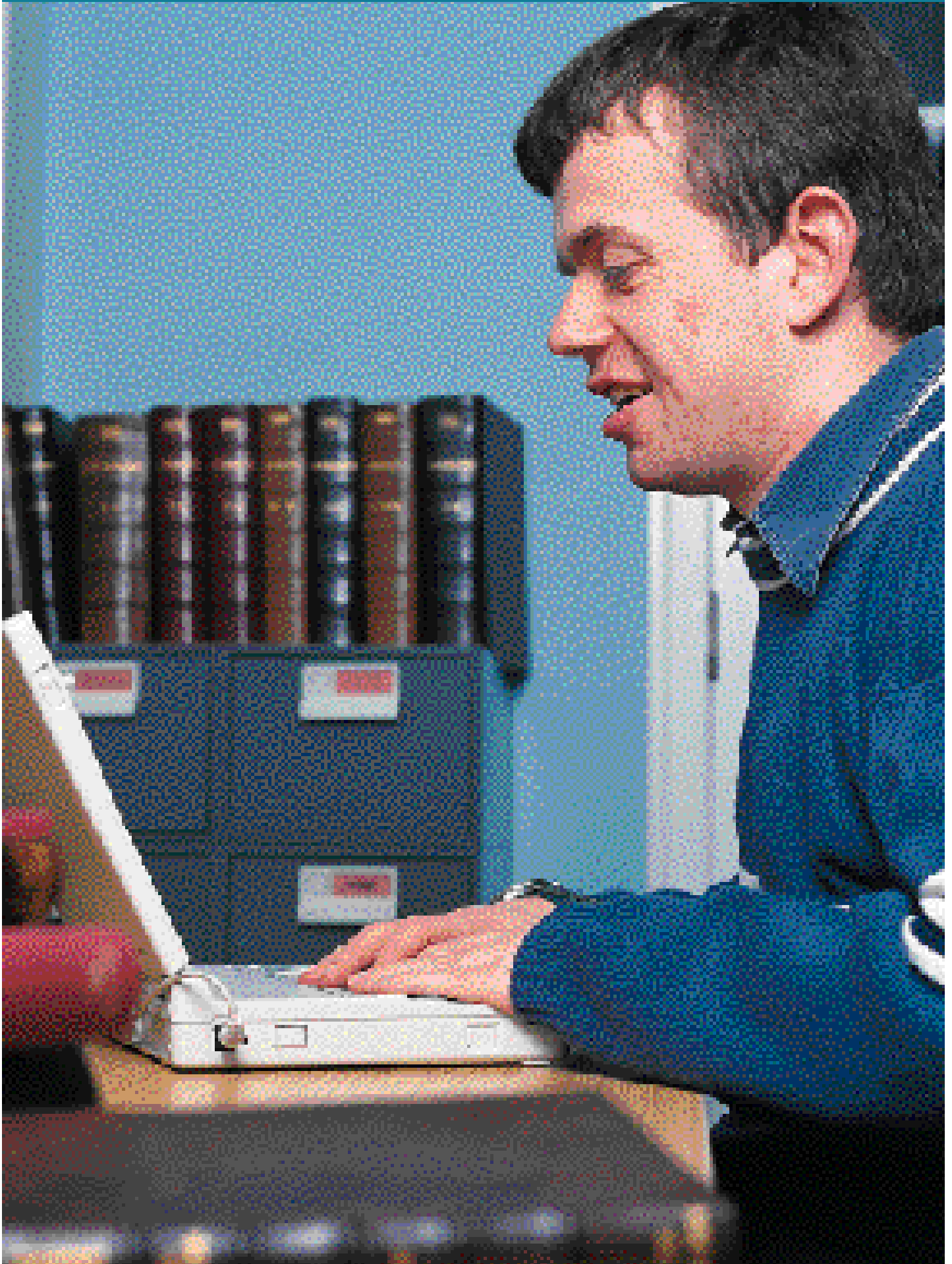
50 Looking at models of **managed clinical networks** in the health service, we recommend that those with an interest in this area come together to set up a national service network for children and adults with **autistic spectrum disorders**. The Scottish Society for Autism supported by the National Autistic Society should bring this group together. They should draw up a description of what the national network will do, and when local services should call on it for help. The PIPs should set out how local services will link into the national network. Health boards and local authorities should also identify a named professional within their service who will be responsible for improving local services for people with **autism** and for linking local services to the national network. This may be a local area co-ordinator.

51 Local areas should develop levels of service, such as child care, education, short breaks for carers and social supports based on their best estimate of the number of people with **autistic spectrum disorder** in their area. This estimate should draw on local authority education statistics, research and other information about how many people with an **autistic spectrum disorder** might be expected in a given population. Health boards

28 The same as you?

and NHS trusts should make sure that GPs, health visitors, school nurses and relevant social services and pre-school staff know about and are trained to use current screening and assessment tools such as the Checklist for Autism in Toddlers (CHAT). Local PIPs should include proposals for how local authorities and their partners will meet the needs of people with an **autistic spectrum disorder** in the area, and cover **mainstream** and specialist services. Agencies should find out how much training front-line staff in their services will need to improve their awareness and understanding of the needs of people with an **autistic spectrum disorder**. They should decide how to deliver the training needed to relevant staff by 2003 and ask the Scottish centre for learning disability to help them with this.

Recommendation 7 The Scottish Society for Autism by working with the National Autistic Society and health boards and local authorities should develop a national network for people with an autistic spectrum disorder.



3 Better choices, stronger voices

1 Better information, communication and **advocacy** are central to making any changes and putting the principles into practice. If we are to include people with learning disabilities fully in our communities, they need to have accurate information so they can make informed choices and decisions about their lives. People with learning disabilities need to be able to have their say. They need to be supported if necessary to make their point. During the review people with learning disabilities and their families made it clear that they wanted to be consulted more and have a greater say in decisions about the support they need to live a full life.

Information for people, professionals and planners

2 Many people using services and their families told us they had trouble finding out what social work, health or other services were available. Families from ethnic-minority backgrounds said there was a serious lack of information available in community languages. In our survey of users and carers quite a few parents said that the only way to find things out was by 'constantly hassling' professionals. People described this process as a 'fight' or a 'battle'.

'You have to find out about services for yourself. No-one comes to you automatically to inform you of what services there are, or asks you if there anything you want to know.'

3 Family carers often described other parents as the best source of information and said that professionals did not always take time to listen to or speak to their sons or daughters.

4 Other people said that professionals themselves lacked information and knowledge about learning disabilities, and some professionals acknowledged to us that this was the case. Many primary care and social work staff said they did not have enough training about learning disabilities, and often did not work with enough people with learning disabilities or their families to develop the expertise they needed. Many said they did not always know about the full range of services that might be available in their own area, especially if they were provided by agencies other than their own.

5 The Scottish Executive is currently supporting a number of ideas to improve information for people with disabilities, carers and others. However, many of these ideas are still at an early stage. The Scottish Accessible Information Forum (SAIF) is being funded to co-ordinate a national strategy to make sure that all information is accessible to people with disabilities, and their carers. Already a new national disability information service 'Update' provides a service to agencies which deal directly with the public. The Social Work Information Review Group (SWIRG) made up of Cosla, the Association of Directors of Social Work, the Accounts Commission and the Scottish Executive is also carrying out a review of information needs for social work in Scotland. The Disability Rights Commission (DRC) will be active in Scotland from April 2000. Enquire, run by Children in Scotland, provides a national advice and information service for families and carers of children with special educational needs.

6 Services to carers will also be widely promoted through the recently launched Strategy for Carers in Scotland. By Spring 2000 the NHS Helpline will be extended to provide information on access to social care services and support for carers, as will NHS Direct when it comes on line.

7 You can already find information through web pages such as Scottish Health on the Web (SHOW) and the Health Education Board for Scotland's website. Social care information will be available through the SHOW site as well as through the NHS Helpline and NHS Direct.

8 Helpful as these initiatives are, none of them provide the one-stop wide-ranging information about local learning disabilities and services that families and carers actually want. There is a danger their needs will be overlooked.

An example of good practice

The Enable family advice service in East Renfrewshire is a local independent service, funded by East Renfrewshire social work department and managed by Enable. It offers clear, accurate, independent information on anything which affects people with learning disabilities and their families in the East Renfrewshire area. It is linked to, and backed by, Enable's national information service but can offer the ongoing face-to-face support and knowledge of local networks and services that individuals and families need.

32 The same as you?

9 If those who make policies and planners are to provide the services people need, they have to gather better information about the numbers and needs of those with learning disabilities (and their carers) locally, and also crucially, about how well different service options work. As we said earlier, only three areas in Scotland could give us reasonably wide-ranging information about the numbers and needs of people with learning disabilities. Most appear to rely on **prevalence data** to plan services. This is surprising since we were told that all education authorities will know about all children with learning disabilities and children with more **complex needs** will be known to local child health services.

10 People with learning disabilities, their parents and families, professionals, policy-makers and planners all need reliable information of different kinds at different times.

An example of good practice

An example of good practice, FAIR in Edinburgh, provide a range of user-friendly booklets on housing, work, leisure, after-school provision and much more.

People using services need to know:

- where to go and who to ask to get answers to their questions;
- about particular conditions and disabilities and their effects;
- how to get help and who makes decisions about this;
- how professionals carry out assessments and make decisions;
- what social, healthcare and other services and support are available locally, nationally and internationally;
- how to change or challenge professional decisions or complain if they are not happy with what is happening; and
- how to get in touch with other people and families with similar needs and problems.

11 Above all people need a service that is easy to find, easy to understand and where they do not feel passed from 'pillar to post'. We believe people with learning disabilities, their families and carers need a specifically-targeted information service.

Recommendation 8 The Scottish Accessible Information Forum should consult local authorities, health boards and users and carers on how best to provide joint, one-stop, free and accessible local information services for people with learning disabilities, their families and carers. Information must also be available in community languages.

Professionals need to know:

- about the effects of learning disabilities on development and daily living or how to find out about this;
- about up-to-date research, policy and the best way to help people with learning disabilities and their families;
- about good practice and developments in other fields which can be used to care for people with learning disabilities, for example, in rehabilitation or **palliative care** services;
- where they can get the right advice and expertise so they can help families as best they can; and
- where to refer families if they cannot provide help directly.

12 Many professionals need better training before they qualify and after they qualify to improve their knowledge of learning disabilities. They also need access to up-to-date research and to know about local as well as national resources. Much of this could be provided by the Scottish centre for learning disability.

Planners need to know:

- how many people have learning disabilities, or more **complex needs** in their area;
- what the range of needs is likely to be;
- whether this is likely to change in future and why;
- how many people with learning disabilities currently use their services;
- how much services cost; and
- how well different service options work and what people think of them.

Planners should work with others, both within local authority departments and across agencies so that any information they gather can be shared.

34 The same as you?

13 Local authorities and health boards need to work together to improve and develop the information they currently have about the numbers and needs of people with learning disabilities and their families and carers. Setting up the local registers we refer to in chapter 2 will help this process.

Recommendation 9 The first PIP agreements should set out how local authorities, health boards and primary care trusts will set up and maintain local registers.

Communication

14 At least 50% of people with learning disabilities have significant communication problems with up to 80% having some communication difficulties³¹. People who find it hard to make their views known because their speech is impaired, or who use different ways of communicating, need skilled and regular help from speech and language therapists. Yet users and carers told us that it was very hard to get these services.

15 Communication is central to being included in society. People with learning disabilities and their families may need help to communicate their views and their knowledge. The starting point must be that professionals can communicate clearly and in ways that make it easy for people to understand them.

16 People with learning disabilities need time, help and sometimes independent advice and support to put across their views. People with more **complex needs** are most likely to have difficulty in expressing their views. Communication with them may mean a great deal of support is needed and may be very slow. More positive efforts may need to be made to involve them and their families. Professionals may need help from families and carers to make communication possible in many circumstances. Families and carers may need to make the time, and will sometimes need outside help, to make their communication with their family member as good as it can be.

17 Speech and language therapists are an important resource in helping to develop communication. They sometimes work with a **clinical engineer** to do this. Other professionals also contribute, such as educational and clinical psychologists, as well as art, music and drama therapists.

We were told:

'It's important you take time to listen – not only to our words. Some people have difficulty with words.'

18 Scottish Ministers in their response to the Riddell Committee³² suggested that the Scottish Executive would review with Cosla and relevant health agencies the use and effectiveness of current funding in relation to speech and language therapy for children. We believe that also needs to include adults.

Recommendation 10 The Scottish Executive's review of the effectiveness of funding speech and language therapy for children should also include services for adults.

Advocacy

19 Many people with learning disabilities, their carers and professionals recognise that an independent person standing up for the person with a learning disability can help find the right solutions to very difficult problems. Although **advocacy** is now more widely available, our survey of users and carers found that it did not play a large part in people's lives. This suggests that there is a significant gap in the range of support available.

20 Advocacy allows people to have a greater say in decisions which affect their lives. People with learning disabilities find it useful, and they enjoy the company and friendship that their **advocates** often offer. A user in our survey said:

'I just know her – she is my friend. I meet my friend, go out places ... Ellen is there and Ellen helps me.'

The review found that very few people with learning disabilities have access to an **advocate**.

21 Research shows that people with **complex needs** are more at risk of a wide range of poor outcomes. These include:

- less choice about their lives;
- less involvement socially;

36 The same as you?

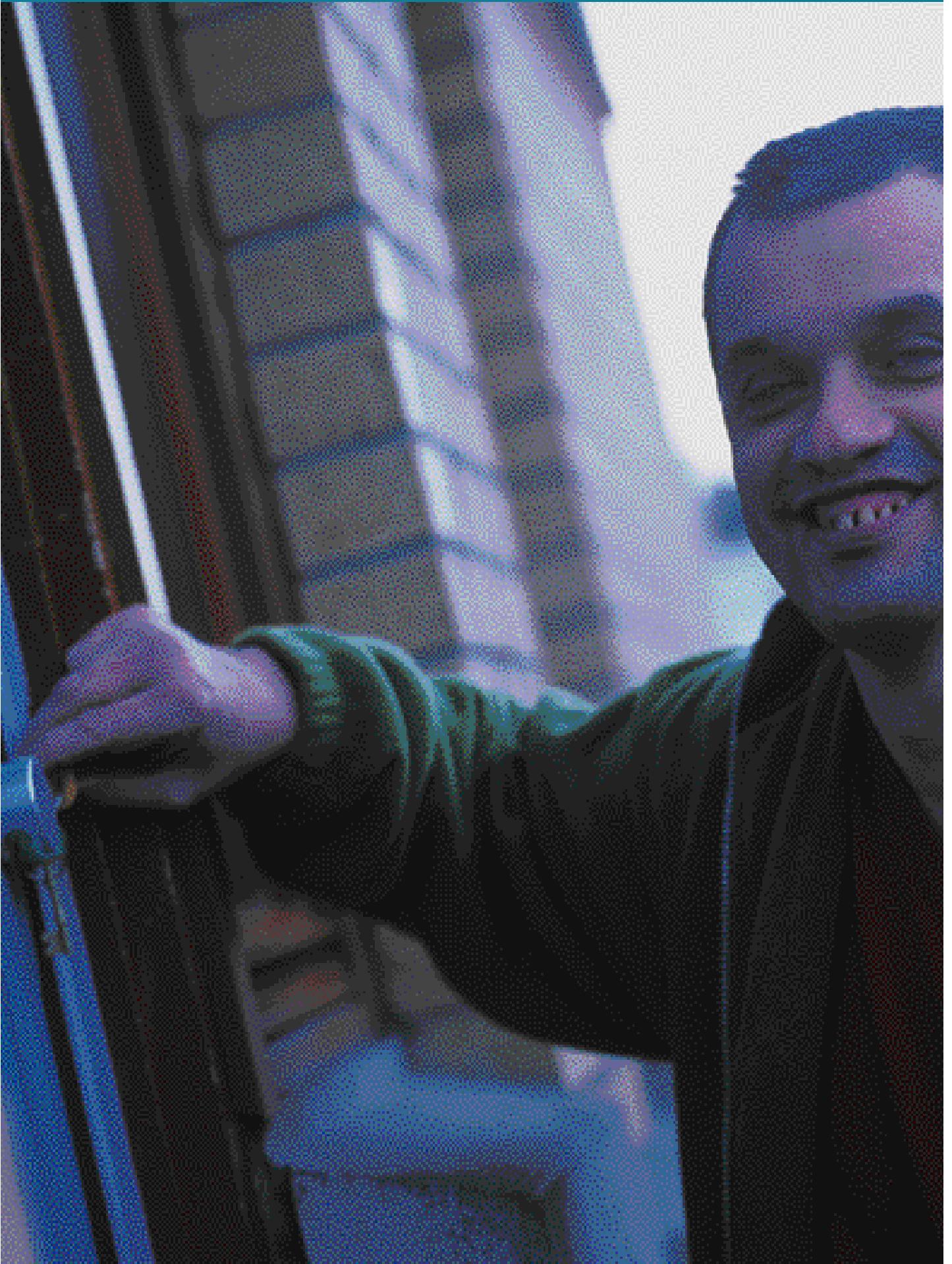
- fewer chances of employment;
- less active lifestyles; and
- greater health needs^{33, 34}.

They are most likely to have difficulty expressing their needs and as a result need more help.

22 National guidance on **advocacy** covers the types and benefits of **advocacy** and factors to consider in getting advocacy services started³⁵. The guidance is as relevant to improving the lives of people with learning disabilities as other care groups and the review recommends it to organisations which commission and plan services. The Scottish Executive has sponsored further work on **commissioning** and supporting independent advocacy services which it will issue in the near future³⁶.

23 **Advocacy** can take different forms. Many people with learning disabilities want to be able to speak up more for themselves. They would like to be trained to represent themselves or others. **Citizen advocacy** is when a committed person supports a person with a learning disability. **Advocacy** needs to be more widely available. We need to build towards a position where everyone who has **complex needs** or is particularly vulnerable has ready access to an **advocate**.

Recommendation 11 The Scottish Executive should continue to encourage the development of local independent advocacy services.



4 A full life - where you live

Where we are now

1 As we said in chapter 1, the number of people with learning disabilities generally has increased by over 1% each year over the last 35 years. Estimates suggest that there are about 120,000 people with learning disabilities in Scotland (up to 20,000 with severe disabilities), compared with 83,000 (and 13,000 with severe disabilities) about 35 years ago. This trend will continue for at least another 10 years. As a result more people are living with their families or on their own and can access local services, in the community. This means that these local services are being asked to meet needs more than ever before.

2 Most children and adults with learning disabilities live with their own families. The number reduces as they get older but many still live with their families in middle age. A small number already live in their own homes. In 1998, just under 2,450 people with learning disabilities still lived in hospitals³⁷. About 4,800 lived in residential care or nursing homes for people with learning disabilities^{38, 39}. About 600 lived in settings with good visiting support⁴⁰. The range of those supported living options has increased a great deal in recent years.

3 The numbers of people in hospital have reduced from nearly 6,500 in 1980 to fewer than 2,450 in 1998 (an estimated 2,200⁴¹ in 1999) and they are still going down⁴². There are now 25, mostly small, hospital sites. Two (with 360 places) have Ministerial approval to close. Firm proposals to close sites apply to another 950 places and sites with a further 350 places are gradually being scaled down when appropriate replacement services, care and accommodation are set up. (There is no timetable for this action.) In the short term, on health boards' current plans, the largest institutions will close by the end of 2002, leaving about 700 to 800 places in total. The larger sites include Merchiston (179), Kirklands (179), Craig Phadrig (53), Strathmartine (99) and Ayrshire and Arran (110).

4 Reducing the number of around 4,000 people in hospital has been broadly matched by an increase in the number of people in nursing or residential care homes. This group now make up 66% of total residents, compared with 14% in 1980. And, about 600 people now live in informal supported accommodation. This suggests that while many more people now live in less institutionalised forms of care, the increase in the number of

people with learning disabilities in Scotland has been supported by community-based, rather than hospital or residential or nursing home services. In neither case does this mean that people in the community are living as independent lives as possible.

Where we want to be

5 In future, both children and adults with learning disabilities should, wherever possible, be supported to lead a full life with their families or in their own homes. Some people may be best in a setting which is not an ordinary house owned or rented by them or their family. But whatever it is, it should allow them to live a full life and be included in society while providing privacy and allowing them to develop. Hospitals are not places where people with learning disabilities can live full lives. We asked someone we met in hospital what he wanted out of life. He said:

‘Somewhere decent to live, a job, some friends – the same as you really.’

6 What would supported living look like which successfully promotes choice and independence? We surveyed examples in Scotland, and paid for research on the position in other parts of the world^{43, 44}. People want the following.

Choice of bricks and mortar

People want a full range of housing options in which they may live in groups or on their own with support. Supported individual or joint tenancies and ‘assisted home ownership’ are popular.

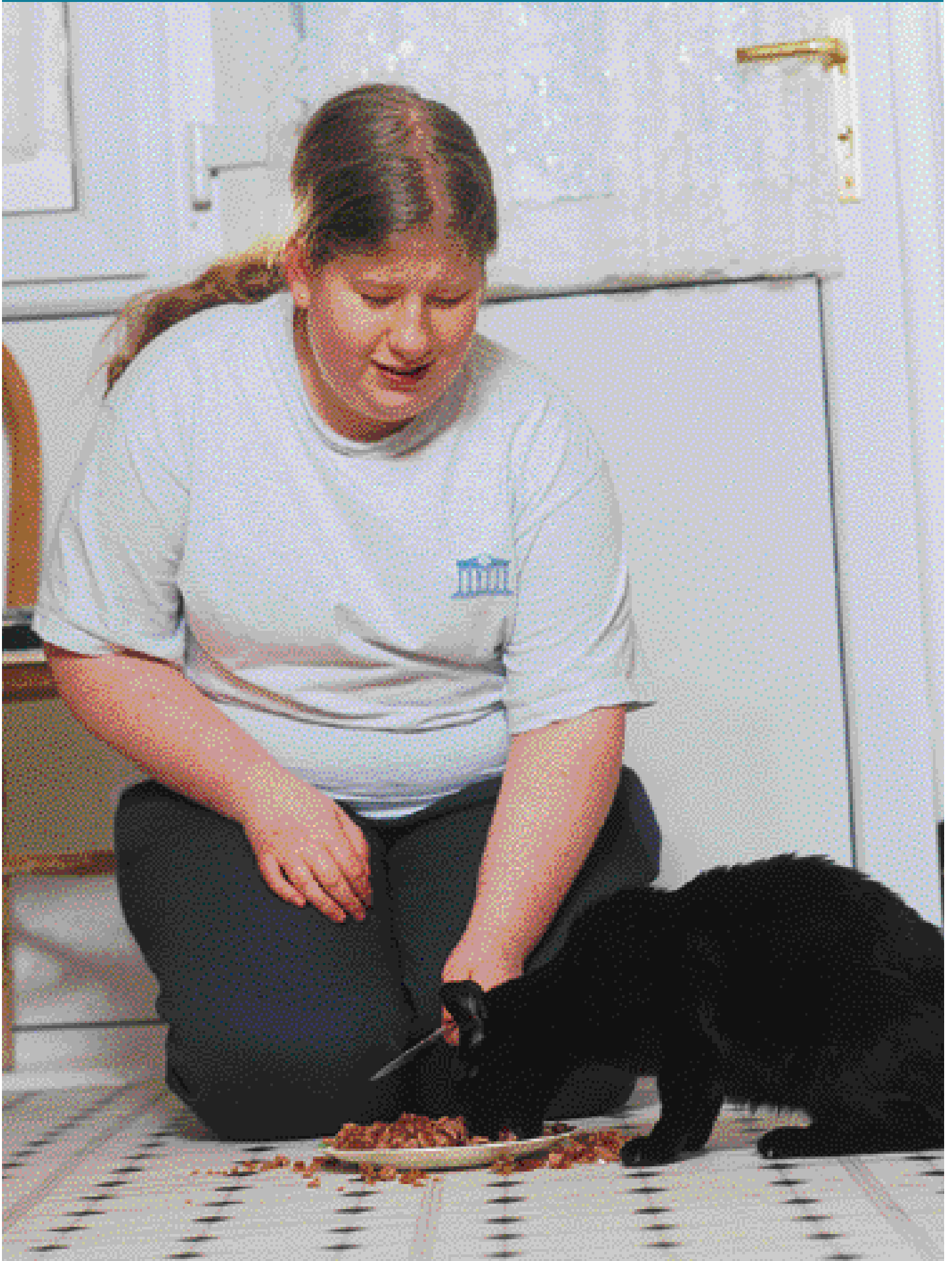
An example of good practice

Home Ownership

Home ownership is a good option for some people with learning disabilities. Ownership Options in Scotland:

- helps people with disabilities overcome barriers;
- provides a consultancy service,
- provides financial help and advice;
- arranges maintenance and is a link between those looking for property and potential buyers.

40 The same as you?



To make the decisions about where to live

Housing solutions should be based on discussing them with the person with a learning disability.

A network of active support

This should come from staff on site, **peripatetic support staff** or local **domiciliary services**, to help individuals live in the community.

An example of good practice

Flexible, person-centred care planning

Inclusion Glasgow's packages of care include a one-off resource to support people immediately after they leave hospital. The organisation place the agreed funding for the person in a bank account, known as the service fund. How the fund is managed and used is decided in the person's plan. They can spend it on care at home, in work or for leisure pursuits. Out of 28 people who used to be in Lennox Castle, all have their own home, seven own them and some have jobs. None has returned to hospital. As planned, **natural supports** and networks play a more significant part in the overall pattern of support, and the cost of the care package should reduce.

Flexibility

The people being supported will change. Some will become frailer and some moving into the community will respond positively to a change of environment and begin to be less dependent. Services need to adapt to people's needs as they change.

To build links with neighbours and the community

We cannot separate accommodation from other areas of support for daily living. This should include considering how to help people form neighbourly relationships and use local services.

42 The same as you?

An example of good practice

Community placements

Placement with families has been a small but important part of the programme of resettling people from Lynebank Hospital. These placements can be either short or long-term, or for respite care. Evidence suggests that individuals have more access to people and activities in the community through being part of a family. It is also cost-effective.

Consultation

People need to take part in consultation to inform strategic planning for housing services.

7 This chapter recognises the growing pressures on local authorities and others to meet, appropriately, the accommodation and care needs of an ever-growing population of people with learning disabilities who live in the community. It also recognises the need to provide supported living options for most people currently in long-stay hospitals or care homes. Change is necessary at a number of levels, some of which will have greater priority than others. Supporting people better in the community and closing long-stay hospitals must come before the much more gradual shift from care homes to supported living. This will cost money, but we have to judge the benefits to people against that cost.

How do we get there

8 Two pieces of research on the costs and benefits of different support models have been or are about to be published. One compares the costs and values of housing, residential campuses on NHS sites and village communities⁴⁵. The other compares the costs of a variety of settings, for people with low, moderate, high and intensive needs

9 These studies show the relative total costs and the benefits of a range of options. The table below, based on these studies, shows the range of costs according to need. Comparing costs is not always what might be expected (partly because of the limited size of the sample). Options providing

independence and choice cost more for people with intensive needs, but may cost less for others with lower levels of need. Adult placements consistently cost less across the range of needs.

Figure 2 Total costs of different types of care

Type of support	Low	Moderate	High	Intensive
Self-contained independent (including supported living)	-	-	£22,059	£59,242
Self-contained network (see note 1 below)	£20,172	-	£29,186	£58,199
Single-site cluster (see note 2 below)	£22,494	£20,495	£37,444	£53,878
Small shared (2 to 4 people)	£31,446	-	£33,672	£50,038
Large shared (5 or more people)	-	-	£39,790	£51,477
Adult placement	-	£18,174	£21,659	£29,665
<p>Note 1 This mainstream housing is usually self-contained and linked with other accommodation through a shared support service.</p> <p>Note 2 This is group units of accommodation on a single-site, with support usually from a specific team.</p>				

10 By comparison, a nursing home place in Scotland costs about £21,000 each year and a residential place about £26,000 each year. The total cost of a hospital place is about £45,000. This cost is higher because of some non-recurring, double-running costs.

11 These studies bring out three main messages. First, on a range of measures, NHS residential campuses offered poorer-quality outcomes than housing. Second, costs vary significantly from model to model, both within and between categories of special needs. Carefully matching individual needs with the model of care is essential in terms of both care and costs. Third, although small group living costs more than living in larger groups, it

44 The same as you?

has considerable advantages for people with learning disabilities. These advantages include:

- better staffing;
- a reduction in the use of anti-psychotic medication;
- an increase in access to independent advocacy;
- an increase in choices for residents;
- an increase in becoming involved more socially;
- an increase in hours of scheduled activities during the day; and
- an increase in the number of recreational and community-based activities.

12 Better outcomes also rely on other factors for example:

- carefully assessing and planning for, the needs of the person;
- the choices available being clearly presented to the individual, their carer or **advocate**; and
- support staff being trained to help the person live in the community.

13 The research evidence and indeed local authorities' own best-value reviews point broadly towards the benefits of supported living as opposed to residential care. Older people (75 and over) with learning disabilities who have spent a large part of their lives in a long-stay hospital may consider a move to a nursing home. As with others what the person prefers is important in making the decision. But for younger people, other solutions are best.

14 Recognising people's changing needs is important. The support individuals need in the community will, in some cases, reduce as their experience and confidence grows. In other cases needs will increase. As a result of this, the cost of the support will change.

15 In coming to decisions on the best care option for each person, local authorities should fully take account of:

- the costs of various care options;
- the possibility that people's need for support may well reduce as they settle into their new lives or may increase as they grow older; and
- the benefits to the individual of supported living options.



46 The same as you?

People already living in the community

16 Most people with learning disabilities live in their own or family homes in the community. They and their families will have new or changing needs and expectations in future. Young adults may want to move to a home of their own. Younger parents may increasingly expect their child to live independently, whereas older parents may be more concerned about who will look after their child when they die. Others may not have the right package of housing and support to help them live properly in the community.

17 Some will benefit from other changes proposed in the review, such as better respite care and **direct payments** which give better and more flexible care. If they need a new or extended package of housing and care we expect agencies to provide this in line with the aims of the review. Our user and carer survey, submissions and other sources all confirmed these pressures, but did not put a cost to them. However, they are probably the greatest priority. We would want to use any 'change fund' to make progress.

Providing services in the community instead of long-stay hospitals

18 Learning disability hospitals have provided a resource for people, often with **complex needs** or who are statutorily **detained**, because it would not be possible to support them in their own home or in local community settings. They also provide short-stay assessment and treatment facilities, respite care, **palliative care** for people with gradually worsening conditions (such as Down's syndrome combined with dementia), and day care.

19 We decided that people's homes should not be in hospitals. Hospitals are not appropriate settings for social care, and they are not necessary settings for most healthcare. Over the next five years, services should be built up in the community to allow the long-stay hospitals which are left to close by March 2005.

Recommendation 12 Health boards should make sure they have plans now for closing all remaining long-stay hospitals for people with learning disabilities by 2005.

20 However, we will need to keep a small number of in-patient places for some people with learning disabilities.



48 The same as you?

These will be for the following people.

- Those whose need for specialised or complex health assessment or treatment cannot be met in the community (probably not more than 150 to 200 people in Scotland). We will need clear conditions for using these facilities to make sure that people with learning disabilities move on from them to more appropriate care settings as soon as possible.
- People on statutory orders (currently 178), some of whom will be offenders with mental health problems. The government is currently reviewing the law on these cases and proposals are currently out for consultation. Changing the law may lead to other care options.
- A small number of people whose treatment may be lengthy or who need a more supportive setting for a long period.

21 We estimate that we may need *a total* of 300-400 places across Scotland to cater for those needing in-patient assessment and treatment and, under the present law, those on statutory orders. We believe there will be an increased need for assessment and treatment places as long-stay hospitals close.

22 Local authorities and health boards should meet the **continuing care** needs of people with learning disabilities, as far as possible, in their own homes or in small domestic settings in their own communities. They need to develop ways to improve joint working to make sure they meet health needs, where possible, outside hospital.

Recommendation 13 Health boards should aim to reduce their assessment and treatment places specifically for people with learning disabilities to four for every 100,000 population across the country as a whole. Health boards should plan for appropriate community services to avoid in-patient assessments and treatment.

23 As long-stay hospitals and homes are closed, health boards should transfer part of this cost to local authorities who will become responsible for the care needs. Health boards will hold back an element for health services in the community. Local authorities will pay any extra social care costs from the increasing resources made available to them for their social work services (£1.1 billion in 1999-2000).

24 Under their existing financial plans, by 2002, health boards and local authorities will have resettled most of those living in long-stay hospitals in 1998. However, to close long-stay hospitals will mean losing another 700 to 800 places from 2002 to 2005. Bridging costs to the NHS for 800 places might amount to about £9 million a year (about £35,000 for each place) over that period. Health boards' general allocations include an amount for the costs of moving people as hospitals scale down and new services are added in the community.

Recommendation 14 Health Boards with sites remaining after 2002 should develop, with their partners, other services in the community as a priority and set aside resources to meet these costs. This will feature in planning guidance and the boards' performance management arrangements.

An example of good practice

Gogarburn Hospital, a long-stay hospital on the outskirts of Edinburgh, is the first of its type to close in May 1999. Those involved needed:

- new resources if residents were to enjoy a better quality of life;
- a pact of the four councils, the health board, the NHS trust, Scottish Homes and housing associations and the voluntary sector to create a structured approach;
- a wide range of solutions to meet people's needs;
- tight control and a strong financial structure (deciding what the financial limits are at the beginning and managing them);
- to create new systems through ideas such as **benchmarking**, to achieve better use of resources, better relationships with providers and better targeted services for users;
- clear communication between agencies and patients, relatives and staff; and
- a wide-ranging staff plan.

25 In considering how to provide for the 700 to 800 people who will still be in hospital in 2002 (less those who need assessment and treatment and those on statutory orders) local authorities will need to recognise that while some residents will be older and so more likely to be suited to nursing or care homes, most will need more imaginative options.

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26 We became aware, during the review, that local authorities are having some difficulty in arranging supported living options. Nursing homes are being used more and more, partly for economic reasons. And significant numbers of people who expected to leave hospital to go to supported living are now moving into large group homes or nursing homes. We think this should be avoided wherever possible.

27 The total cost (including healthcare costs in the community) of providing a mix of adult placements, small group homes, supported living and nursing or care homes would be £17.3 million for 400 people. This would compare with the recurring hospital costs for 400 people of about £15 million (see appendix 4). New hospital places might require **capital** of about £18 to 25 million over three years. Some of this may be paid for using the proceeds of selling sites. Other **capital** charges may be about £1.5 million each year.

28 So if we take **revenue**, **capital** and **bridging finance** together, the cost of providing for 700 to 800 people in the community less the 300 to 400 who will stay in the NHS will be about:

- £2 million of extra **revenue** each year for local authorities by year three;
- £1.5 million for other **capital** charges (NHS);
- £9 million over three years of non-recurring **bridging finance** (NHS);
- £6 million **capital** for housing, spread over the three years⁴⁶; and
- £18 to 25 million of health **capital**, spread over three years, which could be paid for using the proceeds of selling sites.

The NHS would still fund the other 300 to 400 places, at a cost of around £15 million each year.

Healthcare for people leaving long-stay hospitals

29 We should meet the general healthcare needs of people with learning disabilities in the same settings as the rest of the population. We should meet specialist needs related to their disability in the least restrictive setting possible, and ideally in the community.

30 Hospitals currently oversee the day-to-day medical and health needs of residents, including screening. Developing services in the community, including health services, is the way ahead. This means developing a new structure to assess and support people in different settings, including people with more **complex needs**. Some are already in place and working effectively. Trained nurses are working alongside social care staff in a person's own home or in other community settings. Some areas have developed plans, supported by training, to allow non-health staff to give medication and carry out other health-related tasks.

31 Extra support for people with **challenging behaviour** or offending behaviour has also led to more people being able to live in the community and use **mainstream** services. These are good examples of developing links between learning disabilities, other specialist services and older people, mental health and physical disability services, and they lead to our relying less on sending people into hospitals. We look at primary and general healthcare again in chapter 6.

Making sure there is quality for people living in care homes

32 For some people, nursing home or residential care will be appropriate forms of care. We are improving the quality of care in both these and other settings. The Scottish Executive is committed to setting up a new organisation, the Scottish Commission for the Regulation of Care (SCRC) in 2001 to make sure the quality of care wherever it is provided is consistent. This applies in someone's own home, in a care home, or in supported living. The Scottish Executive has set up a National Care Standards Committee to draw up national standards for care in all these settings, with people's quality of life as the central focus. But whatever the setting, quality has to be determined from the inside, rather than enforced from the outside. It has to be part of planning services, and providing and monitoring them.

33 The emphasis on including people in society, and on continuing development applies equally to residential or nursing home care. Individual solutions, based on individual needs and choices, should always be the aim.

34 Some local authorities are already examining the role and functions of residential care, most of which is provided by the voluntary sector. One has carried out a best-value study. Its conclusions point broadly in the same

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direction as our review, in other words helping people stay in supported living. However, achieving the better outcomes will be more expensive. There will also be costs involved in getting there.

35 We expect change in two ways. First, people who used to go into residential care (about 400⁴⁷ each year) or nursing homes (unknown, but quite small) will instead be placed in other forms of accommodation, wherever possible. Second, as part of the change of direction locally, some people will move out of residential care or nursing homes to more suitable settings. We see this as a gradual process based on considering the availability of suitable accommodation and support locally. Local authorities and health boards need to include people with learning disabilities currently living in homes for other care groups in these considerations.

36 About 1,800 people classed as being in a 'residential home' already live in supported accommodation of different sorts. Over time, and recognising the local nature of these considerations, we expect to see a shift to the pattern of care. We expect:

- considerably fewer people (including older people) in nursing homes; and
- most people in various forms of supported accommodation, with particular emphasis on adult placements, small group homes and supported living arrangements.

37 This review has given a lead on the direction we want to travel. Decisions about the need for, scale and pace of any shifts are best left for local decisions.

38 There will be some extra costs, but also benefits for people. This is one of the areas where a 'change fund' would clearly be a good idea. We discuss this more fully in chapter 2.



5 A full life - what you do

1 This chapter looks at the value of good-quality and stimulating day opportunities and short breaks for people with learning disabilities and their families. It ends with a section which highlights the need for the general public to understand more about learning disabilities.

2 Support for people with learning disabilities, whatever its focus, must strengthen their ability to make their own contribution. This may be either to their community, their family, or their workplace. Those who work with people with learning disabilities need to build on what each individual can do to make a real difference to their quality of life.

Day opportunities - Where we are now

3 Day care costs local authorities about £53 million each year⁴⁸. The number of people with learning disabilities going to social day centres has grown from 4,400 in 1980 to 8,300 in 1998⁴⁹. A place costs about £7,000 a year. In March 1998, hospitals had 270⁵⁰ day places for 489 people, at a cost of just under £2 million⁵¹.

4 93% of people going to day centres do not have paid work⁵². Only 20% of activity in day centres takes the form of education and employment, while 28% involves leisure and recreation⁵³. Similarly, only 25% of sheltered workshop spending goes on learning disabilities⁵⁴.

5 We learned of people going to day centres for many years without a formal assessment. Most people using services who were interviewed as part of our user and carer survey described day centres as boring and lacking in direction. However, they did value the chance to access health services and to meet friends.

6 Carers' perspectives may be different. Day services give them valuable opportunities to follow other interests, education or work. Carers are understandably concerned at any suggestion that services might be taken away, and their own opportunities restricted. It would be pointless if new developments place heavier burdens on family carers.

7 Many day services for adults are not focused enough on continuous learning and development. Day care is not seen as a stepping stone to new experiences or to employment. It does not challenge and stimulate each person enough.

8 That said, a number of people with **complex needs**, but particularly those with **multiple** and **profound disabilities** and some people with **autistic spectrum disorders**, will continue to need structured day opportunities. Some day services provide high-quality care and involve people with **profound** and **multiple disabilities** in everyday activities in the community (with support). Health boards need to consider developing more outreach services for people in these settings.

An example of good practice

The Aveyron day centre was set up by a parents' group and now receives funding from South Lanarkshire social work department. It provides day care for up to 18 people many of whom have other physical disabilities, severe health problems, **sensory impairment** or **challenging behaviour**. The local community learning disability team work closely with centre staff to support those who go to the centre.

The future scope of day services

9 Day opportunities are important to people with learning disabilities. But traditional day services are no longer appropriate descriptions of the ways in which people with learning disabilities want to spend their days. They value a structured day, especially one with meaningful activities.

10 People with learning disabilities want fuller lives, and to be able to join in more with others in the community. Services need to be more flexible and meet people's needs if this is to happen. Local authorities need to look at their current day care services to see how they can include people more in the community.

An example of good practice

The Carisbrooke day centre provides day care for those with significant physical and health needs. There are close links with primary care and specialist health services.

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11 The role of day centres should change. They should increasingly become resource centres, offering only some in-house activities and support. They need to use more community resources and help people with learning disabilities get continuing education and development, real jobs and more involved in sport and leisure activities. Community education also has an important part to play. Local authorities are currently drawing up their first community learning plans which have to include the needs of people with learning disabilities. Nobody should go to a day centre full time, but they could use it as a base to identify and go to activities in the wider community. In some areas day activities can come to the person (for example, one-to-one outreach), or to a group.

12 Local authorities will want to give particular care and attention to how day opportunities can meet the needs of people with **multiple** and **profound disabilities** or those who may not be able to benefit from employment or continuing education. Opportunities will vary from person to person but need to focus on personal and social development. Services will need to be available for people with specific and other health needs. Good day opportunities are particularly valuable to people who have **challenging behaviour**⁵⁵. Organisations will need to provide appropriate staff training to support these changes.

An example of good practice

The White Top Centre in Dundee provides day care for 15 people with **profound** and **multiple**, physical and learning disabilities. The centre opened in 1994 with funding from a charitable trust and is now supported by Dundee social work department. Tayside health board pay for some health posts. Nursing, physiotherapy and social care staff work together to support those who use the centre and their families.

13 Local authorities need to review their day care services. In doing so, they will want to be sensitive to the anxieties and views of users and carers. They need to balance the needs of users and carers so that they help the person with disabilities and prevent family breakdown. Good personal planning for the person with learning disabilities will take full account of the needs of their carer.

14 Local authorities should be able to use existing resources better by taking advantage of services and opportunities in the community and looking for real jobs. This is an approach already used in many areas which are successfully remodelling services. However, changing the current style and shape of services will take time. Extra money from a 'change fund' would help to make that shift.

Recommendation 15 Local authorities and health boards, should both examine what they provide and develop more modern, flexible and responsive services which support people in the community through employment, lifelong learning and getting them involved socially. Day healthcare services for people with learning disabilities should be mixed with those in the community.

New opportunities for lifelong learning and development

15 Lifelong learning is important to people's development and provides opportunities for people to feel more included. The Higher Still Programme provides a framework for people of all abilities, from those with profound learning difficulties through to those sitting Advanced Higher. So, it could offer young people with disabilities excellent opportunities for lifelong learning.

16 Many people with learning disabilities already take part in educational activities within day centres and in further education. There is a lot more scope for continuing education to play a bigger part in their development. Well-planned learning opportunities can have significant and long-lasting effects. They can improve the quality of life for people with learning disabilities and help them to take advantage of other activities and employment. They can also help them to develop independent living skills so that they rely less on others.

17 The main recommendation of the Beattie Committee is that **post school education** should aim to include more people. This should mean that it is better designed and delivered to meet the needs, abilities and hopes of young people within a supportive environment. What is provided should match needs rather than asking the young person to adapt to the learning environment.

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18 Adults with learning disabilities, like any other adults, need learning opportunities throughout their lives. They want to learn skills for work, enjoy leisure activities, improve their skills (especially communication) develop self-confidence and **self-advocacy**, and learn to use facilities in their local communities.

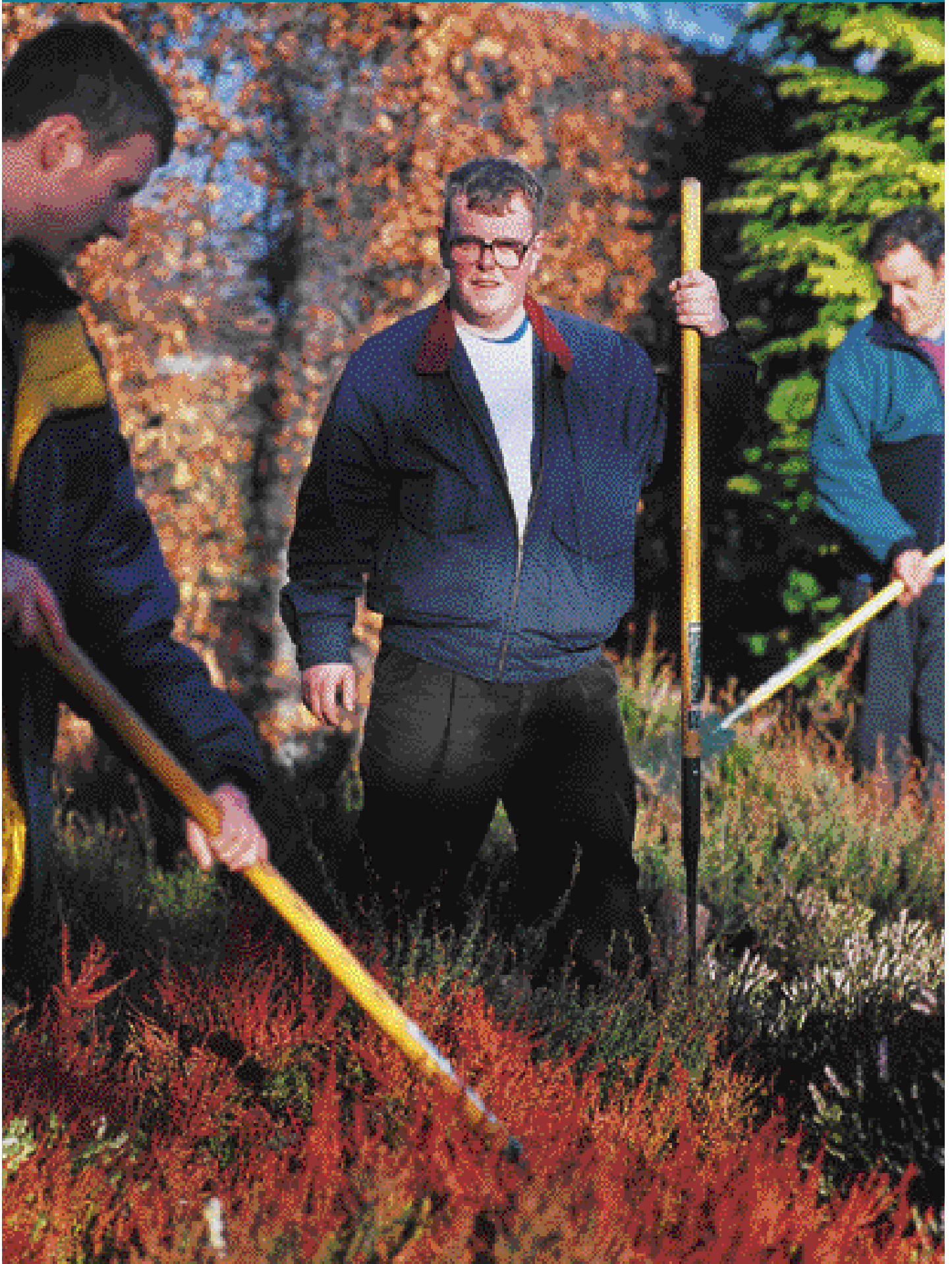
19 Most further education colleges are now controlled by new boards of management. They have an important contribution to make to post school learning. Colleges, training providers and local authority community learning services should work together to make sure that an imaginative range of opportunities is available. They should work with those who provide other services to make sure that learning is relevant to the individual and consistent with the needs assessment and 'personal life plan'.

20 The Beattie Committee asked the Learning Disability Review to consider whether their proposed National Action Group should set up a challenge fund to support and test work on improving access to continuing learning for those who need a lot of support. We approve of this recommendation, but would want to widen the opportunity to access continuing learning to *all* people with learning disabilities. The Director of our proposed Scottish centre for learning disability should be a member of Beattie's proposed National Action Group to make sure the voice of people with learning disabilities is heard on employment issues at a national level.

Developing employment opportunities

21 Many people with disabilities want a decent job. They want to get on in life and have friends at work. The Scottish Executive's **social inclusion** strategy ranks having a job high in the list of measures to help people to be included in society. Employment has, so far, rarely been an option for people with learning disabilities. If they are to be usefully included in society, that has to change.

22 During the course of the review we heard about some very successful employment projects. Many of these have been created by the voluntary sector, for example, Enable in Paisley. Others include Jobs 4 All, a not-for-profit recruitment agency for people with disabilities run by North Highland College, and North Lanarkshire Council's Supported Employment project. They focus on helping people with learning disabilities get real jobs. The



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Employment Disability Unit in Dundee has had considerable success with a job club, a sheltered placement scheme and a work experience programme. We met people who had gone to day centres for over 20 years and who are now satisfactorily in full-time jobs. Unfortunately there are only a few of these projects. One person told us:

'I keep on being assessed for employment but never get a job.'

23 The New Deal for Disabled People is experimenting with new ideas. Personal adviser services will be the first step in transforming the way in which the benefits system supports disabled people who want to work.

24 Many employment projects centre around employment development workers. They need a broad range of skills from negotiating and marketing, to offering on-the-job support and training, and working with parents and others. They match the employee to a job and train and help him or her into employment. They also provide gradually-reducing support in that employment. Some New Deal for Disabled People pilot schemes include development workers. The responsibility on the employer is to treat and support their employee with learning disabilities in exactly the same way as any other. Those who employ people with learning disabilities have shown they value them.

25 Employment development workers should:

- work towards including people with learning disabilities in ordinary work settings;
- help people find jobs which offer the same pay, terms and conditions as employees doing the same kind of work;
- offer people the necessary support to be able to work on their own, with appropriate risk assessment and management; and
- help those with **complex needs** to find work and provide ongoing support where necessary.

26 However, real jobs may not be everyone's aim. Opportunities also have to be found for 'tasters', part-time opportunities and voluntary activities. There is still a place for sheltered workshops. Whatever the setting, the aim ought to be to help the person develop, and wherever possible to get them fully involved in society.

27 Employing people with learning disabilities or arranging it is not the responsibility of any single agency. Agencies involved in care, health, employment, benefits and indeed in the business world need to work together. As we mentioned earlier, the Beattie Committee is proposing a National Action Group. But it is likely to consider strategies and practical approaches to developing employment, for example, in promoting social firms which help young people move into employment. We suggest that Enable, as the national organisation for people with learning disabilities, should contribute to this work. And, local authorities and health boards could give a lead to local employers by taking on more people with learning disabilities.

28 Supporting people into employment offers them the opportunity to be included, to gain more self-esteem and to meet new people. It can also be cost effective for authorities, compared to the cost of day care (£7,000 for each place each year). Moreover, once the support is withdrawn, local authorities can use that same resource for someone else. In terms of comparing other costs, we were told that a 'Training for Work' place costs about £3,200, and that the Department of Employment will pay up to £4,760 for a full-time worker on a supported employment scheme. So, there can be advantages for people and local authorities in following-up employment led solutions.

Recommendation 16 Local authorities need to give much greater priority to developing a range of employment opportunities for people with learning disabilities. And, with health boards those authorities should lead by example in employing more people with learning disabilities.

Enough money to join in?

29 Benefits play a big part in the lives of people with learning disabilities. Most are not, or have not been, wage earners, and benefits are often their only source of income. So their ability to lead a normal and fulfilling life is governed by benefits. Making the most of income from benefits is an important part of the Scottish Executive's plan to include more people in society.

30 Some benefits provide a source of income for everyday living expenses (Severe Disablement Allowance, Income Support, Housing Benefit, Incapacity

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Benefit and so on). Benefits also help people who may be able to work to gain employment. There are a number of New Deal initiatives to help people on long-term Incapacity Benefits move into work. These include the following.

- Increasing the therapeutic earnings limit in Incapacity Benefit and Severe Disablement Allowance to £58 a week from April 1999. Disabled people who carry out therapeutic work can then benefit from the national minimum wage.
- Introducing a 12-month linking rule for people on long-term incapacity benefits in October 1998 to reassure them that they can try work without losing out if they fall ill again.
- Removing the 16-hour restriction on the amount of voluntary work that people can do who receive incapacity benefits.
- Piloting (for a year from April 1999) a package of four measures in 15 areas (including south-west Scotland, Grampian and Lanarkshire) to help people with disabilities who want to return to work. The pilot allow those on incapacity benefits to earn a small amount of money (up to £15) without losing benefit; and to try out a job for a trial period while still on benefit. They also allow access to a Jobmatch payment of £50 a week for people moving into part-time work; and a Jobfinder's Grant of £200 for those starting full-time work.

31 Users and carers told us that the New Deal for Disabled People is still in pilot form. Unfortunately, since most people with learning disabilities do not get Jobseeker's Allowance, they cannot join the main scheme. However, the experience of the few people with learning disabilities who have been able to get through the system suggests it is effective in helping get them into employment.

32 Benefits also help with the other costs of disability. The Independent Living Fund (ILF) is a trust fund which can make discretionary grants. It can make life better for some people by supporting independent living. People do not always understand why some people get it and others do not. More specifically, the limit on earnings for support under ILF may have had a negative effect on getting people to work. For that reason, the Government has increased the limit they can ignore on earnings under the fund.

33 People who have been in care homes since 1993 and have preserved rights to higher DSS benefits are worried about moving to other housing options. The Department of Health and the Department of Social Security are

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currently looking at the effects on local authorities if they have preserved rights cases transferred to them.

34 A person's ability to make financial decisions for themselves is often governed by the decisions of others. For instance, someone in a registered home would have their care and accommodation costs paid for, but would be left with only a small income for them to use. The same person in a supported living setting could be left with much more choice about how to use this money. Charging policies can eat away personal income in accommodation which is not registered. Different decisions on Housing Benefit at a local level can lead to different outcomes for people.

35 The benefits system is complicated and getting the right advice and help is essential. The range and level of benefits varies considerably according to personal circumstances. The research paper we commissioned identifies some of the difficulties people face in getting benefits⁵⁶. People with learning disabilities and their representatives told us repeatedly that they found the benefits system difficult to understand and to find their way around.

Recommendation 17 The Scottish Executive should consider raising, with the Department of Social Security, specific areas of concern related to benefits and support for people with learning disabilities.

Leisure and recreation

36 Leisure and recreation are important to all of us, and we do not all like to do the same things. This is also true of people with learning disabilities. Currently about 28% of activity in day care takes the form of leisure and recreation inside and outside day centres. Much of this time is spent with others who have learning disabilities.

37 A better approach would be for people to mix with others of their own age and interests in the community. If these links do not exist at the moment, agencies need to encourage and develop them. Befriending schemes can help with this. People with learning disabilities need to be involved in activities enjoyed by the public generally. They need to use public facilities more alongside non-disabled people, with less segregated sessions, events, shows and activities. In reviewing their day care opportunities local authorities should consider developing befriending schemes and links with other community groups.

Transport

38 Getting around means a lot to people with learning disabilities. During our review it became clear that they are not satisfied with local transport services. Improving transport for people with learning disabilities means:

- for the less able, having access to special transport for care and social activities;
- for those who are more able, making more use of public transport (either on their own or with others), wherever possible; and
- having a transport system which meets people's needs.

39 Developments such as the Scottish Executive's rural transport initiative are helping certain areas, but we think we need better transport networks generally. There are already arrangements in place within Scotland and the Department of the Environment, Transport and the Regions (DETR) on issues such as access.

40 Training drivers is also important. DETR issued guidance in 1997, 'Taking Care of Your Passengers', and bus operators throughout the country have just issued a video 'It's a Bloody Nuisance' related to the needs of people with disabilities. Closer to home, the Scottish Executive is shortly publishing a research study, 'Transport Provision for Disabled People in Scotland', which identifies gaps in the current system and recommendations for action, locally and nationally. This offers a new opportunity to look at concerns in Scotland.

41 Timetables need to be very clear if people are to understand them. And, bus drivers need to realise what the needs of people with learning disabilities are, which may not be obvious. To overcome this, one group has produced a small card explaining that the holder has a learning disability, and inviting the driver to remember this. It has been widely welcomed by both drivers and users and is a good example of an effective idea which is relatively cheap to put into practice.

Recommendation 18 Local authorities should review their local transport services, to make sure that people with learning disabilities can use public services wherever possible.

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The importance of short breaks – where we are now

42 Most people spend time away from their parents and families. They go to school, they visit relatives and friends, and spend time with other people, doing different things. Children have tea or stay overnight at a friend's home, adults may see friends, partners or colleagues outside their own home, go to leisure facilities or clubs, or do evening classes. People with learning disabilities, and their families often need help to arrange these simple but very important matters. One carer told us:

'Fun, interesting activities, making friends her own age, are the most important things for my daughter. I need to know she is happy and secure.'

43 Research on respite care suggests that what is offered is directed more at carers' needs rather than the needs of people with disabilities⁵⁷. Many families are unhappy with the term 'respite', and prefer to use 'short breaks' which shows that the services should be designed to meet both sets of needs.

44 Where families have access to a short break service they value it highly, but they report they rarely receive enough to meet their needs. While the number of services providing short breaks has grown a great deal over recent years, they are still not meeting the demand⁵⁸. And the effort needed to actually get a short break can be tiresome. We were told:

'It's a performance trying to book respite.'

45 The number of children with learning disabilities in **mainstream** and specialist education in September 1998 was 8,800, but there is no record of the numbers within this group who need or actually receive short breaks⁵⁹. The Accounts Commission produces information about the numbers of *all* children with disabilities in each local authority who received respite care at least once. They found that out of 3,800 children assessed (in 1997-98) as needing a respite place, 3,300 actually got one⁶⁰. Because these figures include children with other types of disability, it is not possible to give the exact number of children with learning disabilities who actually received respite care. These figures also do not include those whose needs are not assessed. We do know that where new respite for children has been developing it tends to focus on the needs of children with learning disabilities⁶¹.



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46 The Accounts Commission also produces figures for adults with learning disabilities in each authority who received respite care at least once. These tell us that the number of short breaks provided across Scotland varies a great deal. For instance, an adult with learning disabilities in one area is 11 times more likely to get a short break than someone in another. Overall in 1997-98, out of 3,600 adults assessed who needed a short break 3,200 got a service. Again it is relevant to note these figures do not include those whose needs are not assessed.

47 Using long-stay hospitals for respite for people with learning disabilities continues to grow. Out of 4,100 people with learning disabilities who went into hospital in the year to March 31 1998, 3,400 people went for holidays and respite. A sizeable number were children. (However, it is likely some people will have been counted twice as some may have had more than one period of respite care during this time⁶².) As long-stay hospitals run down, local authorities and health boards will need to provide appropriate alternatives in the community. And, many general hospitals continue to provide respite for children in long-term paediatric wards. This is usually for children with special medical needs, and on an unplanned basis.

48 There are good examples of jointly-funded short break services for children with **complex needs** in community settings. Nursing staff work alongside organisations providing social care to meet healthcare needs. This prevents using hospitals unnecessarily.

An example of good practice

Highland health board and Highland social work department jointly-fund the Orchard. This is a residential respite service for children and young people with **complex needs**.

49 What is clear is that the chances of being able to get a break varies significantly across the country and there is still a need for more short breaks for both children and adults. While there is an overall shortfall in what is being provided, it is difficult to work out accurately by how much.

An example of good practice

Aberlour Child Care Trust has a respite care residential service for children in the Borders. Other health needs are met by nursing staff from Borders General Hospital paediatric services. Nursing staff are seconded to work alongside social care staff to make sure they meet children's health needs to prevent them going into hospital.

50 The Scottish Executive launched their Strategy for Carers in Scotland in November 1999. It means local authorities need to spend £10 million of their grant-aided spending for 2000-01 on services for carers (including short breaks), £5 million from their present budgets and a further £5 million from the new resources made available in that year. The Scottish Executive wants to formally involve carers' organisations in considering how these resources should be used. This should lead to a real increase in short breaks. Ministers have made it clear they will consider targeting extra resources if it does not. The Scottish Executive will monitor the outcome of the carers' strategy for people with learning disabilities. However, we were so struck by the pressure on families of people with learning disabilities that we believe there will be a need for further investment. A carer told us:

'Caring is demanding and stressful. We need to feel that we are doing a good job. If there is no support for us, we cannot continue to care.'

A structured approach to planning short breaks

51 We see two main themes coming from the review.

- Families want more breaks and want flexible planned breaks at home and elsewhere.
- Parents want a wider range of social and leisure experiences for their families through better access to **mainstream** play and out-of-school activities, child care services, education and leisure facilities.

52 Short breaks need to be flexible and meet the individual needs of children, adults and those with more **complex needs**. Carers of people with learning disabilities need better support if they are to continue to care and avoid caring crises.

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An example of good practice

The National Children's Home – Gilmerton Road project in Edinburgh provides respite care, residential and peripatetic services for children and young people who have learning disabilities and emotional and behavioural difficulties.

53 Good arrangements for short breaks and shared care depend on simple procedures. Whether the short break is provided by another family or by an agency, the worker's role is to help with this process. They need to be as flexible as possible.

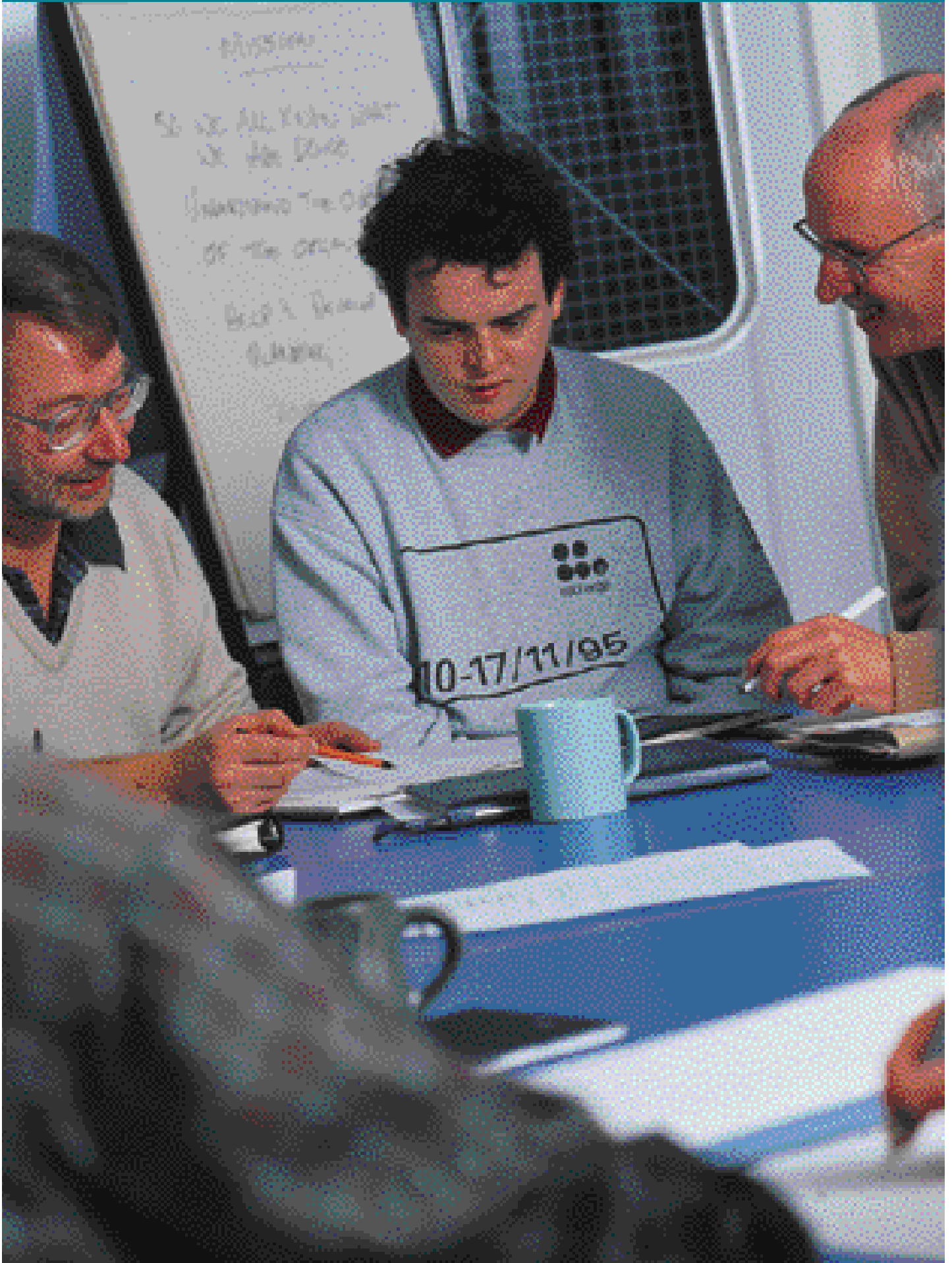
54 No child or adult should have a short break in a hospital setting unless they are in need of specialist treatment or assessment that cannot reasonably be provided elsewhere.

Recommendation 19 Health Boards should contribute funding and resources (for example, training for residential and family carers) to developing community-based short breaks alongside local authorities. Local authorities will also be able to bid for any 'change funds' which may be made available for further developing short breaks for people with learning disabilities.

Recommendation 20 The Scottish Executive and local authorities should review their guidance and procedures to make sure that local authorities and health boards can arrange their short break and shared care arrangements for children and adults flexibly and with as little bureaucracy as possible.

Public attitudes

55 We paid for research to find out about public attitudes to learning disabilities by surveying over 1,000 adults in Scotland⁶³. Most felt that people with learning disabilities are just like other people and have the right to live, learn and work alongside everybody else. Most thought that people with learning disabilities should not live in hospitals. However, the survey also showed that ordinary people do not know very much about learning disabilities and that this may lead to prejudice and confusion.



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56 Giving people with learning disabilities a more positive profile in communities and schools is an important step on the way to changing public attitudes. Research shows that effective strategies for changing public attitudes work best when there is a positive personal contact for example, helping a customer with learning disabilities. Sharing relevant personal information such as encouraging people with learning disabilities to talk about themselves and their lives, also works well.

57 Regrettably, bullying and harassment are all too often part of the life of people with learning disabilities. A recent report says that 65% of people who took part had experienced bullying; 38% of them said it happened regularly⁶⁴. Many of those responsible were children and young adults. Most victims felt uncomfortable about reporting incidents. If they did, it was effective in 38% of cases.

58 It seems obvious that the general public needs to have a better understanding of people with learning disabilities. That need is greatest among children and young adults. The Scottish Executive has already a programme against bullying in schools.

Recommendation 21 There should be a long-term programme to promote public awareness about learning disabilities and including people with disabilities in the community. This should include programmes from the earliest years of education. The new centre for learning disability could be responsible for taking this forward.



6 Working well together

1 Good partnerships between all the people, agencies and professionals involved in supporting people with learning disabilities are essential if they are to get the services they need when they need them. This chapter focuses on:

- the importance of professionals working closely with people with learning disabilities, their families, friends and relatives and building on these natural forms of support;
- the need for professionals to work together better so that the vulnerability and risk experienced by many people with learning disabilities in different areas of their lives is managed better; and
- professionals working better together to help people through the many different stages in their lives, as they develop and their needs change.

At the end of this chapter, we consider:

- the role of primary and general healthcare;
- people with learning disabilities who have mental health problems;
- people with **challenging behaviour**;
- people with learning disabilities in the criminal justice system; and
- people with profound and multiple learning disabilities.

Where we are now

2 We all use family, friends and people in the community to help us in our daily lives. People with learning disabilities are no different and the contribution made by this natural form of support is not only significant in itself, but also important for other services to recognise and build on. Yet this does not tend to be the starting point of planning and delivering services. As we highlight earlier there are many information gaps, but the greatest are to do with carers and family support.

3 People with learning disabilities are vulnerable. They suffer high levels of both physical and sexual abuse⁶⁵. People with learning disabilities are often the victims of crime, many of which are not reported or followed up

through the criminal justice system⁶⁶. The Mental Welfare Commission for Scotland drew attention to the lack of proper assessment and co-ordination of care in relation to one vulnerable person with a learning disability in their 1998/9 Annual Report⁶⁷. We look at this case in more detail below.

4 Present arrangements for assessing, planning and support are not working as well as they could. Professionals do not work as well as they should with the person with learning disabilities or their family. Nor do they always work well with each other. People are assessed by many different agencies and professionals for different and limited purposes, yet too often no clear plan of action is made as a result. For instance, it is not uncommon for people to find themselves in contact with more than one occupational therapist either from:

- a medical service;
- a learning disability service; or
- social work services.

5 We were also told that information about good practice between professionals working with people with learning disabilities is not shared enough. This also applies to those in other specialist services, such as for people with mental health problems, older people and so on.

6 There is general agreement that the everyday health needs of people with learning disabilities too often go unrecognised and untreated. Health promotion and health screening services, hearing and sight tests which are accessible to most of the population are under-used by people with learning disabilities⁶⁸. Everyday health needs are the responsibility of GPs and the primary care team. However, it has been reported that two-thirds of people with learning disabilities need more health support than primary care can provide⁶⁹. Specialised health needs often need referring on to other specialists, for example, specialist consultants, professionals allied to medicine and community learning disability teams. For many young people with **complex needs** the supports they need will be lifelong.

7 People in our user and carer survey were concerned that healthcare professionals did not spend enough time in assessing the health needs of the person. Some parents believed that healthcare professionals did not know enough about learning disabilities because they had not been given enough

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training. There is evidence that when professionals train together they develop a better understanding of each other's roles.

8 Planning for the different stages in people's lives is also neglected. In our user and carer survey most families felt that assessments do not take account of their children's future needs, such as moving from:

- school to further education or resource centres;
- education to employment;
- hospital to community placements;
- services for children to those for adults or older people.

Even more importantly, they reported a lack of co-ordinated planning for the time when they would no longer be there.

An example of good practice

PAMIS (Profound and Multiple Impairment Service) runs training workshops for parents and carers on future planning, legal, financial and housing issues.

9 Caring for a person with a learning disability can be a worthwhile and rewarding experience for many family carers. However it can also place a strain on their emotional well-being, health, finances and relationships. Studies of the psychological well-being of mothers caring for disabled children show higher levels of anxiety and depression compared to women in general. These levels are significantly higher for those caring for children who have other learning disabilities and **complex needs**⁷⁰. During the review carers highlighted the fact that the issues they face are a *constant* feature of their lives. The opportunities they want to take and the problems they try to overcome are not simply present when they get professional attention.

10 Too often at the moment services for people with learning disabilities do not take a wide enough view. Services need to be much more centred on the experience of the people involved, both to meet their needs and to be effective. A system that arranges a tenancy for a person with a learning disability, but leaves them lonely with nothing to do is based around the

service, and does not put the person first. A professional who does not take account of parents' views when they have provided care for 25 years is not setting the service in the full context of the lives of those involved.

11 Effective partnerships between all the people and professionals involved in supporting people with learning disabilities depend on developing **natural supports** in the community such as family and friends *and* using specialist knowledge and expertise to build and maintain long-term benefits. Professionals and others do best when they arrange the service they offer by taking account of the lives of the people they are trying to help.

12 By building natural links and relationships into assessment and planning and developing care, agencies will use their resources more effectively and get better results for people.

Vulnerability and risk

13 Risk features in several different areas of life for people with learning disabilities. Their general vulnerability makes them a target for abuse. They may be exposed to risks in leading a full life. Sometimes, there are risks for them and others, for instance, around taking and giving medicines. These risks need to be assessed and managed. They should never be an excuse for not taking action or taking inappropriate action which does not take account of what users and carers want and need to lead as full a life as possible.

14 We have already said that, wherever they live, people with learning disabilities sometimes experience high levels of sexual or physical abuse and are more likely to be victims of crime. The Mental Welfare Commission's 1998/9 Annual Report highlights a particular case of someone with a mild to moderate learning disability who lived a chaotic life after her mother died, being exploited by several people. She was seriously assaulted and continued to be vulnerable even when it was obvious to professionals that her learning disability was affecting her judgement.

15 The inquiry decided that there had not been enough supervision and protection during the period under review and that the assessment of risk was not dealt with well enough in case discussions. It is very important that social work departments understand when it is appropriate to resort to using compulsory powers to protect through **guardianship**.

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16 The Mental Welfare Commission's Report made some far-reaching recommendations including that the **Care Programme Approach** should be used for people with learning disabilities who have **complex needs**. We agree with this recommendation. We have responded to some of their other recommendations here and elsewhere as they are relevant to our concerns to strengthen assessment and planning care. They are also relevant to improving the knowledge and skills of the various professionals who work with people with learning disabilities.

17 Many of those we interviewed during the review told us that too much time, money and energy was spent on over-protecting people with learning disabilities. As ordinary citizens we can make many decisions about the risks we take in our lives. We may choose to go rock-climbing, knowing that injury is possible, but the sense of achievement makes it worthwhile. People with learning disabilities need support to achieve their personal goals. This should not mean putting them at risk but it also does not mean over-protecting them. For this to be possible, users, carers, support staff and managers need to be clear about what risks are acceptable. The Scottish Executive has recently issued guidance for nurses, health visitors and midwives on protecting vulnerable people⁷¹. Some local authorities already have a policy and provide staff training on assessing and managing risk. This should be the case for all.

Recommendation 22 The Scottish Executive's National Care Standards Committee is currently developing standards for residential and nursing care homes for all care groups including people with learning disabilities. These standards should look clearly at assessing and managing risk in working with vulnerable people.

Recommendation 23 All local authorities in association with health boards, NHS trusts and other agencies should develop policies and guidelines on protecting vulnerable adults. Social work departments should review their procedures on guardianship to include making a formal assessment of risk a normal part of deciding whether an application should be made. Local authorities and health boards should use the Care Programme Approach for people with learning disabilities who have complex needs whether these needs are caused by disability or vulnerability.

Handling transitions better

18 The needs of many people with learning disabilities are lifelong and change as they get older. It is very important that services recognise this and work together to make sure moving from one stage of a person's life to another is planned for and managed as smoothly as possible. This section suggests ways in which agencies might manage this better. It links back to our proposal for personal life plans.

Early years

19 When parents are told that their newborn baby (or child) has a condition which includes learning disabilities, their lives are changed for ever. Their child may still be the greatest source of joy and inspiration and bring pleasure and pride to them, their family and friends. However, their world will not be as it was. They may face many challenges, some of which may frustrate or exhaust them.

20 If a child is born with a learning disability or fails to reach expected early developmental milestones families need:

- information, practical help and emotional support from knowledgeable professionals;
- access to ongoing advice, local child care, paediatric and child health services which can meet their child's needs;
- therapy services included with ordinary children's services;
- programmes which teach parents and carers in nurseries, schools and respite settings how best to help each child develop; and
- early information, advice and options for pre-school and primary education.

School years

'The most important rights of children and young people with Special Educational Needs (SEN) are the right to an appropriate education and the right to be fully integrated into the community to which they belong when they are adults. Inclusion in ordinary schools or, segregation into special classes or schools, is only defensible if it facilitates these two rights' (Hornby)⁷².

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21 The Scottish Executive's current policy aims to increase **social inclusion** but accepts a need for special schools. Every child should have full-time education that meets their needs, and support to make the most of the learning opportunities available. The new Education Bill before Parliament plans to bring forward a provision at the committee stage of the Bill to the effect that "It shall be presumed that, where under the 1980 Act an education authority are to provide school education for any child of school age, such education shall be provided in a school other than a special school." Local authorities have particular responsibilities to assess and support children with special educational needs. This includes children with learning disabilities.

22 Special schools provide for a smaller number of children whose needs are too great for most ordinary schools to meet, such as those with **profound and multiple disabilities**. Some profoundly disabled children manage well in **mainstream** classrooms with a lot of support. The Scottish Executive has issued guidance for staff working with children in educational settings on providing intimate care for children and young people with disabilities⁷³. The most important consideration is that the education should be good-quality and meet the child's needs, not least their wish to be included and have friends.

23 We share the view of the Riddell Advisory Committee on Education Provision for Children with Severe or Low Incidence Disabilities that, in future, a higher number of children with severe low-incidence disabilities will be included in **mainstream** schools close to home. However, they will need specialist services to make sure that their education, health and social needs are met⁷⁴. Specialist and **mainstream** services need to work together to achieve these aims. Setting up a National Special Educational Needs Advisory Forum, to be chaired by the Deputy Minister for Education, Culture and Sport will give the Scottish Executive a way of monitoring developments in this area.

24 Whatever form of provision is most suited to a child's needs, it should form part of the family's wider network of support so that the family experiences a 'seamless' service. A number of people told us there is little continuity of service or staff, and relevant information is not exchanged when children move from early years to primary and then secondary education.

Future Needs Assessment

25 Future Needs Assessment and putting it in place is particularly important to young people with learning disabilities. When a child has a **Record of**

Needs and reaches 14, education authorities must get ready to carry out a future needs assessment (FNA). This, and the action that follows from it, is particularly important to young people with learning disabilities. This should consider whether the child would benefit from school education after he or she has reached the statutory school leaving age (16), whether the Record should be continued throughout the period the young person is still at school and what provision is needed after school. The Record must be discontinued when the young person stops receiving school education or reaches his or her eighteenth birthday. Social work services have a duty to assess whether a recorded child is disabled and, if so, to carry out an assessment of the young person's need for social care services.

26 There are several difficulties with the current arrangements:

- the child and family may have had little contact with social work services before the FNA;
- the social work contribution to the FNA is usually from children's services, which may have limited knowledge of **post school education**, and welfare services available to young adults;
- at the point of handover to community care services for adults there may be a need for a further assessment;
- there is no legal duty on agencies to put the FNA into practice as there is with the **Record of Needs**;
- healthcare needs are not always considered;
- social work services rarely offer options that would include committing financial resources two to five years ahead;
- there is a focus on existing services, and access to day care, rather than needs-led person-centred planning;
- education authorities have no responsibility for putting the FNA into practice after the child has left school; and
- putting the FNA into practice often proves difficult as it relies on resources provided by other agencies.

27 We believe it is necessary to introduce a new duty for local authorities to identify a responsible person (who could be the local area co-ordinator) to advise and help the person with learning disabilities and their family put the FNA into practice (unless they say otherwise).

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Recommendation 24 The Scottish Executive should consider introducing a new duty on local authorities to identify a responsible person to advise and help the person with learning disabilities and their family put the FNA into practice.

28 On leaving school young adults and their families may no longer have access to the same short break services, with which they are familiar and comfortable. And the educational opportunities to learn and develop which they had at school may not be available. Local authorities are responsible for meeting these needs, and for co-ordinating the contribution of other partners (including further education college boards of management). GPs, paediatric, learning disability and physical disability services should agree arrangements for people moving from child to adult services to make sure people have appropriate continuity in the healthcare they receive.

29 Making an early start on changing the existing patterns of service is important. We realise that a number of authorities have taken policy decisions not to place any future school leavers in existing day centres. We believe that local authorities throughout Scotland should consider this approach.

Adulthood

30 Needs change over time and as people take up new opportunities they may blossom and look for more. A person leaving hospital may be happy in a small group setting at first but eventually want a home of their own. A person leaving school may want some further education but eventually want a job. Some people with learning disabilities will develop long-term relationships and a number will want to get married. Professionals need to be ready to respond to changing needs as people develop.

31 Professionals and services need to recognise that adolescents and adults with learning disabilities have sexual rights and needs, while at the same time making sure those who may be vulnerable to abuse are protected. The current review of the Mental Health Act is considering how best to protect people with learning disabilities. At present, it is an offence for a man to 'knowingly have sexual intercourse with a woman if she is suffering from a state of arrested or incomplete development of mind which includes significant impairment of intelligence or social functioning'⁷⁵. While this

provides appropriate protection for some people, there are also concerns that people's right to express their sexuality is denied by some services. Some agencies in Scotland have developed policies on sexuality and relationships for people with learning disabilities and we agree with this.

We think local joint policies should include:

- appropriate and accessible information;
- advice and guidance to staff supported by appropriate training;
- access to family planning services; and
- an assessment of risk and the need for protection.

32 Some people with learning disabilities may choose to be parents. As with other parents, they will need a range of support and other help from their families and other agencies. Like other people, parents with learning disabilities can benefit from training and support in developing parenting skills. Some areas offer extra support which is helpful to them and their children⁷⁶.

An example of good practice

Grampian primary care trust employ a specialist health visitor to support parents who have learning disabilities. This project involves clinical psychologists, social workers and primary care staff working together.

33 Local authorities and NHS trusts should make sure that the needs of parents with learning disabilities and their children are identified and met.

Growing older

34 Improvements in health and social care mean that people with learning disabilities can now expect to live longer. While people with **complex needs** and people with Down's syndrome still have a reduced life expectancy, people with milder learning disabilities now have a life expectancy similar to other adults in the general population⁷⁷. Older people with learning disabilities should not be seen as different from older people generally. Services need to reflect all the needs of older people and the extra needs of those with

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learning disabilities. A recent review of the literature identifies large areas of need which have not been met amongst older people with learning disabilities and services are often not aware of them⁷⁸.

35 Local authorities and health services need to make sure that older people with learning disabilities have the same access to health and social care support as older people generally. They should make sure there are links with **mainstream** services for older people and those with dementia to identify the most appropriate services to provide. Specialist knowledge is important here as elsewhere and health boards and local authorities should make sure that there are local professionals who have appropriate expertise to make sure dementia is diagnosed early on. Health services should promote the health and well being of older people with learning disabilities.

36 Older people with learning disabilities and people with dementia will need appropriate day services and recreational opportunities with appropriate links to the **mainstream** services for older people. Health boards, NHS trusts and social work departments should make sure that care staff and support workers have the training they need to meet the needs of older people and those with dementia.

Recommendation 25 Health boards and local authorities should make sure that local professionals are trained to look out for early signs of dementia and so can provide assessment and appropriate responses and services.

37 Older people with learning disabilities are often cared for by parents who become frail and less able to provide the physical support or care needed. In particular the effect on family carers of caring for children and adults with more **complex needs** has been shown to result in greater health needs, stress, anxiety and depression for the carers⁷⁹. Many parents who are carers find it hard to plan for the future.

38 Professionals should respond to carers' readiness to plan and be sensitive to cultural and ethnic influences that may affect attitudes to family caring. They should consider carers' needs as a very important part of any care package for people with learning disabilities.

An example of good practice

Glasgow primary care NHS trust has developed an ethnic and cultural service for people with learning disabilities by working with the community learning disability services. It provides information and support.

Recommendation 26 Life plans for people with learning disabilities who live with their parents should include plans for a time when parents may no longer be able to provide care.

Bereavement

39 We all experience loss in our lives but for people with learning disabilities the loss of a parent who is a carer may lead to a double crisis. For adults who live with family members, death or increasing frailty of parents may mean having to move home. This can have huge health consequences and the process needs to be handled very carefully⁸⁰. Maintaining as much contact and continuity as possible with friends and others is essential. It is also very important that people with learning disabilities have the time and space to grieve.

The role of primary and general healthcare

40 A general practice with 1500 patients can expect to have 22 to 30 people with mild learning disabilities and up to six people with severe disabilities. People with learning disabilities have a greater need for primary care support but tend to use it less than the general population. People with learning disabilities also may need longer appointments to be able to communicate what they need and this does not always happen. There are some initiatives being developed to help people with learning disabilities communicate more clearly about pain and illness⁸¹.

An example of good practice

SENSE Scotland has developed a health log for people with **complex needs** which is maintained by support providers. The log is used to monitor health issues and help when communicating with health professionals.

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41 Health boards should offer regular health checks for all people with learning disabilities. Health professionals should pay particular attention to people with **complex needs**. GPs, paediatricians or specialists in learning disabilities all have a part to play. Primary care NHS trusts need to make sure that there are appropriate links between community learning disability specialists and primary care services. Community learning disability nurses have a particularly important role working between primary care and specialist services. Larger primary care centres might consider choosing a GP with lead responsibility for managing and co-ordinating primary healthcare for people with learning disabilities and their families.

42 The healthcare needs of people with learning disabilities are not always looked at well enough in medical education, including continuing education. Nor are the wider issues about how doctors should best communicate with them. Medical schools and those involved in medical education should examine how good their training is in these respects.

Professions Allied to Medicine (PAMs)

43 **PAMs** work in a number of health, education and social work settings such as health centres, hospitals, schools, nursing homes, day centres and in people's own homes. They can also provide a specialist service as members of community learning disability teams. The main professionals involved in assessing and treating people with learning disabilities include physiotherapists, occupational therapists, speech and language therapists, chiropodists, dieticians and creative therapists such as art, drama and music therapists. Most health boards have specialised paediatric therapists who work with children and families, GP, paediatricians and schools. We were impressed by the quality of service in many areas although staff shortages and an increasing number of referrals of people with **complex needs** has led to difficulties in providing a fair service across the country. We heard of children waiting for up to two years in some areas to see an occupational therapy assistant.

44 While most therapists are employed by the health service some schools employ their own physiotherapists, speech and language therapists and occupational therapists. Local authority social work departments also provide occupational therapy services for people living in the community and there are developing links with health service occupational therapy services in some areas (such as providing equipment). A number of health boards and social work departments have set up joint equipment stores for people using

services and have introduced new arrangements to avoid overlapping assessments. In some areas they are making progress towards a joint occupational therapy service.

45 PAMs have a very significant role to play in services for people with learning disabilities. Many people will be able to use general community and hospital based services for specific treatment. Some people with learning disabilities will need support to use these services. Children and adults with extra and **complex needs** will need ongoing services from a range of **PAMs** linked to community learning disability services. Young people have had difficulty in accessing services when they leave school.

People with learning disabilities and other problems

46 Some people's needs will be lifelong. Others will have particular needs for services at different times in their lives. More **complex needs** may arise from:

- significant difficulties with communication, moving about or physical or social development;
- the complicated nature of support and services needed to help a person with a learning disability cope with mental health problems, or getting into trouble with the law;
- the difficulties for the person or families, carers and others caused by people who injure themselves, who are aggressive or destructive or who display socially-unacceptable behaviour or other challenges;
- the extraordinary services that may be needed to cope with unusual or rare conditions; and
- specific medical problems such as epilepsy, disruptive or disordered sleeping patterns, problems with eating and poor physical and mental health.

We cover some of the main areas below.

People with mental health problems

47 Local psychiatric services and learning disability services should focus on maintaining positive mental health and providing appropriate assessment and treatment by closely working with social work and primary care colleagues. Some people with learning disabilities who also have mental



health problems are rough sleepers and use night shelters. Ending the need to sleep rough is a key commitment for the Scottish Executive and needs all **mainstream** services to work together better.

48 Health boards should make sure that there are appropriate arrangements for people with learning disabilities who have mental health problems going into hospital. In setting up services, health boards should consider the need to have staff trained in learning disabilities *and* staff trained in mental health. Health boards should make sure that there is agreement on the roles and services provided for children with learning disabilities and mental health problems across paediatric services, learning disability services and child and adolescent mental health services.

49 We need to give special consideration to a small number of people affected by the Mental Health Act. Since 1913 people with learning disabilities have been specifically included with those with mental illness in Scottish Mental Health law. The review of the Mental Health (Scotland) Act 1984⁸² is considering whether to continue to include people with learning disabilities within mental health law. In Scotland there are 178 people with learning disabilities **detained** in hospital. 44 are in the State Hospital Carstairs⁸³. Most have a mild degree of learning disability. About one-third of people with learning disabilities who are **detained** in hospital have been diagnosed with a mental illness. However, mental illness is also recognised as a feature for a number of other people who are also **detained**.

People with challenging behaviour

50 The term '**challenging behaviour**' has replaced other terms such as 'difficult' and 'problem' behaviour and is less offensive to many people with learning disabilities. It also emphasises the origins of the behaviour, highlighting the role services need to play rather than blaming the person. The term 'interactional challenge' has recently been suggested as a more appropriate term⁸⁴. This emphasises how the person acts in response to the environment. For the purpose of our review the term '**challenging behaviour**' includes people whose behaviour is very challenging to services, whatever the presumed cause.

51 A small number of people often show **challenging behaviour** frequently, while others display **challenging behaviour** on and off and may only need specialist services at a particular time.

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52 Many professionals agree that we should not separate services to people with **challenging behaviour** from general services. However, extra support and specialised services may be necessary. The Department of Health commissioned a report in 1993 which agreed with this view⁸⁵.

An example of good practice

The Additional Support Team provides a service to adults with learning disabilities whose support needs are a challenge to existing services. The team's major strength lies in its ability to provide a service that meets the individual's needs in a responsive and flexible way.

53 There should be a range of clinical services and treatments available such as **psychotherapy, cognitive behavioural approaches** and **behaviour analysis**^{86 87 88}. Successful and long-term **therapeutic interventions** will be those that avoid looking at only the specific problem behaviour.

54 Health boards, NHS trusts and social work departments should make sure that care staff and support workers have appropriate training to meet the needs of people with **challenging behaviour**. They also need to consider the support needs of parents and families where children have **challenging behaviour**⁸⁹.

55 Joint policies on using restraint⁹⁰, and managing aggression, should be in place, supported by training. These policies should also be constantly monitored.

Recommendation 27 Health boards and local authorities should make sure that there is appropriate specialist support such as additional support teams to improve services for people with learning disabilities who have challenging behaviour. The aim of the specialist services should be to support mainstream services and to help people stay in their own homes as far as possible.

People with learning disabilities in the criminal justice system

56 There is some evidence that people with learning disabilities may be over-represented at all levels in the criminal justice system^{91, 92}. We do not

have enough information on people with learning disabilities who may be in prison and their needs and vulnerability. People with **autistic spectrum disorders** may also be included in this group. A number of people with learning disabilities who offend may be managed appropriately within the criminal justice system. Using probation and delayed sentencing alongside a therapeutic programme has been shown to be effective at reducing the risk of offending for some people with learning disabilities⁹³.

57 A small number of people are **detained** under the Mental Health (Scotland) Act because of offending and other 'seriously irresponsible' behaviour. People **detained** because of their learning disabilities and offending or seriously irresponsible behaviour may have a mental illness. The current review of Mental Health law is considering options for this group. We recognise the need for a legal framework for the very small number of people who are a risk to themselves or others.

58 The Mentally Disordered Offenders Strategy⁹⁴ identifies the particular needs of people with learning disabilities who show offending behaviour. It also makes appropriate recommendations for providing community services with effective training and support.

59 Health Boards and local authorities should make sure that there are local professionals with expertise in working with offenders with learning disabilities. Services should make sure an appropriate risk assessment is carried out and that treatment and ongoing support are provided as far as possible within the community.

60 Health boards should make sure that secure accommodation is provided for the small number of people who need this. There should be links between secure settings and less-secure forms of accommodation in the community. There should be enough properly-planned aftercare, including access to a range of rehabilitation and training facilities and opportunities. Life plans should include assessing need as part of the planning process for leaving any secure setting. From April 2000 a valid community care assessment is a condition of having support charges met by Housing Benefit if somebody is living in the private rented sector.

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Recommendation 28 The Scottish Executive should commission research into the number of people with learning disabilities in prison or in secure accommodation and the arrangements for assessing and providing them with care. Health boards, local authorities, and police forces should make sure that an appropriate adult scheme is in place to meet the needs of people with learning disabilities who come into contact with the police.

People with profound and multiple learning disabilities

61 The terms '**profound** and **multiple disabilities**' or '**profound** and **complex needs**' have replaced terms such as 'special care', and '**profoundly** handicapped' and are seen as recognising the very specific needs of this group.

62 As well as **profound** learning disability, people will have other physical disabilities and **sensory impairment** or both. Most will also have significant healthcare needs. 66% will have severe epilepsy, most will have difficulties in eating and drinking, and problems with their breathing. As a result, services should meet this range of needs.

63 Information and support for families typically does not include specific information on **profound** and **multiple disabilities**. So, it is important that carers get information on learning disabilities and physical disabilities and **sensory impairment**.

64 Staff providing services to people with **profound** and **multiple disabilities** would benefit from national standards for training in specific procedures. These procedures should include tube-feeding, **continence management**, inserting rectal diazepam and using equipment such as **suction machines**.

An example of good practice

Epilepsy Association of Scotland provides guidelines for training staff in inserting rectal diazepam.

Recommendation 29 Local authorities, by working with health boards and the voluntary sector, should make sure that they look at the extra needs of those with profound and multiple disabilities and those of their carers. The centre for learning disability should set up a national network of support to local providers offering advice and training on the extra needs of people with profound and multiple disabilities.

7 Summary

1 We recognise that services could do more to help people with learning disabilities to achieve a full life. Our main aim is to help them to be included - in community life, in education, in leisure and recreation, in day opportunities and particularly in employment. They should also have far greater access to **mainstream** services and rely less on specialist services.

2 To achieve these goals means considerable change. We need to improve, reshape and reorganise services, and the public needs to better understand people with learning disabilities and their needs.

3 At the centre of this is a major shift to person-centred and needs-led approaches, which put the individual at the heart of any decisions made. For that to work, people with learning disabilities need better information to make more informed choices, to be supported by an **advocate** if they want, and to have more control over their lives and services.

4 We want to improve systems. The local area co-ordinators will:

- co-ordinate and arrange support and services;
- act as a voice for people with learning disabilities;
- have a budget to buy new, local and cost-effective services.

These co-ordinators will replace care managers, and care management, which is not performing well enough. And, to plan for the medium and longer terms, every person who wants to have one should have a 'personal life plan'.

5 The role of services also needs to change. We want them to focus now on including people with learning disabilities in the community, supporting their personal development and their carers. The balance of care needs to shift. People want to have their own homes in the community. Very few people should have hospital as their home, and other forms of shared living should reduce. Day services have to modernise and focus more on education, employment and personal fulfilment. We need more support for carers. This means more flexible and fresh ideas for short breaks.

6 People with learning disabilities, their carers and providers need someone to act for them and promote a better general understanding of learning disabilities. The Scottish centre for learning disability would do this by being a centre of excellence, providing leadership to agencies in the field and advice in general.

7 To serve people with learning disabilities better, agencies need to be much clearer about their roles and the opportunities for working with others (particularly for people with extra and **complex needs**). We need effective partnerships between agencies, between professionals, and between users, carers and professionals.

8 We need to add to all these steps by helping the public generally to be more aware and understanding of learning disabilities. We believe our on-going programme of awareness will achieve this.

9 The scale of change we are looking for from the review has never been seen before in learning disability services in Scotland. We cannot achieve this using current resources. But spending on learning disability services is already considerable, and making better use of that is an essential starting point. A 'change fund' to help local authorities deliver the new agenda seems essential.

10 Finally, we need to monitor practice and progress to make sure that the changes we have mentioned in this review take place and are developed and maintained. The proposed centre and the new Commission will have important roles in making sure that this happens. The real test will be that the lives of people with learning disabilities and their carers are made richer and fuller as a result of the changes proposed here.

11 Users and carers have waited a long time for this review. They have told us very clearly and consistently what they want and need to lead lives which are as fulfilling as possible. What they are asking for is no more than all of us want for ourselves and our children. We do not think that is asking too much.

Appendix 1 List of recommendations

Recommendation 1 Each local authority or group of authorities and health boards should draw up a 'partnership in practice' agreement by 1 June 2001. **2-18**

Recommendation 2 Health boards and local authorities should agree to appoint local area co-ordinators for learning disabilities from current resources used for managing care and co-ordinating services. Initial training for putting local area co-ordinators in place will begin in Autumn 2001. **2-20**

Recommendation 3 Everyone with a learning disability who wants to, should be able to have a 'personal life plan'. (Recommendation 26 builds on this.) **2-22**

Recommendation 4 The Scottish Executive should set up a 'change fund' to help local authorities put in place the recommendations in this review. **2-24**

Recommendation 5 By 2003, anyone who wants direct payments should be able to have them, and local authorities should be included in the list of possible providers. **2-25**

Recommendation 6 The Scottish Executive should set up a new Scottish centre for learning disability. This would offer advice, training and support to agencies, professionals, people with **2-27**

Recommendation 7 The Scottish Society for Autism by working with the National Autistic Society and health boards and local authorities should develop a national network for people with an autistic spectrum disorder. **2-29**

Recommendation 8 The Scottish Accessible Information Forum should consult local authorities, health boards and users and carers on how best to provide joint, one-stop, free and accessible local information services for people with learning disabilities, their families and carers. Information must also be available in community languages. **3-33**

Recommendation 9 The first PIP agreements should set out how local authorities, health boards and primary care trusts will set up and maintain local registers. **3-35**

Recommendation 10 The Scottish Executive's review of the effectiveness of funding speech and language therapy for children should also include services for adults. **3-36**

Recommendation 11 The Scottish Executive should continue to encourage the development of local independent advocacy services. **3-37**

Recommendation 12 Health boards should make sure they have plans now for closing all remaining long-stay hospitals for people with learning disabilities by 2005. **4-46**

Recommendation 13 Health boards should aim to reduce their assessment and treatment places specifically for people with learning disabilities to four for every 100,000 population across the country as a whole. Health boards should plan for appropriate community services to avoid in-patient assessments and treatment. **4-47**

Recommendation 14 Health Boards with sites remaining after 2002 should develop, with their partners, other services in the community as a priority and set aside resources to meet these costs. This will feature in planning guidance and the boards' performance management arrangements. **4-48**

Recommendation 15 Local authorities and health boards, should both examine what they provide and develop more modern, flexible and responsive services which support people in the community through employment, lifelong learning and getting them involved socially. Day healthcare services for people with learning disabilities should be mixed with those in the community. **5-56**

Recommendation 16 Local authorities need to give much greater priority to developing a range of employment opportunities for people with learning disabilities. And, with health boards those authorities should lead by example in employing more people with learning disabilities. **5-60**

Recommendation 17 The Scottish Executive should consider raising, with the Department of Social Security specific areas of concern related to benefits and support for people with learning disabilities. **5-63**

Recommendation 18 Local authorities should review their local transport services, to make sure that people with learning disabilities can use public services wherever possible. **5-64**

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Recommendation 19 Health Boards should contribute funding and resources (for example, training for residential and family carers) to developing community based short breaks alongside local authorities. Local authorities will also be able to bid for any 'change funds' which may be made available for further developing short breaks for people with learning disabilities. . . . **5-69**

Recommendation 20 The Scottish Executive and local authorities should review their guidance and procedures to make sure that local authorities and health boards can arrange their short break and shared care arrangements for children and adults flexibly and with as little bureaucracy as possible. . . **5-69**

Recommendation 21 There should be a long-term programme to promote public awareness about learning disabilities and including people with disabilities in the community. This should include programmes from the earliest years of education. The new centre for learning disability could be responsible for taking this forward. **5-70**

Recommendation 22 The Scottish Executive's National Care Standards Committee is currently developing standards for residential and nursing care homes for all care groups including people with learning disabilities. These standards should look clearly at assessing and managing risk in working with vulnerable people. **6-76**

Recommendation 23 All local authorities in association with health boards, NHS trusts and other agencies should develop policies and guidelines on protecting vulnerable adults. Social work departments should review their procedures on guardianship to include making a formal assessment of risk a normal part of deciding whether an application should be made. Local authorities and health boards should use the Care Programme Approach for people with learning disabilities who have complex needs whether these needs are caused by disability or vulnerability. **6-76**

Recommendation 24 The Scottish Executive should consider introducing a new duty on local authorities to identify a responsible person to advise and help the person with learning disabilities and their family put the FNA into practice. **6-80**

Recommendation 25 Health boards and local authorities should make sure that local professionals are trained to look out for early signs of dementia and so can provide assessment and appropriate responses and services. **6-83**

Recommendation 26 Life plans for people with learning disabilities who live with their parents should include plans for a time when parents may no longer be able to provide care. **6-83**

Recommendation 27 Health boards and local authorities should make sure that there is appropriate specialist support such as additional support teams to improve services for people with learning disabilities who have challenging behaviour. The aim of the specialist services should be to support mainstream services and to help people stay in their own homes as far as possible. **6-89**

Recommendation 28 The Scottish Executive should commission research into the number of people with learning disabilities in prison or in secure accommodation and the arrangements for assessing and providing them with care. Health boards, local authorities, and police forces should make sure that an appropriate adult scheme is in place to meet the needs of people with learning disabilities who come into contact with the police. **6-90**

Recommendation 29 Local authorities, by working with health boards and the voluntary sector, should make sure that they look at the extra needs of those with profound and multiple disabilities and those of their carers. The centre for learning disability should set up a national network of support to local providers offering advice and training on the extra needs of people with profound and multiple disabilities. **6-91**

Appendix 2 National implementation plan

May 2000	Launch the report for consultation
June 2000	Issue specification and invite bids for setting up the Scottish centre for learning disabilities
October 2000	Receive responses
March 2001	National Care Standards for people with learning disabilities in care homes completed
March 2001	Standards for day and domiciliary services completed
April 2001	'Change fund' for developing local services launched
2001	Scottish Commission for the Regulation of Care set up
2001	Scottish Social Services Council set up
June 2001	First 'partnership in practice' agreements to Scottish Executive
Spring 2001	Award the contract for setting up the centre for learning disabilities
Autumn 2001	Initial training for putting local area co-ordination in place
Summer 2002	Local area co-ordinators in place
Summer 2002	PIPs fully in place
Spring 2002	All local area co-ordinators electronically linked
2003	Mandatory direct payments introduced
2005	All long-stay hospitals closed

Appendix 3 Definitions

During the review, we consulted on how relevant and what purpose a definition in relation to using the term 'learning disability' would be.

We considered the need for an appropriate and meaningful description of the needs of people who may need services or other support because of their learning disabilities. We agreed that there is a need to make sure that people are not disadvantaged as a result of being unable to use appropriate services because of 'definitions' and 'cut-off' points. Likewise, people should not be 'pigeon holed' because of definitions which fail to recognise their ability to develop. It is vital that we identify the needs of people with learning disabilities in a way that allows services to respond appropriately.

In agreeing a definition we considered the following.

- How terminology is used and what it means across different agencies and professional groups. For example, there is currently confusion between terms such as 'learning difficulty', and 'learning disability'.
- What effect using inclusion and exclusion criteria would have.
- The effect of redefining learning disabilities under the mental health legislation.
- The links with recent policy guidance.
- The views of carers, users and other people with an interest.

Terminology

The term 'learning disabilities' is now used throughout the UK particularly in health and social care settings. We are aware that there are some mixed views about this. We can review this (not necessarily the definition) at some point in the future depending on the views of users, carers and others. For interest, the term 'intellectual disability' appears to be replacing 'learning disability' in academic journals and in international organisations.

Inclusion and exclusion criteria

It is generally accepted that we can refer to a person as having a 'learning disability' if the disability has been present before the age of 18. So, we do

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not consider a person with previous 'normal' functioning, who has a brain injury after age 18 to have a learning disability. Learning disability services may sometimes provide care and support but it is better if appropriate specialised services for people with brain injuries are available. This review does not cover the needs or proposed services for this group.

We also do not include people with specific learning difficulties such as dyslexia in our definition of learning disability.

People with learning disabilities can experience the same range of mental and physical disorders as the general population. If a person's first diagnosis is learning disability, their needs may best be met by learning disability services and supported by appropriate general and specialist services. However, we should not deny people with learning disabilities access to other specialised services because they are only seen as people with learning disabilities.

The legal background

The Mental Health (Scotland) Act 1984 is currently being reviewed by the Millan Committee and we believe this will mean the current terminology such as mental handicap, mental impairment and severe mental impairment will change. The proposed Adults with Incapacity Bill⁹⁵ has taken on board the current Mental Health Act (Scotland) 1984 definition, although this may be considered again after the Millan Committee's recommendations. Appendix 5 provides a detailed account of the legal framework.

Policy guidance

The Scottish Executive has recently issued some reports of relevance to our review of services^{96, 97}.

The Riddell report uses a definition of 'severe low incidence disabilities' while the Beattie report refers to the needs of young people 'who require additional support to make the transition to **post school education** and training or employment'. This can include people with physical disabilities, learning disabilities, mental health problems, low education and attainment and social, emotional and behavioural difficulties. There is some overlap in relation to the needs of people dealt with by Riddell, Beattie and our own review.

Users' and carers' views

Our analysis of the views of people who wrote to us and our meetings with users and carers identified a range of opinion on using a definition of learning disability and how relevant it is. We have taken account of these views in developing a definition.

The definition

In developing our definition of learning disability, we have taken a flexible approach while making sure that there is a clear definition to help identify need and target resources. An analysis based on needs means that learning disability is not seen as an 'all-or-nothing' condition.

The following definition is based on work done elsewhere⁹⁸:

'A learning disability is a significant, lifelong condition which has three facets:

- reduced ability to understand new or complex information or to learn new skills;
- reduced ability to cope independently; and
- a condition which started before adulthood (before the age of 18) with a lasting effect on the individual's development.'

For the purpose of the review, it includes people with **autistic spectrum disorders**.

People with learning disabilities will need a range of support depending on their needs:

Everyday needs, for example, a place to live, financial security, friendships and opportunities to have a meaningful day.

Extra needs because of their learning disability, for example, help:

- with getting about;
- to use services;
- to understand information; and
- with communication.

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Complex needs, for example, support in crisis situations, treatment to improve mental health or to help reduce **challenging behaviour**.

For any one of these needs the level of support necessary may vary. An individual may need the following.

Occasional and short-term support (intermittent support)

The person will not always need the support or need only short term support during their life. Support may be high or low intensity, simple or complex. It is used for a specific purpose and to provide general support for a person on an 'as-needed' basis. It may also be necessary to support someone in a certain setting.

Time-limited support

This may be high or low intensity and complex. It is limited by time or by some other resource and is typically to support the person through a difficult period or when moving from one stage to another in their lives.

Regular long-term support

This is support involving regular help (for example, daily) in at least some environments and is not limited by time.

Constant and highly-intensive support

This is constant and very intensive support provided across different environments. It could involve medical care to keep the person alive. High-intensive support typically involves more staff and resources.

This approach to a definition should help agencies develop a stronger way of assessing needs and allows for a shared understanding across the different agencies and professional groups.

Appendix 4 The cost of care packages

This appendix compares, in very broad terms, the costs of other care packages and hospital care.

There is very limited information available on the cost of packages and the needs of individuals. The only accurate sources are the studies for the Department of the Environment, Transport and the Regions and the Department of Health we have referred to in chapter 4 of this report. But even these sources acknowledge the small scale of their samples.

The table below offers another pattern of care for the 700 to 800 residents in long-stay hospitals after 2002 (less the 300 to 400 to be held in the NHS) and costs involved.

Figure 3 Other patterns of care

	Number of places	Total revenue cost (see note 1 below)	Net revenue cost (see note 2 below)	Total net revenue cost £million
Adult placements	40	£30,000	£26,000	1.1
Small group homes	130	£50,000	£46,000	6.0
Supported living	200	£59,000	£48,000	9.6
Nursing and residential homes	30	£25,000	£20,000	<u>0.6</u>
Hospital places	400	£45,000 (see note 3 below)	£38,000 (see note 4 below)	<u>17.3</u>
Extra net cost	2.1			

Note 1 The total cost of care packages in studies for DETR/DOH referred to in Chapter 4.

Note 2 The cost after taking away benefits income and the cost of **capital**. The result is the on-going running costs of (social and health) care and accommodation.

Note 3 Scottish hospital costs - cost each week of inpatient care.

Note 4 Cost at (3) less assumed allowance for non-recurring, double running costs.

Appendix 5 What will progress look like?

This review aims to change people's lifestyles for the better. Improving the range and quality of services, and the way that agencies work together contribute to that goal. Some benefits should emerge quite quickly, while others will take longer. Our ability to measure progress also varies. Some elements, for example, shifts in the balance between services should be self-evident; but others such as how well people are integrated into the community, are more difficult.

The review expects major changes. Progress should be recognised in the following way.

A Scottish centre for learning disability

- The centre promoting change locally in the way people understand learning disabilities, in the information available to people with learning disabilities and in the range of support available.

A major shift in the balance of care and support services

- All but a small number of long-stay hospital places will go, with specialist healthcare provided in other settings.
- Less formal residential and nursing home care will be provided and many more supported accommodation and adult placements will be used.
- Much less formal day care and many more day opportunities, provided, for example in education, leisure and employment.
- Considerably more people will have real jobs, and others will have a range of employment opportunities.
- More children will be educated in **mainstream** schools.
- Most people with learning disabilities will have access to **mainstream** health, social care, education and employment services.

New and better ways of working

- Local area co-ordinators will be the focal point for securing services and support.

- Jointly commissioned services will be provided for people with **complex needs**.
- People with learning disabilities will have access to independent **advocacy** when they need it.
- **Direct payments** will be available to people who want and can use them.
- Every person who wants one can have a life plan.

A better quality of life

- People with learning disabilities will use independent advocacy and **direct payments** to give them more control of their lives and the services they receive.
- People with learning disabilities will be much more part of the community; living in the community, working in the community, enjoying education, leisure and recreation in the community.
- Measures will be introduced to reduce bullying and harassment of people with learning disabilities.
- People with learning disabilities will enjoy better health and being part of routine screening programmes.

Some of the information to show change will come from existing sources. Some new information will need to be gathered, and because quality of life is such an important element, some specific work (for example, a quality of life survey) may be appropriate.

Appendix 6 The legal background

The main legal requirements for local authorities and health boards to provide social, health, housing, education, employment and services for people with learning disabilities are set out below.

Social Work (Scotland) Act 1968

Section 12

This places a general duty on every local authority to promote social welfare by making advice, guidance and help available on a scale appropriate for their area.

Section 12A

This was added by the National Health Service and Community Care Act 1990 (see section 55). The Social Work (Scotland) Act 1968 was also amended by the Carers (Recognition and Services) Act 1995. This places a duty on the local authority to carry out community care assessments and then decide whether to provide services.

Section 14

This places a general duty on every local authority to provide **domiciliary services** for households where there are people in need. It also gives the power to provide laundry facilities for these households.

Chronically Sick and Disabled Persons

(Scotland) Act 1972

This Act extends sections 1 and 2(1) of the Chronically Sick and Disabled Persons Act 1970 to Scotland.

Section 1 (of the 1970 Act)

This places a duty on every local authority (which has a role under section 12 of the 1968 Act) to know about the numbers of disabled people living in their area and the need to make arrangements for these people. Every local authority should publish general information about the services they provide.

They are also to let disabled people know about relevant services that they know others provide.

Section 2(1) (of the 1970 Act)

This lists the arrangements that can be made to help disabled people. These include:

- practical help for that person in his or her home;
- getting, or helping someone to get a radio, tv, phone, or specialist equipment to be able to use a phone;
- help in using library, recreational or educational facilities;
- providing facilities to, or helping with travel to and from home;
- adaptations to the home;
- holidays; and
- meals.

Section 21

This is the Orange Badge Scheme of parking concessions for disabled and blind people.

Employment and Training Act 1973 (as amended by the Trade Union Reform and Employment Rights Act 1993)

This sets out the duty of the Secretary of State for Scotland to provide relevant services for helping people in education to decide on future employment, and what training may be necessary to fit them for this employment.

Sections 10(1) and 10(2)

These say 'in doing so the Secretary of State shall have regard to the requirements of disabled persons.'

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Education (Scotland) Act 1980**Section 1**

This places a general duty on education authorities to provide adequate and efficient school education for their area. This must include special educational needs, which covers those with learning difficulties which may arise from a disability.

Section 60(2)

So that education authorities can fulfil their duties in terms of special educational needs, they must find out which children belonging to their area (who are two years old or over but under 16) have obvious, specific or complex special educational needs which need to be reviewed. They must open and keep a **Record of Needs** for any children who, following assessment, have these needs. They also have the power to carry out these functions for children aged between 16 and 18 who are still at school.

Section 65B

This places a duty on the education authority to provide a future needs assessment for any child with special educational needs so that children may benefit from local authority services after leaving school.

Mental Health (Scotland) Act 1984**Sections 2 to 6**

These provide for the Mental Welfare Commission for Scotland whose main function is to use their general protective functions for people with mental disorders. This includes those with learning disabilities. The Commission's powers cover people in the community as well as those in hospital or other care settings.

Sections 7 and 8

These give power to local authorities to make arrangements for providing services for people with mental disorders. This includes accommodation for those not in hospital, and, in particular, for after-care services for those who are or have been suffering from mental disorders.

Section 11

This says local authorities must provide training and jobs for people with learning disabilities.

Sections 17-35

These cover care and treatment of patients with mental disorders in hospital. Section 17 sets out the conditions for going into hospital.

Sections 35A to 35K

These sections were introduced by the Mental Health (Patients in the Community) Act 1995. They cover community care orders for people who have left hospital to make sure they receive the services they need while in the community. (However, they do not allow for compulsory treatment in the community).

Sections 36-52

These cover **guardianship** for people with mental disorders if this is appropriate. The **guardian** may be the local authority or an individual.

Sections 60-76

These set out conditions relating to hospital orders and restriction orders for people with mental disorders who have been charged with offences. They also cover transferring prisoners with mental disorders to hospital where appropriate.

Section 94

This covers managing the property of patients who are receiving treatment in hospital for mental disorders (whether or not they are formally held under the Act) and who cannot manage their own affairs.

Part X covers treating mental disorders of patients who are held to whom Part X applies. In particular, it regulates certain treatments (at present electro-convulsive therapy, drug treatment for more than three months, psychosurgery and implanting hormones). Part X1 covers other conditions including offences against people with mental disorders. Part XI contains offences

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against people with mental disorders (particularly section 106, which regulates sexual relationships with women with learning disabilities). It places a duty on professionals to give information to relatives and carers of patients under **guardianship**. It grants powers to Mental Health Officers and the police to intervene if people with mental disorders are neglected or abused, or need care in a public place.

Disabled Persons (Services, Consultation and Representation) Act 1986

Section 4

This places a duty on the local authority to decide whether the needs of a disabled person call for a range of services in line with section 2(1) of the 1970 Act if the disabled person, his or her representative or carer ask for this.

Section 8 (1)

This places a duty on the local authority to take account of the ability of the carer to continue to provide care.

Section 13

This deals with disabled people leaving special education in Scotland. Under this section local authorities have a duty to assess the needs of disabled children in relation to providing services 'in accordance with the welfare enactments, and for that assessment to be carried out'.

Housing (Scotland) Act 1987

Section 1

This places a duty on local authorities to consider the housing needs of their area, and in doing so, take account of the needs of chronically sick or disabled people.

Section 236

This gives local authorities the power to pay improvement grants to, amongst others, disabled occupants.

National Health Service and Community Care Act 1990

Section 47 (2)

This says that if, during an assessment of need, a person appears to be disabled, the local authority will move automatically to make a decision on services.

Section 55

This added a new section 12A into the 1968 Act under which the local authority would carry out assessments of needs and would then decide whether these needs call for services.

Enterprise and New Towns Act 1990 (as amended by the Trade Unions Reform and Employment Rights Act 1993)

Section 2(3)

This deals with Training for Work. It says that Scottish Enterprise and Highlands and Islands Enterprise must each make appropriate arrangements for helping people to train so that they may get and keep suitable jobs.

Section 2(4)

This says that the above should include arrangements for encouraging more opportunities for (and types of) employment and training that are available to disabled people.

Further and Higher Education (Scotland) Act 1992

Section 1

This says the Secretary of State has a duty to "secure adequate and efficient provision of further education in Scotland". Further education which this duty applies to is described in the Act as amended by Schedule 5, paragraph 8, of the Education (Scotland) Act 1996. In carrying out his duty, the Secretary of State "shall have regard to the requirements of persons over school age who have learning difficulties". The term learning difficulties is used in the Act in its broad sense to include difficulties in learning and barriers to learning.

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Carers (Recognition and Services) Act 1995**Section 2 (1)**

This changes section 12A of the 1968 Act to make an independent assessment of carers' needs when they ask for this. However, this only applies if the care they offer is substantial and regular.

Disability Discrimination Act 1995**Section 19**

This makes it illegal for anyone providing services to discriminate against a disabled person in relation to access, for example, how information is used and how communication is used.

Part V

This is a matter for the Westminster Parliament and covers regulations to set minimum conditions for providing access for disabled people to public transport vehicles. Rail Vehicle Accessibility Regulations came into force on 1 January 1999. Regulations on access to buses, coaches and taxis are at various stages of being prepared.

The Children (Scotland) Act 1995**Section 22**

This places a duty on local authorities to protect and promote the welfare of children in need in their area.

Section 23

This introduces a new legal framework for assessment, services, and support to children with disabilities, children affected by disabilities and their families. The principle behind this is that services are designed to reduce the negative effect of the child's disability and improve the child's opportunity to lead as normal a life as possible.

Section 24

In carrying out an assessment to decide on the needs of a disabled child the local authority must assess a carer's ability to provide, and to continue to provide, care for that child.

Criminal Procedure (Scotland) Act 1995

Sections 52 to 63

These cover putting people accused of offences in hospital if they have mental disorders.

Sections 60 to 76 of the 1984 Act set out the conditions relating to hospital orders and restriction orders for people with mental disorders who have been charged with offences. They also cover transferring prisoners with mental disorders to hospitals where appropriate.

Direct Payments Act 1996

This amends the Social Work (Scotland) Act 1968, section 12B and section 12C.

The Adults With Incapacity (Scotland) Act

This Act will replace current arrangements for **curators bonis**, **tutors**, **tutors dative** and **guardians** appointed under the Mental Health (Scotland) Act 1984. All of these office holders can currently make decisions about either the finances or the welfare of people who do not have the ability legally to make their own decisions.

Prospective Education Bill

This will mean local authorities must provide pre-school education for every three-and four-year-old whose parents want a place. Children with learning disabilities stand to benefit from this duty no less than others.

Appendix 7 Who was involved in the review

Steering Group

The steering group had a responsibility to send Ministers a strategic framework for developing social and healthcare for adults and children with learning disabilities. This had to recognise the importance of access to other relevant services and opportunities.

Members

Mrs Gillian Stewart	Head of Children's and Young People's (Chair) Group
Dr Andrew Fraser	Deputy Chief Medical Officer, Health Department
Mrs Joan Fraser	Education Department (from December 1999)
Mr Richard Grant	Housing Division, Development Department (until June 1999)
Dr Sandra Grant	Chief Executive, Scottish Health Advisory Service
Mr Bob Irvine	Education Department (until September 1999)
Mrs Liz Lewis	Community Care Division, Scottish Executive Health Department
Mr Ian McGhee	Enterprise and Lifelong Learning Department
Mrs Jean MacLellan	Social Work Services Inspectorate
Mr David Meikle	Community Care Implementation Unit
Mr Bill Moore	Housing Division, Development Department (from June 1999)
Mrs Gillian Ottley	Assistant Chief Inspector, Social Services Inspectorate
Mr Angus Skinner	Chief Inspector, Social Work Services Inspectorate
Mrs Jenny McNeill (Secretary)	Community Care Implementation Unit

Plus two representatives from the Users' and Carers' Reference Group, who were nominated to go to each meeting.

Working Group

Members

Mrs Gillian Ottley (Chair)	Assistant Chief Inspector, Social Work Services Inspectorate
Mr Bruce Barnett	NHS Management Executive (until July 1999)
Dr Ken Black	Health Department (until September 1999)
HMI Dr Mike Gibson	Education Department
Mr Tom Leckie	Social Work Services Inspectorate
Mr George McLachlan	NHS Management Executive (from November 1999)
Mrs Jean MacLellan	Social Work Services Inspectorate
Ms Jackie McRae	Social Work Services Inspectorate
Mr David Meikle	Community Care Implementation Unit
Mr John Payne	Community Care Implementation Unit
Dr Pauline Robertson	NHS Management Executive
Mr Robert Samuel	NHS Management Executive
Mr John Templeton	NHS Management Executive
Dr Margaret Whoriskey	Scottish Health Advisory Service
Dr Hugh Whyte	NHS Management Executive
Mrs Jenny McNeill (Secretary)	Community Care Implementation Unit

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Stakeholders' Reference Group**Members**

Mrs Gillian Ottley (Chair)	Assistant Chief Inspector, Social Work Services Inspectorate
Mr Bruce Anderson	Grampian Health Board
Ms Liz Catterson	Enable
Dr Sally Cheseldine	Lanarkshire Healthcare NHS Trust
Mr John Dalrymple	Support for Ordinary Living
Ms Roseanne Fearon	Lynebank Discharge Programme
Mr Max Gallagher	Real Jobs
Mr Stewart Gibb	Homelink
Professor James Hogg	Dundee University
Dr Ros Lyall	Lothian Primary Care NHS Trust
Mrs Jean MacLellan	Social Work Services Inspectorate
Mr Mike Martin	Capability Scotland
Mr Malcolm Matheson	Key Housing
Mr Colin Meehan	West Dunbartonshire Council
Mr David Meikle	Community Care Implementation Unit
Professor Sheila Riddell	Glasgow University
Mr Pete Ritchie	Scottish Human Services
Mr Denis Rowley	New Directions, City of Edinburgh Council
Mr Chris Taylor	Carr-Gomm
Ms Ann Walker	Camphill Scotland
Dr Iain White	GP, Lossiemouth
Mrs Carole Wilkinson	Falkirk Council
Mrs Jenny McNeill (Secretary)	Community Care Implementation Unit

Users' and Carers' Reference Group

Members

Mrs Marjorie Arthurs	Partners in Advocacy
Mr David Barraclough	Enable
Mrs Ivy Blair	Shared Care Scotland
Ms Amanda Brown	Barnardo's
Mrs Ursula Corker	Carers National Association
Mr Norman Dunning	Enable
Ms Mary Earl	Enable
Mr Tom Leckie	Social Work Services Inspectorate
Mrs Marion McArdle	PAMIS
Mr James McIntosh	Capability Scotland
Mr James McNab	People First Scotland
Mrs Elizabeth Melville	PAMIS
Mrs Ruth Price	Barnardo's
Mrs Nancy Simpson	Relatives and Carers Group, Gogarburn Hospital
Ms Pam Smith	Scottish Society for Autism
Ms Karen Watchman	Scottish Down's Syndrome Association
Ms Gill West	National Autistic Society
Ms Sheila Williams	Capability Scotland
Mrs Barbara Johnson	Community Care Implementation (Secretary) Unit

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Best Practice Task Group

This group was responsible for identifying good practice which provides opportunities for people with learning disabilities to lead fulfilling lives.

Members

Mrs Jean MacLellan (Chair)	Social Work Services Inspectorate
Dr Ken Black	Health Department
Ms Linda Headland	ELCAP
Mr Duncan Macauley	City of Edinburgh Council
Mr Michael McCue	Additional Support Team, Glasgow
Mr John Payne	Community Care Implementation Unit
Mr Dennis Rowley	New Directions, City of Edinburgh Council
Dr Kirsten Stalker	Scotland Human Services
Dr Margaret Whoriskey	Scottish Health Advisory Service

Best Value Task Group

The group assessed whether services make best use of available resources and achieve fairness for people (adults and children) who have learning disabilities.

Members

Mr David Meikle (Chair)	Community Care Implementation Unit
Dr Ken Black	Health Department
Mr John Payne	Community Care Implementation Unit
Mr John Templeton	NHS Management Executive

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Children's Services Group

A small group drew upon the expertise of the stakeholders' and users' and carers' groups and involved a wide range of professional and carers' interests by using workshop discussions and consultation and co-ordinated material and issues from other sources.

Members

Ms Jackie McRae, (Chair)	Social Work Services Inspectorate
HMI Dr Mike Gibson	Education Department
Ms Jean Swaffield	NHS Management Executive
Dr Margaret Whoriskey	Scottish Health Advisory Service
Dr David Will	NHS Management Executive

We want to give particular thanks to Partners in Advocacy, Shared Care Scotland, Barnardo's Scotland and Enable for helping us with the workshop on Children's Services.

Complex Needs Task Group

The group was responsible for identifying how services can best meet the needs of those with **complex needs**.

Members

Dr Margaret Whoriskey (Chair)	Scottish Health Advisory Service
Dr Sally Cheseldine	Lanarkshire Healthcare NHS Trust
Mr John Dalrymple	Support for Ordinary Living
Mr Tom Leckie	Social Work Services Inspectorate
Mrs Jean MacLellan	Social Work Services Inspectorate
Ms Marion McArdle	PAMIS
Dr Pauline Robertson	NHS Management Executive
Mr Robert Samuel	NHS Management Executive

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Mapping Task Group

The group found out about current services and looked at needs and definitions.

Members

Mr David Meikle (Chair)	Community Care Implementation Unit
Dr Ken Black	Health Department
Mr John Payne	Community Care Implementation Unit
Mr John Templeton	NHS Management Executive
Dr Margaret Whoriskey	Scottish Health Advisory Service

Training Task Group

This group was responsible for identifying staff development needs.

Members

Mrs Jean MacLellan (Chair)	Social Work Services Inspectorate
Ms Pat Bagot	Scottish Homes
Dr Ken Black	Health Department
Mr Ian Murray	National Board for Nursing
Mr Brodie Paterson	Stirling University
Mr Ray Pavey	Central Council for Education and Training in Social Work
Ms Kate Pryde	Falkirk Council
Mr Robert Samuel	NHS Management Executive

Appendix 8 Glossary

The following glossary explains the meaning of words that appear in the text.

Advocate/Advocacy	Someone who helps people with learning disabilities to say what it is they need and to make their own decisions. See citizen advocate and self-advocate.
Asperger's syndrome	This is a type of autism (see below) that some people of average intelligence and language ability have. They find it particularly difficult to understand what other people think and this makes it hard for them to communicate and act appropriately.
Autism	This is a lifelong developmental disability that affects the way a person communicates and relates to people around them. People with autism can often have learning disabilities but everyone with the condition shares a difficulty in making sense of the world.
Autistic spectrum disorder	Autism can happen in people with different degrees of learning disability as well as in people of average intelligence, for example, those who have Asperger's syndrome. Because of this wide range, we talk about a spectrum of autistic disorder.
Behaviour analysis	Looking into the cause and effect of behaviour based on what has happened in the past.
Benchmarking	Working out how good a service is by comparing it to another service that has set a high standard.

Bridging finance	Money that the Scottish Executive gives to health boards to help them set up new services in the community while they are still paying for running hospitals.
Brokerage service	Somewhere people with learning disabilities can go to get independent help in deciding on and buying the services they need.
Capital	Money spent on buying things that will last longer than a year, for example, land, buildings, equipment.
Care Programme Approach	A way of making sure that all those with serious mental health problems and complex needs have an assessment and care plan that all the different professionals agree on (for example, social workers and doctors). This is checked regularly to see how well the person is doing.
Challenging behaviour	A term used to describe when someone is acting in a way that might do themselves or others harm. People who care for these people are 'challenged' to stop the harm. That is why we call it 'challenging behaviour'.
Citizen advocate	An 'unpaid' volunteer who is independent of the services, a person with learning disabilities receives. This advocate represents the needs of the person and supports them to make sure they get their rights.
Clinical engineer	Someone who helps to improve mobility in a variety of ways including providing wheelchairs.
Cognitive behavioural approaches	Ways of understanding and changing what people do and feel – mostly used by psychologists and psychiatrists.

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Commissioning	Deciding what services are needed and then getting someone to provide these by signing a contract.
Complex needs	This describes the needs a person has over and above their learning disability. For example, extra physical or mental health problems, challenging behaviour or offending behaviour.
Continence management	Trying to help people who have problems with bladder and bowel control.
Continuing care	Nursing or medical help or both of a level that cannot be provided in a care or nursing home.
Curator bonis	A person appointed by the court to manage the whole of another person's property and money.
Detained patient	Someone who is made to stay in hospital under a section of the Mental Health (Scotland) Act 1984 or the Criminal Procedure (Scotland) Act 1995.
Direct payments	Local authorities giving people money to buy their own social care services so that they have more say in how their needs are met.
Domiciliary services	Care services provided to a person in their own home.
Dual diagnosis	Where someone has both a learning disability and mental health problems.
Early onset dementia	A term used to describe people who get dementia at an earlier age than might be expected. This leads to a variety of

problems, including difficulties in remembering, making decisions, and learning new skills. These difficulties get worse as time passes.

Guardian/guardianship

A guardian for a child is someone appointed by a parent, or, where necessary, the sheriff, to take over parents' responsibilities and rights after a parent dies. The guardian's role applies until the child is 18.

A guardian for an adult with a mental disorder is someone appointed by the sheriff who has the power to say where the person lives, gets education and training and also makes sure that doctors can see a person without difficulty.

Learning difficulty

Pre-school and school-age children are usually described as having a learning difficulty rather than a disability when they have special educational needs that need extra or different approaches to the way they are taught.

Mainstream

Generally available to all members of the community.

Managed clinical network

Where healthcare professionals who have an interest in the same area of work share their knowledge and resources to get the best care for patients. A network can be local, regional or national depending on what the work is.

Mapping of services

Finding out what services there are and what they are like.

Mobility

Being able to move from one place to another with or without help.

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Multiple disability needs	Where someone needs help with several aspects of life which may include health, education, leisure, financial or housing support and being part of the community.
Natural supports	People who help those with learning disabilities like family and friends and are not paid to do this.
Palliative care	Managing care for someone who is not going to get better.
Peripatetic support staff	Staff who go from place to place to do their work rather than staying in a single centre.
Post school education	The range of education that takes place after school leaving age. It may include further education, community education, higher education, adults going back to school, other kinds of informal education and vocational training.
Prevalence data	A way of working out how many people in a population are likely to have a learning disability.
Professions Allied to Medicine(PAMs)	These are physiotherapy, occupational therapy, chiropody, radiography, dietetics, remedial gymnastics, orthoptics, art, music and drama therapies.
Profound disability needs	A term used to describe someone who has a very severe degree of learning disability which may be associated with complex needs . For example, this could include feeding difficulties, physical disabilities or sensory impairment.
Psychotherapy	A psychological treatment based on talking and usually designed to help the person understand what is happening now and how to change it.

Record of Needs	A document opened by an education authority for a child with pronounced, specific or complex educational needs which will lead to regular review and which helps to fund the best way of providing what is needed.
Rectal diazepam	This is a drug inserted up a person's bottom to stop severe epileptic fits.
Revenue	Money spent on day-to-day costs like paying for staff and services.
Self-advocacy	Where people with learning disabilities promote their needs and wishes for themselves.
Sensory impairment	A loss of sight or hearing or both.
Social inclusion	Helping people to feel and be part of the society in which they live. They are 'socially included'.
Suction machine	Equipment used to remove saliva and so on, from the mouth and the back of the throat.
Therapeutic interventions	Giving treatment of any kind – drugs, physical or psychological therapy – to promote a person's well-being.
TUPE	This stands for the Transfer of Undertaking (Protection of Employment Regulations) 1981. It is an agreement about how staff are to be treated if they need to change jobs.
Tutors	The Court of Session can appoint a tutor-at-law or a tutor-dative to an adult with incapacity. Tutors-at-law manage the adult's personal welfare, property and financial affairs. Tutors-dative only have powers over an adult's personal welfare and the court may limit that to particular areas of welfare.

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Learning Disability Advisory Group

Report to the National Assembly for Wales

"Fulfilling the Promises"

Proposals for a framework for services for people with learning disabilities

MAHI - STM - 083 - 2087
June 2001

Preface

The Learning Disability Advisory Group was established by the National Assembly for Wales to prepare a draft service framework for people with learning disabilities. The Advisory Group first met in December 1999 and concluded that the service framework should cover services for children, adults and older people and should encompass all aspects of a person's life including: education, training and development including lifeskills and lifelong learning, accommodation, leisure and work as well as the more usual services from social services departments and the National Health Service.

In undertaking its work, the Advisory Group has sought to ensure that the views and hopes of people with learning disabilities and their families and carers have been taken fully into account. This has been done through three main strands:

- by including representatives from People First Wales, the All Wales Forum of Parents and Carers, SCOVO and Mencap Cymru as members of the Advisory Group;
- by taking fully into account the findings and outcomes from the stakeholders conference report "Moving Forward to a Better Future: Conference Report and Agenda for Action"; and
- by establishing focus groups across Wales comprising people with learning disabilities and their families and carers initially to seek their ideas about what should be included in the service framework and then to consider whether our draft proposals reflected their needs.

The Advisory Group's report to the National Assembly has five main sections:

- the first section contains the Advisory Group's guiding principles; our vision for services for 2010; our recommended priorities, targets and performance indicators; our proposed Action Plan approach to implementation and our initial assessment of the financial implications;
- the second section sets the context of our work including the National Assembly's and Advisory Group's vision for people and services in Wales and the policy context in which we have developed our proposals;
- the third section is an assessment of the progress in the development of services since the Welsh Mental Handicap Strategy was launched in 1983;
- the fourth section looks at the population changes that will influence services and service development over the coming years; and
- the fifth section are our detailed proposals for the framework for services;

A summary of this report is attached as Annex B.

The Advisory Group wishes to thank the many other individuals who contributed to the work of its sub groups, other organisations that wrote to convey their views/ideas and the National Assembly for providing the secretariat support.

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Section One

1.1 Principles

"Disabled people, whatever their origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible."

United Nations (1975) The Declaration on the Rights of Disabled Persons

First published in 1983, the All Wales Mental Handicap Strategy sought to enable people with learning disabilities to enjoy the full range of life opportunities and choices, to have positive identities and roles in their families and communities, to exercise choice and to develop independence, self respect and self fulfilment. It established the rights of people with learning disabilities to normal patterns of life within the community, to be treated as individuals, and to receive additional help and support from the communities in which they live and from professional services in developing their maximum potential.

The Learning Disability Advisory Group endorses the continued relevance of the Strategy's aims and guiding principles particularly as these can now be seen as a specific expression of the vision recently set out by the National Assembly in Better Wales. The National Assembly want Wales to be a place where its citizens:

- are united, confident and creative
- are committed to fostering its unique and diverse identity, and the benefits of bilingualism, while looking confidently outwards and welcoming new cultural influences,
- are prosperous, well-educated, skilled, healthy, environmentally and culturally rich,
- are active in local communities, where the voice of local people is heard
- are treated fairly, while everyone is valued and given an opportunity to play a full part
- want to live, work and enjoy a high quality of life, and
- are served by modern, effective, efficient and accessible public services.

The Advisory Group welcomes, and shares, the National Assembly's core values set out in Better Wales for social inclusion, equality of opportunity and the promotion of a tolerant society, within which diversity is valued.

The Advisory Group believes that it is a sign of the progress made in the last twenty years that the vision for people with learning disabilities can now be understood in terms of their right to be included in the general hopes of society as a whole. In this respect, we now have a clearer view as to what inclusion and equality of opportunity means to people who may be excluded. In the inclusive society envisaged in Better Wales, the aspiration for a decent quality of life, and all that follows for progression through life and experience of its full richness, is recognised for each and every citizen. The Advisory Group equally believes that people with learning disabilities need to be empowered and (where appropriate) supported to face the challenges and the disappointments of day to day living.

In putting forward our proposals, the Advisory Group has sought to achieve positive outcomes across a range of human concerns. Achieving the best quality of life across all these human concerns should be the aim of us all.

In seeking to support and add to the AWS principles in line with the vision set out in Better Wales, and in recognition of the current concern with quality of life issues, the Learning Disability Advisory Group commend the following principles that people with learning disabilities:

- are full citizens equal in status and value to other citizens of the same age
- have an equal right to expect a high quality of life - in practice this means having exactly the same expectations of decent health, education, housing, safety and financial security, protection from harm, positive social relations and roles within family and community, employment opportunities, personal development, emotional well-being and civic rights
- have a right to decide for themselves and to join in all decision-making which affects their lives, with support if necessary
- have access to the support of their families and the communities, of which they are a part, and to general and specialist public services to improve their chosen quality of life.

1.2 The Advisory Group's Vision for services in 2010

The 1983 All Wales Strategy and the updated 1994 Guidance, set out proposals for the development of services consistent with the principles which underpinned the Strategy and the aim to improve the quality of lives for people with learning disabilities, their carers and families. The process of service development is far from finished. The Advisory Group wants to see the continuation and hopefully the acceleration of that development until all people with learning disabilities receive services which are modern, flexible, appropriate to their needs and circumstances and accessible.

All services must aim to secure the inclusion of people with learning disabilities. Everyone should have appropriate support to allow them to take their place in their communities.

There is a need for clear direction from the National Assembly to bring service support throughout Wales up to similarly high standards. The National Assembly's Better Wales document sets a deadline of 2010 for the achievement of its vision and objectives. The Advisory Group's vision for 2010 is that by that time services for people with learning disabilities in Wales will:

- provide comprehensive and integrated services that will effectively support and enable people to achieve social inclusion in all aspects of life and society in Wales
- be person centred (i.e. respond to individual needs, including language, race, gender and religious requirements and circumstances)
- improve empowerment and independence, with the individual having the maximum possible control of their lives
- ensure effortless and effective movements between services and organisations at different times of life (individuals and services should be properly prepared in advance for these movements)

- be holistic in approach and delivery taking fully into account an individual's preferences, hopes and lifestyle.
- ensure that a range of appropriate advocacy services is available for people who wish to use them
- be accessible - in terms of both service users and their carers and families having full information about availability and service users receive services as close to their home as possible.
- have fully developed collaborative partnerships to deliver flexible services, which are able to respond appropriately and quickly to the changing needs of users.
- be developed on evidence of their effectiveness and transparency about their costs
- be delivered by a competent, well-informed, well-trained and effectively supported and supervised workforce.

Underlying this 2010 vision for services is the necessity for people living inappropriately in long stay learning disability hospitals to have been resettled into the community. The Advisory Group believes that without the early completion of the National Assembly's resettlement programmes to enable all people to return to live in the community, Wales cannot claim to be a country where every person is valued and given an opportunity to play a full part.

1.3 The Advisory Group's recommended priorities, targets and performance indicators

After careful consideration the Advisory Group has agreed 17 priorities for action by the National Assembly and others. These are not ranked priorities as all must be progressed in parallel. Without the full and effective implementation of these priorities, the Advisory Group does not believe that its vision for services in 2010 will be achieved. The priorities, targets and performance indicators are set out in the following paragraphs. The targets are those that will apply to all authorities and provide a measure of progress made in the implementation of the priorities across Wales. The performance indicators provide the National Assembly and authorities and other stakeholders with a structured, systematic and comparative framework for the measurement of local progress on the implementation of more specific aspects of service change and development.

A. Policy Direction

The principles of the 1983 All Wales Strategy have commanded broad support. The aims of the AWS remain entirely consistent with policy developed since that time, as confirmed in Better Wales and other key documents. The Advisory Group do not consider that there is a need to change policy direction but rather to reinforce it.

The National Assembly should reaffirm its commitment to develop the means to extend to all people with learning disabilities in Wales the opportunity to lead a life consistent with the AWS and this Report.

Local authority elected members, members of Health Boards and Local Health Groups and senior managers in authorities should promote and introduce policies to achieve the aims and targets of this Report.

Target

By Spring 2002, all Authorities will have reviewed their services against the 'Service Principles' and 'Service Responses' set out in Section 5 of this report.

B. Funding

The Advisory Group is keen to emphasise the link between policy aims, their implementation and financial realities. The previous AWS set out a potential 40-year investment programme aimed at both reform and growth of services. Further considerable additional investment will be required to meet demographic changes and the proposals in this Report.

The National Assembly should consider introducing a structured investment programme to increase and develop service availability in line with this Report.

Target:

By July 2002, all Authorities will have prepared Health and Social Care Plans, which include costed 5-year projections of needs, targets, and service developments for people with learning disabilities.

Performance Indicator:

The amount spent by Authorities on services for people with learning disabilities as expressed as a rate per head of the (16-64) population.

C. Completion of Existing Programmes of Reform

The Advisory Group agrees with the priority placed by the National Assembly on the long stay hospital closure programme and the re-provisioning of services to achieve this. We also commend the central planning and funding role of the Assembly in resettling people into the community and securing the closures.

The National Assembly should review its commitment to achieve the closure of long stay hospitals and set a new target date for completion of 2006 or preferably earlier. It should also extend the scope of this initiative to include other inappropriate accommodation settings.

Target:

By 2006 all resettlement programmes should be completed and all long-term hospitals should be closed. By 2010, other inappropriate accommodation should be phased out.

D. Individual Planning (Person Centred Planning)

People with learning disabilities tend to be lifelong consumers of health, social care education, housing and other support services. Person centred planning should be confirmed as the key mechanism to plan people's care and support for their whole lifetime.

The National Assembly should confirm that person centred planning is fundamental to addressing individual needs and aspirations. The cornerstone should be multi-disciplinary and multi-agency Community Learning Disability Teams and the National Assembly should promote this approach. The National Assembly should consider how to meet any additional resource requirements within its larger investment programme.

The National Assembly should review the requirements placed on local authorities in relation to social care and educational planning for individuals and consider whether a more coherent approach could be adopted.

Target:

By 2003/2004, all people with a learning disability will have an individual person centred plan, normally reviewed annually.

Performance Indicator:

The number of people whose plan has been reviewed expressed as a percentage of the number of people with learning disabilities known to the Authority.

Performance Indicator

The number of people with learning disabilities receiving a written statement of their needs and how they will be met (NAWPI 3.9)

E. Independent Assessment of the Needs of Carers

The Advisory Group recommends that these parallel but separate assessments should adopt best practice standards similar to those proposed for Individual Planning.

The National Assembly should invite the Carers Strategy Review Panel to consider best practice standards, training requirements and resource implications of separately assessing carers needs and to respond appropriately within its National Carers Strategy.

Target:

By 2001/2002 independent carers assessments will be available as of right.

Performance Indicator:

The number of carers assessments expressed as a percentage of the number of people with learning disabilities helped to live at home.

F. Information

The Advisory Group believes that service users and carers should have good quality and accessible information on the help and support that is available and on their rights to participation in service planning. Consideration will need to be given to information that should be made available on a national level and that expected to be provided locally.

The National Assembly should commission research to identify best practice in respect of the collection, provision, sharing and dissemination of information. The National Assembly should consider what information could appropriately be provided on a national level across Wales.

Target:

By 2002/2003 all Health and Social Care Plans and Annual Statements/Reviews for services for all people with learning disabilities will include the programme of public information about services and service developments

Target:

By 2002/2003 arrangements will have been made to ensure local and national information is widely available to all people with learning disabilities, their parents and carers using all appropriate formats.

G. Advocacy

There are no precise estimates of supply and demand for advocacy. Consultation exercises indicate that advocacy services are inadequate to meet demand.

The National Assembly should evaluate how a centrally funded advocacy service can be developed and regulated on a national basis. These services should include citizen advocacy, self-advocacy and paid advocacy. Any evaluation should take full account of the UK Government's response to the advocacy section of the Disability Rights Task Force report.

Target:

By 2002/2003, the National Assembly will have completed its evaluation and be consulting on proposals to introduce a national centrally funded advocacy service.

H. Partnership in Planning

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It is recognised that effective joint agency planning is important but such arrangements must also include service users, parents, carers and other interested organisations including service providers. This will be of particular significance when addressing low incidence needs.

The Advisory Group believes that the local authority via its Social Services function should continue to be the lead authority and should recognise the importance of effective strategic planning for learning disabilities services.

The National Assembly should reaffirm the lead role of the local authority Social Services function and make available further resources to facilitate implementation of the increased flexibilities under the Health Act 1999.

The National Assembly should ensure that national guidance requires authorities to constructively include users and others in the planning and development of services. Agencies should agree protocols for joint working and the National Assembly should facilitate the pooling of resources between agencies to remove the financial incentive accompanying the redefinition of responsibility from one agency to another.

The National Assembly should introduce a financial and management information framework with standard definitions, for authorities to collect, collate and distribute data on capacity, usage and expenditure on all learning disability services.

Target:

By 2003/2004, authorities will have published plans to improve the joint working of health, social services and other agencies including the use of pooled budgets, integrated provision and lead commissioning of services and facilities.

I. Children and Families

The Advisory Group believes that children with learning disabilities have a right to normal childhood experiences. This includes both equality of access to pre-school and later provision with the opportunity for additional support when required.

The National Assembly should invite services and education bodies to review the availability of:

- **effective early intervention targeted at promoting the child's development and the prevention of challenging behaviour**
- **effective ways of supporting and encouraging integration in general pre-school and later provision**

Services and education bodies should then develop an action plan to make effective services and supports generally available.

Target:

By 2003/2004, Childrens Services Plans should promote equal opportunities and inclusion and indicate how local agencies and partner agencies propose to develop community based support strategies to enable younger people with learning disabilities to be included in mainstream activities as much as possible.

Performance indicator:

The percentage of cases of children with learning disabilities with an allocated social worker who are providing a service appropriate to the child's needs expressed as a percentage of all children with learning disabilities (P/A).

J. Education and Life Long Learning.

The Advisory Group believes that every person should benefit from an education that enables them to develop their maximum potential alongside non-disabled children and provide life long learning opportunities.

The National Assembly should :

- **Develop educational and life long learning policies which encourage arrangements consistent with inclusion**
- **Provide the resources to provide appropriate additional educational support to those with special needs**
- **Ensure that all teachers and teaching assistants receive appropriate training to effectively support learning and the development of people with learning disabilities**

Target:

In 2004 to have significantly improved the quality of education for children with special needs by completing the three-year action plan and the introduction of a new Special Educational Needs Code of Practice.

Performance Indicator:

The number of children educated in special schools as a rate per 1000 of the school population for the local area.

K. Community Living - Help in the Family home.

Significant increases in the number of families receiving help in the home and an increase in short term breaks have been real achievements of the AWS. The Advisory Group does, however, consider that service availability is still likely to be below that required to meet need.

The National Assembly should through its Carers Special Grant and other policies encourage authorities to make available a range and sufficient quantity of flexible support services and positive options for short term breaks.

Target:

By 2005, there should be a significant increase in the range and quantity of flexible support services and positive options for short term breaks.

Performance Indicator:

The number of people with learning disabilities whom the local authority helps to live at home expressed as a percentage of those with learning disability known to the local authority. (P/A)

Performance Indicator:

The number of nights of short-term care received by people with learning disability expressed as a percentage of the number of people with learning disabilities the authority helps to live at home.

L. Community Living – Support to Live Independently.

The Advisory Group considers that there has been no significant expansion of residential supports to promote and develop independence. We believe that a considerable expansion of service availability will be required. Effective planning and significant financial investment will be needed.

The National Assembly should make available additional resources to significantly increase the number of people who are able to access appropriate accommodation away from the family home.

Target:

By 2010, to have significantly increased the number of people who can realistically be expected to live independently with appropriate support irrespective of age or impairment - by 2010 this will require at least an additional 1,500 people with learning disabilities to be supported outside of the family home.

Performance Indicator

The unit cost of residential and nursing care for adults with learning disabilities (NAWPI 3.6)

Performance Indicator:

The number of people with learning disability living independently in the community as a percentage of all those with learning disabilities known to the local authority.

L(i). Direct Payments.

The Advisory Group acknowledges the importance of the Direct Payments Scheme in promoting independence and helping people to take control of their lives.

The National Assembly should consider changing the existing arrangements to enable local authority services to be encompassed in the Direct Payments Scheme.

Local authorities should design schemes to be accessible to people with learning disabilities and provide the right support to help them to manage a direct payment and remain in control

Target

By 2003, all local authorities are operating an appropriate direct payments scheme for people with learning disabilities.

Performance Indicator:

The number of people with learning disabilities receiving direct payments as a percentage of those receiving community based services.

M. Community Living- People with Complex and Challenging Needs

People with complex or challenging needs can be supported to live in ordinary accommodation in the community as long as extra facilities, support and professional inputs are planned and made available.

The National Assembly should ensure that authorities use their strategic planning processes to:

- **Provide up-to-date estimates of the accommodation and support needs of people with complex or challenging needs.**
- **Ensure carers are assisted to develop appropriate skills and have access to staff with specialist expertise who can assess complex needs and provide advice and support**
- **Develop plans to increase the availability of intensive rehabilitation services so that people in need of 'low security' can be placed within Wales.**

Target

By 2008, the number of people with learning disabilities accommodated in specialist facilities outside of Wales should be reduced by 50%.

By 2003, community facilities and intensive rehabilitation services to support people with complex or challenging needs must be an integral part of reprovisioning plans following the closure of existing long stay hospitals.

Performance indicator

The number of people with learning disabilities accommodated outside of Wales in specialist facilities.

N. Community Living - Day Activities.

The Advisory Group believes that priority in this area must be given to helping more adults with learning disabilities gain paid employment or to participate in meaningful day time activities including opportunities provided by local community consortia for education and training.

Currently, social security benefit regulations constrain the extent to which people with learning disabilities take up paid employment.

The National Assembly should set targets for the expansion of supported employment and supports for other socially integrative and educational and training opportunities.

The National Assembly should discuss with the UK Government how social security impediments to paid employment can be removed.

Target:

By 2004/2005 to have opened up opportunities for all people with learning disabilities by encouraging lifelong learning opportunities, more flexible ways of formal and informal learning, increasing the access to quality careers advice and supported employment.

Performance Indicator:

The gross expenditure on day services for people with learning disabilities as a percentage of all expenditure on non-residential services for people with learning disabilities.

Performance Indicator:

The number of adults with learning disabilities receiving college/educational opportunities as a proportion of all people with learning disabilities known to the authority.

Performance Indicator:

The number of adults with learning disabilities in supported employment schemes as a proportion of all people with learning disabilities known to the authority.

Performance Indicator:

The number of people with learning disabilities in work as a proportion of those with learning disabilities known to the authority.

O. Health

There is strong evidence to show that people with learning disabilities have poorer general health and more specific health needs than the general population. The Advisory Group believes that the overall health of people with learning disabilities can be improved with better access to ordinary services.

The National Assembly should make resources available to enable every GP to adopt the proactive identification and health checking recommendations contained in this Report.

Target:

By 2010, to have improved the health of people with learning disability and reduced any differences between the rates of illness and mortality experienced by them and overall national rates.

O. The Workforce

People with a learning disability when using any service should be able to rely on a workforce that is appropriately qualified, well trained, effectively supported and managed and properly regulated.

The National Assembly should extend the qualification regime and targets to include all the social care workforce and set complementary targets for the training of the NHS workforce as part of its Human Resources Strategy.

Target:

By 2005, to have all social care managers and 50 percent of the social care workforce providing services to people with learning disabilities with a listed qualification.

Target:

By 2005, the training of doctors, dentists, opticians other NHS staff, housing and benefit agency staff, teachers and the police to include an element that helps them to have a better understanding of learning disability issues.

Performance Indicator:

The number of social care managers with a listed qualification as a percentage of social care managers responsible for services to people with learning disabilities.

Performance Indicator:

The number of social care staff (excluding managers) with a listed qualification as a percentage of all social care staff working with people with learning disabilities.

1.4 Implementing the Advisory Group's proposals - an Action Plan approach

The Advisory Group considers that the most effective way of implementing our priorities and other proposals in this Report and to enable the National Assembly to make informed investment decisions and monitor progress would be to use an Action Plan approach. This would require the National Assembly to provide any additional resources to local authorities as a central direct grant rather than through the Revenue Support Grant mechanism. For health and education bodies an appropriate ring fenced funding arrangement would also have to be used.

The Action Plan would have to cover a long time period and therefore has to be organic and dynamic. A possible timetable for the first five years of the Action Plan is set out below:

Spring 2002

All authorities to have prepared, consulted upon and completed an audit of their services to people with a learning disability. It will include:

- A projection of the number of people with learning disability living in the area up to 2010
- An appraisal of their services against the 'Service Principles' and 'Service Responses' set out in Section 5 of this Report
- Broadly costed 5 year projections of needs, targets, and service developments
- Costed priorities for investment within the 5-year projection.

This Audit will form the basis of any request for investment in learning disability services to be made to the National Assembly.

The National Assembly to have established monitoring arrangements to advise on the implementation of the service principles, targets and performance indicators set out in the Advisory Group's Report.

Summer 2002

All Authorities will submit to the National Assembly their Health and Social Care Plans including statements about the development of services to people with learning disability which will form the request for National Assembly grant resources for investments in learning disability services.

Authorities will have produced their Second Round Education Strategic plans and their Childrens Services Plans will be published stating how they will promote equal opportunities and inclusion for children.

2002/2003

Authorities will have reviewed their three-year education action plans and the implementation of the revised Special Education Needs Code of Practice.

Authorities will have developed, consulted upon and published their joint health and social services arrangements for the provision of services to people with learning disability.

The National Assembly will have completed its evaluation and be consulting on proposals to introduce a national centrally funded advocacy service across Wales.

All SSIW Inspections and Joint Reviews will use the 'Service Principles' and 'Service Responses' as a basis for evaluating services for people with learning disabilities,

2003/2004

The programme of learning disability performance indicators will have been considered by all the agencies involved and implementation, collection and publication arrangements agreed.

The National Assembly commences the rollout of the centrally funded advocacy services across Wales.

The final reprovisioning plans for the closure of existing long stay hospitals are completed and authorities submit to the National Assembly and publish their first implementation progress report on changes to community based services for people with learning disabilities

2004/2005

Authorities submit to the National Assembly and publish their second implementation progress report on changes to community based services for people with learning disabilities

2005/2006

Authorities submit to the National Assembly and publish their third implementation progress report on changes to community based services for people with learning disabilities

2006

All hospital resettlement programmes completed and the long-stay learning disability hospitals are closed.

The National Assembly undertakes a full review of progress achieved across Wales and identifies any specific actions/approaches necessary to secure the

2010 vision of services set out in this Report.

5. Workforce Training

People who use health and social care services in Wales should be able to rely on a workforce that is appropriately qualified, well trained and properly regulated. It is also essential that those who work in health and social care settings are effectively supported and receive recognition for the important work they do.

Key challenges facing the Learning Disability workforce.

Learning disability services at present face the following challenges:

- The achievement of the objectives of this Report when associated with changing demographic factors have brought about the need for changed patterns of service delivery and for a workforce with a diversity of skills and competencies.
- Staff in health and social care settings need, between them, to have a full range of skills which can be brought together to provide a seamless and comprehensive treatment, care and support service. Staff need to :
 - know both their own roles and the roles of others; and
- be confident in working in multi – professional teams and across agency boundaries.

Good joint working is essential at all levels of health and social care organisations to meet the needs of people with learning disabilities. The option of making use of the increased flexibilities, introduced by the Health Act 1999, makes it all the more important that the whole workforce has common values and standards. Training and qualifications enable staff to transfer from employment in one sector to the other where this promotes good and efficient practice.

Recruitment and retention of good quality staff is a fundamental issue for this sector. The social care workforce in Wales is predominantly made up of people over 35 and on the whole is not attracting younger people. The work, though rewarding, can be stressful and challenging and some of the hours anti-social. It is therefore essential that good working conditions, effective training and supervision and adequate reward are available to staff so that they feel supported and valued. Authorities should take into account in their contracting arrangements the resource implications of ensuring a properly trained workforce.

The difficulty of recruitment and retention of a range of clinical professionals including speech and language therapists, physiotherapists and clinical psychologists is a particular issue for community based teams across Wales.

To work effectively with people with learning disabilities staff in education or social care settings will require knowledge and training in dealing with some clinical procedures e.g. administration of medication. The initial and ongoing training and monitoring aspects of this need to be integral to the work programmes of relevant staff. Protocols should be developed between the authorities to govern local practice, and implications for staff such as insurance and accountability, should be properly addressed to safeguard both trainers and trainees.

As well as delivering services directly, the training of staff with specialist skills, knowledge and experience of working with people with learning disabilities

should help to develop a better understanding of people with learning disabilities and their needs among other professionals such as doctors, dentists, opticians and other NHS staff, housing and benefit agencies, teachers and the police.

Developing the workforce

The Human Resource Strategy for NHS Wales, *Delivering for Patients*, aims to promote and support the delivery of high quality services in Wales. A comprehensive workforce planning process, supported by a new computer based system will be introduced for the NHS in Wales. Shortages and trends will be monitored, targets set to reduce turnover and improve retention rates and NHS Wales together with higher education institutions will enable people to access the professional education they need.

The Welsh NHS plan makes a commitment to extend the workforce and to increase the number of people in training in health-related fields. By 2004 there will be 1,360 more students on such courses than there are in 2001.

Over 60,000 people are employed in social care in Wales, many work in the private or voluntary sectors. Of these over 80% do not have the qualifications they need for the job they do. Estimates indicate that if annual expansion in this sector continues at its current rate approximately 2,000 new staff will be needed every year until 2006.

The Care Standards Act 2000 provides for the establishment of The Care Council for Wales on 1 October 2001. The main functions of this new body will be:

- to regulate the social care workforce in Wales through the registration of the individuals who make up the workforce.
- to drive up levels of training and qualifications
- to improve standards in social care through codes of conduct and practice for employees and employers.

The new Council will take over the task of regulating social work training, currently undertaken by the UK-wide Central Council for Training and Education in Social Work (CCETSW), and it will take over the functions in Wales of the National Training Organisation for Social Care (TOPSS). It is expected that TOPSS will produce a draft National Training Strategy in the summer of 2002.

The Training Support Programme (TSP) for the personal social services in Wales has the objective of increasing the proportion of staff with the specific qualifications, skills and knowledge they need for the work they do. The following targets are already in place for learning disability services and further targets will be set in the future.

Service	Staff	Proportion with a listed qualification	By 30 Sept
Residential care	Officer in charge	80%	2003
Residential care	Care officer / assistant	40%	2003

The Advisory Group endorses the target setting approach set out in the Assembly's TSP circular but believes that the targets should be more challenging

than those proposed. The Advisory Group also believes that the Assembly should set further robust targets to ensure that our recommendations set out in this report are effectively implemented. The Group's proposals are that;

- the qualification regime and targets should be extended to include all the social care workforce;
- all social care managers should have a recognised qualification by 2005;
- by 2005 a minimum of 50% of the social care workforce should attain NVQ level 2; and
- the Human Resource Strategy for the NHS in Wales should set complementary targets for the training of its workforce

Involving service users and carers in training.

The direct involvement of service users and carers in training is currently too patchy. Such personal involvement helps front line staff and managers to understand the needs, aspirations and expectations of service users and their families/carers and how best to meet these. The Advisory Group believes that the National Assembly should positively encourage authorities to enable service users to play an effective role in the design and delivery of training.

1.6 Financial Implications

Firm and detailed costs for implementing the priorities and other proposals in this Report will not be known until the Summer of 2002 when all authorities have undertaken their audit of existing services and submitted to the National Assembly their costed priorities for the development of their services. That there will be significant additional resource implications cannot be denied, but the Advisory Group does not accept that this provides any substantive reason for the National Assembly and other authorities to shy away from addressing the issues raised in this Report. Authorities can absorb some of these costs by investing existing resources differently. But this re-investment of resources will not be sufficient to achieve the full vision of services set out in this Report.

The Advisory Group considers that the capital and revenue resource requirements to provide and sustain independent living for an additional 1,500 people by 2010 and to implement our other services development proposals for the NHS and local authorities will require an incremental new investment approach. The Advisory Group estimates that the National Assembly will need to provide at least an additional £20 million to be invested in 2003-04 rising cumulatively to £40 million in 2004-05 and £60 million in 2004-05. These investment figures will continue to rise in each year from 2005-06 to 2010. Only with such levels of new investment will the Group's vision for services in 2010 be attained.

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Section Two

2. The National Assembly for Wales' and Advisory Group's Vision

2.1 The National Assembly for Wales : Better Wales

The Advisory Group has worked within the context of the National Assembly's vision set out in its Better Wales document which was issued in March 2000 and in the light of other related policy strategies including the Social Services White Paper 'Building for the Future' and 'Putting Patients First'. These Assembly strategies seek to ensure that Wales is served by modern, accountable, effective, efficient, appropriate, responsive, flexible, user centred, safe and accessible public services. That the voice of local people is heard and everyone is valued and given an opportunity to play a full part. The Assembly also emphasises that to achieve its policy objectives in the health and social care fields, agencies must work together in an effective partnership to provide wherever possible joined-up services.

The National Assembly's Better Wales sets out several themes that will influence the way in which the Assembly intends to develop its policies, budgets and programmes over coming years. These are :

- **Tackling social disadvantage** - the development of an inclusive society where everyone has the chance to fulfil their potential;
- **Equal opportunities** - the promotion of a culture in which diversity is valued and equality of opportunity a reality; and
- **Sustainable development** – meeting the needs of the present without compromising the ability of future generations to meet their own.

In October 2000, the National Assembly published Putting Wales First : A Partnership for the People of Wales. This first partnership agreement of the National Assembly committed the Partnership Government to the three guiding themes of Better Wales

2.2 The Advisory Group

In taking forward our work and in putting our proposals, the Advisory Group are seeking to ensure that people with a learning disability should enjoy as full a range of life opportunities and choices as their families, friends and other people living in the community. They should be empowered and enabled to play their full part in the community and should not be devalued because of their intellectual disabilities. Help in making opportunities and providing the kind of choices that make for a full life is not only the concern and responsibility of professionals but of everyone. The role of professionals should be to guide, to counsel and to encourage as well as to provide appropriate direct services.

It is not enough to provide services and to promote the integration of people with learning disabilities in their communities unless these efforts help to develop independence and self-fulfilment. There is not one answer or single model of service that can be prescribed for all the needs of people with learning disabilities. Each individual has different needs, capabilities and hopes which need to be identified and which must guide the efforts of service providers. Care must be primarily a way of encouraging development and widening opportunities for a fuller life, which must also involve a degree of adventure. Service providers will need the active guidance and support of their employing authorities to establish an approach to the needs of people with learning disabilities which emphasises their development and quality of life and which enables them to encounter and overcome the ordinary hazards of day to day life without being overly-protected.

The Advisory Group believes that there must be equity in provision of and access to services for people with learning disabilities wherever they live in Wales. The Advisory Group also believes that services should be designed to meet the identified needs of individuals. Access to services should not be restricted because of other existing health problems or because of an individual's age, ethnic origin, gender, culture, religion or sexuality.

This will require services for people with learning disabilities to be appropriate, flexible and responsive. Planners and commissioners of services should encourage and accept the involvement of users, their families and carers in the planning, development, delivery and monitoring of services.

The Policy Context

2.3 The All Wales Mental Handicap Strategy

Services for people with learning disabilities have been developing for nearly twenty years following the 1983 All Wales Strategy for the Development of Services for Mentally Handicapped People and updated 1994 Welsh Mental Handicap Strategy Guidance. This Strategy and Guidance are still in force to this day. The Advisory Group firmly believes that the three main principles that underpin this strategic approach remain valid today and for the future. These principles are that people with learning disabilities have:

- the right to an ordinary pattern of life within the community
- the right to be treated as an individual
- the right to additional help and support in developing their maximum potential.

The 1994 Strategy Guidance has at its heart the need for each person with a learning disability to have an individual and dynamic plan co-ordinating care throughout their life which properly reflects their needs and choices. The Strategy Guidance also says:

"The dignity and self respect of individuals often depends on their ability to make everyday decisions and to feel that they are not only consulted but that they are listened to before decisions are made for them. Good quality care must not only meet the needs of the people it supports, but must also reflect their wishes and preferences."

These statements remain equally true today and we have sought to breathe life into this approach in drawing up our proposals.

2.4 Social Services White Paper : "Building for the Future"

This White Paper was issued in March 1999 and sets out the National Assembly's vision for modernised and revitalised social services. It is based on five key principles:

- to promote an inclusive society
- to support and promote effective social services providing Best Value on a fair and consistent basis for those who need them
- to provide support for those who need it in a safe environment which preserves dignity
- to encourage and support those who can do so to build their independence
- to promote the continued development of a high quality workforce

The Advisory Group fully endorses these principles and we have sought to apply them in preparing our proposals.

2.5 'Putting Patients First'

This document sets out how the NHS Wales is to be rebuilt with all parts focused on and expected to contribute to the achievement of seven core values. These are :

Fairness – patients should have access to treatment and services according to their clinical needs

Effectiveness – treatments should reflect the most up-to-date scientific evidence and clinical practice

Efficiency – NHS Wales should achieve best value in its use of resources

Responsiveness – services should be designed with the individual patient's needs in mind

Integration – NHS Wales and other organisations should work together to deliver integrated packages of care for patients

Accountability – NHS Wales should be more accountable to people

Flexibility – services should be flexible enough to meet local needs, while also delivering wider improvements in health.

The Advisory Group's proposals will support the achievement of these core values.

2.6 Education

The National Assembly through its Action Programme for Special Educational Needs is seeking to strengthen and improve the support and advice made available for children with special educational needs and their parents and carers; give them a greater involvement in the decision making surrounding that support; and strengthen the arrangements for planning the transition of young people with special educational needs to further or higher education and adult life.

Our proposals are consistent with and complement these Assembly policy developments.

2.7 Partnership

Delivering co-ordinated packages of care to individuals is central to the National Assembly's Better Wales and the more specific proposals being put in place as part of the Social Services White Paper and Putting Patients First. To achieve this requires an effective partnership approach.

Local Authorities have a crucial and important role in driving forward in a corporate way the social services, education, housing, leisure and social inclusion agendas that are cornerstones of learning disability policies. More needs to be made of these new agendas and the opportunities that increased flexibilities will bring to enable traditional and new partners to create innovative models and approaches to the development of learning disability services and the systems that support them. It is also about good government, using resources wisely and efficiently, and by listening to users, their families and carers to provide services that meet peoples needs, wishes and hopes. Local authorities will also play an important part in the achievement of quality and equity in the delivery of learning disability services through their community care and social care responsibilities. Through the planning process of social care they must take account of the health and other needs and aspirations of people with learning disabilities and their carers. This approach needs to be supported and developed in order that meaningful participation and involvement in the planning and running of services leads to a fuller empowerment of service users, their carers and families

The NHS, the voluntary and independent sectors will all have critical roles to play in this partnership. All parties involved must be sure that there is a seamless approach to meeting the needs and hopes of people with learning disabilities. There must be a high level of commitment from the organisations and individuals to ensure the partnership works effectively for the benefit of people with learning disabilities. The role of all those involved in the partnership must be valued and their contributions must be properly and fully taken into account.

2.8 The National Assembly's Programme of Reform

The National Assembly is presently taking forward a substantial programme of reform that puts people and their improved health and well being at the forefront of their activities. This includes :-

- introducing new "flexibilities" for funding and commissioning to create the right climate to maximise the benefit of collaboration between health and social care agencies for the benefit of the user
- the implementation of "Improving Health in Wales"
- the development of a NHS user and public empowerment strategy
- developing a new Health and Social Care Charter which will set out key national standards which reflect best practice across health and social care services
- reviewing the NHS complaints procedure to see if it can be made more open, more objective and more responsive to patients
- the development of a Carers Strategy to improve the long term health and well being of carers and those for whom they care, including a right to assessment for respite needs
- the proposed amendments to the Mental Health Act legislation and the proposals for updating the Welsh Adult Mental Health Strategy and introducing a new Children and Adolescent Mental Health Strategy
- the proposed changes included in the Supporting People programme
- the implementation in Wales of the Government's response to the Royal Commission on Long Term Care
- the establishment of the Care Council for Wales and the Care Standards Inspectorate for Wales who will be responsible for raising professional standards for the social care workforce; protecting vulnerable people from abuse and neglect and promoting the highest standards of quality of care that people receive, whoever is providing it to them.
- the implementation of the 'Children First' programme.

2.9 Contribution to achieving Better Wales objectives

We consider that our proposals will help achieve many of the key National Assembly's objectives as set out in Better Wales, in particular, to:

- ensure that the needs of disadvantaged groups are better met by involving patients, users, carers and voluntary organisations in the planning and review of health and social services programmes
- raise standards of social care
- help the elderly and those with disabilities to live independently, and support their carers
- achieve an equitable distribution of health resources in line with the best evidence on needs and to ensure that all health authorities have Health Improvement Plans in place which allocate resources in line with health and service needs
- deliver joined up and more effective services for users and carers by making full use of the flexibilities available under the Health Act 1999 to improve joint working between health and social services, including the use of pooled budgets, integrated provision and lead commissioning of services
- assist at least 90% of those assessed as needing community care to receive support to allow them to live at home
- reduce unemployment and inactivity amongst groups which have traditionally experienced high unemployment such as young people, lone parents, ethnic minorities, disabled people and the over 50's
- encourage young people and people from excluded backgrounds to participate more and have their voices heard
- achieve a significant improvement in the quality of education for children with special needs
- open up opportunities for everyone, whatever their age and wherever they live, by encouraging lifelong learning and more flexible ways of formal and informal learning

The Advisory Group is also satisfied that our proposals are fully consistent with the Assembly's Voluntary Sector Scheme and the Human Rights Act 1998.

Section Three

3. Progress in the Development of Learning Disability Services to date

3.1 Intentions set out in 1983

The All Wales Strategy for the Development of Services for Mentally Handicapped People (AWS) was launched in 1983 to "correct the historic anomaly ... which has left the bulk of public service provision in large and, for many, remote hospitals whilst the great majority of mentally handicapped people and their families receive little or no support in their homes where it is most needed". It set out three guiding principles and emphasised that these applied to all people with learning disabilities, however severe their disability. People were to have rights to normal patterns of life within the community, to be treated as individuals, and to receive additional help from the communities in which they lived and from generic and specialist professional services in order to develop their maximum potential as individuals. The AWS set a direction for the development of a range of local services and gave explicit guidance on the form of some of the needed services. It was given an initial life of ten years, during which additional recurring revenue investment would grow to approximately £26 million per annum at 1983 prices. However, neither the initial term nor the additional funding on offer was sufficient to make the pattern of services envisaged by the Working Party, which preceded the AWS comprehensively available throughout Wales. The intended financial investment in the first ten years was about a quarter of that estimated to be eventually required.

The AWS reflected the idea of a comprehensive local service of its time; it was clearer in some areas than in others. However, it stated that "the concept of new patterns of comprehensive services lies at the heart of the Strategy".

Fundamental change in the nature of residential provision was central to its implementation and symbolic of the move from institutional to community services. The AWS was very clear: "support staff should be available to help run a range of accommodation ... which caters for individual preference and ability ... in ordinary houses ... made available from local ... housing stock". The Working Party Report estimated that provision for between 7,300 and 11,200 adults was ultimately required, based on a then total population of 2.8m. This compared to the current level at the time of 3,200 places, mostly in the long-stay hospitals (2,300 places) and hostel accommodation (the majority of the remainder). The provision target converts to a rate of 260-400 places per 100,000 total population.

Development of other community services stemmed from "the pre-eminent importance of the family ... and the heavy burden on the family that is caused by stress and lack of help". In response, "short-term relief should be readily available ... (and) locally based, flexible and capable of responding to emergencies', and help to families was also to include "a range of domiciliary support ...(such as) family aid (sic) services". The Working Party Report gave target provision figures for families with children only, in view of the comprehensive targets set for alternative supported accommodation for adults. Both respite and domiciliary support services were to be sufficient to provide for a total of 2,700 children and families, rates that convert to 96 per 100,000 total population.

The AWS was less specific on education and day services. It endorsed section two of the 1981 Education Act and sought "the maximum possible access and integration with ordinary education facilities" but without giving any guidance on minimum targets or reasonable achievement. In keeping with the times, it did not set a clear vision for day services for adults. Existing segregated and centralised day services (adult training centres, social education centres and the like) were seen as the primary source of day provision, a situation that would continue into the future for many service users. The AWS recognised some of the inherent problems in the model: such centres "provide an all-purpose service which is not conducive to the promotion of independence or responsive to individual needs". It therefore sought a broadening of the range of options available: "more appropriate forms of constructive activity need to be developed,

(and) there needs to be imaginative developments ... to create employment opportunities and ... better career guidance and work preparation courses". The AWS, therefore, called for innovation and the development of diversity; it did not provide a clear direction towards a new pattern of local day services. The Working Party Report set a target for the combined extent of day service options of 6,500 places for working aged adults (232 per 100,000 total population) and 800 places for adults over 65 years (28 per 100,000 total population).

For each person and family, the AWS sought "full access without question to the same services, including health services that are available to the rest of the community". It wanted to help general service providers to be more open to serving people who had traditionally been marginalised, a task it saw primarily as educational. It also sought to promote professional input and a greater network of community support: the availability of "advice, support and teaching from social workers, community nurses, care assistants, other parents and voluntary organisations ... as and when required".

Ultimately, the AWS sought to influence the place which people with learning disabilities had within society, substituting a life apart or on the margins for one of full involvement. "Provision for recreational and social opportunities" was urged "in parallel with dwellings" and success was seen as dependent "on the involvement of the general public ... (which) service providers should place special emphasis on sensitive and imaginative efforts to develop". Establishing neighbourhood networks of voluntary help was also seen as desirable.

Finally, consistent with its individual focus and with the emerging idea that effective support required the pulling together of services and resources, the AWS advocated the widespread introduction of individual planning. "Staff should work together with mentally handicapped people and their families in the preparation, implementation and regular review of individual programme plans for the development of the mentally handicapped person". Co-ordination of the individual planning system was to be done by multidisciplinary professional teams established locally. Each person with a learning disability was to have a nominated keyworker. In addition to providing specialist professional input, the multidisciplinary team was to act as a single point of contact for individuals, families and generic services alike, and be a focus for local planning and the collation of information on individual need which could be fed into the county planning system. Involvement of the consumer - the individual with a learning disability and the family - in the decisions surrounding the provision and review of services was an avowed commitment. Such involvement was mirrored by a similar commitment to representation in local and county planning forums. Both commitments were an attempt to make needs led and individually focused service provision a reality.

The AWS, therefore, set a framework for the administrative arrangements to be followed. It put forward a model planning system in which representatives of consumers and all relevant agencies met at county level to produce a single joint plan. It was made plain that the Welsh Office would expect people with learning disabilities, their families and voluntary sector representatives to be widely consulted about the content of plans and have a permanent place in the planning and monitoring of services. Local authority social services were given 'lead agency' status in recognition of the shift from the medical model to a social care definition of the prime task to be achieved. This clearly signalled the eventual patterns of resource investment in the area. The AWS envisaged that the expenditure tied up in traditional services would be liberated as new and better services were developed and that this would be available for reinvestment. Increased revenue could also come from local authorities. However, the allocation of additional funding as part of the AWS recognised that the redevelopment and growth in the scope of services was of such a scale that it would need to be largely funded by central government.

3.2 Progress against AWS objectives

(a) Financial investment

The level of investment promised by the AWS was slightly more than delivered. Social services expenditure in 1994-95 was £93.3m (£55.04m at 1983-84 prices) and the AWS (then) Welsh Office grant allocation for that year was £49.2m. Since then, the central funding of strategic development of services has continued in a more limited way. A second phase of central funding to achieve the broad targets of the AWS was not pursued. Rather, central investment was increased to progress the hospital resettlement programmes only (see Table). The total budgeted social services expenditure for 2000-01 is £142.2 m (£71.25 m at 1983-84 prices). However, despite increase in the resettlement grant allocation, the proportion of personal social services expenditure on people with learning disabilities has remained almost constant since 1994 (21.7% in 1994/5, 22.1% in 1999/00). Thus, learning disabilities has not received a proportionate share of other growth in PSS expenditure, a sign of the lower priority accorded learning disability service development since the ending of the

first phase of the AWS. In addition, the increase of the mainstream AWS grant at a rate less than actual cost inflation has placed pressure on local authority finances.

Table: Personal Social Services Expenditure on Learning Disabilities (£m)

Year	PSS* spend on Learning Disabilities (£m)	Proportion of Total PSS* Expenditure	AWS Mainstream Grant (£m)	AWS Resettlement Grant (£m)
1994/5	93.3	21.7	49.2	
1995/6	101.3	20.9	57.1	
1996/7	117.1	22.2	57.4	1.8
1997/8	125.4	22.4	27.7**	11.1
1998/9	132.9	22.3	28.0	12.0
1999/00	136.8	22.1	28.2	17.2
2000/01	142.2		28.4	19.1

* Personal Social Services

**£28.4m of mainstream grant transferred to LAs

Estimated expenditure by health authorities on learning disability services in 1999/2000 was £56.5m. Combined health and local authority expenditure in that year is estimated at £193.3m, which converts to a sum of approximately £66 per head of population. This is in line with Scottish Executive estimates. They report that the spend per head of population on supporting people with learning disabilities is

1. £63 in Wales
2. £59 in England
3. £54 in Scotland.

(b) Residential service provision

Providing supported accommodation in the community is the main way to enable adults with learning disabilities to leave the family home and live typical mature lives, consistent with AWS principles. Welsh Health Circular (85) 46 requested health authorities to prepare proposals for the future of the long-stay hospitals and indicated that the progressive reduction of long-term hospital populations should be an integral part of such proposals. The development of accommodation in ordinary community housing was one of the core priorities stated following the 1988 review of progress, and the need to accelerate resettlement was explicitly recognised. As a consequence, Wales has made great progress in reforming the nature of residential services so that in contrast

to what existed in 1983, available services are smaller in scale, within ordinary housing stock, and local to the communities which they serve. At 31 March 2000, there were 366 people still resident in long stay hospitals and the National Assembly has set a target to close all remaining long stay hospitals by no later than 2010. Otherwise, settings provided by local authorities and the independent sector in Wales in 1995 had average residential groups of approximately three people. By way of comparison, the character of English services was very different. English local authority accommodation in 1995 had resident groups of just under 13 on average. They provided no 'small' homes with fewer than four places. In addition, independent sector homes had average residential groups of six. Such differences may be related to differences in assessed quality. Compared to a random sample of services in England conducted at about the same time as research on housing services in South Wales, the houses in South Wales were smaller and more individually-oriented, allowed more choice and promoted greater community integration.

However, while the quality of residential provision has improved, no progress has been made in extending service availability towards the comprehensive levels envisaged by the AWS. Wales began the AWS with a low rate of residential service provision (approximately 105-110 places/100,000 total population). By 1995, the rate of provision was assessed as 98-places/100,000 total population. The AWS years may have seen an increase in supporting people to live more independently in accommodation outside of that notified in official returns but it is likely that overall service provision was certainly no more extensive in 1995 than in 1983. (It is conceivable that the level of service provision may have fallen, as provision was not made for revenue to be redirected into community services when individuals died in hospital.) In 1991, Wales had a lower rate of provision than all but one English Regional Health Authority and a lower rate than the average in England and Scotland. Although provision estimates are now somewhat dated, it should be remembered that the priority throughout the 1990s was on hospital resettlement. It is unlikely that the 1995 figures seriously underestimate the total service availability currently. Therefore, one can conclude that the current rate of provision in Wales is lower than (a) the level of provision in England (by about 20 places/100, 000 total population), (b) the norms set in the 1971 White Paper (by about 32 places/100,000 total population), (c) its 1980 update (by about 55 places/100,000 total population) and (d) the eventual comprehensive provision estimate discussed by the AWS Working Party Report (by at least 160 places/100,000 total population). It should be remembered that the 1971, 1980 and 1983 estimates took no account of the need to increase provision in line with better survival of people with learning disabilities.

(c) Family-support services: respite and family aides

The development of respite and family aide services was a high priority of the AWS. The number of individuals and families in Wales in 1995 using respite services was 2,278 and receiving domiciliary support worker input was 1,914. It is not known whether comparable growth in family aide provision has occurred in England but it is perhaps less likely given the strong deinstitutionalisation emphasis to English policy. However, developing respite services has been a priority throughout Britain. According to the second national survey of family-based respite care, Wales had more family-based respite care services in ratio to population (9.0 per million) than the United Kingdom as a whole (5.8 per million), although they were biased more towards children (25 services to 1) than in the UK generally (257 children's services to 74 for adults). The same source estimated that 9,821 children and 2,960 adults received some family-based respite care in the UK in 1992 (a combined rate of 22.4 per 100,000 total population). The number of Welsh users in 1995 was 739 (a rate of 25.5 per 100,000 total population). It is important to emphasise that none of the figures reflect whether the extent of offered support or respite per family is adequate or even differentially related to assessment of need. It is also possible that service availability has continued to expand since 1995 despite the emphasis on resettlement and the absence of central funding for purposes beyond this.

Calculation of need for family support and respite is clearly relative to the level of other services. If, for example, adults were supported to live in homes of their own, then the remit for family support services would be reduced to supporting children, as originally envisaged by the AWS Working Party. At the end of March 1999, the 12,363 people recorded on learning disability registers were reported as living in the following circumstances: 9,776 in their communities, and 2,010 in statutory or independent sector residential accommodation. Were residential support for adults to increase to the comprehensive level envisaged by the AWS Working Party, the numbers living in their own rather than parental homes would need to increase by some 4,800. The 1995 availability of domiciliary support and respite services exclusively focused on this smaller target population would meet a high proportion of potential need. However, until such service expansion has occurred, family support services are likely to be insufficiently extensive and, therefore, effectively rationed.

(d) Day Services for Adults

The AWS recommended greater variety in day provision and less reliance on large, multi-function day centres, although it was not specific on the form of service support to be developed to take their place. In 1983, there were about 3,000 day centre places together with just under 200 day service places in the large hospitals, giving a combined rate of provision of about 110 places/100,000 total population. By 1988, day centre places had increased to just under 3,200 places. Since that time, there has been an increasing diversity of day service options and an increase in sessional attendance at both the new and more traditional service forms. Twenty-three percent fewer people attended day centres in 1995 than did in 1988 although it was still the dominant form of provision. There was increased attendance at satellite units, colleges of further education, work experience, paid employment and a range of other service and community placement options. A few Adult Training Centres or Social Education Centres have been completely reprovided and the old centres closed.

As a consequence of more recent trends towards sessional attendance, it is difficult to convert figures on the number of attendees to the number of whole-time-equivalent places available. Nor is it possible to add the number of attendees across different service forms without double counting of individuals. About 3,500 people with learning disabilities were reported as being provided day care commissioned by local authorities during the week ending 1st March, 1998, although the balance between full and part-time provision is not clear, a rate of just under 120/100,000 total population. The available evidence therefore suggests that total service availability has not altered greatly since the start of the AWS. It would certainly be safer to assume that there has been no overall increase as a sample survey of the services received by people with learning disabilities in four local government districts in Wales between 1986 and 1990, the middle four years of the first 10-year phase of the AWS, found that the proportion receiving a full-time day service had declined and the proportion receiving either no day service or only a part-time one had increased.

Development of day services for adults under the AWS has been, therefore, somewhat similar to the development of residential accommodation in that reform of large centralised provision has taken precedence over expansion of service availability in line with demographic change and progress towards more comprehensive provision. However, reform of the nature of day services achieved to date, although significant, is not as complete as that brought about in relation to residential services. Further reform is anticipated. The 1971 White Paper reported that there were, on average, 113-day service places in hospitals or the community in England and Wales per 100,000 total population in 1969. It set a target for this to increase to 195 places/100,000 total population, which would imply 5,750 places in Wales overall. The AWS Working Party estimated a need for 6,500 places for adults of working age (about 220-places/100,000 total population). The 1994 Guidance reported that 3,665 individuals received "new patterns of daytime care" in 1993, which represented 53% of potential need. This suggests that support would need to extend to 6,915 individuals for it to be regarded as comprehensive (about 235-places/100,000 total population).

There is now considerably more emphasis being given to supporting people in productive employment rather than programmes of diversional activity than at the beginning of the AWS. Supported employment in Wales has grown more rapidly in ratio to population than elsewhere in the UK. However, available evidence suggests that the costs of supported employment outweigh savings. Current welfare benefit arrangements lead to a high level of part-time working in line with the therapeutic earnings disregard. This often means that savings in welfare benefits payments or from reduced use of alternative services are minimal. Reform of welfare benefit regulations could alter this greatly. Analysis suggests that supported employment could become cost effective with a higher level of full-time working. The impact of supported employment on day service provision may remain marginal if reforms, which would facilitate this, do not occur.

Greater survival is also seeing the beginnings of a significant population of people with learning disabilities of retirement age (possibly up to about 850 people over 65 years). This is creating the need for a new form of service support. The AWS Working Party Report anticipated this trend by estimating a need for about 800-day places to support people in retirement. This is equivalent to a further 28 places/ 100,000 total population.

In summary, reform of the nature of day services has occurred in line with the direction set by the AWS in bringing a greater variety of options. However, the large day centre is still the core of provision and much redevelopment is still required. Supported employment has grown and is seen as having great

potential to meet the fundamental AWS principle of individuals living as normal and productive a life as possible. Wales has led in the development of supported employment in Britain. Co-ordinated policy developments are required across government departments to allow its potential to be reached. Across all forms of day provision, service availability is substantially lower than estimates of what is required. Greater survival of people with learning disabilities means that (a) it will become increasingly difficult to meet the needs of school leavers, and (b) policy and service development are required for day support of people of retirement age.

(e) Multi-disciplinary community teams and individual (person-centred) planning

The development of multi-disciplinary community teams in Wales was rapid in the first years after the inception of the AWS; only one of the 37 teams in existence in 1987 pre-dated the AWS. Such development followed similar development in England and could therefore be construed as catching up, at least initially. It is not known whether the professional infrastructure is now better established or organised in Wales than elsewhere. Moreover, since the research conducted in Wales on community teams predated the introduction of the purchaser-provider split, care management and local authority reorganisation, what was known about their working is unlikely still to apply.

People with severe learning disabilities tend to be lifelong consumers of health and social care services. They also make a heavy demand on education services during their developmental years. The AWS proposed that strategic and operational planning should be underpinned by a comprehensive system of Individual Planning (IP), detailed reviews of people's objectives in life and the service supports required to realise them. Such IPs were to be regularly conducted at least annually if not more frequently and differ from more traditional case conferences in that they would be held to consider the effectiveness of service supports even though changes in service placement were not pressing. At an individual level, such planning was to inform the service elements and processes required to meet the person's needs. At an authority level, an overview of such plans and identified service deficiencies was to inform strategic development.

Individual Planning (IP) as a means of service co-ordination and review grew in Wales but was only ever available to a minority of service users. Service authorities launched IP systems without thorough assessment of the resource implications of comprehensive implementation. IP systems were often established but not sustained. When first established, community teams experienced early difficulties in progressing towards the idea of IPs for all. By 1987, 68% of teams had done either no IPs or had done them for less than 10% of users. Only five of the thirty-seven teams claimed a 25% or greater coverage. Three years later a family survey found little advance with only 11% of carers identifying an IP meeting in the previous twelve months, though other forms of meeting were recorded, e.g. case review, service review, case conference. This figure, however, concealed considerable variation in the prevalence of IPs between counties (from 3% to 30%), reflecting both the priority accorded IPs by senior managers and the available staffing levels in community teams. A survey of four local government districts at about the same time, which included people living in different types of residence as well as the family home, reported higher coverage of IPs but there had still only been a marginal increase in coverage from 29% to 33% between 1986 and 1990. Whether IP was more or less available in Wales than in England is not known.

Now, the emphasis on IP within statutory sector planning has been replaced by care assessment introduced by the NHS and Community Care Act and formulation of school transition plans introduced in 1994 but now subsumed by the 1996 Education Act. Care assessment has been viewed as a return to a resource rather than needs-led approach to planning. Proponents of a more person-centred approach now refer to Person-centred Planning rather than IP. The 1994 AWS Guidance maintains reference to IP as a process of co-ordinating care in a way, which properly reflects individual's needs and preferences. It recommends that IP should begin in early childhood and persist throughout life, and be available to everyone who wants one. Current policy, therefore, endorses a cradle-to-grave, comprehensive, system of multi-agency, multi-disciplinary co-ordination and review.

While policy reference to some form of IP has been long-standing, realistic assessment of the resources required to instigate and sustain such a system of planning has never been undertaken. Even care assessment has been achieved for only a minority of people at any one time. Expressed as percentages of the number of persons with learning disabilities on local authority registers, the number of assessments undertaken was 22.6% in 1994, 12.5% in 1995, 8.2% in 1997, 13.3% in 1997 and 11.8% in 1998* (*returns from two authorities are missing from the 1998 numerator).

(f) Joint planning and family and user consultation

In establishing the social services department as lead agency, Wales has achieved a more wholehearted transition from health to local authority commissioning of social care services than elsewhere in Britain. Allied to this, the then Welsh Office insistence on the creation of a single joint agency plan at county level, although creating a challenge to all concerned, eventually produced a distinctive level of joint agency collaboration. However, reforms of recent years have not helped to further this. The separation of purchasers from providers divided the interests of newly established collaborators both between the statutory agencies and between statutory agencies and voluntary bodies. Health and local authority reorganisations removed the high level of territorial coterminosity which previously existed. The creation of a large number of small unitary authorities, coinciding with the evident weakening of policy priority, broke up pre-existing specialist learning disability planning teams which had thrived under the AWS.

Alongside the development of joint agency planning under the AWS was the injunction to develop consumer representation in planning at local and county levels. Family representation was the easier to establish and came first but the number of self-advocacy or service user groups which had representation on local or county planning groups grew between 1986 and 1994, reflecting the growth of such groups (from 2 in 1985 to 58 in 1994). There was a strong association between whether such groups were funded, usually through AWS monies, and (a) the numbers of representatives at local and county planning levels and (b) whether such representatives were likely to have paid supporters with them at meetings. Little is known about the impact of consumer representation on the plans formulated but reflection by those involved suggested that families did exert an influence, particularly in the emphasis given to developing family support services, but that representatives with learning disabilities largely did not.

A small, number of citizen advocacy projects developed in Wales at the end of the 1980s and beginning of the 1990s. The projects were geographically scattered and covered only a small proportion of Wales. It proved difficult to recruit advocates. In 1992, a particularly high point in terms of advocate numbers, the four longest established projects had a total of 50 advocates. Their total funding was £124,500, around £2,500 per advocate per annum. Compared to the 8,886 adults with learning disabilities over 16 years of age recorded on health and social services registers in Wales in 1992, this number was insignificant. Even within the catchment areas they served, the availability of advocates was low. For example, the project with the most citizen advocates (27) and the smallest catchment area of all projects in Wales served an area which had over 300 registered adults with a learning disability, together with a hospital population that was still over 100.

(g) Comprehensive provision

The concept of comprehensive services was said to lie at the heart of the AWS. Comprehensiveness implies service availability commensurate to need. It also implies equality of provision and access to services across the localities and communities which constitute Wales. Yet, there is clear evidence that change in service provision has neither been uniform across Wales nor evenly distributed. For example, rates of residential provision across the former counties in 1994/5 varied between 60 and 214 places per 100,000 total population, an inequality which has given the recently created 22 unitary authorities very different service inheritances. Those of the old counties, which had concentrations of traditional hospital provision, became authorities with higher provision rates of alternative community residential accommodation. Provisional personal social services expenditures on learning disabilities for 1989/99 show considerable variation across unitary authorities, with higher spending per head of population being associated with proximity to traditional hospital provision (Newport, Gwynedd, Cardiff, Bridgend and Powys being the five highest). Redevelopment of other major services, such as day provision for adults, is equally patchy.

With the benefits of hindsight, despite its strategic intent, the AWS was characterised by pragmatic rather than strategic planning, shifting priorities and a sense among families and people in need in the community of opening and closing windows of opportunity. Difficulties of co-ordinating large, multi-agency joint planning groups were identified as contributing to poor strategic planning and the absence of a comprehensive view. Failure to estimate need at the population level or to aggregate assessed individual need (impeded by the low level of IPs) meant that AWS proposals were developed expediently. The absence of quantified, developmental stages for the unfolding of the comprehensive intent of the AWS produced an inability to determine how the incremental year-by-year progression contributed to a final coherent pattern of local services. This sense of incomplete and patchy development has an obvious corollary that some individuals and families benefited from the AWS and others did not. It would be safe to assume that precisely who benefited and in what ways they benefited varied from county to county. However, the status of information on the demand and supply of services at local level is too uncertain as to be able

to elaborate on this further.

Clearly the central goal of the AWS remains to be achieved both in terms of equality of access and adequacy of service availability. That the AWS has not resulted in a comprehensive pattern of services by this stage is not in itself surprising given that the original Working Party calculated that the investment provided in the first phase was only about a quarter of that required. Given no change to the aims of the AWS, the constraint on additional central resourcing after 1993 and its narrow focus on achieving hospital closure did not appear to stem from an evidence-based assessment of how much of the envisaged service reform had been achieved.

(h) Improving Service Quality

Significant areas of service reform, such as deinstitutionalisation and provision of supported community housing, day services and supported employment, and the provision of family support services, have been the subject of evaluation. A number of broad generalisations are possible:

- (i) Compared to hostel or hospital accommodation, supported community housing provides (a) a better material environment, (b) a more resident-oriented social milieu, (c) more staff attention to residents, (d) greater access to community activities, (e) greater opportunity for the use of skills, (f) greater choice, (g) increased constructive activity, and (h) residents with greater satisfaction with life.
- (ii) Day centres differ greatly in the activity programmes that they offer service users and in the number of hours per week that they offer organised activities. The 'working week' often lacks intensity. Little is known about the relative merits of many alternative day services. Managers of various community or employment focused alternative day services in Wales thought that those using the services increased in personal competence, had a sense of achievement and enjoyed greater community integration. Evaluation of supported employment has shown that supported employees gained income, spent more time constructively occupied than when attending day services and had greater contact with people without learning disabilities other than paid care staff.
- (iii) The growth in domiciliary and respite care services have been deeply appreciated by family carers and led to improvements in their quality of life, particularly in relation to helping carers balance the time demands of their caring and other commitments. Extended caregiving has become less claustrophobic as a result. However, important questions remain concerning the extent to which carers are able to increase their social participation or participation in the labour market as a consequence of receiving support as currently conceived. Carers still feel excluded from these areas of life, an exclusion which contributes significantly to their distress. Support services are generally insufficiently extensive, scheduled at the right times or flexible to allow carers to achieve significant ambitions in these areas.

(i) Service costs and quality

Economic evaluations have attempted to identify the costs associated with particular approaches to providing supports for people with learning disabilities. Much of this work has examined the costs of residential supports. The research indicates that:

1. Costs vary dramatically within all forms of providing residential supports
2. A significant proportion of this variation is associated with varying levels of need or dependency
3. Supports provided in newer community-based services are generally more expensive than support provided in old 'learning disability' hospitals (although this is probably mostly due to avoidance of some of the worse inadequacies of traditional services being repeated in the new community services rather than through inherent economies of scale within the large hospitals)
4. Once levels of need or dependency are taken into account, there is little association between size of home and costs, although cost inflation may set in at very small scale
5. Village communities and other campus-style arrangements may be marginally less costly than community-based provision.

Variation in costs has also been found to be a feature of day services for adults, with ten percent of local authorities reporting average gross revenue costs of £13 a session or less and ten percent £39 or more. This is consistent with a three-fold difference in staff: user ratios between day centres at either end of the range in a recent sample in eight English local authorities and a five-fold difference in an earlier survey of Welsh centres. In the latter, smaller centres were more costly than larger ones.

Comparison of outcome in new community services with that found in traditional hospitals has shown that there is a quality gain to set against the increase in costs. However, there are no simple associations between the costs and quality of services.

The largest element of the revenue costs of services is attributable to staffing. The majority of economic evaluations of specific forms of support services for people with learning disabilities (e.g., residential supports) have reported a modest positive association between indicators of 'need' and the costs or staff: user ratios of provision.

To look at the association between costs and quality, therefore, it is also necessary to take into account differences between services in the needs of people served, especially as there is extensive evidence to suggest that people with greater or more complex needs often experience poorer outcomes. Studies that have done this suggest that the link between resources (costs or staff: user ratios) on the one hand and quality on the other is tenuous indeed. Some studies have reported that increased resources are linked to an extent with increased quality but others have failed to find a link at all.

Section Four

4. People with Learning Disabilities and Demographic Change

4.1 Defining learning disabilities

Stephen Dorrell, then Minister of Health, first officially used the term 'learning disabilities' in a speech to MENCAP in 1991. Learning disabilities replaced previous terms that now seem very pejorative, such as 'mental handicap', 'mental retardation', 'mental subnormality' and 'mental deficiency'. The term 'learning difficulties' is used in the education system, though with a broader meaning, and some health and social care professionals and agencies, in common with some self-advocates, also prefer this term. The term 'intellectual disabilities' is increasingly used in international dialogue.

The formal definition of 'learning disabilities' or 'intellectual disabilities' includes the presence of:

- A significant intellectual impairment and
- Deficits in social functioning or adaptive behaviour (basic everyday skills)
- Which are present from childhood.

'Significant impairment of intelligence' is usually defined as an intellectual quotient (IQ) score more than two standard deviations below the general population mean, in other words an IQ below 70 on a recognised IQ test. Deficits in social functioning or adaptive behaviour refer to how well people cope with both the natural and social demands of the environment. This may be assessed by a normed behavioural checklist covering such areas as communication, daily living skills and socialisation like the Vineland Adaptive Behavior Scales and the AAMR Adaptive Behavior Scales - Residential and Community.

4.2 Causes of Learning Disabilities

It is well established that biological, environmental and social factors are all relevant in the causation of learning disabilities. Historically, it used to be asserted that severe learning disability was due to biological variables whereas mild learning disability was due to social and environmental factors. It is now known that the picture is not quite as clear cut as this.

It has been long established that there is a relationship between the occurrence of mild learning disabilities, parental social class and instability of family background (such as changes of carers, abuse, neglect) which is not as evident in relation to severe learning disabilities. However, advances in understanding have increased the proportion of children with mild learning disabilities where there is a known biological contribution to 20-40%. Contributory biological factors can be identified for around 80% of children with severe learning disabilities.

The majority of these factors operate pre-natally. Together they account for two-thirds to three-quarters of all cases of severe learning disabilities. The most common pre-natal factors are chromosomal and single gene errors, such as Down's syndrome or Fragile-X syndrome. Disorders of development (such as neural tube defects) and intrauterine problems, such as foetal alcohol syndrome, listeria infection, rubella embryopathy, account for the remaining pre-natal factors. The peri-natal disorders include birth trauma and cerebral hypoxia, while the post-natal causes include accidents and infections.

4.3 How Many People Have a Learning Disability?

Most epidemiological studies of learning disability typically use IQ assessments to classify a person as having either a mild or severe learning disability, rather than using the combination of IQ and adaptive behaviour assessments recommended in current classification systems.

The birth prevalence of learning disabilities is difficult to estimate as it is not until later in life when IQ can be tested as a result of the characteristic delays in social functioning and adaptive skills becoming clear. Only a proportion of the conditions associated with even severe learning disabilities are identifiable at birth. Typically, the age-specific prevalence of severe learning disabilities grows through the pre-school and school years as children are identified. Estimates at the beginning of the 1990s suggested that there were about 5 people with severe learning disabilities per 1,000 total population aged 15-24 years. Allowing for mortality during childhood gave an estimated birth prevalence of at least 6 per 1,000.

The major factor underlying upward pressure on the prevalence of learning disability is increased life expectancy. For example, one would have expected, on average, about 3.5-4.0 people per 1,000 aged 25-44 years, 2.0-2.5 per 1,000 aged 45-64 years and 1.0-1.5 per 1,000 aged over 65 years. The overall prevalence rate for people with severe learning disability was estimated at between 3 and 4 per 1,000 total population, probably in the region of 360-380 per 100,000. Applied to the population of Wales such a rate would have suggested that there were about 10,830 people with severe learning disabilities living in Wales.

Population screening studies of mild learning disability yielded much higher prevalence rates (about 25-30 people with mild learning disability per 1,000 total population) than studies using administrative populations (i.e., those known to agencies that provide specialist services to people with learning disabilities) (less than 10 per 1,000). The former figure is approximately what would be expected given a normal IQ distribution. Including a measure of adaptive behaviour would be likely to reduce such a rate considerably, in line with the lower administrative prevalence.

4.4 Is the Number of People with Learning Disabilities Changing?

Learning disabilities is not a single condition. Therefore, it is likely to vary in occurrence as the factors, which influence its causes, vary. As an example, variation in prevalence between birth cohorts from under 2 to over 7 per 1,000 has been reported. One should only consider trends in broad terms, for example at a national level where one can expect variation across localities in a given time period to cancel out.

Upward pressures on the incidence of learning disabilities include:

- increases in maternal age (associated with higher risk factors for some conditions associated with learning disability, such as Down's syndrome)
- improved survival of 'at risk' infants, such as low birthweight infants, due to improved health care
- increases in more recently significant pre-natal threats such as HIV infection and substance abuse
- an increase in the proportion of children growing up in poverty.

Downward pressures on incidence of learning disabilities include:

- the impact of prenatal screening for Down's syndrome (estimated to reduce a 'natural rate' of 1.5 per 1,000 births to about 0.9-1.1 per 1,000)
- improved health care and support resulting in fewer 'at risk' infants developing learning disabilities.

The major factor underlying upward pressure on the prevalence of learning disabilities is their increasing life expectancy. Indeed, the fact that increased survival would lead to the need for increased service availability was predicted in the White Paper, 'Better Services for the Mentally Handicapped' as long ago as 1971, although the provision norms set at that time were not adjusted for such an increase. Although some changes since then have reduced the occurrence of learning disabilities, increased life expectancy has outweighed downward trends. It is now thought that most adults with learning disabilities in developed nations who live past their third decade are likely to survive into old age and experience the normal ageing process. There are more adults with severe learning disabilities aged over 45 years than there are such children aged under 15 years.

In addition, there also appears to have been a 'bulge' in the UK childhood prevalence of learning disability for births between the mid-1950s and mid-1960s, suggesting a higher prevalence for adults currently in their late 30s and 40s. Fryers estimates that the age-specific rates of severe learning disabilities in the UK (per 1,000 total population) have changed between 1990 and 1998 as follows:

Age 1990 1995 1998

25-29 4.5 4.5 4.3

30-34 4.0 4.0 4.5

35-39 3.5 3.8 4.0

40-44 3.0 3.3 3.5

45-54 2.5 2.8 3.0

55-64 2.0 2.3 2.5

65-74 1.0 1.3 2.0

75+ very few 1.0? 1.3?

In other words, there have been increases in the prevalence of people with severe learning disabilities between 1991 and 1998 in every 10-year age band between 35 years and 64 years of between 15 and 25 percent, together with a doubling of the prevalence of people aged between 65 and 74 years and the beginnings of a significant very old population. These estimates are consistent with the 22% reported increase in the number of people on local authority

registers for people with learning disabilities in Wales between 1990 and 1999. Estimates from the Department of Health statistician suggest that the trend towards an increasing number of people with learning disabilities will be sustained over the first two decades of the Twenty-first Century.

The comparison between 1990 and 1998 above shows that the higher mortality of people with severe learning disabilities reflected in declining age-specific rates as people age is reducing. Early mortality was greatest among people with multiple disabilities and, therefore, greater survival implies not only the emergence of a significant elderly population but also increased numbers of people with complex needs requiring support throughout adulthood.

Change in prevalence among non-white ethnic groups is likely to be greater than among white groups. The absolute numbers of people from ethnic minority populations with learning disabilities and the proportion of people with learning disabilities from ethnic minority populations are likely to increase throughout the adult age range as a result of the very young age structure of that population currently. Research has also found tentative evidence to suggest higher prevalence rates of learning disabilities amongst some minority ethnic groups, for example, South Asian groups. Higher prevalence rates in South Asian communities are most notable for children and young adults with severe learning disabilities. (It is unclear whether these higher rates are biologically or genetically linked with ethnicity, or are the result of other factors that have an impact upon minority ethnic groups, such as socio-economic status, poverty, access to health care or classification practices. For example, a study in Pakistan showed very high prevalence rates of learning disabilities in poor rural areas, compared with prevalence rates similar to North America and Northern Europe in wealthier middle class areas.

4. 5 Autistic Spectrum Disorders

In the early 1940s, Kanner, working in Baltimore, and Asperger, working in Vienna, separately published accounts of children with autism. There were some differences in their two descriptions but the two disorders, Autism and Asperger's syndrome, are now considered by many people to be part of the same autistic spectrum or continuum. They are also referred to as 'pervasive developmental disorders' that have an onset before 3 years of age.

The crucial symptoms for autism are now considered to be:

- Absence or impairment of social relationships
- Delayed and abnormal language and imagination
- Narrow, rigid, repetitive activities and interests.

This is known as the 'triad' of impairments and must be present in all those diagnosed with autism, though levels of ability may vary, (about 20-25% of children with autism have a non-verbal IQ in the normal range). Asperger's syndrome is usually only diagnosed when a child (or adult) has a social impairment, very limited and rigid interests and rituals, an IQ in the normal range, and no significant delay in early language (though there may be severe impairments in the social aspects of language). Technically, then, people with Asperger's syndrome do not have learning disabilities. They may, however, sometimes receive learning disability services because their impairments are not well understood elsewhere.

Early studies reported a prevalence of four or five children in every 10,000 with classical autism. Later studies tended to find somewhat higher figures (for example, about 10 per 10,000). A recent review concluded that the median prevalence for autism was 5.2 per 10,000 and acknowledged that prevalence rates reported in later studies were somewhat raised (median 7.2 per 10,000 in studies after 1989).

Very few of these studies have attempted to cover the whole autistic spectrum. The prevalence of all spectrum disorders in children with learning disabilities has been reported to be about 20 children per 10,000.

All prevalence studies have shown a greater number of boys than girls with autistic spectrum disorders (the male: female ratio being about 3:1 or 4:1 on average, with an even greater number of boys (6:1) among individuals with an IQ in the normal range.

Section 5

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INDIVIDUAL PLANNING (PERSON-CENTRED PLANNING)

Good quality service support should reflect individual needs, goals and preferences. The failure to individualise service design tends to result in the provision of relatively similar forms of service provision, which may not be capable of adapting sufficiently to individual difference. By concentrating on the needs of individuals, individual planning should support greater service innovation and inform the strategic planning process.

Evidence shows that only a minority of people had the opportunity for their needs to be assessed and service supports to be developed through a process of Individual Planning. The 1998 Conference report suggested that plans were not always comprehensive in scope or sufficiently multi-disciplinary and multi-agency; and that individuals were not being fully and properly consulted about their needs, goals and preferences.

There are a number of factors that may have contributed to the above problems. Plans may not integrate social support, health, education and other perspectives if commitment to the process is not genuinely multi-agency and involving all stakeholder interests appropriate to the individual's age. Models of best practice were not disseminated across Wales. Given available resources, the intensive nature of individual planning was in competition with the goal of widespread implementation. These problems may reflect the absence of a strategic, national plan to meet the resource costs of comprehensive implementation and overcome the complexities of multi-agency co-ordination involved at different times of the service user's life cycle.

Unless real efforts are made to place the user at the centre of planning, there can easily be an unequal relationship between the care planner/manager and the individual. Understanding the views of people with limited language becomes more difficult with greater severity of learning disability. Sufficient resources (time and expertise) are not always given/available for intensive attempts to be made to understand individual wishes. In addition, resources are required to establish a range of advocacy services capable of representing the best interests of individuals who cannot represent themselves personally because of their disability.

Individuals with complex needs require agencies to work closely together to prepare a single individual plan. Concerns about the 'shunting' of costs between health and social care agencies has hindered agreeing individual plans and flexibly responding to need. The development of eligibility criteria to operationalise separate health and social care responsibilities has not been helpful in the development of joint commissioning and delivery of services. Protocols for joint commissioning and joint working are required. Arrangements for pooling resources between agencies are required to remove the financial incentives accompanying the redefinition of responsibility from one agency to another

The extent to which the individual gives informed consent for the sharing of information contained in the individual plan is a difficult area. First, there is the question of deciding who is capable of giving informed consent. Second, the plan cannot meet its service co-ordinating objectives if it is not shared between the agency professionals whose action is required to implement the plan. Third, family and advocates who may in practice represent the individual's interests need to see the plan to check that it contains what was agreed.

SERVICE PRINCIPLE	SERVICE RESPONSE
Each person with a learning disability has a right to an individual plan to co-ordinate care from early childhood throughout life and properly reflect his or her needs, goals and preferences. There should be consistency across Wales in terms of the availability of individual planning.	The resource costs of comprehensive implementation need to be calculated and a strategic investment plan drawn up.
Individual planning should provide a single, comprehensive review of need for each person to which all agencies are party.	Agency responsibilities and commitments at different stages of a person's life need to be defined. Consideration should be given to relevant agencies pooling funding to provide a single multi-agency individual planning mechanism.
There should be consistency across Wales in terms of the quality of individual planning.	<p>Best practice standards and criteria need to be agreed to provide the basis for a uniform approach. Standards to include:</p> <ol style="list-style-type: none"> 1. access to named key worker and named care manager 2. use of specialist assessors as necessary 3. use of a person-centred approach 4. minimum review frequency 5. eligibility criteria which interface with other service sectors (NB some people outside of usual eligibility criteria for specialist learning disability services may need support in some areas of life e.g., employment, mental health needs) 6. coverage of quality of life concerns: <ol style="list-style-type: none"> i) Health/appearance (my treatment) ii) Accommodation (my home, my family/fellow householders) iii) Support needs (my helpers) iv) Pre-school provision, schooling, college, work or retirement provision (my career, my occupation) v) Education (my skills, my independence) vi) Domestic/Community lifestyle (my self-care, my household arrangements, my use of community amenities)

	<p>vii) Leisure (my interests, my hobbies, my social activities)</p> <p>viii) Relationships (my family, my friends)</p>
SERVICE PRINCIPLE	SERVICE RESPONSE
	<p>ix) Development (my skills, my independence, my autonomy)</p> <p>x) Finance/security (my income/benefits, my legal status/rights)</p> <p>xi) Emotional wellbeing (my happiness, my self-image)</p>
Each service user must be enabled to play an integral part in the planning of their own lives and have the opportunity to state his or her wishes and preferences and have these fully taken into account.	Guidelines and training should be available to people with learning disabilities about individual planning to help them state preferences and formulate decisions. Attention should be given to the ways which people with limited communication skills can express preferences in a way, which will inform individual decision-making.
Where the person's learning disability inhibits understanding of the issues involved in decision-making, individuals should be represented by people who can represent their best interests.	<p>Individuals may be represented by their next-of-kin.</p> <p>Access to a range of advocacy services should also be available (see the Advocacy section).</p>
Individual planning should provide a future-planning perspective that anticipates future needs, forestalls crises and allows individuals, relatives and service agencies to plan well in advance, particularly at times of transition. This should set the occasion for continuity of service arrangements as individuals move from the care of one agency to another	Individual plans should reflect realistic time perspectives (for example, over the next five-years). Special attention should be given to transition planning (see Transition Planning section).
Individual care plans should have an agreed and regular review process	Standards should be set for the frequency of review within best practice guidance (see above). Normally, such review must be undertaken annually, although there may be circumstances when it is necessary for them to be more frequent. Each individual plan should specify a review date and plans should be presented in such a way that outcomes can be evaluated.
Information protection must be consistent with statutory requirements and relevant guidance	Guidelines and protocols are required about the sharing of information within the standards and criteria for best practice recommended above.

SERVICE PRINCIPLE	SERVICE RESPONSE
Individual planning and care management should take into account the costs of service provision in order to ensure best value is being provided.	The development of service unit costings is required to enable care managers to identify cost-effective packages to meet support arrangements generated by individual planning.
Carers are entitled to separate assessment of needs under the Carers (Recognition and Services) Act 1995. Implementation of the Carers and Disabled Children Act 2000 will entitle carers to services in their own right.	Separate but parallel planning mechanisms are required for carers. Best practice standards and criteria are required for carer needs assessments (see similar item above in relation to individual planning for cared for individuals).
The information obtained from individual planning should inform the strategic planning process.	Reliable and relevant information should be systematically abstracted from individual plans to inform strategic service development.

INFORMATION PROVISION

The provision of information empowers users and carers to make informed decisions, access services and exercise their rights. Currently, the provision of information lacks consistency and is not always available in a co-ordinated way or accessible format.

Individual agencies and organisations will be aware of the barriers to the free exchange of information and urgent attention will have to be given to this if partnership arrangements are to be productive and effective.

SERVICE PRINCIPLE	SERVICE RESPONSE
Service users and carers should have good quality and accessible information on the help and support available to them and their rights to participation in strategic and person centred planning.	<p>Organisations should ensure that there is accessible information on the full range of services and facilities available. This information should be relevant, clear, timely and produced in a range of formats to ensure the most widespread and effective communication with potential audiences. Authorities should consider how the range of information can be made available in a co-ordinated way.</p> <p>Authorities should publicise the rights of users and carers to participate in an informed way in the services planning systems/processes.</p>

ADVOCACY

Better Wales.com emphasises the need to ensure that the voice of disadvantaged people and groups is heard and their views taken into account in policy decisions. The empowerment of individuals so that they play a full role in decisions surrounding and affecting their lives is an important aspect of the AWS.

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The 1994 AWS guidance specifies such need in relation to users, and parents or carers. The 1998 Conference report suggests that Local Authorities do not see advocacy as important with individuals being given very limited advocacy choice leading to their believing that they are not always being listened to or taken seriously.

It may be necessary for a person to make extensive use of advocacy services in order to assist their active participation in individual planning processes and to ensure that their views on their life are properly represented, understood and taken into account. In addition, clear and simple explanations of official decisions and policy are often best made by an independent advocate. This will be particularly the case where an individual has communication problems or perhaps belong to a minority ethnic group. These considerations apply equally to children with disabilities with or without supportive family. It should also be noted that parents and carers may often be in need of an advocacy service.

There are strong arguments in support of the independent funding of advocacy services.

SERVICE PRINCIPLE	SERVICE RESPONSE
A full range of independent advocacy services must be established to ensure that the views of vulnerable people can be listened to, understood and acted upon	<p>Independent advocacy services should be made available whenever a need has been identified for a vulnerable person to have independent representation of their views.</p> <p>Authorities should encourage the growth and use of a range of appropriately trained and regulated independent advocacy services.</p>

PARTNERSHIP IN PLANNING

Experience in many parts of Wales after the launch of the 1983 All Wales Strategy showed clearly that joint working between local authority departments, health organisations, voluntary organisations, and parents, carers and service users had significantly improved. Equal partners in the planning, development and monitoring of services, led to decisions which had common ownership, were better informed and were more sustainable.

The thrust towards effective joint working has been promoted in subsequent National Assembly guidance to authorities and reinforces the need for the participation of parents, carers and service users in the planning process.

Since local government reorganisation, it would appear that there are significant variations in the planning process arrangements for learning disability services. Effective planning arrangements will require fully developed, collaborative partnerships which entitle service users, parents and carers to make meaningful contributions into service provision and development.

SERVICE PRINCIPLE	SERVICE RESPONSE

All authorities must work closely with stakeholders to maintain a planning function for learning disability services which regularly appraises policies and the performance of existing services and develops new objectives and service patterns

Authorities must consider the breadth of stakeholder interests and develop procedures in consultation with interested parties for their participation in the planning systems/processes.

Local partnership planning should :

- Include user and carer views and perspectives and summarise the results of local consultations about needs for local services.
- Establish the core aims and long term strategic, financial and performance objectives for services.
- Decide service priorities for competing resources and set out the basis on which they have been determined
- Report on achievement against the performance criteria and objectives that have been set, incorporating user evaluations of services.

These arrangements must be considered in the context of any national and local strategic objectives and local joint planning initiatives.

Authorities should ensure that the reasonable costs of small voluntary user and carer group participating in the planning process are met through suitable arrangements.

CHILDREN AND FAMILIES

Better Wales sets out a vision of Wales as a place which:

- values its children and where young people want to live, work and enjoy a high quality of life; and which is
- committed to fostering its unique and diverse identity, and the benefits of bilingualism, while looking confidently outwards and welcoming new cultural influences.

It includes among its core values the statement that:

children and young people should be treated as valued members of the community, whose voices are heard and needs considered across the range of policy-making.

The principle that a child with a learning disability is a child first is central to the Children Act 1989, the National Assembly's 'Children First' programme and our report, The early years are an important period and present real opportunities to promote the development of a child and the ability of the family to provide a secure and nurturing environment. Skilled and sympathetic disclosure of disability and subsequent counselling for the family and effective early intervention for the child can help these aims.

From the beginning, the child and their family need to be at the centre of all decisions about their needs. This should enable families to be well informed and to feel in control of their lives. It follows that parents should be treated as equal partners in any planning processes.

The All Wales Strategy brought about many positive changes in the lives of people who have a learning disability in Wales. Research into the effectiveness of the Strategy, showed that many carers and professionals believed that the needs of children had been largely overlooked. In particular, people felt that educational provision remained mostly unaffected. However, there have been significant moves towards inclusion within educational policy. The Welsh Office

Green Paper 'BEST for Special Education' (October 1997) stated the desire for children with special educational needs to be educated in mainstream schools, wherever possible, and the UK Government promises in the forthcoming SEN and Disability Rights in Education Bill to introduce a new positive principle for inclusion.

The principle of inclusion must also extend to, and be embraced by those concerned with, the health care (which is addressed in the Health care section), local authority support and generic services provided for children, young people and their families.

Care and Support

SERVICE PRINCIPLE	SERVICE RESPONSE
Parents, carers and professionals must recognise that children and young people with special needs require care and support that promote health and well-being, protect from harm, minimise disadvantage and maximise potential.	The principle of inclusion must be applied by authorities in complying with regulations and statutory guidance when developing their guidance, policies, practices and procedures.
Parents and carers should be informed of the child's disability in a sensitive and sympathetic manner and have access to appropriate and timely counselling and information about the help and support that is available.	Authorities should ensure that all professionals involved in disclosure and counselling should have received training in line with best practice. Comprehensive information in an accessible form on help and support available should be provided when required. The aim must be for parents and carers to be kept fully and promptly informed of the child's diagnosis, prognosis and genetic implications.
Parents should be actively involved in the decision-making processes relating to their child.	The principles within the Individual Planning approach set out earlier should apply. Parents should be given the information and support that they need to participate effectively.
Children have a right to normal developmental experiences. This encompasses both equality of access to pre-school and later provision and opportunity for additional developmental input	Authorities should review the availability of (a) effective early intervention targeted at promoting the child's development and the prevention of challenging behaviour, and (b) ways by which they can support and encourage integration in generic pre-school and later provision. The review should then be followed by the preparation and implementation of an action plan.

Education

SERVICE PRINCIPLE	SERVICE RESPONSE

<p>The child should benefit from an education which enables him/her to develop their maximum potential, alongside their non-disabled peers.</p>	<p>Sufficient support staff should be provided to ensure that children with learning disabilities are included and that other children in the classroom are not disadvantaged.</p> <p>Funding arrangements for early years education should allow for a choice of providers and settings.</p> <p>All teacher training should include content on working with children with a learning disability.</p> <p>Existing teachers should receive in-service training on inclusion.</p> <p>Core competencies and qualifications should be identified for all teaching assistants.</p> <p>LEA's to publish information in their Education Strategic Plans about their policy on inclusion and the progress being made towards it.</p> <p>LEA's to monitor admissions of children with SEN into mainstream schools.</p>
<p>The child should not be discriminated against by the school of his/her choice.</p>	<p>Implementation of SEN and Disability Rights in Education Bill.</p> <p>Funding should be provided for physical adaptation to school buildings to enable inclusion.</p>
<p>The child should ordinarily access their local school unless their Individual Plan indicates clear benefits from attending a school further away.</p>	<p>Additional costs incurred by local schools to be built into fair funding formulae for schools.</p> <p>Out of area placements to be kept to a minimum and reviewed regularly.</p>

TRANSITION PLANNING

It is important to recognise that individuals will experience many important changes and phases during their life. One transitional period is that between the ages of 14 and 19 years old. Education legislation and guidance requires that a transition plan be drawn up. This plan may need to take into account that arrangements for education and training established during this period may extend until the person is 25 years old.

There are examples of good practice in respect of planning for individuals but this is not consistent across Wales and links between social services, education and health are often not effective. There needs to be recognition that time and resources have to be dedicated to transition planning if it is to be undertaken successfully. Consideration also needs to be given to how those involved in transition planning span the last years of schooling and the transfer to services for adults. The consequence of poor planning and ineffective co-ordination between agencies is inadequate provision of support and services. (It is anticipated that person-centred Individual Planning will become the established process for considering individual need and the appropriate delivery of support throughout the life span. At this time, such planning processes are not fully developed and therefore additional mechanisms are required to ensure that Transition Planning is undertaken effectively.)

There should be named agency and individual responsibility for Transition Planning for all young people of appropriate age to ensure that all relevant aspects of the person's life are properly considered.

SERVICE PRINCIPLE	SERVICE RESPONSE
Transition planning should achieve a smooth, seamless change from child-centred needs to adult-focused needs, involving comprehensive review across all relevant agencies	Education, social services, health, ELWa and Careers Services should develop a joint protocol for undertaking transition planning. This should include: nominated individual and agency co-ordination arrangements, resource implications and mechanisms for joint funding, sharing of information about need and timetable for the planning process. The protocol should also state that transition plans should be consistent with best practice standards and criteria that apply to individual planning (see Individual Planning section). Full account should be taken of other plans, which are made for some young people e.g. Care Plans and Pathway Plans for children who are looked after.

COMMUNITY LIVING

Better Wales.com establishes the target that by March 2003 at least 90% of those assessed, as needing community care should receive support to allow them to live at home.

Community living extends to all ages and means living with family, friends or independently and playing a full part in the society in which we all live. It cannot be promoted without recognising that it requires the will and resources to make it rewarding. It is not just a matter of accommodation standards, although these are important, but of the active promotion of independence, citizenship, relationships and lifestyles.

Social services, health, education, housing and provider organisations should be working together, in both planning terms and day-to-day provision, to make life, lifestyle and well being of an individual compare with those ordinarily available.

The achievement of community living requires a range of community services and supports to be available to and sensitive towards the needs of people with learning disabilities. Accommodation, for example, should reflect a range of individual choices and preferences, and arrangements should help rather than hinder community life and offer tenants and owners the same rights as are available to others regardless of disability.

Recognition should also be given to the fact that some individuals may need additional help to maintain an acceptable lifestyle in the community. This should be available from people who have received the appropriate level of instruction for the tasks they face and at an acceptable cost. It should, moreover, be flexible and available at times when it is most needed rather than when provider organisations can deliver. The Direct Payment Schemes may provide opportunities for care responsive to individual requirements to be made available.

The needs of those who provide informal care, whether as family members or concerned others, should also be recognised and appropriate arrangements for a variety of support, including respite, should be readily available.

There are also concerns about specific aspects of learning disability services. These mostly relate to those people who may find it more difficult to use ordinarily available facilities because of aspects of their disability. Older people, for example, may require more individualised approaches than has been the case in the past. Certainly this will be the position for those with complex and challenging needs but they too have the right to live in ordinary housing and enjoy local community life. In some situations special arrangements may be required to manage the possible risks that they pose to themselves and others.

There will be situations, particularly at times of crisis, where sudden, short or longer term interventions will be required and it is essential that the kind of resource to meet this need is readily available. Success will be seen as a return to community living.

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Ultimately, community living is about personal lifestyles and the networks of friendships, support arrangements and opportunities that are available to individuals. It is important to remember that understanding about how to provide effective service supports continues to develop and, therefore, achievement of community living will require constant innovation to ensure that lifestyles keep up with changing individual and social circumstances, new ways of looking at individual needs and how they can be best met.

SERVICE PRINCIPLE	SERVICE RESPONSE
All adults with a learning disability, including people with complex and challenging needs, should have access to housing in the community, independent of the family home. Nobody should live in hospital. Accommodation should be available to meet a range of preferences and abilities of a size appropriate to the individual's choice, control, independence and privacy.	Social and health care authorities and housing providers should work together using their strategic planning processes to set out accommodation plans to achieve this principle in a way which reflects the demographics of the locality. This will include up-to-date estimates of the accommodation and support needs of those with complex and challenging needs. Individual planning should ensure that prospective tenants are consulted whenever possible about their housing arrangements, and that, over time, adaptations are made to reflect changing needs.
Housing arrangements should facilitate access to the local and wider community and offer tenants the chance to build a variety of personal relationships.	Consideration should be given to the neighbourhood and to access to community activities, shops and public transport when making accommodation arrangements.
Adults with learning disabilities living in community accommodation should have the same tenancy rights as other people.	Models of service should be developed which allow tenancies to be granted. This should provide equality of treatment with regard to the payment of Council tax, access to grants or any other issue.

Support Arrangements

SERVICE PRINCIPLE	SERVICE RESPONSE
People of all ages should receive support commensurate with their needs to enable them to live in their own homes or with their families. This will include people with complex or challenging needs.	An appropriate range of flexible support services should be available capable of responding to changing need. This will include positive respite care options such as respite at home, family placements and other age-appropriate provision.
The needs of individuals should be met by a skilled, well supervised, stable, motivated and well trained workforce. This will include enhanced competencies for working with people with complex and challenging needs.	The Workforce should be well managed, have the opportunity to progress. NVQ competencies should form the basis of staff development. Service contracts should be explicit in their expectations about support levels and quality of process and outcome. Best practice guidance should be available about exposure to risk.
Natural and informal support networks should be encouraged.	Support providers should explore every opportunity to develop personal and local networks to meet individual's support needs rather than relying exclusively on formal paid support

SERVICE PRINCIPLE	SERVICE RESPONSE
Supporting people to participate in leisure and community activities and to form personal relationships is as important as supporting other aspects of their lives and requires planning.	Service providers should assess individual preferences for leisure activities and plan how to teach and support people's effective participation in their chosen activities. Adoption of a 'natural supports' perspective and interventions such as 'Circles of Support' may broaden the range of personal relationships open to individuals. Friendships that people have formed with other people should be considered when planning transitions and included in individual plans. Existing ties can be positively nurtured and family involvement and the employment of local staff can assist with this. Statements to encourage this aspect of life should be written into service contracts.

Older People

SERVICE PRINCIPLE	SERVICE RESPONSE
The increasing longevity of people with greater and lesser disabilities must be recognised in the services provided.	Specific policies/strategies to meet the needs of older people with learning disability should be prepared both nationally and locally. They should reflect the chronological age differential between older people with learning disabilities and others and the non-normalising character of most generic services. They should include consideration of the resource implications of specialist services. Particular attention should be given to specific health risks, which may require specialist intervention.

Crisis Provision

SERVICE PRINCIPLE	SERVICE RESPONSE
Help must be available at times of crisis for people with ordinary, complex or challenging needs. Various events can precipitate these situations and a range of responses should be available to support the individual in either their own home or in an acceptable alternative location as need arises.	Such services should help the individual to remain in their own home and local community. Where this proves to be difficult or impossible to achieve, temporary residential provision and support may be appropriate and the individual should be helped to return to their home (or to a new long-term home) at the earliest opportunity.

EMPLOYMENT, FURTHER EDUCATION AND DAY ACTIVITIES

The chance to work or do other normal activities is a very reasonable expectation and should be available to all adults with a learning disability of working age. It is important to maximise individual potential and this can be helped by appropriate support which seeks to support the development of skills in every service user.

It is important to provide services and support processes that reflect need and respond to changing wishes. Opportunities for employment, further education and other meaningful activities must be considered within the person's Individual or Transition Plan (see earlier sections). This process will need to involve, as appropriate, the Community Consortia for Education and Training.

It is now generally agreed that traditional large day centres cannot provide the range of occupation required. Recent years have seen the development of a range of alternative day activities, such as community enterprises, social firms, increased attendance at colleges of further education, supported employment and the provision of more localised supports to access community activities. Whilst some change has taken place, traditional services are still common and further change is required. Moreover change has not been consistent across Wales and the resulting inequality of opportunity needs to be addressed.

Service models such as supported employment, which obtain jobs for people and then train them on site have been shown to be more effective for people with more severe learning disabilities and those with complex or challenging needs than traditional employment training. The progress made in helping people to obtain paid jobs through supported employment in the United States, and more recently in Wales, suggests that there is considerable potential to support a higher number of adults with learning disabilities in paid employment. However, the benefit system limits many people to part-time working and this reduces the benefit of the reform both in terms of lessening the need for alternative day services and the time taken to establish workplace skills. Supported employment requires well-trained job finders and job coaches and extra training may be required for effective support of people with complex and challenging needs.

There is still a small number of adults with learning disabilities in paid employment. While expansion of supported employment is an important goal, other routes to employment through, for example, social firms, and other meaningful day activities, such as community volunteering or individual occupation and training programmes, are still needed.

Vocational Training

SERVICE PRINCIPLE	SERVICE RESPONSE
<p>People with learning disability have a right to equal access to government training schemes and other educational opportunities, when such training would help their personal development and careers.</p>	<p>ELWa need to fund and regulate post 16 education and training so that people with learning disabilities can access a full range of opportunities alongside non-disabled people.</p> <p>Vocational training should reflect the available jobs market. Contracts with training providers should require training providers to develop their ability to provide individualised supports and amended courses to help people with learning disabilities progress on real work related courses. There should be appropriate records of achievement. Colleges should be encouraged to construct curricula and assessment so that individuals can build a portfolio of achievement (e.g., NPTC system).</p> <p>Comprehensive information, advice and counselling should be provided to all young people.</p> <p>Vocational training should normally result in individuals gaining a qualification recognised by employers. There need to be realistic entry criteria so that those accepted on courses have a reasonable expectation of reaching the required standards. Assessment of whether vocational training would be a productive route for people to follow should be part of their Individual or Transition Planning. People who do not reach entry criteria are probably better served by place and train approaches to gaining paid employment (i.e., supported employment).</p> <p>Support to gain employment is required for people leaving vocational courses. Determining the nature of this support should be part of their Individual or Transition Planning.</p>

Adult Education and Lifelong Learning

SERVICE PRINCIPLE	SERVICE RESPONSE
People with learning disabilities have a right to adult education and lifelong learning which contributes to their own development.	<p>Opportunities should be available throughout life, based on assessed need identified in the Individual Plan. Each person should have a learning portfolio, linked to their Individual Plan.</p> <p>Education should be provided within integrated classes not just in integrated settings. College staff need to have an opportunity to upgrade their skills and knowledge for working with people with learning disability. Support to the individual should be identified and provided. ELWa should monitor all post 16 education and training provision to ensure that it promotes the inclusion of people with learning disabilities and require providers to take action.</p>

Supported Employment

SERVICE PRINCIPLE	SERVICE RESPONSE
People with learning disabilities require systematic training and support to enable them to gain employment in real workplaces.	<p>Social services, education and employment services should use their strategic planning processes to increase the number of supported employment services in Wales and the number of people supported in paid employment by them. There should be good links between employers, supported employment services and both social care day services and mainstream employment services so that supported employment can provide a bridge to the workplace for people moving out of traditional day services and those graduating from schools, colleges or other forms of vocational training.</p>

Other Constructive Occupation

SERVICE PRINCIPLE	SERVICE RESPONSE

Outside of open employment and engagement in further education, people with learning disabilities have a right to day services, which provide them with meaningful and rewarding activities, which reflect their interests and develop their confidence and skills.

Authorities should use their strategic planning processes to ensure that a range of options are available in local communities which are collectively sufficient to meet need. Options to include: social firms, community enterprises, local community bases, programmes of individual community-based activity, involvement in civic works and voluntary activity, and retirement schemes. Consideration should be given to preventing unnecessary travel thereby promoting people's participation in their local communities.

Appropriate support may be provided as part of the service (e.g., within a social firm) or as an outreach programme from a local base (e.g., to a programme of community-based activity or voluntary placement).

Day activities should reflect people's interests and ambitions. They need to link in with other leisure, social and educational activities in people's lives. Co-ordination and forward planning should be achieved through Individual Planning.

Voluntary placements should be provided as something positive in their own right, not as a simpler alternative to supporting a person in paid work. People should be linked to a mainstream volunteering scheme wherever possible.

Services for People with Complex or Challenging Needs

SERVICE PRINCIPLE	SERVICE RESPONSE
People with complex or challenging needs should be included in the options available to other people with learning disabilities.	<p>Authorities must systematically review the range of options available to people with complex or challenging needs. In so doing, authorities should ensure that there is a sufficiently skilled workforce, professional input and enhanced support that may include specialist equipment and environmental adaptations to meet peoples needs.</p> <p>Authorities must work effectively together to end any dichotomy between 'health care' and 'social care' responsibilities (see the Severe Challenging Behaviour section).</p>

GENERAL HEALTH NEEDS

There is strong evidence that people with learning disabilities have poorer general health and more specific health needs than the general population. The Health Evidence Bulletin-Wales indicates that there is increased illness in a number of areas, such as problems with hearing and eyesight, psychiatric and behavioural difficulties, epilepsy, thyroid disorders, heart disorders and dental problems. Specific health needs may also arise from some of the known causes of learning disability.

However, despite this increased need there is evidence that people with learning disabilities do not always receive the health provision required. There may be a lack of recognition of common and treatable medical conditions, particularly if the individual has difficulty in communicating symptoms, and carers lack training in the identification of health problems.

Problems in providing adequate health care may arise from:

- a. lack of accessible information about health promotion,
- b. varied attitudes of professionals in primary care,
- c. inadequate training related to the needs of people with learning disabilities and difficulties in communication, judging capacity and consent, and
- d. difficulties in accessing services that may be available.

Regular health checks have been shown to assist in identifying unmet need and requirements for action to address health problems.

SERVICE PRINCIPLE	SERVICE RESPONSE
<p>People with learning disability of all ages have a right to similar good health as other people.</p>	<p>People with learning disability should have information in an accessible form to make choices about exercise, diet, alcohol and cigarette consumption, level of activity or exercise, oral health and dental care, substance misuse and sexuality. The individual plan should specify responsibilities and actions to meet agreed goals in these areas. Training of carers should include the promotion of healthy life styles, the recognition of symptoms of ill health or dental caries, and the recognition that medical or dental intervention may be required.</p>
<p>People with learning disability of all ages should have their general health needs met by primary health care services and equality of access to secondary and specialist health provision as appropriate.</p>	<p>Each GP practice should develop a Learning Disability database, to allow the practice to identify and target health interventions and health promotions accurately.</p> <p>All practices should produce clear policies on how people with learning disabilities will be supported to access their services. These should recognise that longer consultation times may be appropriate.</p> <p>Each individual should have regular health checks carried out by their Primary Healthcare Team. These checks should include regular reviews of prescribed medication. Various professionals may contribute to this care including GPs, practice nurses, community nurses and Health Visitors. They should be appropriately trained and working within the context of agreed, evidence based protocols e. g., the Cardiff Health Checks. There should be a system for ensuring follow-up action is undertaken after the health check.</p> <p>All people with a learning disability should be registered with a GDP who should be able to access specialist support from the community dental services and specialist hospital provision (including emergency dental treatment where needed).</p> <p>Health Authorities should require all Health Care Trusts to develop clear policies on how individuals with learning disabilities of all ages will be supported to access their services, including effective speech and other therapies and psychology services.</p> <p>Individually held personal health records should improve communication between relevant health care providers. Pilots should be set up to assess their effectiveness.</p>

SERVICE PRINCIPLE	SERVICE RESPONSE
People with learning disability have a right to expect treatment from health care workers who have received adequate training in the recognition and provision of appropriate health care to people with a learning disability.	Curricula/programmes for all health care professionals must include training in learning disability issues, including special health care problems, discrimination, communication, capacity and consent.
Aids to daily living and adaptations to premises and property, which contribute to the development and independence of individuals, must be available to them and their carers.	Health, housing and social services authorities should develop joint protocols for the assessment and where appropriate provision of aids to daily living and adaptations to ensure an accountable and effective response is made to requests.
Young people and adults should be able to access confidential advice and information about personal relationships and development.	Clear policies, curriculum coherence and co-ordination between agencies should ensure that appropriate advice is available to individuals about personal relationships and sexuality. Information and advice should be made available to carers about the policies that are in force.
Skilled specialist help should be available to diagnose and, if required, manage and provide appropriate support for particular conditions, such as autistic spectrum disorders, to promote inclusion.	The specialist nature of these disorders should not prevent individuals having access to those resources which will enable them to remain in their own homes and communities.

SERVICE PRINCIPLE	SERVICE RESPONSE

People with a learning disability who have acute mental health needs should be able to access their local acute mental health services.

Acute mental health services should provide the same level and quality of service for all, regardless of whether they have a learning disability.

Active efforts should be made to provide additional training for nursing and medical staff in acute mental health services concerning the needs of people with learning disabilities.

Local community learning disability teams should retain contact with their clients during periods when they are admitted to acute mental health units. Local community learning disability teams and their mental health colleagues should work collaboratively and learning disability teams should provide advice and support if and when admission to acute care is needed.

There should be no decommissioning of existing specialist services before adequate and appropriate mental health services are established.

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COMPLEX HEALTH NEEDS

Some people with learning disabilities have complex health care needs due to the co-occurrence of physical disabilities, hearing/eyesight problems, epilepsy, chest problems, swallowing problems, and other chronic medical conditions. Advances in medical technology and care may mean that this group is growing in number.

Particular specialist arrangements may be required for people with complex health needs in order that their needs are met effectively and safely whilst still enabling the individuals to enjoy an ordinary life in their local communities.

The growing recognition by all organisations of the requirement to address this range of needs for increasing numbers of people is very important, Joint working in terms of service provision and personnel training will be essential. Well-trained and supported carers (both family and paid carers) can be taught to undertake specific clinical procedures safely. Individual clinical risk assessments should be done and regularly reviewed on a case-by-case basis.

SERVICE PRINCIPLE	SERVICE RESPONSE

People with learning disabilities of all ages who have complex health needs have a right to an ordinary life and to have their needs met at home in their local community.

Childcare teams and community learning disability teams for adults should provide a link between the home and primary care and specialist services. Teams should have a mix of staff skills, and include all relevant clinical disciplines.

Team members should develop the skills of carers by, as well as training them when specific procedures are required, providing them with regular consultancy and support.

Paediatric and learning disability services should review and strengthen their recruitment and retention strategies to ensure that specialist multi-disciplinary skills are available within the community.

Workforce planning should be sensitive to the need to train sufficient staff in the various clinical professions to meet the staffing needs of teams.

Standard protocols should be produced that clarify standards, responsibilities and accountability concerning the administration of clinical procedures by unqualified staff and family carers. These policies should include specific recommendations concerning administration of intrusive clinical procedures

SEVERE CHALLENGING BEHAVIOUR

Some 12% to 17% of people with learning disabilities show challenging behaviour and of those 40% to 60% will show more severe problems. This may include the committing of criminal offences. The critical issues concerning such people focus on how best to meet their needs effectively and safely whilst enabling the individuals to enjoy an ordinary life in their local communities and ensuring appropriate provision for those people who are detained under civil or criminal Sections of the Mental Health Act (1983).

In considering the needs of this group, the All Wales Advisory Panel report "Challenges and Responses" (1991) advised that provision should be developed to enable such individuals to live in ordinary housing, use local community facilities and wherever possible, participate in a stimulating and enjoyable day occupation preferably in an integrated setting, and thus have a genuine presence in their community. The Advisory group support this approach. This is reflected in the Community Living and Work and Day Services sections.

In addition to the regular social and health care services that people with learning disabilities require, those who have challenging needs also require specialist input:

- Early assessment, advice and support from professionals who have expertise in the analysis and design of intervention procedures for people with challenging behaviour. This can be provided from specialist challenging behaviour support teams or from community learning disability team professionals. The purpose of their work is to reduce the challenging behaviour, design management strategies, help carers to develop coping skills, and develop a plan to promote the quality of life and community participation of the people concerned. Much of their work involves providing

consultancy, training and support to regular carers and service providers.

- At times of acute crisis, regular service provision needs to be improved with the aim that people remain in their homes and local communities. Where this proves to be impossible to achieve, temporary alternative accommodation and residential support may be needed until they can return home or go to a new long term home (see item on Crisis Provision in Community Living section).

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Currently, there is scarce provision for people detained under the Mental Health Act particularly if there is a need for long term treatment or management for mental impairment or severe mental impairment. Some people have been transferred to hospitals or services in England and this has created difficulties for family to maintain contact.

There is, however, a difference of opinion concerning whether the provision of accommodation, residential support, respite services and day services for people with such behaviour is considered to be "social care" (and be commissioned and funded by local authority social services departments) or "health care" (and be commissioned and funded by health authorities). The "health care" - "social care" split has proved to be a barrier to progress in recent years and continues to pose problems in assessing and categorising people. A system of genuine joint commissioning and "pooling" of resources for people with severe challenging behaviour could overcome these difficulties.

SERVICE PRINCIPLE	SERVICE RESPONSE
People with learning disabilities who present challenging behaviour should receive care and treatment appropriate to their needs as close as possible to their home, irrespective of the severity of the level of challenge.	Authorities in each area of Wales should ensure that there is access to staff with specialist expertise in the analysis of challenging behaviour who have a remit to provide a pro-active assessment, advice and support service. This service can be provided from specialist resource teams or from individual professionals in local community learning disability teams. The aim is to enhance the capacity of regular carers and service providers to meet the needs of people with severe challenging behaviour through the training and support provided.
People who are detained under civil or criminal sections of the Mental Health Act (1983), should be placed as close as possible to their home location	<p>Out-of-area placements may still be the most viable means of providing for people with learning disabilities that require high or medium secure hospital accommodation because of their extremely low numbers.</p> <p>Sub-regional intensive rehabilitation units should be provided in Wales for people requiring low security (also in relatively low numbers). In deciding the size and distribution of such units across Wales, issues that need to be considered include:</p> <p>(a) average length of stay</p> <p>(b) the need to build a 'critical mass' of clinical expertise</p>

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(c) the need to develop local follow up provision. Planning arrangements should recognise the possibility for people to step down from low security provision to enhanced community living schemes.

Clear co ordination links should be established in each area of Wales between the judicial, probation, health and social services in respect of individuals with a learning disability who have offended and are likely to be subject to the requirements of the courts and/or the Mental Health Act.

MEMBERSHIP OF THE LEARNING DISABILITY ADVISORY GROUP (WALES)

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Howard Sinclair, Mencap in Wales

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Dr Sean O'Reilly, GP

Dr Peter Woods, Welsh Clinical Psychologists Advisory Group

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A SUMMARY

The number of people with severe learning disability increased significantly between 1991 and 1998. Official sources indicate that these trends will be sustained over the first two decades of the 21st Century. There is also the beginnings of a substantial group of older people with severe learning disability. Increases in numbers, increases in expectations and increases in aspirations require a new approach to the provision of effective and efficient services to people with learning disabilities.

The draft service framework prepared by the Learning Disability Advisory Group sets out the vision and guidelines, principles, the policy context, priorities, performance indicators and an action plan to ensure the highest standards of service to this growing number of people. It provides guidance to authorities and organisations who have responsibilities to secure the social inclusion of people with learning disabilities into all aspects of life and society in Wales and to provide the support to allow them to take their place in their communities.

THE VISION FOR SERVICES IN 2010

The Advisory Group believes that the principled service development initiated by the 1983 All Wales Strategy (AWS) should continue. By 2010 services for people with learning disabilities will be more accessible, comprehensive and person-centred than ever before. They will be more responsive to individual preferences, and reflect a greater commitment to partnership-in-provision, workforce training and best value.

POLICY CONTEXT

The vision for service and the standards of every day service provision mirror the policy context of modern day Wales.

The National Assembly's vision for Wales is set out in Better Wales. The present proposals are consistent with this report as well as the strategic planning arrangements the National Assembly for Wales is putting in place for Social Services, Health, the Special Educational Needs programme, the Carers Strategy and the Supporting People proposals. Moreover, it includes the necessity for people living in long stay learning disability hospitals and other inappropriate accommodation to have been resettled into the community.

PROGRESS AND CHALLENGES

When launched in 1983, the AWS was a far sighted policy which progressively gained popular support among people with learning disabilities, their families and carers, professionals and service authorities. Understanding about how to plan and implement effective service supports has developed since that time but the vision and strategic direction it set remain widely

endorsed. It provides a frame of reference against which the progress of the past and the challenges of the future can be measured.

Funding The level of investment promised by the AWS in its first 10 years was delivered. Since 1994, the central funding of strategic development of services has continued in a more limited way to progress hospital resettlement. Despite increases in the resettlement grant allocation, the proportion of personal social services expenditure on people with learning disabilities has remained almost constant since 1994.

Supported Accommodation Wales has made great progress in reforming the nature of residential services. In contrast to what existed in 1983, available services are smaller in scale, within ordinary housing stock, and more local to the communities which they serve. However, while the quality of provision has improved, no progress has been made in extending service availability. Wales has a low rate of residential service provision in comparison to other countries of the UK, much below policy targets set in 1971 and 1983.

Family-support The growth of respite and family aide services was a high priority of the AWS and progress has been made. However, more needs to be done.

Day Services for Adults In line with AWS recommendations, there is now a greater variety in day provision and less reliance on large day centres. However, reform of the nature of existing services is not complete and there has been only limited expansion of service availability. Continuing reform and extending service availability now need to go hand in hand.

Expanding access to supported employment services is a particular priority. However, current welfare benefit arrangements lessen the cost effectiveness and potential impact of supported employment.

Greater survival is seeing the beginnings of a significant population of people with severe learning disabilities of retirement age and the need for appropriate support services.

Individual (person-centred) planning Individual Planning (IP) as a means of service co-ordination and review grew in Wales after 1983 but was only ever available to a minority of service users. Care assessment introduced by the NHS and Community Care Act has been viewed as a return to a resource rather than needs-led approach to planning. While policy reference to some form of IP has been long-standing, realistic assessment of the resources required to instigate and sustain such a system of planning has never been undertaken.

Joint planning and family and user consultation In establishing the social services department as lead agency, Wales has achieved a more wholehearted transition from health to local authority commissioning of social care services than elsewhere in Britain. The AWS saw the development of a distinctive level

of joint agency collaboration and consumer representation in planning. However, reforms of recent years have not helped to further this and some good practice may have weakened. Advocacy has become established but is widely regarded as insufficient to meet need.

Pattern of provision It is clear that service development has not been evenly distributed across Wales. Current variation in local authority expenditure on learning disability services reflects prior institutional service concentrations.

Improving service quality It is now evident that resettlement from hospital or hostel accommodation to supported community housing leads to quality of life gains, moving from traditional day services to supported employment results in financial gains, more constructive activity and greater social integration, and also that the growth in domiciliary and respite care services has been deeply appreciated by family carers and led to improvements in their quality of life.

Service costs and quality It is also clear that quality of outcome and costs vary considerably across outwardly similar services, and that quality and costs are only weakly related to each other. Differences in what staff actually do seem to be the key to differences in quality.

SETTING SERVICE PRIORITIES AND TARGETS

The Advisory Group recommends that local authority elected members, members of Health Boards and Local Health Groups and senior managers in statutory and other organisations should promote and introduce policies to achieve the priorities and targets set out in this report as speedily and effectively as possible. The Report sets out 17 priorities for action by the National Assembly and others. These are not ranked priorities as all must be progressed in parallel. Each has an associated target and timescale. The National Assembly should:

1. *Policy Direction* - reaffirm its commitment to develop the means to extend to all people with learning disabilities in Wales the opportunity to lead a life consistent with the AWS and this report

Target - By Spring 2002, all authorities will have reviewed their services against the 'Service Principles' and 'Service Responses' set out in the SERVICE FRAMEWORK Section of this summary and Section 5 of the main report

2. *Funding* - consider introducing a structured investment programme to increase and develop service availability in line with this report

Target - By July 2002, all authorities will have prepared Health and Social Care Plans which include costed 5 year projections of needs, targets and service developments for people with learning disabilities

3. *Completion of Existing Programmes of Reform* - review its commitment to achieve the closure of long stay hospitals and set a new target date for completion of 2006 or preferably earlier; and extend the scope of resettlement to include other inappropriate accommodation

Target - By 2006, all long term hospitals should be closed following completion of resettlement and by 2010 other inappropriate accommodation should be phased out

4. *Individual Planning* - confirm that person centred planning is fundamental to addressing individual needs and aspirations and that the cornerstone to their conduct should be multi-disciplinary and multi-agency Community Learning Disability Teams; any additional resource requirements should be considered within the National Assembly's larger investment programme

Target - By 2003/2004, all people with a learning disability will have an individual person-centred plan, normally reviewed annually

5. *Independent Assessment of the Needs of Carers* - invite the Carers Strategy Review Panel to consider best practice standards, training requirements and resource implications of separately assessing carers needs and to respond appropriately within its National Carers Strategy

Target – By 2001/2002 independent carers assessments will be available as of right

6. Information - commission research to identify best practice in respect of the collection, provision, sharing and dissemination of information; and consider what information could be appropriately provided on a national level across Wales

Targets – By 2002/2003, (i) all Health and Social Care Plans and Annual Statements/Reviews for services for all people with learning disabilities will include the programme of public information about services and service developments, (ii) arrangements will have been made to ensure local and national information is widely available to all people with learning disabilities, their parents and carers using all appropriate formats

7. Advocacy - evaluate how a centrally funded advocacy service can be developed and regulated on a national basis; these services should include citizen advocacy, self-advocacy and paid advocacy; any evaluation should take full account of the UK Government's response to the advocacy section of the Disability Rights Task Force report

Target – By 2002/2003, the National Assembly will have completed its evaluation and be consulting on proposals to introduce a national centrally funded advocacy service

8. Partnership in Planning - reaffirm the lead role of the local authority Social Services function; make available further resources to facilitate implementation of the increased flexibilities under the Health Act 1999; ensure that national guidance requires authorities to constructively include users, carers and others in the planning and development of services; facilitate the pooling of resources between agencies to remove the financial incentive accompanying the redefinition of responsibility from one agency to another; introduce a financial and management information framework with standard definitions for authorities to collect, collate and distribute data on capacity, usage and expenditure on all learning disability services

In support of this, agencies should agree protocols for joint working

Target – By 2003/2004, authorities will have published plans to improve the joint working of health, social services and other agencies including the use of pooled budgets, integrated provision and lead commissioning of services and facilities

9. Children and Families - invite services and education bodies to review the availability of (i) effective early intervention targeted at promoting the child's development and the prevention of challenging behaviour, and (ii) effective ways of supporting and encouraging integration in general pre-school and later provision; and subsequently to develop an action plan to make effective services and supports generally available

Target – By 2003/2004, Children's Services Plans should promote equal opportunities and inclusion and indicate how local authorities and partner agencies propose to develop community based support strategies to enable younger people with disabilities to be included in mainstream activities as much as possible

10. Education - develop education and lifelong learning policies which encourage arrangements consistent with inclusion; provide resources to provide additional educational support to those with special needs; and ensure that all teachers and teaching assistants receive appropriate training to effectively support the learning and development of people with learning disabilities

Target – By 2004, to have significantly improved the quality of education for children with special needs by completing the three year action plan and the introduction of a new Special Educational Needs Code of Practice

11. Help in the Family Home - through its Carers Special Grant and other policies encourage authorities to make available a range and sufficient quantity of flexible support services and positive options for short term breaks

Target – By 2005, there should be a significant increase in the range and quantity of flexible support services and positive options for short term breaks

12. Support to Live Independently in the Community - make available additional resources to significantly increase the number of people who are able to access appropriate accommodation away from the family home

Target – By 2010, to have significantly increased the number of people who can realistically be expected to live independently with appropriate support irrespective of age and impairment – this will require at least an additional 1500 people with learning disabilities to be supported outside of the family home

13. Direct Payments - consider changing the existing arrangements to enable local authority services to be encompassed in the Direct Payments scheme

Target – By 2003, all local authorities are operating an appropriate direct payments scheme for people with learning disabilities.

14. People with Complex and Challenging Needs - ensure that authorities use their strategic planning processes to provide up-to-date estimates of the accommodation and support needs of people with complex and challenging needs, ensure carers are assisted to develop appropriate skills and have access to staff with specialist expertise who can assess complex needs and provide advice and support, and develop plans to increase the availability of intensive rehabilitation services so that people in need of 'low security' can be placed within Wales

Targets – By 2003, community facilities and intensive rehabilitation services to support people with complex or challenging needs must be an integral part of the reprovioning plans following the closure of existing long stay hospitals; By 2008, regional services should be available and the number of people placed outside of Wales reduced by 50%

15. Day Activities - set targets for the expansion of supported employment and supports for other socially integrative and educational opportunities; and discuss with the UK Government how social security impediments to paid employment can be removed

Target – By 2004/2005, to have opened up opportunities for all people with learning disabilities by encouraging lifelong learning opportunities and more flexible ways of formal and informal learning, and by increasing the access to quality careers advice and supported employment

16. Health - make resources available to enable every GP to adopt the proactive identification and health checking recommendations contained in this report

Target – By 2010, to have improved the health of people with learning disabilities and reduced any differences between rates of illness and mortality experienced by them and overall national rates

17. The Workforce – extend the qualification regime and targets to include all the social care workforce and set complementary targets for the training of the NHS workforce as part of its Human Resources Strategy

Targets – By 2005, (i) to have all social care managers and 50% of the social care workforce providing services to people with learning disabilities with a listed qualification, and (ii) the training of doctors, dentists, opticians, other NHS staff, housing and benefit agency staff, teachers and the police to include an element that helps them to have a better understanding of learning disability issues.

THE SERVICE FRAMEWORK

The service framework sets out the Service Principles and the recommended Service Responses as a guide to those who commission or provide services. Altogether there are nine areas covered: Individual Planning, Information Provision, Advocacy, Inclusion and Participation, Children and Families, Transitions, Community Living, Work and Day Services, and Health Care.

The main recommendations are summarised below:

Individual (Person-centred) Planning

Agency responsibilities and commitments at different stages of a person's life need to be defined.

Best practice standards and criteria need to be agreed to provide the basis for a uniform approach.

Guidelines and training should be available to people with learning disabilities to help them state preferences and formulate decisions.

Individuals may be represented by their next-of-kin. Access to a range of advocacy services should also be available.

Individual plans should reflect realistic time perspectives and standards should be set for the frequency of review within best practice guidance.

The development of service unit costings is required to enable care managers to identify cost effective packages to meet support arrangements.

Separate but parallel planning mechanisms are required for carers.

The resource costs of comprehensive implementation need to be calculated and a strategic investment plan drawn up.

Information Provision

Organisations should ensure that there is accessible information on the full range of services and facilities available.

Authorities should publicise the rights of users and carers to participate in planning.

Advocacy

Independent advocacy services should be made available whenever a need has been identified for a vulnerable person to have independent representation of their views.

Authorities should encourage the growth and use of a range of appropriately trained and regulated independent advocacy services.

Partnership in Planning

Authorities must consider the breadth of stakeholder interests and develop procedures in consultation with interested parties for their participation in planning.

Local partnership plans should include user and carer perspectives and summaries of consultations, establish core aims and strategic, financial and performance objectives, decide among competing priorities and report on achievements against objectives and on user evaluations of services.

Authorities should ensure that reasonable costs of user and carer group participation in planning are met.

Children and Families

The principle of inclusion must be applied by authorities in complying with regulations and statutory guidance when developing their guidance, policies, practices and procedures.

Authorities should ensure that all professionals involved in disclosure and counselling should have received training in line with best practice.

Parents should be given the information and support that they need to participate effectively in Individual Planning.

Authorities should review the availability of (i) effective early intervention targeted at promoting the child's development and the prevention of challenging behaviour, and (ii) ways by which they can support and encourage integration in generic pre-school and later provision. The review should then be followed by the preparation and implementation of an action plan.

Sufficient support staff should be provided to ensure that children with learning disabilities are included in mainstream educational classes and that other children in the classroom are not disadvantaged.

Existing teachers and teachers in training should receive training on inclusion and how to work with children with a learning disability.

Education Strategic Plans should state policy on inclusion and provide monitoring information on the placement of children with SEN in schools.

Funding should be provided for physical adaptation to school buildings to enable inclusion.

Transition Planning

Education, social services, health and the Careers Service should develop a joint protocol for undertaking transition planning in line with best practice standards and criteria that apply to individual planning.

Community Living

Social and health care authorities and housing providers should work together using their strategic planning processes to set out plans for all adults with a

learning disability, including people with complex and challenging needs, to have access to housing in the community, independent of the family home.

Consideration should be given to the nature of the neighbourhood and to access to community activities, shops and public transport when making accommodation arrangements.

Models of service should be developed which allow tenancies to be granted.

A range and sufficient quantity of flexible support services should be available capable of responding to changing need. This will include positive respite care options such as respite at home, family placements and other age-appropriate provision.

The workforce should be well-managed and competent and service contracts should be explicit in their expectations about support levels and quality of process and outcome.

Support providers should encourage natural and informal support networks.

Service providers should assess individual preferences for leisure activities and plan how to teach and support people's effective participation in their chosen activities.

Specific policies/strategies to meet the needs of older people with learning disability should be prepared both nationally and locally.

Help at times of crisis should be directed towards helping the individual to remain in their own home and local community.

Employment, Further Education and Day Activities

ELWa need to fund and regulate post 16 education and training so that people with learning disabilities can access a full range of vocational training opportunities alongside their non-disabled peers. Contracts with training providers should develop their ability to provide individualised supports and amended curricula to help people with learning disabilities progress on genuinely vocationally-related courses. There should be appropriate records of achievement and vocational training should be associated with an expectation of gaining a qualification recognised by employers.

Opportunities for adult education and lifelong learning should be available throughout life.

Social services, education and employment services should use their strategic planning processes to increase the number of supported employment services in Wales and the number of people supported in paid employment.

Authorities should use their strategic planning processes to ensure that a range of other day activity options are available in local communities which are collectively sufficient to meet need.

Authorities must systematically review the range of options available to people with complex or challenging needs.

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General Health Needs

People with learning disability should have information in an accessible form to make choices about exercise, diet, alcohol and cigarette consumption, level of

activity or exercise, oral health and dental care, substance misuse and sexuality.

Each GP practice should develop a Learning Disability database.

Each individual should have regular health checks and review of their medication.

All people with a learning disability should be registered with a GDP who should be able to access specialist support from the community dental services and specialist hospital provision

Trusts should develop clear policies on how individuals with learning disabilities of all ages will be supported to access their services

Curricula/programmes for all health care professionals must include training in learning disability issues.

Health, housing and social services authorities should develop joint protocols for the assessment and where appropriate provision of aids to daily living and adaptations to ensure an accountable and effective response is made to requests.

Clear policies, curriculum coherence and co-ordination between agencies should ensure that appropriate advice is available to individuals about personal relationships and sexuality. Information and advice should be made available to carers about the policies that are in force.

Complex Health Needs

Child care teams and community learning disability teams for adults should provide a link between the home and primary care and specialist services.

Team members should transmit their skills to carers.

Paediatric and learning disability services should review and strengthen their recruitment and retention strategies to ensure that specialist therapy skills are available within the community.

Workforce planning should be sensitive to the need to train sufficient staff.

Standard protocols should be produced that clarify standards, responsibilities and accountability concerning the administration of clinical procedures by unqualified staff and family carers.

Severe Challenging Behaviour

Authorities in each area of Wales should ensure that there is access to staff with specialist expertise in the analysis of challenging behaviour who have a remit to provide a pro-active assessment, advice and support service.

Out-of-area placements may still be the most viable means of providing for people with learning disabilities who require high or medium secure hospital accommodation.

Sub-regional intensive rehabilitation services should be provided in Wales for people requiring low security.

Clear co ordination links should be established in each area of Wales between the judicial, probation, health and social services in respect of individuals with

a learning disability who have offended and are likely to be subject to the requirements of the courts and/or the Mental Health Act.

Additional Mental Health Care Needs

Acute mental health services should provide the same level and quality of service for all, regardless of whether a person has a learning disability.

Active efforts should be made to provide additional training for nursing and medical staff in acute mental health units concerning the needs of people with learning disabilities.

Local community learning disability teams should retain contact with their clients during periods when they are admitted to acute mental health units.

Workforce Training

Authorities should take the resource implications of ensuring a properly trained workforce into account in their contracting arrangements.

The Training Support Programme qualification regime and targets should be extended to include all the social care workforce.

All social care managers should have a recognised qualification by 2005.

A minimum of 50% of the social care workforce should attain NVQ level 2 by 2005.

The Human Resource Strategy for the NHS in Wales should set complementary targets for the training of its workforce.

Authorities should enable service users to play an effective role in the design and delivery of training.

FINANCIAL IMPLICATIONS

A number of the Service Principles and Service Responses will be implemented through the everyday development of service provision but to meet the full range of aims and targets the Advisory Group believe that the National Assembly will need to make available at least an additional £20 million from 2003-04 rising to £40 million in 2004-05 and £60 million in 2005-06. These requirements are likely to continue to rise each year up to 2009-10. Only with such levels of investment particularly in the accommodation sector will the vision for services in 2010 be attained.

THE ACTION PLAN APPROACH

The Advisory Group consider the most effective way of responding to the priorities and other proposals in this report would be to adopt the Action Plan Approach. As a first step, authorities will be required to carry out an Audit of their services and identify their priorities for action. Once this has been done (by July 2002) additional resources can be made available as a central direct grant and as a ring fenced funding arrangement to health and education authorities to meet the individual priority areas identified in the Audits. A possible timetable for the first five years of the Action Plan is set out in the Report.