MUCKAMORE ABBEY HOSPITAL INQUIRY

SITTING AT CORN EXCHANGE, CATHEDRAL QUARTER, BELFAST

HEARD BEFORE THE INQUIRY PANEL

ON WEDNESDAY, 27TH SEPTEMBER 2023 - DAY 62

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Gwen Malone Stenography Services certify the following to be a verbatim transcript of their stenographic notes in the above-named action.

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THE INQUIRY RESUMED ON WEDNESDAY, 27TH SEPTEMBER 2023, AS FOLLOWS:

CHAIRPERSON: Good morning.

MS. TANG: Good morning Chair and Panel. This morning the Inquiry is going to hear the evidence from the mother of a former Muckamore patient. The witness will be addressed by her first name, which is Tara, and her late daughter Ashley was a patient at Muckamore for a time. 10:00

I should say, the witness is content for her and her daughter and her other family members first names to be used.

CHAIRPERSON: Fine. Okay. That makes it easier. 10:00

MS. TANG: Yeah. She has also confirmed that some photographs of her daughter Ashley that she provided as exhibits can be shown at the end. I will give you the opportunity to review those.

CHAIRPERSON: Thank you very much indeed. All right. 10:00

MS. TANG: So if there are no other issues we could call the witnesses.

CHAIRPERSON: And no Restriction Order?

MS. TANG: No Restriction Order, Chair. That's correct. 10:00

P114'S MOTHER, HAVING BEEN SWORN, WAS EXAMINED BY

MS. TANG AS FOLLOWS:

CHAIRPERSON: Good morning, and I gather it's all right to call you Tara?

A. It is, yes. 10:01

CHAIRPERSON: Thank you very much for coming to assist the Inquiry. And I'm sorry I didn't - I wasn't able to come and meet you outside, which I sometimes can do. I think the only problem for you is going to be keeping your voice up. You've got a very soft voice, so could 10:01 I just pull - if you pull the microphone a bit. That's it. It's important, because there's another room that is listening to this evidence and it is important everybody can hear what you say and we don't want you to have to repeat everything. 10:02

A. Okay.

CHAIRPERSON: Can I thank you very much for coming to help us and I will hand you over to Ms. Tang.

MS. TANG: Good morning again, Tara. Yes, you and I met a short time ago, just to remind you. I'm Shirley 10:02 Tang. I'm one of the barristers on the Inquiry. Thank you for providing your statement. I'm going to begin by reading key paragraphs of your statement, I'd like you just to listen to that and after I've done that I'll ask you just to confirm if you're happy to adopt 10:02 it as your evidence.

CHAIRPERSON: And you've got the statement in front of you to follow, if you want to.

A. Yes. Okay. Thanks.

MS. TANG: Thank you. So the statement is dated the 11th September 2023. You give your name and you confirm your connection with Muckamore is that:

"I am a relative of a patient who was at MAH. My daughter Ashley, now deceased, was a patient at MAH. The relevant time period that I can speak about is from early February 2013 to the 26th of November 2013. 10:03

My daughter Ashley was born in 1987 and passed away at Antrim Area Hospital on 26th November 2013 when she was 26 years old. Ashley was the eldest child from my first marriage. I was Ashley's sole carer from her very early childhood. 10:03

I met my second husband, James, when Ashley was nine years old and we had twin daughters. The twins were born in February 2004 when Ashley was around 17 years old. When Ashley was only a few weeks old she had epileptic episodes and as she got older she failed to meet the normal developmental milestones. I was advised by medical staff, I cannot recall who or when, that she has global developmental delay. Her motor skills were very limited, she cried a lot, and it was obvious to me as her mother that she had additional needs and a learning disability. Ashley was formally diagnosed with Angelman syndrome when she was approximately seven years old at the Royal Victoria Children's Hospital, Belfast. Angelman syndrome is a 10:03 10:04

genetic disorder. It causes delayed development, problems with speech and language and learning disability.

I was not able to work for a long time after Ashley's birth. There were no childcare facilities to deal with Ashley's needs and I was her sole carer. 10:04

Ashley had a very happy and sociable personality with an infectious laugh. She had limited speech, however she could communicate with her family non-verbally and we knew what she meant. Although Ashley was largely non-verbal she could say "mama" and "gaga". "Gaga" was for her twin sisters who she adored and they adored her. She would also say "bush" for the school bus." 10:04 10:05

You then go on in the next two paragraphs to speak about some of her interests.

I'm going to go down to paragraph 9. 10:05

"Ashley's condition meant that she had no idea of danger. Ashley could not manage day-to-day tasks independently and she relied on me for everything. For example, she could not make a cup of tea for herself. I attended to all of her personal care needs. She loved a bath and would only get out when I took the plug out and the water had drained away. 10:05

I cared for Ashley at home on my own until she was approximately nine years old, when I met my second husband. As I have no brothers or sisters I had very little family help other than my auntie and my granny. Auntie and granny had a lovely relationship with Ashley and we visited them often. We made a good team." 10:05

You then go on to describe some details of Ashley's schooling in the next two paragraphs. 10:06

Moving down to paragraph 13:

"Shortly before the twins were born in 2004, when I was about 30 weeks pregnant, I had a pregnancy health scare which required me to attend hospital. I was giving Ashley a bath and I had some bleeding afterwards. I was advised by the medical staff that I needed to rest until the birth of the twins. Managing Ashley's day-to-day needs was physically demanding and I could not do this in the late stages of my pregnancy. I followed the medical advice and placed Ashley in respite care in Ballymena. This was a very difficult decision to make, but I did not have any choice. 10:06 10:06

When the twins were born I knew that I could not manage Ashley's needs in addition to the newborn twins and, therefore, Ashley stayed in respite care from 2004 to 2005 when she was approximately 17 or 18 years old. Ashley was still under children's care at the time when 10:06

her social worker was Maureen Colemyer. I believe she has now retired."

You then go on in the following paragraphs to detail Ashley's time at a care home, and I'm going to move forward to paragraph 26, which is where you begin to speak about her time - leading up to her time in Muckamore. 10:07

At paragraph 26: 10:07

"Ashley's behaviour was her form of communication. She was non-verbal but could express her emotions through her behaviour. This was her way of communicating when she was upset and distressed in her care home. Her physical and mental state had deteriorated further whilst she was there. For example, she was previously always very responsive to me, however, Ashley had stopped engaging even with me. This was very upsetting. 10:07

I raised these growing concerns at a meeting with the nurse in charge at the time, her deputy and Ashley's social worker. I cannot recall their names. The nurse in charge told me that Ashley needed nursing care that they could not provide. She said that Ashley was too difficult to manage. She stated that Ashley should be..." 10:08

CHAIRPERSON: Sorry, just hold on a second. Is there a

problem?
SECRETARY: Yeah. There's no sound on the link.
CHAIRPERSON: I'm so sorry. Can you just stop, just pause for a second.
SECRETARY: We may need to rise for a second. 10:08
Apologies.
CHAIRPERSON: Can I just apologise to you particularly. These things do happen. But I can tell this isn't an easy experience for you, and so, it's extremely unfortunate. We will stop and then I'll ask 10:09
Ms. Tang to start again at the last paragraph. I'm very sorry. Just five minutes.
SECRETARY: You don't even need to rise. If you just give us like two minutes, but it'll be five minutes maximum. 10:09
CHAIRPERSON: Okay. That's better if we can. All right.

SHORT PAUSE

10:10
CHAIRPERSON: Is it working? Okay. So I think - does that mean that the feed wasn't going through on Zoom or to Room B?
SECRETARY: I'm not sure. I think Room B was okay. It was just... 10:10
CHAIRPERSON: Just the Zoom. Can I just apologise to everybody who has now joined us on Zoom and apparently couldn't hear. The transcript of this evidence will be available in due course, but it's not fair to the

witness to ask her for the whole thing to be repeated. We've just got to paragraph 26 of the statement, and perhaps we can start again at that. Thank you.

MS. TANG: Yes, of course. So at the start of paragraph 26, which is on page 8 of the statement. 10:11

CHAIRPERSON: All right.

MS. TANG:

"Ashley's behaviour was her form of communication. She was non-verbal but could express her emotions through 10:11 her behaviour. This was her way of communicating that she was upset and distressed in her care home. Her physical and mental stated had deteriorated further whilst she was in the care home. For example, she was previously always very responsive to me, however, 10:11 Ashley stopped engaging even with me. This was very upsetting.

I raised these growing concerns at a meeting with the nurse in charge at the time, her deputy, and Ashley's 10:11 social worker. I cannot recall their names. The nurse in charge told me that Ashley needed nursing care that they could not provide. She said that Ashley was too difficult to manage. She stated that Ashley should be sectioned under the Mental Health Act and taken to 10:12 hospital. She said that her medication could be stripped back and they could investigate the cause of why Ashley was so distressed. I was very scared about Ashley being sectioned as her rights were going to be

taken away. I thought that once she was sectioned and admitted to hospital I could not take her out of it until the doctors said she was fit to go. I really wanted Ashley to get the help she needed but I did not want her to be sectioned. I asked if I could admit Ashley as a voluntary patient to get the care that she needed. I did not understand why sectioning her was necessary. I was told by the nurse in charge (I cannot recall her name) that in order to deal with Ashley as an emergency case she had to be sectioned. I tried to think of this as perhaps a lifeline. I would have agreed to anything at that time as I was eager for Ashley to get the care, support and treatment that she needed. I was desperate. I talked myself into it and said to myself "That is where we're going to get Ashley back to Ashley again." 10:12 10:12 10:13

I reluctantly agreed for Ashley to be sectioned under the Mental Health Act and taken to Muckamore. I picked her up on the 3rd or 4th of February 2013 and one of the nurses from her care home came with me. I cannot recall who. 10:13

I remember Ashley sat in the front of the car with a smile on her face for the whole journey, like she was drugged. The nurse from the home sat in the back seat. When we arrived, Ashley was placed in a wheelchair and taken to the ICU ward at MAH. Ashley could walk, but not for long periods of time. As soon as we went 10:13

through the doorway she started to scream. She was really distressed. She was taken off me by a member of MAH staff. I do not know the name. I was taken into a separate room. I could hear Ashley crying and screaming in the background. I was told subsequently (I do not know by who) that this was protocol for new patients. 10:13

A male nurse took Ashley's details, but I cannot recall his name. He asked a lot of questions and about our family history, which was upsetting and confusing because I thought it was irrelevant to what was happening to Ashley. I do not recall whether I was asked whether Ashley was to be assisted with food at meal times. I do not recall whether I was asked about the speech and language therapist advice, however this was in her care plan which I assumed would be passed on to MAH. 10:14 10:14

I told the MAH staff member about Ashley's personality and routine and what made her anxious or distressed, and how to calm her if this happened. When Ashley was admitted to MAH her mobility was unstable. She required assistance for all of her personal care, including eating. 10:14 10:14

Ashley was distressed in the new environment at MAH. The male nurse recommended that we did not visit for a few days to allow Ashley to settle. I wanted to come

in with her, but the male nurse stated that it was not safe for me on the ICU ward. I remember saying to him "If it's not safe for me, how is it safe for Ashley?" I found this very unusual as I have never been asked to leave Ashley before. It was overwhelming. I found it very difficult to leave her there and hoped that she would be okay eventually. I thought that this was not going to be an easy journey, but this was a hospital and these were the experts who were going to help. 10:15

10:15

After Ashley was admitted I called the ICU ward every morning and evening, and sometimes three times a day. I cannot recall who I spoke to. I was told that Ashley was not settling well and that she refused to sleep on a bed. The staff placed a mattress on the floor for her. I always asked what Ashley was eating. I was obsessed about Ashley's eating at this stage and about her getting her proper nutritional intake. I was told that she was not eating well. I assumed that she was being assisted with eating as that was in her care plan. 10:15 10:16

I repeatedly asked the staff for a visit on my daily calls and eventually I was told that I could visit. I cannot remember how long Ashley had been in MAH at this stage, but it was a number of days. 10:16

James and I attended on the first visit and we were met at the front door by a male staff member. We had to

wait about 10 or 15 minutes to be let in. This visit was a bit of a blur to me because I was very anxious and upset. I cannot recall the staff member's name who let us in. We were led into a corridor. There were two or three doors ahead of us, and I could see Ashley through the glass panel doors. We could not get through the doors as they were locked. She was sitting on the ground rocking, not looking up. Eventually a female member of staff unlocked the doors from the other side and let us in. She told us that we could not go on to the ward, so we had our visit in the doorway of the ward with Ashley on the ground. Ashley did not look up, but she was rocking and she was breathing very heavily. She had a foot dressing which was bloody, very dirty and hanging off. We tried to talk to Ashley but she did not respond. This was not a long visit as a result of Ashley's distress and as it was very upsetting for us to see her like this. Ashley was moving away from me when I reached out to her and she was very closed off emotionally. I cannot recall much other detail as I was so focused on Ashley. 10:16 10:16 10:17 10:17

A number of days after Ashley's admission I received a phone call from a member of MAH staff (I cannot recall who) to say that a doctor had examined Ashley. They had advised that this was protocol for new patients and that Ashley had a fractured toe which had been bandaged. She had previous issues with her toes, so this was not a surprise, but I do not know if the toe 10:17

fracture occurred at MAH or the care home. I was advised that the toe was so bad that it needed to be removed at the Royal Victoria Hospital (RVH) in Belfast, and Ashley was booked in for an operation the next day.

I'm unsure of the exact date, but it was still in February 2013, so not long after her admission. I did not ask questions about the operation as I was feeling very anxious at that time. I thought that this was just one awful experience after another for Ashley. I recall feeling helpless.

On the morning of the planned operation I rang MAH to check on Ashley. I was advised by a member of staff (I cannot recall who) that Ashley had Weetabix that morning for breakfast and had vomited. Ashley was transported to the RVH by MAH staff. James and I met Ashley at the RVH to be with her for the operation.

When I went in to the room, Ashley smelt strongly of vomit and her clothes were covered in what looked like the remnants of Weetabix and vomit. She was drifting in and out of consciousness. A doctor came in and took her observations. He was very concerned. He said that Ashley was dangerously ill and needed to be ventilated as her oxygen levels were so low. He said that this was a life and death situation. She was taken immediately to the Intensive Care Unit in the RVH.

We were told by the doctors that Ashley had aspirated and had inhaled vomit in both her lungs. She was sedated and ventilated. As she was already sedated, the doctors proceeded with the operation to remove her toe in the RVH. I asked the doctor how old the fracture of the toe was, but he was not able to tell me.

10:19

That evening Ashley was stabilised and moved to the Intensive Care Unit in Belfast City Hospital. I do not know why she was moved.

10:19

I do not have any information from MAH as to why Ashley was sick on the morning of her operation, other than what I was told on the phone that morning. Ashley had vomited once before when she was very scared and distressed in an ambulance when I was with her. She was very distressed as she did not understand what was happening and where she was going. Ashley was around 17 years old at the time. This was the only time that that had happened prior to her being admitted to MAH. I did not tell MAH staff about this as it only happened one time and was not a regular occurrence. I did not think about it again until after she aspirated at MAH.

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10:20

10:20

I do not know if Ashley was assisted or supervised when she was eating her breakfast on the morning of the operation. I do not know whether the Weetabix had been

prepared properly. I do not know if the staff at MAH were aware of the advice from the speech and language therapist, which was in her care plan, but I always assumed they were.

10:20

I do not understand why she was even having breakfast if she was on her way to hospital for an operation. Surely she should not have eaten before an operation. I would like to have these questions answered.

10:21

Ashley remained in BCH for a few weeks. She had a tracheotomy fitted and a tube for feeding. She went back to the RVH for a short period and then to the Intensive Care Unit at AAH. Eventually she was moved to a room on her own in AAH. Ashley slowly began to 10:21
improve and was eating again with assistance. This was a traumatic period in our lives and I cannot recall the specific dates. I am not sure of the date of Ashley's transfer to AAH, but it was before her birthday in April 2013. I remember thinking that she was still in 10:21
hospital for her birthday. She was transferred from the ICU in AAH to a side room. She was strong enough to leave ICU but not to eat. I recall that she had a nasogastric tube fitted and that she pulled it out. I raised concerns about this to the AAH staff, but Ashley 10:22
had to wait hours to have it refitted, and I was concerned that she was not getting any sustenance at this time.

I was advised around this time that she was going to be discharged back to the care home. They had retained her place while she was in MAH and were still receiving the payment for her bed. However, the day before Ashley was due to be discharged, we were advised by 10:22
Ashley's social worker (I cannot recall her name) that the home would not allow Ashley to return there. For this reason, Ashley was discharged back to MAH. I am unsure of the exact date. The social worker advised me that the reason the home refused to allow Ashley to 10:22
return there was because they said they could not meet her needs anymore.

Ashley was placed in Cranmore Ward for a few weeks and then moved to Greenan Ward. I think this was a medical 10:22
ward. We were allowed to visit on Cranmore Ward and we did so approximately three times a week. Sometimes I visited on my own and sometimes James or the girls visited with me. Ashley had her own room and we were allowed to have our visits there. We went to reception 10:23
and were taken into the locked ward and then to a room by a member of staff. I cannot recall any of their names.

When Ashley was moved to Greenan Ward she had a 10:23
screened off area at the bottom of the corridor. She still did not like to sleep in a bed and her mattress was placed on the floor. Ashley had no daycare activities on the Greenan Ward.

I always took her out for a drive in the car. Ashley enjoyed that. We just drove around the countryside or went to a park.

10:23

Ashley was in a wheelchair as she was silly very weak. I did not think Ashley was herself during the time at MAH. She seemed very subdued and withdrawn, although I do not think she was self-injurious at this time.

10:23

A few weeks after she was back in MAH I received a phone call from the MAH staff. I cannot recall who phoned me. They told me that Ashley had aspirated again and had been taken to AAH. This happened a few times. During this period I would have visited Ashley around three times a week. On the third occasion Ashley aspirated (I cannot recall the date), James and I were advised by the medical staff at AAH that she was not strong enough to be sedated and ventilated. Ashley remained in AAH in a side room for a number of months. There was always a staff member from MAH with Ashley at AAH 24/7. We were never told by MAH what happened to cause Ashley to aspirate again on any of these occasions.

10:24

10:24

The MAH staff at AAH were pleasant and chatty and took an interest in Ashley's well-being. I visited every day. I would drop the twins to school and then go to AAH. I would go back, pick the twins up from school,

get a babysitter for them and then around return to AAH. James worked one week away from home and one week at home, so I had very little support.

We were advised in or around June 2013 that Ashley was very ill and the medical staff were going to start palliative care. Around this time there were moments when Ashley came back to being Ashley. She sat on my knee, cuddled with me and said "mama". Ashley slept a lot at this time. She slept with her head on my knee. I assisted her with eating and taking her medication. One time the nursing staff gave her a bubble bath. I had not seen Ashley naked in such a long time and was shocked by how much weight she had lost. She dipped her head underneath the water and was covered in bubbles, but she did not stay long in the bath. 10:25 10:25 10:25

Ashley passed away on 26th November 2013. I got a phone call at 4:00am from AAH to say she was very weak. I rang my friend, Kathleen, who came to look after the twins. I rang James who was away at work and he made it to the hospital in the morning before she passed away. MAH advised us that they were going to withdraw their staff from AAH, and the morning she passed away was the last day they were due to attend. 10:25 10:26

I recall a big heavy man from MAH came to Ashley's funeral, but I do not know who he was. We did not receive any belongings back from MAH nor did we request

anything back. She did not have many belongings, other than some clothes.

As a family, we remain very distressed by the events that led to Ashley's death. We've never had an explanation as to why she aspirated in MAH on the first occasion or any of the other occasions. I believe that the first aspiration suffered by Ashley eventually caused her death, and I would like to understand the circumstances surrounding that. Ashley's cause of death on her death certificate was aspiration pneumonia. No-one has explained to us what happened. As far as we are aware nobody has investigated Ashley's death. 10:26 10:26

Ashley's feeding needs were part of her medical notes and records. After the first incident Ashley should have been classed as very high risk. If you have aspirated once you're at a very high risk of doing so again. You cannot ever get all of the food or vomit out of the lungs properly and it can cause serious health issues. I believe if she had not aspirated then she would still be alive and this could have been prevented if the right interventions had been put in place. 10:27 10:27

Also, I do not know if the fracture on Ashley's toe was sustained in the care home or if it was a new fracture sustained at MAH. I really want the answers to these

questions, but I've never felt strong enough to ask them before now.

I gave Ashley the best of care when she lived at home with me. As a mother, I feel very guilty that Ashley had to go into respite care when I was pregnant with the twins. I feel that if she had not done so then none of this would have happened and she would still be alive today. I know that there was no other choice at the time, but I cannot help feeling like this. It is very distressing to think back on this and I have a lot of complex feelings about it, which are difficult to articulate in this statement. 10:27 10:28

After Ashley went into respite care I felt very much out of control of Ashley's care and it was like a domino effect of incidents after that, one after another. 10:28

I am glad to have this opportunity to tell Ashley's story and for her voice to be heard. I hope that the information is of assistance to the Inquiry." 10:28

And you then go on to confirm your wishes around giving evidence, and the statement is signed and dated 11th September 2023. 10:28

Can I confirm that having heard your statement you are content with the contents?

A. I am.

1 Q. And are you content to adopt that statement as your evidence to the Inquiry?

A. I am.

2 Q. Thank you. I just have a few questions for you around the contents of your statement. Can you tell me a little bit about Ashley when she was a wee girl? How was she when she was at home with you? 10:29

A. Ashley was really, really - she just loved to have fun and to laugh. She was obsessed with the TV programme "Who Wants to be a Millionaire?", and as soon as it would come on she'd like clap her hands and she'd just be like just so gleeful, and it was just like - even if you said to Ashley "Who Wants to be a Millionaire?" anywhere you were, she'd be like "clap clap clap" and just be so happy. Yeah. She loved music. One of her favourite songs was - well, she loved the album from Pink Floyd, probably because I used to play it all the time, but she really loved it. She just loved music. She had a big giant yellow ball as well that she used to love to play on, and she would lie top of it and you had to like kick it and she loved the vibrations. She was a big flirt. Whenever the postman used to come to the door, if he had a parcel, Ashley would try to pull him in. And I do recall one time as well she made a phone call to the police by accident, and the police appeared at the door, which was good, and they were like "We received a phone call. Somebody was just breathing really heavily", and there was Ashley in the 10:29 10:29 10:30 10:30

background. She just used to like sit on the phone and tap the buttons, but somehow she had managed to phone the police. Yeah. And then when Kami and Chalia (sic) were born she absolutely - she just knew that they were her sisters. And they used to sit on each side of her 10:30
wheelchair and she'd would have their arms around them and she'd like - when Ashley gave you a hug it was like the strongest biggest hug ever like, and she just would say "gaga, gaga". And she enjoyed sitting with me and looking through magazines. So sometimes Ashley's 10:31
magazine would be upside down, but she just did it because she copied what I was doing and it was like, you know, she just loved doing that. And we'd have a box of dry cereal in between us and I'd have some and she'd have some. It was Cheerios usually. Yeah. She 10:31
had a fun childhood. I had a wee dog as well, a wee Scotty dog called Sasha, and she just used to like rub him just to make him growl. I think she thought he was a toy.

3 Q. You've said that she was to a degree non-verbal but 10:31
there was some words. Was she able to say...

A. She could say "Mama". She started to say"Mama", and it was - it sounded French. She'd be like "Mama. Mama".

4 Q. Okay.

A. It was the most amazing thing. And she could say 10:31
"Bush", because she loved her school bus. Ehm, and "ba" for bath. If she wanted a cup of tea, she'd come in and hit you with a cup and go "ah".

5 Q. So she was able to tell what you she wanted to in her

own way?

A. Yes. Yes. Yes. Mhm-mhm.

6 Q. Yeah. And if she was upset, were there certain things that she would do that would tell you she was upset?

A. Yeah. 10:32

7 Q. Or how would you know.

A. Yeah. Absolutely. You could tell 100% if she wasn't happy about anything, like she would just shout and yell. For some reason she hated going into garages when you had to put fuel in the car. As soon as you 10:32 went into a garage, she would just, you know, the feet would go down and she'd be in -- at this point she would be sitting in a car seat in the back, and the feet would go down like, but you'd feel them hitting against the driver's seat and she'd be like going 10:32 "ahhh", you know. You could just tell like she just wasn't happy about anything. Yeah. She loved food. McDonalds was her favourite. Yeah.

8 Q. And was she able to feed herself at all or would you have had to feed her? 10:33

A. When she was at home Ashley would have had a spoon, and she could eat her cereal with a spoon, and she could manage -- she was very messy, but she could manage on her own. It was just she kind of lost skills a wee bit through being in the care home and stuff. So, yeah. 10:33

9 Q. Okay. You've told us at paragraph 28 of your statement that Ashley went to Muckamore in February 2013, and from paragraph 9, that there was some discussion with the staff about her care needs. Can you recall

discussing the issues around feeding herself and swallowing with the staff?

A. No, I don't recall being asked anything specific about that at all, no. But it was a major concern that Ashley was to get the right like sustenance, because of things that had happened, and she had microcytic anaemia and she had been in hospital and she had needed a blood transfusion. So she did really need assistance with eating to ensure. And plus her swallow had been assessed. So her food had to be of the right consistency. 10:34 10:34

10 Q. Had she had any kind of dietetic assessment as part of her care plan that you know of? Or, you know, food and nutrition assessment. Was there anything specific to that, that she was... 10:34

A. It was -- when she was discharged from getting the blood transfusion it was recommended by the medical staff that she would get a lot of green leafy veg, you know, she needed. And a very protein rich diet. Yeah.

11 Q. Okay. In paragraph 30 of your statement you tell us that Ashley was very distressed in the new environment in Muckamore. What was it about her demeanour or her behaviour that told you she was so distressed? 10:35

A. She was totally withdrawn and she had went past -- like initially whenever we brought her in to Muckamore, you know, she was very - like screaming and crying. Like it was horrendous to have to listen to her. I didn't even know where she had been taken. But whenever we eventually did go and see her that first time, she was 10:35

just - she just didn't want - like normally whenever I would have seen Ashley she would have associated seeing me with like going somewhere and, you know, she would be wanting to leave and go out in the car. She didn't even look at me. She just sat away from me on the ground and she was rocking. She just was just like looking at her hands, and there was no real expression. She just didn't - she just - I could just tell like she just was not -- I don't know, I can't even put in to words what it was. 10:35 10:36

12 Q. Had you ever seen her like that before in any other setting?

A. Not that I can recall. No. Ashley was always responsive to me. Always, you know. We had a great - an absolutely amazing relationship. 10:36

13 Q. So it sounds -- what you're saying is it was a big change in her way of being. Did you discuss that with the staff or ask them what was?

A. No, I was beside myself. Yeah, it's even - it's like a blur sometimes even trying to think back on it, because I think I was just going through the motions and it wasn't really registering, and it's taken me to now to be able to actually do this, to be fair. 10:36

14 Q. Yeah. Do you know of anything that they did to try and help her to settle? Was there anything... 10:37

A. No idea.

15 Q. You don't. Okay. You had mentioned then at paragraph 31 that she didn't want to sleep in her bed, she wasn't happy to go in the bed at Muckamore. Is that something

that you had ever noticed her show before that time or had she been happy enough?

A. No. She slept in beds, yeah.

16 Q. She didn't want to have the mattress on the floor or anywhere else then? 10:37

A. No. No.

17 Q. Okay. Did you get to see her bedroom at all?

A. In Cranmore, yes.

18 Q. Later?

A. Yes. 10:37

19 Q. Yes. Okay. And you mentioned that she wasn't eating well. At that stage, the age that Ashley was, if she hadn't been assisted could she have fed herself at all?

A. No.

20 Q. Is it fair to say that if nobody spoon fed her or whatever... 10:37

A. I don't think she would have been able to eat herself. I don't think she had - I think she was very closed down and she just - I don't know. I just can't -- no, I don't think so. 10:38

21 Q. Okay. Did you notice any change in her appearance at this time? I know you've talked about a change in her behaviour, but how was she looking?

A. Physically?

22 Q. Yes, physically? 10:38

A. Well, again, just the one thing that stuck out to me was the bloody bandage on her foot. It was like unravelled and it was dirty and like blood on it. She had clothes on. She just - I don't know. I can't

recall. There's nothing else stuck out.

23 Q. Yes. Okay. You did mention, I think it was at paragraph 32, about the foot bandage and that it was dirty and hanging off, and you also go on to mention that she had a history of foot problems. 10:39

A. Yes.

24 Q. Could you tell me what you mean by that?

A. She had bad circulation in her feet. She wasn't diabetic, but it was as if she had diabetic feet.

25 Q. Okay. 10:39

A. And she would have been very hard on her feet like, and would have got a cut, or it took a long time for to try and get to heal. She would have had regular podiatry appointments, and she did wear especially made boots to try and alleviate some of that. She had had two toes 10:39 taken off previous.

26 Q. Okay. Yeah. And that injury, it seems, led to the planned operation that was going to happen in the Royal Victoria. You mention that in paragraph 34?

A. Yeah. 10:39

27 Q. Arranged the day before, is that your recollection?

A. Yeah, in my recollection it was all very quick. It was very like "All right, so the doctor said this toe is definitely fractured and it is so bad", yeah.

28 Q. It has to come off? 10:40

A. Yeah.

29 Q. And was it your understanding she was going to have a general anaesthetic for that operation?

A. I just assumed so, you know. I didn't even ask

anything.

30 Q. Okay.

A. It was -- again, I was just going through the motions of this whirlwind of stuff that seemed to be happening.

31 Q. I understand. So she was transferred across to the Royal Victoria and you and your husband met her there and you noticed she was covered in vomit? 10:40

A. She had dried vomit on her jumper and it smelt of like vomity Weetabix. It was a very distinct smell. I do remember that. 10:40

32 Q. Yes. Do you recall any of the staff at the Royal Victoria mentioning that issue?

A. No.

33 Q. You've also said that she was extremely ill whenever she was at the Royal. Was there any discussion with you about how she had got into that condition, you know, how she got to be so poorly? 10:40

A. No.

34 Q. No. Okay. Do you feel the staff at Muckamore understood Ashley's physical health needs? 10:41

A. No.

35 Q. Do you feel that to a degree they were met or were they...

A. It's just the period of when she was in the ICU in Muckamore I just don't think - I don't believe Ashley should have been there in the first place, and I just don't think - I have no idea what happened. Yeah, I just -- I would say that her needs weren't met to the way they should have been. Yeah. She was very 10:41

vulnerable.

36 Q. You've asked for some of the photographs that you very kindly provided of Ashley to be shown.

A. Yeah.

37 Q. If we could bring those up now, please? And what age was Ashley in this one, can you remember? 10:42

A. Yeah, Ashley was 10. That was taken by my Auntie Kay. It was in her house.

38 Q. Okay. And this is Ashley. She looks older in this picture? 10:42

A. Yeah. She was about 14 or 15. Yeah. That was Ashley looking through a magazine. It might have been the right way round actually. (Laughs). Yeah. That was me and Ashley and our two dogs, Storm and Sasha.

39 Q. Okay. 10:43

A. And me and Ashley again.

40 Q. Has she a doll there or...

A. Yeah, it was like -- it's called a Jibber Jabber. She loved anything that made a noise and it went [sound made]. That's Ashley on the phone to the police. 10:43 (Laughs).

41 Q. Was she phoning the police!

A. And that was one of the photographs from school. She loved her time at school, and she loved water, so, yeah, she was having water play there. 10:43

42 Q. Okay. There's some bubbles there by the look of it.

A. Yeah.

43 Q. Okay.

A. And that was taken just after she had had a bath. That

was a picnic time.

44 Q. With her sisters?

A. Yes. That was a school photo. Yes, she's a rebel.

45 Q. Very good. How old would she have been in this photograph? 10:44

A. 15.

46 Q. Okay.

A. She always looked really young for her age.

47 Q. Okay.

A. That was taken when she wasn't very well. 10:44

48 Q. What age would she have been?

A. That was in hospital.

49 Q. In Antrim Area Hospital?

A. Yeah. And that one, that was actually the day she was in Cranmore. That was her first day there. 10:44

50 Q. Okay. That's her school photograph then.

A. That's my wee granny and Ashley. She's on the phone again.

51 Q. Okay.

A. And that was not long before Ashley passed actually. 10:45

MS. TANG: Thank you for sharing those photographs with us. Those are all my questions, but the Panel and the Chair may have some questions for you, if you could remain seated for another little minute. 10:45

QUESTIONED BY THE CHAIRPERSON

CHAIRPERSON: I just want to understand something about timing.

A. Yeah.

52 Q. When Ashley went into MAH would she have been about what, 26? 10:45

A. No.

53 Q. 25.

A. Yes. Even. Sorry.

54 Q. It might be my maths.

A. No. No, she was, yeah. She was. 10:45

55 Q. Because she went in in February 2013.

A. She was 25 and she turned 26.

56 Q. Yeah. Exactly. Yeah. Yeah. Up until that point, had you had problems feeding her at home? Obviously she was a messy eater as it were. 10:46

A. Yeah, she was a messy eater. Yeah.

57 Q. But if she was assisted, did she eat all right?

A. Yeah.

58 Q. And did you have any problems then with vomiting or aspiration? 10:46

A. No. Never. I mean Ashley didn't require a special diet back then or anything. Everything was grand. She was fine.

59 Q. So you had never been aware of that as an issue at all?

A. No. 10:46

60 Q. Then obviously she is admitted to hospital for the removal of the toe and she had aspirated. Did you - and one completely understands if you didn't, but did you make any enquiry of MAH about that? Did you write

to MAH or say "Look, why was she given food before an operation?".

A. I didn't.

61 Q. No.

A. I just didn't. 10:47

62 Q. And you didn't get any explanation from them?

A. No. No.

63 Q. There was a time when I think she was in AAH and you saw her and you were very upset at how much weight she had lost? 10:47

A. Yes.

64 Q. How long had she been in AAH by that point, can you remember?

A. I think that was her third admission. She had been back and forth from Muckamore to Antrim, and then that 10:47 was her third longest and final stay. Yeah.

65 Q. But when she had been at Muckamore you hadn't noticed a loss of weight while she was there, or you had?

A. Oh, no, I did. Yeah, she was.

66 Q. Right. 10:47

A. She was very thin then too, yes. Yes.

67 Q. So just tell us about that. What did you notice?

A. She just was very -- like there was a photograph there of Ashley whenever she was really well with the twins when we were having a picnic... 10:47

68 Q. Yeah. Yeah.

A. And she was very - like a good healthy weight, you know. She was probably maybe about nine or 10 stone at that weight. And when she was in Muckamore she

probably would be lucky if she was maybe seven and a half. Looking, she just was skinny. Her face was skinny. She was just skinny.

69 Q. And can you remember back then if you spoke to anybody about her loss of weight? 10:48

A. No. I just assumed this like...

70 Q. That they were looking after her?

A. Yeah. And I was just hopeful that this was all going to get better. Like this was maybe just the start of something that could change, but it didn't. 10:48

71 Q. No, I understand. All right. All right. That is all that we want to ask you.

A. All right.

CHAIRPERSON: Can I just thank you very much for coming along, and also thank you to James and others who have 10:49 come along to watch. It's obviously been difficult for you too, and also for your daughter, it's obviously been difficult for you to come and give evidence, and reliving this I'm sure has brought back all sorts of memories too, but I hope some of them are happy 10:49 memories, as we've been able to see from your expression, and it has been nice to see the photographs of Ashley in happier times. So can I thank you very much for coming to assist the Inquiry and speaking on behalf of Ashley. All right. If you would like to go 10:49 with Jaclyn.

THE WITNESS WITHDREW

MS. TANG: Chair, the next witness is P115's father, and Ms. Briggs will be taking the witness through his evidence. I understand the witness may be able to attend slightly earlier than the scheduled time of 12:00.

CHAIRPERSON: He has attended. He is here. But we won't start straight away. We'll take a bit of a break. We'll probably try to start about twenty past eleven. All right. Okay. Thank you very much indeed.

10:49

10:50

THE HEARING ADJOURNED FOR A SHORT PERIOD

MS. BRIGGS: Good afternoon, Chair, and members of the Panel.

CHAIRPERSON: It is still the morning, but it might feel like the afternoon.

11:19

MS. BRIGGS: Oh! You're right, it is.

CHAIRPERSON: You're trying to catch me out!

MS. BRIGGS: I'm ahead of myself. This afternoon I'm going to be -- this morning I'm going to be taking the oral evidence of P115's father, who has confirmed he is content to be known as by his first name, Danny.

11:19

The evidence is about his late son, who can be called Eoin, and Eoin passed away in 2017. The statement reference is STM-143-1. And there are four exhibits to the statement, and I will touch upon those in due course. And unless there's anything further this morning, Chair, the witness can now be called.

11:20

CHAIRPERSON: Okay. Lovely. Let's bring him in.

P115'S FATHER, HAVING BEEN SWORN, WAS EXAMINED BY MS. BRIGGS AS FOLLOWS:

11:21

CHAIRPERSON: Good morning. Thank you very much for coming to assist the Inquiry. I gather it's all right if I call you Danny?

A. Yep.

CHAIRPERSON: I know you were sitting in the public gallery, so you've seen how this works. Your statement is going to be read through with you, and if you'd like to follow it and then you'll be asked some further questions. But thank you for coming to assist us, and I'll hand you over to Ms. Briggs. 11:21

MS. BRIGGS: Danny, as has been said, I'm going to start by reading your statement into the evidence. As I've explained to you already, I won't be reading the entirety of that statement, but I have reassured you that the Panel have the entirety of the statement, but 11:21 I will be reading certain parts of it out into the record this morning. And then I will ask you some questions about it. And I've explained to you this morning that we avoid using names where possible. We're going to call you Danny, and your son Eoin, but 11:22 in relation to other names, where possible we avoid using those, and you have a list of ciphers in front of you, if you do feel, when you're giving your evidence, that there's a name that you want to use, if you could

refer to that cipher list. But as I've explained, don't worry, if you accidentally slip in a name we can deal with that. Okay.

So I'm going to go ahead at this stage and read your statement into the record. If that can be brought up onto the screen? 11:22

This statement starts as follows:

"My connection with MAH is that I am the father of Eoin (deceased) a former patient of MAH. I attach a photograph of my son Eoin at Exhibit 1." 11:22

And we'll come to that shortly.

"The relevant time period that I can speak about is between 1996 and 2010.

I am the father of Eoin, who was the youngest of my three children. Eoin was born..." 11:22

And you give the date in 1991. You say:

"My eldest daughter was seven years older than Eoin..." 11:23

And you say his brother was one year older:

"When Eoin was about two years old he was seen by a

consultant paediatrician in the Royal Belfast Hospital for Sick Children (The Royal). I cannot recall exactly who referred Eoin to this consultant, but it was because he was not hitting his milestones. He could not support himself and was floppy in how he carried himself.

The consultant paediatrician in the Royal diagnosed Eoin with a learning disability and thought he was on the autistic spectrum, but Eoin was not formally diagnosed with autism at that time. I always thought that Eoin was autistic. 11:23

As well as his learning disability Eoin was subsequently diagnosed with epilepsy, and he was described medically as having "challenging behaviour", which is how they termed it then. 11:23

When still a toddler, Eoin was assigned a social worker called H489." 11:23

And you say where that social worker was based.

"Later when H489 was on leave or unavailable there was also a social worker SW15 who worked with Eoin, but I cannot recall the exact years for either. SW15 was based..." 11:24

-- and you say where that was.

"I am unsure of her surname. They were the two main social workers for Eoin, but there may have been others involved at different times.

Managing Eoin at home was challenging. I was unable to toilet train him and the routine in the house was largely organised around Eoin and his needs. The social worker H489 suggested that a period of respite care for Eoin in MAH would benefit both Eoin and my family. Initially I was against the idea of respite care as I did not want Eoin to be sent away from the family, but at this time I had received a grant from the Housing Executive to get an extension built on our home and for other modification work to assist in meeting Eoin's needs. As he would not have coped well with the noise of the building works when it was being done, I agreed to Eoin's first admission to MAH for the duration of the extension work. 11:24 11:24 11:24

Eoin was admitted to Conicar Ward in MAH in 1996 when he was about five years old, for long-term respite. This allowed my family home to be adapted to make it more suitable for his means. I cannot recall any forms being filled in on Eoin's admission, or any discussion around whether he would receive any treatment while he was in MAH. I think he went to a playschool on site while he was there, but I cannot recall what the routine for that was. 11:25 11:25

Eoin did frequently come home for visits, and I would have also gone to see him in MAH. I would usually have gone up to MAH on my own and visits took place in either a dining room or a wee room off to the right as you went into the ward, which had a couple of chairs in it. I would have brought him a wee package with juice and things in it. 11:25

Conicar Ward had a cook on-site and he adored Eoin, who loved the cook's Guinness pie. The cook came across as being very good to Eoin, but apart from this everything was very lock and key. Regimental. You had to wait when you went through one door for it to close before you could go to the next door. You were always made to stand and wait while Eoin was brought down by a staff member. 11:25 11:26

I cannot recall Eoin's emotions around these visits, but it was very difficult on me. I had to sneak out the door when leaving MAH after a visit so as not to draw attention to the fact I was leaving. However, I recall that when I was dropping Eoin back to MAH after home visits he would not want to get out of the car and would hide down in the footwell. 11:26 11:26

During Eoin's time in MAH I believe that he was restrained. At one point he came home for a visit and his walking seemed to be impaired, so I examined his

foot and noticed his big toe was bruised and the toenail on it was cracked. Eoin also had four bruises on one side of his arm and another bruise on the other side of his arm, as if someone had grabbed him. There were similar bruises on the other arm. 11:26

I have kept a pair of Eoin's boots that were damaged and dented from where I believe he had been restrained. Eoin wore these boots as his usual footwear because they gave him some stability and he could not take them 11:27 off easily.

I was concerned that these injuries had happened to Eoin in MAH and this led me to make a complaint to the RUC about this incident. Two police officers came out 11:27 to my house from Grosvenor Road Police Station and there was then a further meeting at Grosvenor Road on a later date. I had to bring Eoin to the Royal, and there was a photographer who took pictures of Eoin's arms. My wife, however, did not want to pursue a 11:27 complaint with the police.

There was a multi-agency meeting with Social Services about this incident, and Eoin's consultant psychiatrist or psychologist, I am not sure, which was there. They 11:27 were based off the Malone Road, Belfast, and worked with Eoin both in and outside of MAH. From memory H486 senior social worker was there and Eoin's social worker H489. I am not sure if anyone from MAH actually

attended this meeting, but either directly or through someone, MAH put forward different scenarios to explain what happened.

Firstly they said that Eoin might have been leaning back on a chair and the back legs of the chair might have come down on to his boots. That Eoin might have caused the bruises on his arms by himself, or alternatively they suggested Eoin or someone else opened a door on to his boots. I do not know who from MAH provided these accounts, but none of them seemed plausible to me. It was not considered that Eoin might have been purposely harmed by someone and nobody answered any of the questions I was asking about the incident. I was, however, also very mindful that Eoin was going back to MAH and so I was afraid to rock the boat too much. 11:28 11:28 11:28

I was told there would be an investigation, but I am not aware if this happened or any outcome. I do recall being told there was a recommendation that Eoin should have one-to-one care after this, but I am not sure if this happened. 11:28

I also recall around this time there was a publication in a newspaper, perhaps the Irish News or Belfast Telegraph, and they had an article explaining how MAH staff had been trained in restraint. This was presented as a positive publication, but I do not 11:28

understand how any restraint which caused injury could be regarded as positive.

I understand now that Social Services should have had a care plan in relation to Eoin, but I was never shown one and never had any input into producing any care plan. 11:29

Eoin was on epilepsy medication, but this was all I was aware he was being prescribed. I do not recall being asked to attend any meetings to review his circumstances during his time in MAH. 11:29

Eoin was discharged from MAH in or around 1997, as the home extension was finished. There was no transition or preparatory work. Eoin just came home one day. I cannot recall if there was any communication with MAH staff after he came home. He was still involved with the consultant in the Royal for his seizures, and I had no issues with this care. 11:29 11:30

Generally speaking I would have gone to our GP if there were any issues and Eoin was still involved with the social work team. He attended a school once he had been discharged from MAH. The school was for children with autism at that time. He was there for around four to five years and then attended another school..." 11:30

- and you say where that is.

"...which is a school for children with learning disabilities.

Within about a year of Eoin being discharged from MAH my wife and I separated. I got custody of Eoin when he was around eight years old, and from that time on I have looked after Eoin as his primary carer. 11:30

At this time I enrolled and completed studies to gain further knowledge of Eoin's autism and specific needs. Although Eoin was non-verbal, he was able to communicate using the picture exchange communication system (PECS), and as I was keen to help Eoin as much as possible, I completed a course on PECS. I also completed many courses in applied behaviour analysis (ABA) at the Ulster University." 11:30 11:30

In the next number of paragraphs 25 through to 35, you describe incidents at Eoin's school when he was around 11. The fact that he was suspended and he was out of school indefinitely on suspensions, and ultimately excluded from school, and you describe how there was a lack of support at that time, and about two years later, after you had set up a school for Eoin at home, he went to another school when he was about 13? 11:31 11:31

A. Yes.

72 Q. Then going to paragraph 35, you describe issuing legal proceedings on behalf of Eoin and being awarded

compensation in relation to the issues with his education provision. And I'm going to pick up halfway through paragraph 35, and it is on page 8. I'm just waiting for that to be brought up on screen.

CHAIRPERSON: Paragraph 35. 11:31

MS. BRIGGS: Paragraph 35, page 8. Thank you very much. So halfway through there:

"As part of this it was said Eoin had to have behavioural intervention..." 11:32

- and you were referring there to the legal proceedings:

"...and the only place this was provided was in MAH, so 11:32 this led to his voluntary readmission aged 15.

In 2005, when Eoin was 15 years old, he was treated for his seizures by a consultant paediatric neurologist at the Royal. That doctor considered that Eoin was in a 11:32 high risk category for SUDEP, Sudden Unexpected Death in Epilepsy. I am aware from Eoin's medical notes and records that she also alerted Dr. H49, consultant psychiatrist in MAH, to this, and her recommendation that rescue medication for seizures be held by staff at 11:32 respite units and school, and that this information should be shared with parents. However, this information was not shared with me.

At this time as well as the care provided by the consultant paediatric neurologist there was also an going monthly respite care arrangement for Eoin at either MAH or the children's home in..."

11:33

- and you say where that was.

"I understand this respite could have continued until Eoin was sixteen and a half years old, but it was stopped prematurely when he was 15 because of insufficient space.

11:33

I subsequently applied to the Belfast Health and Social Care Trust for a direct payment scheme to allow carers to help me. This scheme would have given me invaluable assistance with Eoin's care and was greatly needed by me at this time, however I did not receive any response to my application.

11:33

Whilst availing of the respite care arrangement with MAH, Eoin's care was monitored initially through Dr. H50 and then Dr. H40. I would have continued to carry out behavioural work with Eoin and would take him for walks, as that seemed to help him.

11:33

11:34

On 27th October 2006, Eoin was re-admitted to MAH and placed on Mallow Ward. I remember the date as it was my birthday, and I was due to be away, but I was told there was no help available at home, no respite, and I

was at the end of my tether.

H486 senior social worker was in MAH when Eoin was re-admitted and she asked if I wanted to go and see Eoin in the ward before I left. However, I said no as it would have ripped me to pieces. 11:34

I was not told the precise purpose of the admission or how long it would be for, but I do remember a behavioural nurse being involved through the education authority liaising with MAH, as she did reports on Eoin for his special educational needs tribunal, and she told me MAH was a great place and that people came from Dublin for assessment there. 11:34

I was told that I could not visit Eoin for the first three months when he was there to allow him to settle in, although there were ward meetings held as Eoin would not eat. 11:34

In 2007/08, well after the three month no contact period, there was a multidisciplinary team meeting in MAH and Dr. H487 sent both myself and Eoin's social worker, and only us, the wrong date/time for the meeting. The MDTM went ahead without us without anyone ringing to see why I was not in attendance. At this time Eoin was between Mallow and Cranfield Wards. MAH, Eoin's social worker, the education authority and the education psychiatrist were all in attendance, along 11:35

with the behaviour nurse. The outcome was reports about Eoin being drafted by this behaviour nurse or certainly drafted with her involvement.

I received a telephone call from this behavioural nurse saying I was going to be shocked by what I would read in the report, which I subsequently received in the post. I asked for a meeting which was attended by the same people as the first MDTM. 11:35

About 15 minutes before the meeting, the senior social worker H486..." 11:35

- and you also provide her married name:

"...took the report out and asked me if I had read it. I said "yes" and she said something along lines that it did not give a true reflection of Eoin in terms of his day-to-day living, and that it would be binned because of its inaccuracies. 11:35

We went up to the meeting and H486 asked those in attendance to take their copies of the report and to tear them up and bin them. However, I kept my copy. The MDTM then proceeded on a more realistic approach with my view put forward, and Dr. H487's opinion, which had been missing before, and we outlined work being done at home and how Eoin was when he was educated at home. 11:36

At this time, I had really hoped that it would be a short lived admission for Eoin, simply to allow the direct payment application for carers to be considered and for support to be put in place for Eoin at home. I was unable to provide Eoin with the necessary support at home without help, which was the reason I made the application. 11:36

A social worker lodged a second application as she said that the first application was wrong and so it had to be resubmitted. While she lodged the second one I never received anything in response, either by way of acknowledgment of it or determination. 11:36

I had been told Mallow Ward in MAH had been upgraded, but from what I could see there was only a coat of paint that had been applied. I cannot recall why, but during Eoin's time on Mallow Ward I had a visit which took place up in his room, which was a shared dormitory room with metal beds. I can recall a date on one of the beds being from the 1950s. 11:37

I also recall a meeting about Eoin's eating with a dietician and manager (H212) who came across as being very fond of Eoin. During this meeting I was told that the outside carers being used were going to be suspended as the food being provided was not up to standard. I believe there was someone from the Mental 11:37

Health Commission also presented at this meeting. The food in Mallow was terrible, in my view. It included things such as spam, beans and eggs, which I witnessed on a visit, and there were flies in and around it all. I said "Eoin doesn't eat that kind of food, and so I was not surprised he would not eat it." 11:38

Eoin lost weight during this time, even though he was still coming home and eating fine with me, and I was bringing him food packages. He was also given two different supplement drinks by staff, one of which looked like concrete. I asked how they got him to drink that and a nurse said that they basically followed him around and cornered him in the room until he drank it. 11:38

When Eoin was first placed in Mallow his teeth were inspected by a dentist who told me that his teeth were fine. In or around 2008/09, Eoin had to be referred to the Royal Dentistry Department. I asked for this referral but was told there was a three year waiting list. I could tell that he was in pain as when he was eating he would lash out. We were seen by the dentist in RVH who said that Eoin needed several fillings and that he had two impacted wisdom teeth which were infected. I could not understand how this had been allowed to happen, as the dentist in MAH said there was nothing wrong with his teeth. Eoin would grind his teeth with seizure activity, which also caused problems 11:38

for his teeth. Eoin was able to see a dentist in Coleraine Hospital, which was funded as part of a scheme to relieve waiting lists in the Royal.

I went with him to this appointment in Coleraine as I was concerned that he was in pain with the infected impacted wisdom teeth. He got a number of fillings and treatment for his infected wisdom teeth, all of which took a number of months. 11:39

I was generally and continuously concerned about the quality of medical care available at MAH. I believe this was of considerable significance for Eoin as infection can increase the frequency of seizures. Eoin's seizure activity increased in July and August 2007 when Eoin had nausea and was vomiting. 11:39

On the 15th August 2007, Eoin was admitted to Antrim Area Hospital because he had gastroenteritis. He was discharged the following day. 11:39

This increase and the link between infection and seizure activity is noted in a letter from Dr. Thornbury, Senior House Officer at Belfast City Hospital, in relation to a clinic on the 13th October 2009. I attach a copy of this letter at Exhibit 2." 11:40

I should pause there. I don't intend to read that exhibit in, but I want to clarify that that appears at

pages 25 to 26 of the statement. It's not labelled Exhibit 2, but it is those pages 25 to 26 that the Panel might want to refer to in due course when they're reading what exhibit.

CHAIRPERSON: Sorry, hold on one second. Sorry, pages 25 and 26? 11:40

MS. BRIGGS: 25 to 26.

CHAIRPERSON: Using the MAH?

MS. BRIGGS: Yes, Chair.

CHAIRPERSON: Well that for me is a photograph and a Coroner's Certificate. 11:40

MS. BRIGGS: The Panel may have an older version of the statement. The 25 to 26 has been added at a later date, if that helps.

CHAIRPERSON: Oh, I see. Okay. We'll check that. Thank you. 11:41

MS. BRIGGS: So that can be flagged for the Panel and the Panel can have the proper copy with 25 and 26 inserted. That's the only difference in page numbering, I should say to the Panel. 11:41

CHAIRPERSON: Oh, I see. Okay. All right. Thank you.

MS. BRIGGS: I'll just check you have that now, Chair?

CHAIRPERSON: Yes. Just give me a second. Sorry. Oh, I see. Yeah. Okay. Thank you. Well we can review these in due course. 11:41

MS. BRIGGS: Yes. Thank you, Chair. As I say, I don't propose to go into that at this stage, but you have that now.

Picking up at paragraph 53 then:

"Eoin was being monitored for seizure activity 24/7 and they usually manifested around once a week, albeit it there were periods of no seizures. Around this time, and with the increase of infection and seizures, I was told by I think Dr. H40 in MAH that Eoin would get better behavioural help if he was transferred to the Psychiatric Intensive Care UNIT (PICU). 11:41

Eoin was transferred, as I understand he could no longer be managed safely in the children's service. After he was transferred to Cranfield PICU I noticed that Eoin's behaviour when he was coming home changed. He was lethargic and sleeping more and wobbly on his feet. I also noticed his eyes jerking. And so when I brought Eoin back to MAH I raised this with staff. I was told by Dr. H40 that Eoin's medication had changed and nurses did not want to wake Eoin at 8:00am to give him his medication, and so now instead of four times daily, he had upped his dosage and it was given twice daily. I think following being told this I put in a complaint and there was a meeting held and attended by Dr. H40, another female doctor, and other MAH staff who I cannot specifically recall. 11:42 11:42

At this meeting I found out that as Eoin was a detained patient I no longer had any input and they basically had control over everything. I contacted Eoin's

solicitor at the time, who could not understand how Eoin was coming home three days a week when he was a detained patient. There was further discussion of what if anything could be done, but nothing came of it.

11:43

When I was on a visit with Eoin in MAH, someone senior came in and said they did not want Eoin's solicitor representing him as they did not know if Eoin had the capacity to appoint them. This man, whose name I do not know or recall, then produced a list of solicitors in the Antrim and Ballymena areas and told me to pick one of them instead. I refused to do so and objected to this, and so a meeting was arranged to discuss the issue.

11:43

11:43

I attended this meeting which was arranged with MAH, and my barrister accompanied me. During the meeting he had to threaten emergency judicial review proceedings about the staff on MAH imposing a legal team on Eoin and about his detention. Prior to this I had never been told that I could apply to a Mental Health Review Tribunal regarding Eoin's detention, and I had never attended any as I was never invited. I do not believe Eoin's solicitor attended or was aware of these Mental Health Review Tribunal's either. I am also not clear about how long exactly Eoin remained detained. He may have remained detained until he was discharged from MAH in 2010, when he was about 19 years old.

11:43

11:44

In or around 2008 there was an Education Tribunal to assess Eoin's educational needs. By this stage Eoin was in Cranfield PICU. I believe that the tribunal was in response to my application about the lack of education for Eoin from when he was excluded from school when he was 13 years old.

At the tribunal the behavioural nurse from MAH said that Eoin could not communicate using PECS, however I knew this not to be true as I have referenced previously in my statement.

I told the tribunal that I had provided MAH with all the materials they needed to help Eoin communicate and I had explained how to use them to a behavioural nurse, who did not know how they worked, and so she had just put them away in a drawer. I was surprised at the time that the nurse did not seem to know about PECS and that she did not make use of the materials after they were supplied much and I had explained them.

The tribunal recommended that those working with Eoin should understand autism PECS and there should be a proper behavioural analysis and interventions. I understood that funding would be made available to provide the recommended training. However, so far as I am aware, the PECS materials were still not used with Eoin during his time in MAH until one nurse later took it on herself to retrieve them and put them up. I feel

that MAH had an opportunity to implement the recommendations of the tribunal but failed to do so.

I believe that both MAH and the school from which Eoin was expelled failed to try and help Eoin develop and that MAH was effectively just containing him. 11:45

Eoin remained in PICU until he was transferred back to Mallow Ward on 23rd of January 2008. On the 17th June 2008, I took Eoin to A&E at the Royal because he had an injury to the big toe on his right foot, which I believed could have been broken. I had noticed Eoin was unable to walk properly and I had difficulty when I tried to get Eoin's shoe on. I checked his shoe and found that some of Eoin's socks had been stuffed up in the top of his shoe before they had been put on him. 11:45 11:46

As waiting times at the Royal were too long for Eoin, my sister, who was a doctor in A&E, looked at his toe instead and advised it was bruised tissue. I made a complaint to the staff in Mallow about Eoin's bruised toe and his difficulty to walk at that stage. The staff were not able to explain the bruised toe. 11:46

The visits home continued with Eoin regularly returning home for a couple of days per week. On the 9th of June 2009, Eoin was at home when he began gagging and finding it difficult to breathe. I called my sister, the doctor who had previously looked at Eoin's toe, and 11:46

she advised me to hang Eoin's chest over the bed. I followed my sister's instruction and Eoin vomited. I recall it smelled very bad and it was mostly bile and fluid. Eoin was sick again and I was concerned about what was coming out, so I called Eoin's GP and put Eoin in the recovery position. The GP called an ambulance and Eoin was admitted to casualty at the Royal. I put the contents of the vomit in a bag in case it was relevant, as to me it looked like part of Eoin's stomach lining, as the GP had raised concerns about this. 11:47 11:47

I was subsequently advised that Eoin had swallowed a paper towel. Given that Eoin had just returned home with me, I believe he swallowed the paper towel when he was in MAH. 11:47

Following this incident I had a meeting..."

- and you say where in Belfast: 11:47

"...with Eoin's social worker H488, together with social workers H486 and H489, and Dr. H40 and Dr. H49. They asked me if Eoin could have got the paper towel in the Ballymac Hotel, which is where I would routinely take Eoin on our trips out of MAH, or in my house. However, he could not have, as when Eoin went to the toilet when I was with him I always accompanied him. I was informed that the manager of Mallow said that none 11:47

of his staff had allowed it to happen. I could not confirm that it was done by a member of staff, I simply wanted to know how had happened. The staff from MAH were extremely defensive about the incident. I recall going to the toilet, finding a paper towel, presenting it and asking them how it could have been eaten by Eoin if he was properly supervised? There should have been minutes of this meeting, however I was not provided with any. I have never seen the outcome of any investigation into this incident. 11:48

After this incident Eoin was on two-to-one observation during the day and one-to-one at night. However, I do not know if those observation levels were always followed. 11:48

In August 2009 I got a telephone call when I was in Donegal from someone in Antrim Area Hospital advising that Eoin had been admitted as he was unresponsive and they could not get a drip into his arm. I did not get a call from MAH to inform me that Eoin had been taken to hospital. 11:48

I travelled to Antrim Hospital and Eoin was in a ward. Hospital staff had successfully got the drip into Eoin and were treating him for dehydration. 11:49

Eoin was discharged the next day back to MAH. I asked MAH how Eoin became so dehydrated as to require

hospital admission, but no explanation was ever given.

Also between 2009 and 2010, when Eoin was in Cranfield, I became concerned that he was being put into a seclusion room. I was told by a staff member that this had been used on Eoin on at least one occasion and in line with new physical intervention tactics. I saw the seclusion room on one occasion. There was no furniture, no sink and no toilet. There was a viewing panel in the door that led into the room. MAH staff called this "the quiet room" which I believe was an attempt to make it sound better. Apparently the staff used the seclusion room and physical intervention tactics to deter Eoin from banging his head.

11:49

My brother came across an article in the Irish Times in which an American expert had recommended the end of use of seclusion in residential facilities. Unfortunately I no longer have the article, but I recall the expert stated that children with autism do not respond well to isolation.

11:49

11:50

With consideration of this article I objected to the use of seclusion for Eoin with a male member of staff in Cranfield PICU, but I cannot remember his name. I also objected to the use of physical restraints on Eoin as I believed, having read this article, that it increased inappropriate behaviours in people with autism. I was never shown any documentation about

11:50

either the use of seclusion or restraint in MAH. The staff eventually agreed that these methods did not work with Eoin and that they in fact did make matters worse.

Throughout Eoin's entire time in MAH I do not ever remember seeing a care plan. 11:50

Eoin's issues with food remained throughout his time in MAH and Eoin was very skinny when he eventually left MAH. This can be seen from a photograph taken about that time (Exhibit 2)." 11:50

That's with the now page 27, Panel, and I will come to that in due course.

"MAH always told me that there were no options for Eoin to leave MAH. Thankfully I was contacted by a group (Autism Initiatives) through someone I had contact with whose son was also autistic, and this is what triggered the steps towards Eoin's discharge. 11:51

After being in touch with this group for only a few months Eoin was resettled to a supported living residential home run by Autism Initiatives..." 11:51

- and you say where that is:

"This was on a trial basis from 23rd June 2010 to the 1st November 2010, to see if it would work. This also

ended any MAH involvement by Dr. H40 regarding Eoin's medication. Eoin was never back in MAH and stayed in the supported living place beyond this trial period for the remainder of his life.

11:51

During the trial period, MAH staff went to the supported living room to teach MAPA restraint techniques, partly due to Eoin's needs and also for another autistic resident. There was some effort on transitioning in that the staff from the supported 11:52 living home went and saw Eoin in Cranfield prior to his move.

Until his discharge date, Eoin remained under the care of Dr. H40, but as soon as he was released I made an 11:52 appointment with the GP regarding his medication. Eoin's Tegretol medication had previously been changed twice daily instead of four times because the morning nurse did not want to wake Eoin. I now know that dizziness, drowsiness and unsteadiness are the main 11:52 side effects of Tegretol.

Eoin's behaviour, including drowsiness and being unsteady on his feet, continued during his time in the supported living home, so I made the social worker 11:52 aware of my concerns and brought Eoin to his community doctor."

- and you say where that is:

"...on the 3rd August 2010. Eoin's medication was changed back to four times daily and the amount was reduced as it was confirmed that the medication was causing the behaviour that had caused me concern. 11:53

I refused to accept Dr. H40's claim that he had control over Eoin's medication until the end of the transition period in November 2010, and I was much happier with the changes made through my contact with the community 11:53 doctor. Dr. H40 tried to object to this change.

I live within a 10-minute walk of the supported living home where Eoin was placed during this time. Eoin was in a downstairs room, which was nice. I would see Eoin 11:53 regularly and we would spend time together. I raised a concern that he had access to a stairwell and the staff were very co-operative in adjusting Eoin's room and bathroom to meet his needs and keep him safe."

11:53

I'm not going to read in the next paragraph, but to summarise it, you described how, whilst in the supported living home, you felt that Social Services prevented some safety measures that might have protected Eoin when he had a seizure or an outburst, 11:53 and you give some examples of that.

So if we pick up then at paragraph 84, which is at the bottom of the page:

"Eoin was happy during the seven years that he was in the supported living home. The relationship between staff and Eoin was friendly and they co-operated fully in trying to make Eoin's placement enjoyable. The staff brought Eoin out in a Volkswagen Caddy. Eoin also got a motability car so that he could go out for trips. The staff in supported living room home brought him out regularly to Helen's Bay and Newcastle and out for food. Eoin also came home from Monday to Wednesday each week. During this time I took Eoin to Dungloe in Donegal once per month, and he was very happy when he visited there. 11:54 11:54

My only real concern was that the staff in the supported living home did not have training in epilepsy management. They had Eoin on two-to-one during the day and one-to-one at night to try and keep him safe, which was the same regime that MAH had introduced. The supported living home staff learned quickly that if Eoin was lashing out it was because he was either in pain or having seizure activity." 11:54 11:54

At the next paragraph, Danny, you describe how Eoin passed away on 23rd April 2017, after having an SUDEP seizure, and he was 26, and I'm not going to read that out. 11:55

At paragraph 87.

"After Eoin died, the supported living home organised a day where they put up all the pictures of Eoin from his time there. It was clear that he was really happy there. In the seven years that Eoin was in that home he only had two outbursts when he was at home, which I believe was an indication of how much happier and settled Eoin was there compared to MAH. I have a copy of Eoin's death certificate which records his death on 25th April 2017 as sudden unexpected death in epilepsy (Exhibit 3). I also have a copy of the verdict on the inquest (Exhibit 4)." 11:55 11:55

I'm not going to go to those at this stage. The Panel has those.

"The Inquest was carried out by Coroner McCrisken. I do not believe that I was appropriately legally represented at this inquest, and I did not fully understand the process. 11:55 11:56

Two staff members from the supported living home gave evidence at the inquest and it seems that neither of them knew that Eoin was at risk of SUDEP, which I find concerning. 11:56

I would like the Inquiry to consider MAH's management of Eoin's transition to the support living home, especially how well MAH staff ensured that the risks to Eoin of SUDEP were properly explained to staff at the

supported living home and that they understood how to manage those risks and had in place an appropriate plan.

This had been clearly explained by the consultant paediatric neurologist at the Royal to MAH as far back as 2005, when she had advised on steps to be taken with staff at Eoin's respite units and school. 11:56

I would also like the Inquiry to consider the inconsistency in approach to Eoin's medication which was a crucial element of Eoin's seizure control as well as his safety, well-being and overall quality of life. 11:56

I have had to attend counselling as a result of the impact of everything regarding Eoin's treatment and care. My only regret in life is that Eoin ever set foot in MAH. He had to endure three years in MAH to get seven years in the supported living home." 11:56

11:57

So if we just skip over the page to page 22 then, you provide, Danny, a declaration of truth in relation to this statement, and you sign and date it, and the date is 5th September 2023, and then thereafter follow the exhibits, which I've already touched upon, Danny. 11:57

So the first and probably easiest question that I'm going to ask you today is: Are you content to adopt the contents of that statement as your evidence to the

Inquiry?

A. Yep.

73 Q. I think you've provided two photographs of Eoin as part of your statement, and we're going to show the former one of those first. It's at page 24. You've indicated you'd like that to be shown today. So if you can bring that up on screen. It is page 24. You can see that there, Danny, can you? 11:57

A. Yep.

74 Q. Yeah. Okay. Is that a photograph of you and Eoin? 11:58

A. Yeah.

75 Q. When was that taken?

A. I think he would have been 20s, early 20s. Maybe around 20.

76 Q. Okay. Why did you select that particular photo? And, Danny, if you need a moment, take your time, please. 11:58

A. That's the family house.

77 Q. Danny, I can move on.

CHAIRPERSON: Let's move on.

A. It's the family house in Dungloe. 11:58

MS. BRIGGS: Family house. We'll move on.

CHAIRPERSON: It looks like a very happy photograph. Was he at home then?

A. Yes.

MS. BRIGGS: We'll take that off the screen. 11:58

CHAIRPERSON: Yeah. Have some water if that helps, and if you want a break we can have one. This sort of thing can catch you unexpectedly.

A. It did.

CHAIRPERSON: We understand that. All right. Are you okay to keep going?

A. Yes.

CHAIRPERSON: All right.

MS. BRIGGS: Are you okay? 11:59

A. Yeah.

78 Q. Are you sure?

CHAIRPERSON: All right. Okay.

79 Q. MS. BRIGGS: All right Danny. We'll take our time and we'll talk about Eoin's communication. Okay. Because 11:59 you described how he would use the picture exchange communication system, and you say that you yourself trained in that?

A. Yep.

80 Q. Can you tell the Inquiry a little bit about how that 11:59 worked?

A. Well, basically it was University of Ulster, there was a doctor up there, Mickey Keenan, he was head of the Psychology Department, was it. I still don't know to this day. We got a letter, they invited some families 11:59 up who had children with autism, and he started teaching us the applied behaviour analysis, and then through that there was a course came up of PECS, the picture exchange communication, and we done it. It was actually over in Malone House we had done that one. So 12:00 it gave me the ability then to, instead of Eoin maybe coming in and hitting you a thump and you were getting frustrated trying to understand what he wanted in the kitchen, for instance, you know, because there was

multiple stuff in there, and they taught us to narrow the stuff down, and put the symbols up. There were six stages, if I remember to it, and we were able to teach Eoin up to Stage 4 in about an hour. He was -- at the start he was a wee bit hesitant on it and didn't want to do it, but then inside an hour we - we actually video'd it and they used it up in the university for other people, you know, that you could make these breakthroughs with the children, and it actually brought down Eoin's frustration because it gave him a better way of communicating than maybe trying to get your attention by lashing out or whatever, you know. It was through the likes of Dr. Mickey Keenan and the ones in the university that gave us the chance to learn this. 12:00 12:00 12:01

81 Q. And did that involve Eoin pointing at pictures of things to say what he wanted? How exactly did that...

A. It actually progressed from if Eoin wanted something say like on the table, we'd have put the symbol here, and if he reached to that he was redirected to the symbol. So he was very fast in learning to get this he had to lift the symbol. Then it went from that on to the wall, so he had a communication wall chart, and then went into like a wee folder book. So he was able to - we had like, on the outside of it we had like a sentence strip they called it, and it had the symbol "I want", and he was able to go into the book, take the appropriate symbol, put it on that and exchange the sentence strip, and then we would have read it out in 12:01 12:01

front of him, and if it was correct he got what he wanted. So it brought all the frustration down, not only on his part but also on mine.

82 Q. It sounds like Eoin took to it pretty well from what you're saying? 12:02

A. He took to it fantastic. He was - I think he was one of the first ones they said he was able to go in, they would call it backward chaining, where if somebody can learn from the back way of doing it to the start, he was able to go in and take it apart and put it back 12:02 together again and then exchange stuff. He was very, very good at it.

83 Q. And it is something that you describe in your statement that wasn't really picked up with him while he was in Muckamore, is that right? 12:02

A. Exactly. Yes.

84 Q. Okay.

A. What had happened was Eoin, after I had taken the legal proceedings against the school, the special needs school, he was out of school for years, and I had 12:02 converted the garage into a wee classroom, multisensory room, and with the help of a few of them out of University Ulster, undergraduates I think they were, they were studying applied behaviour analysis, they would have came down to the house, we'd have taught 12:03 Eoin. But I actually believe that he was taught more in six months, he learned more in six months than he did probably in all the years he spent at the special needs school.

The tribunal eventually came around, the education tribunal actually came around, but every year it was supposed to be - we had a date set that superceded the education statements or something like this here, and it was put off. We weren't allowed to give the evidence from the previous year. So eventually we got there and they recommended that anybody that was in contact with Eoin or working with him should have the knowledge of the PECS and they wouldn't term it applied behaviour analysis, they should have a knowledge of behavioural interventions and an understanding of autism.

12:03

12:03

85 Q. And you say that that knowledge was lacking in the staff at MAH. Is that a fair way to summarise?

12:04

A. Yeah, 100%.

86 Q. You talk about in your statement how Eoin was firstly in Muckamore for respite as a child while your house was being renovated, and that was 1996 to around 1997. You describe in your statement a lack of care planning around Eoin, and you can't recall any discussion at that time about whether he would receive any treatment. Focusing on that period when he went in as a child, do you know if any treatment, other than perhaps medication, was actually provided to him?

12:04

12:04

A. The only thing I can remember back then was he may have had on the odd occasion went round to, I don't know whether it was like a wee child's school or whatever it was, he was taken out of the ward occasionally and

brought round to like a preschool thing, you know, but it was more -- he was up there just -- I didn't see any education or any kind of benefits coming out of his stay even then. It was more just to get him out of the house because this extension was being built for him. 12:05

87 Q. Okay. You go on to describe then Eoin's readmission when he was 15, and that's in 2006, and you say that he went to Mallow Ward. Was that a result of the determination in the legal proceedings that you mentioned, that he required behavioural intervention, 12:05 is that why he went to Muckamore that second time?

A. They insisted that he should get behavioural interventions, even though he was getting the best, I believe the best behaviour and communication interventions at home with the help of the University 12:05 of Ulster. But because of the legal, what I understood was that they kind of demanded before he would maybe be thought of going back into a special needs school, that they wanted these behavioural reports compiled, and it was by the same nurse up in Muckamore that went into 12:06 the schools. So the only place that he could get it was to go back up into Muckamore.

88 Q. So effectively you were being told that he had to go to Muckamore to get that behavioural intervention?

A. Yeah. Plus I was getting no assistance whatsoever at 12:06 the house. So it's not nice to say it, but financially, you know, I couldn't afford any longer to keep implementing the stuff I was doing at home with him.

89 Q. Okay. And what about that behavioural intervention that it was determined that he needed, did he get that while he was in Muckamore?

A. No.

90 Q. No. And was there any other type of treatment or intervention during his time there when he was a teenager until he was discharged in 2010? 12:06

A. No.

91 Q. No.

A. Actually when he was in Cranfield ICU they had like, from what I can remember it was like a fenced off small area out the back, maybe the half the size of this room or something, and that would have been the only place he would have got out into, and the only time he got actually off the ward was when I came up to bring him home for three days. 12:06 12:07

92 Q. You say that you never saw a care plan during that time?

A. No.

93 Q. Okay. So to your mind what was Eoin doing while he was in Muckamore? Was he receiving any type of treatment or specialist care? 12:07

A. I can remember, I can remember one person, staff member, actually saying to me - and I forgot to put it in this - that Eoin's time is basically spent, if he was allowed out into it, in this small confined area outside at the back of the unit, and on some occasions I believe he was actually barefooted. They didn't put his socks or shoes on. 12:07

94 Q. Okay. What about the staff responsible for Eoin's care during his two times at Muckamore? Was there anyone in particular, without naming any names, who took overall responsibility for Eoin's care during that time?

A. If I remember right and supposedly, it was H40. 12:08

95 Q. Would that have been when Eoin was admitted as child or when he was admitted as a teenager or both?

A. Teenager.

96 Q. Teenager. Okay. If we focus then on H40. What was your communication like with H40? How well or not well 12:08 did they keep you informed about Eoin's care in Muckamore?

A. I'm trying to remember back, but I don't think there may have been much communication other than when he was being transferred from Mallow, is it, over into 12:08 Cranfield, then the big issue came about the medication.

97 Q. Okay. And we'll come to that in due course. What about your communication with other staff? How well or not well, as the case may be, did they keep you 12:09 informed about Eoin's progress, or what he was doing, or how he was getting on at MAH?

A. There was none really.

98 Q. And we'll move on, Danny. You described the food on Mallow Ward and how Eoin lost weight when he was there, 12:09 and that he continued, you say, to have issues with food throughout his time at Muckamore. You mention in your statement that there was a dietician for Eoin back when he was 15 or so when he was on Mallow Ward. Did

that dietician give any reason as to why Eoin may have been losing weight when he came onto the ward as a teenager?

A. I actually went to a meeting up in Mallow Ward. It was attended by the manager of the ward, staff, the dietician was actually there, and if I remember right, there may have been somebody there from the mental health review or committee or something like this about this, and they were raising concerns about Eoin's loss of weight, and you came out of the room and you went down, it was like a small dining room, and they had these trays out with the food in it, and there was beans, that spam ham, fried eggs, and it was a warm day and there was flies and wasps flying about it, and I basically said to them like, you know, "That food not suitable for anybody. I wouldn't eat it", and I knew right away that Eoin wouldn't eat anything like that. So -- I actually then had been sharing, maybe bringing him his stuff up to the ward, and it was just beyond me, you know, that he was losing weight. And the dietician had mentioned about Eoin taking two supplements to try and keep his weight on him, and when I was talking to the nurse there was one of them and they actually showed me it, and it was like a very thick substance in the glass, and I asked her actually how she got Eoin to drink that, and she said they basically followed him round the room until they got him in a corner and he had to drink it. 12:09 12:10 12:10 12:10 12:11

99 Q. When you made comment about the quality or lack of

quality of the food at Muckamore, what was the response of the dietician or others?

A. The manager - I can remember that the manager had actually told me that he had disengaged with the -- it was an outside supplier and they were getting a new supplier in.

100 Q. And did that happen?

A. I think so. I can't recall.

101 Q. Can you recall if the quality of the food actually did improve? 12:11

A. I don't believe it did.

102 Q. You don't believe it did. Okay. We do have a photograph of Eoin when he lost some weight, Danny. I don't want to show the photograph on the screen unless you're happy with it being shown on the screen? Would you rather -- 12:11

A. No, you can put it on for the rest.

103 Q. Put it for everybody else to look at, okay, and you can look at me. I'll just ask you about Eoin's weight and that's that. Okay. I think it's at page 27. Okay. You just look at me and I'll just ask you about his weight, and everyone else can get a feel for the photograph that you've selected because you feel that it shows Eoin around the time of his discharge when he was very thin. Okay. Okay. So everyone has seen that now. So we'll take that off. Did Eoin have the continued input of a dietician throughout his time at Muckamore as a teenager? 12:12 12:12

A. I can't recall that, no.

104 Q. You can't recall. Okay. You've also talked in your statement about Eoin's dental care. You said he had his teeth examined by a dentist when he was first placed on Mallow Ward, and about two to three years later the dentist in the RVH said he had problems with his teeth. Are you aware, other than that initial consultation with the dentist when he was first placed on Mallow Ward, whether Eoin had the continuing input of a dentist at Muckamore? 12:12

A. There was actually two I can recall. One of them was that they said they couldn't, you know they were trying to check his teeth. They got the front teeth checked and everything was okay, and then I brought - he had a wee DVD player, so we put snooker on it, and she actually got in and checked all his teeth and said basically they were fine, there was nothing to worry about. But I had noticed when he was coming home, when he was maybe chewing on stuff - it took me a while to catch on to it - he would hit out, you know. So I think I went through his doctor, his community doctor, and got arranged for him to be seen in the RVH dentist, and there was a three year waiting list, but they then contacted me and said that there was a dentist coming down from Coleraine Hospital, that he had got extra funding to bring people off the waiting list and it was him that seen Eoin and told me about what was wrong with his teeth and then brought him up to Coleraine to get the treatment. 12:13 12:13 12:13 12:14

105 Q. Okay. And while he was in Muckamore after he was seen

by those dentists, was he being seen by dentists in Muckamore regularly or do you know, or you don't know?

A. No, I don't think so.

106 Q. You don't think so. Okay. Why don't you think so?

A. Because we had to bring him back up to Coleraine again, it was done over a few months, you know, to get, you know, his teeth sorted. Eoin would have grinded his teeth, you know, with the seizure activity, and if I remember right I think altogether he had eight, maybe up to eight fillings to get, and two wisdom teeth which were impacted, and the dentist actually told me he believed that Eoin's roots were infected. I don't know how he was able to figure this out, but he was saying that because of the amount of infection in the gums that he was able to say that he thought his wisdom teeth were infected for a couple of months. So it was beyond me how a dentist, and this is a dentist that was on site in Muckamore, had previously told me his teeth were fine. 12:14 12:14 12:15

107 Q. Okay. All right. We'll move on to another topic. Okay? You describe how Eoin went in to Muckamore when he was 15, a second admission, as a voluntary patient. And you say later on in your statement that he became or was a detained patient at a later time. Were you informed when or why that change happened from a voluntary patient on admission to a detained patient some time later? 12:15 12:15

A. No. It came about when -- I had noticed Eoin, when he was coming home from Cranfield for his three days, that

Eoin was very floppy, sleeping most of the day, and his eyes were jerking about all the time. He just wasn't himself, you know. When I looked at the medication, they had actually - which I had to follow - they had changed his medication from four daily doses to two daily doses. So it went to he got his medication at lunch hour I think it was, yeah, lunch hour, and then at night-time, and they had also increased the medication which, you know, when I was talking to H40 about, he indicated that it was the nurses in Cranfield thought it was unfair to wake Eoin at eight in the morning to give him his medication, so they just double dosed him, you know, and he was just like a Zombie, you know. 12:16 12:16

108 Q. When you're talking about that, is what you're saying to the Panel the reason they were able to do that was explained to you because Eoin was detained? 12:17

A. Yep.

109 Q. But that had never been told to you. When he changed to a detained patient, you never knew that until that time? 12:17

A. No.

110 Q. You also give evidence about incidents involving Eoin during his time in Muckamore as a teenager, specifically injuries to Eoin. You talk about how he injured a toe, you also talk about how he swallowed a paper towel, and you also talk about another time when he was admitted to hospital with dehydration? 12:17

A. Yeah.

111 Q. There seems to be a theme to your evidence, and correct me if I'm wrong, that explanations were never really provided as to how any of those three incidents came to happen?

A. None. 12:17

112 Q. And when you raised these incidents with staff, and other incidents, is it fair to say nothing was forthcoming by way of response?

A. What they would have said was they would prefer internally to investigate it first, and that would have 12:18 been the Social Services involved from the outside too, and I never received any, any reports or conclusions to them.

113 Q. And when you spoke to staff about these particular incidents, did anyone ever advise you of your ability, 12:18 for example, to put a complaint in writing, or a concern in writing, or use any formal process to do that? Did anyone ever tell you about that?

A. Not that I can recall. You know, I think, you know, maybe you've heard it from other people that have been 12:18 giving evidence, sometimes you're a bit hesitant, you know, you're afraid to go, basically to go at them with what you believe happened because you know your child is still in that environment, and you have this dread that something else could happen, you know, maybe more. 12:19 So you were always kind of very hesitant in what you were saying, but at the same time the issue over the green paper one, like I did produce that in front of them and produced their paper towels and they matched.

The manager, H212, he actually reassured me 100% that the staff would not have, you know, gave Eoin this or, you know made him swallow it, but as I pointed out to him, you know, he couldn't give me 100% because he isn't on the ward 100% of the time, you know, so. But it was as if, you know, let's look at all options and different scenarios, but do not look at our people inside this environment, you know. 12:19

114 Q. And did the likes of H212 or any other staff say to you "Danny, there's a formal complaints process here. You can write stuff down"? Did any staff member ever explain that to you? 12:19

A. Not that I recall. I can recall just having the meetings with them and Social Services up on Mallow itself. I can't recall how they came about. 12:20

115 Q. Did any staff member or anybody else ever say to you that there are patient advocacy groups that families can avail of that might help you and, if so, did you engage with any of those groups?

A. No. 12:20

116 Q. No. Okay?

A. Sorry, the meeting up in Mallow came about after I had came out of the hospital with Eoin and had the green paper towel still in the bag, there was vomit, and I had a meeting in the Marie Sheehan Centre with Eoin's social workers to point out, you know, my concerns, and they in turn were basically asking me would he have got it in the house or in the Ballymac where we would have went for something to eat, and I pointed out that there 12:20

was no chance that that had happened and that I believed it had happened up in the Mallow, and that's how the meeting in then Mallow came about.

117 Q. Okay. You also -- Danny, I'm going to move on. You gave evidence about the use of seclusion and restraint, and you say that ultimately staff agreed with you that it didn't work? 12:21

A. Yeah.

118 Q. And that it made matters actually worse for Eoin?

A. Yeah. 12:21

119 Q. Does that mean that they stopped using seclusion and restraint altogether at that time?

A. I don't know what they done.

120 Q. Okay.

A. You know I even learnt myself, you know, out of just learning the applied behaviour analysis stuff, that if you try sometimes to intervene, you know, it just escalated the behaviours, you know, so you learnt different tactics as you went along, which I believe Muckamore -- they didn't have the knowledge and they didn't know how to implement them. 12:21

121 Q. Okay. I'm going to ask you briefly about his resettlement and particularly the change to his medication that happened at that time?

A. Yep. 12:22

122 Q. You've already touched upon it both in your statement and in your oral evidence. You've said how his medication was brought back when he was resettled in 2010 to four times daily instead of twice daily and the

amount was reduced. How did that change in his dose, the regularity of his dose effect Eoin's presentation?

A. Oh, he came back to -- how that came about, I think Eoin was being resettled about July that year, 2010 was it? And the staff in the supported living, along with myself, were concerned about Eoin's - it was the same again, you know, the eyes darting all over the place and sleeping during the day. So I, along with them agreed, that we -- we made the appointment with his own doctor in the community, and he reduced it right away back down to the four daily, plus I think it was 200mg off the dose, and within a short period he - I could have went over to pick him up and he could at least walk to the car, you know. You could say he was like a drunk person sometimes, but that all started coming back down again, you know. 12:22 12:22 12:23

123 Q. Okay. You use the word in your statement, "inconsistent", that's how you describe the approach to Eoin's medication?

A. Yeah. 12:23

124 Q. What makes you say it was inconsistent?

A. Well, instead of - if I was a doctor in Muckamore and a staff member, you know if I seen a child where you had increased their medication, double dosed it or, sorry, put it on two daily, and you seen a change like that, you know, why keep it going? And even when Eoin came into the care of the supported living, Dr. H40, when he heard that Eoin's community doctor had agreed with us that Eoin would be better going back to the four daily 12:23

dose and reduce it by 200mg, he still, and I believe that he -- because he had outreach to Eoin until November 2010, it was my belief he tried to block that and he wanted his way reinstated again, you know. So there was that kind of approach, you know, that -- and it did frighten me that, you know, here's Eoin starting to settle down after a couple of months in his supported living and you still were going to have this interference, you know, from Muckamore. But thank God like it didn't happen. He was kept on the dose that was recommended by his own doctor and his own consultant. 12:24 12:24

125 Q. Okay. I'm going to ask you then about Eoin's time in his resettlement place before he passed away, and you say and you detail in your statement how he was happy during that time? 12:24

A. Yeah.

126 Q. How would you say his happiness and his well-being compared there to when he was at Muckamore?

A. Well, what we had learnt too was the first, the first few weeks he did, he did kind of hit out, but then this was when he was being double -- or, no, the dosage of the medication was affecting him, and then we discovered he had the teeth problems and different stuff. So when did he settle down he - the staff in the place were young people in maybe in their early 20s, and they were absolutely fantastic with him, you know. He went from a person that was basically -- unless he came home to me three days a week and we went 12:25 12:25

out places, they brought him out places. They got to understand his behaviours. They worked fully with me, and co-operated with me, and they just got to love Eoin, you know, and he got to love them. You know, I think any incidents that they realised very quickly had to do with internal pain, discomfort and stuff like this, and they had -- I can only say, even when we were at the inquest, I didn't want this place that Eoin was in or the staff, it being a negative reflection on them, you know, that he had the seizure and passed away, because I had to remember he had seven fantastic years in it. You know, so. And then his eating, his weight went back on again, it stayed back on again and, Jesus, they spoilt him, you know. It was brilliant. 12:25 12:26

127 Q. All right. Danny, Eoin passed away while he was at his resettlement facility, and I'm not going to ask you about that, but I want to offer my condolences for Eoin's passing. You do mention in your statement how it is important to you to raise that the staff in his resettlement facility may not have been trained in epilepsy in the way they ought to have been and they didn't know about SUDEP. 12:26 12:27

A. Yeah.

128 Q. I just want to give you an opportunity to expand on that a little bit if you want to at this stage. You don't have to, Danny. 12:27

A. I think even myself I became oblivious to the risk because I was used to Eoin having maybe one seizure a week and he recovered, and I knew how to deal with

that. I also had the recovery medication in the house, same as the ones in the bungalow. But it was -- even coming up to that happening in April 2017, I think it was about February -- actually it was on his birthday, I had done another first aid course and offered the staff in it that I would bring them along with me and pay for them, but they weren't able do it because of the shortage of staff. Some of them had done their information about seizures, it was done on-line, you know, for a couple of hours or stuff like this, which I think even in the inquest it was pointed out that wasn't good enough, you know, it should have been more. But, again, I didn't want that portraying this place as a negative place. You know, as a consultant said to me, you know, if Eoin had had the seizure in front of me, even though I knew how to put him in the recovery position and different things, it was going to happen, you know, and there was nothing that could have been done, you know. 12:27 12:28 12:28

129 Q. Okay. 12:28

A. So basically I wouldn't find a fault bar just that wee bit of training, but it wasn't going to help Eoin.

130 Q. All right, Danny. Before I hand over to the Panel who might have some questions, I've said to you that I'm going to give you a chance, if you want to, to say anything else that you feel you want to say about Eoin's time in Muckamore? 12:28

A. I just, I totally regret that as a parent I allowed that to happen. It's something that hangs over your

head, you know, and even earlier when I was listening to that girl and she was talking about the pictures, you know, the happy times with the child, I have fantastic beautiful memories of Eoin, but at times this haunts me. But I would also like to thank the positive people, you know, the people that did help.

MS. BRIGGS: All right, Danny. I'm going to pass over to the Panel now. All right. 12:29

QUESTIONED BY THE CHAIRPERSON

131 Q. CHAIRPERSON: I've just got I think two very short things. Going way back in your statement, you remember when there was some damage to Eoin's feet when he was in Muckamore? 12:30

A. Yes.

132 Q. And you actually went straight to the RUC?

A. Mhm-mhm.

133 Q. I was just wondering about that. Did you go to Muckamore first and say what happened? I'm just wondering how - this was long before any of the wider allegations that we know about happened. 12:30

A. Yeah.

134 Q. So what took you there? 12:30

A. If I can recall, you know, I think I asked them, because I actually do have Eoin's boots with me, you know, from that period, how it came about. We had a multiagency meeting where they came up with these

different scenarios, and they were basically, I believe, proving that their reasons for that couldn't have happened. So that's why then I went to the police.

135 Q. Yeah, I understand. But it wasn't that Muckamore didn't react, as it were, to a complaint? 12:31

A. I think it was more that they didn't - I didn't believe they did, you know, at the time. I didn't believe that they were investigating it.

136 Q. Yeah. You also said during your oral evidence that you were very hesitant to complain? 12:31

A. Yeah.

137 Q. Because you dreaded something worse happening. Can you just explain what you mean by that?

A. I think in the earlier one, you know when Eoin was young, you knew there was an end game, you know, that he was only there and he was still coming home because of the extension being built for him. That's one of the reasons I went to the police to investigate it. The difference with the older one was, when Eoin was older, I didn't know whether or when he would be coming home or I would be getting outside assistance, you know, to help with me. So, it was different then, you know, where you were kind of -- I just dreaded even confronting people, you know. It was the same with the incident in Eoin's school, if I can go on to that, you know, it kept me a year to go to a solicitor after a number of incidents, because I knew he was going to be put out of school and, you know, you're always afraid 12:31 12:32 12:32

to - these people make out, and even the likes of when I put the complaint in to the Social Services, you know, it was like one so-called professional investigating another, and as a parent you were afraid to take these people on. If that makes sense? 12:32

138 Q. Yeah. And that must make you feel very powerless?

A. Yep. I think it's, you know, when you came out of some of them and you were raising your concerns, your reasons or your thoughts of how these incidents happened, and it was like nobody believed you. 12:33

139 Q. Yep. Yep. Is there anything else you want to say to us?

A. I'd just like to thank everybody for giving me the opportunity to raise my concerns, you know, and hopefully it helps you. 12:33

CHAIRPERSON: Well, can I just thank you on behalf of the Panel and the Inquiry generally for coming along to give evidence about Eoin. It's obviously terribly difficult to do what you've just done, and we all understand why at times you got emotional. So, I am 12:33 just going to thank you very much indeed for making the statement, putting yourself through this experience, but I hope it is of some benefit to you, because through you we have heard about Eoin and it's very been very useful. So thank you very much indeed. 12:34

A. Thank you very much.

CHAIRPERSON: All right. If you'd like to go with Jaclyn.

THE WITNESS WITHDREW

CHAIRPERSON: I think the next witness is 2:00 o'clock.
MS. BRIGGS: 2:00 o'clock. It's P107's brother and it 12:34
is Mr. McEvoy will be taking that evidence.
CHAIRPERSON: Excellent. Thank you very much indeed.
We'll try and start promptly at 2:00. Thank you.

LUNCH ADJOURNMENT 12:34

THE HEARING RESUMED, AS FOLLOWS, AFTER THE LUNCHEON ADJOURNMENT

CHAIRPERSON: Thank you. Mr McEvoy.

MR. McEVOY: Good afternoon, Panel. Good afternoon, Chair. In this session the Inquiry will hear from William, who is the brother of John, otherwise known to the Inquiry as P107. There is a statement, the number of which for the Inquiry purposes is 161. 14:02

CHAIRPERSON: Okay. Are we ready for the witness? Thank you. 14:03

MR. McEVOY: Thank you.

P107'S BROTHER, HAVING BEEN SWORN WAS EXAMINED BY MR. MCEVOY AS FOLLOWS: 14:03

CHAIRPERSON: Good afternoon. Thank you very much for coming to assist the Inquiry. We met backstage and, indeed, you and I have met on a number of previous occasions. So you're very welcome. I'll hand you over to Mr McEvoy. 14:04

MR. McEVOY: Thank you, Chair. Good afternoon, Billy. As you know my name is Mark McEvoy. I am one of the Inquiry counsel and, indeed, we've met before also. Billy, for the purposes of the Inquiry today you have produced a statement, which is hopefully before you. It is dated the 20th of September 2023. Do you wish to adopt that statement as the basis of your evidence to the Inquiry? 14:04

A. I do.

140 Q. Okay. Billy, I know you have been following the Inquiry proceedings closely and, therefore, you'll know that what will happen next is I'm going to read the statement into the record and then there will be some questions? 14:04

A. Okay.

141 Q. So:

"I, Billy, make the following statement for the purpose of the Muckamore Abbey Hospital Inquiry. In exhibiting any documents I will number each document. So my first document will be Exhibit 1. 14:05

My connection with Muckamore is that I am a relative of a patient who was at Muckamore. The relevant time period that I can speak about is between 1961 and 2014. 14:05

I am the brother of John, who was a voluntary patient at Muckamore between 1961 and 2014. I attach photographs of John at Exhibit 1. 14:05

John was born on 13th March 1956 and is one of three children. I am the eldest, John is the middle child, and my sister is the youngest. I am three years older than John. We were a family of five, us three children and our parents. 14:05

We grew up..."

- and you give the name of the place in Belfast:

"My father was an engineer in Harland & Wolff who worked throughout the world, and my mother was a housewife.

John is non-verbal and did not go to school. My mother was a housewife and stayed home to look after him. He had very challenging behaviour and had to be watched all the time. From the earliest that I can recall John could suddenly become violent. When I was a child it was never discussed what was "wrong" with John in terms of any diagnosis. We just dealt with it and that was that. I only realised that John was "different" when I became older. At the time I thought John had a learning disability. 14:06

John's behaviour was difficult and challenging. He could become difficult to handle and occasionally aggressive and, as I got older and bigger, he would have hurt you. He was also prone to taking his clothes off. He didn't know any better. Although John was not a big guy we used to call him "The Hulk" because he would rip his clothes off very quickly. 14:06 14:07

He could be set off by simple things. If he took off, our mum found it very hard to control him. When that happened, I would catch him around the waist and lift

him up until he calmed down, if it was required. I was aware as a child that John's behaviour was different to me and my friends.

My sister told me in later years that John had a cerebral haemorrhage when he was about four years old. My sister was told this by a friend of our mother's from the church who she was close to after our mother passed. 14:07

John became very difficult to control and keep safe. At times he was uncontrollable, he was a danger to himself. If there was a door open, he would run out onto the road. He started running around naked. The road beside the house was very busy. It was very strenuous to keep John safe. 14:08

John was also having a lot of seizures and had to be constantly supervised. The first seizure that I remember was when John was about five years old. When John had a seizure he would just drop like a stone. Our family GP at the time on the Newtownards Road was... 14:08

- and she is named: 14:08

"...and our mother sought her assistance with John's seizures. For John, seizures were the big thing. We were all aware of them and would I have watched my

mother and father deal with them, and as I got older I learned how to deal with them as well. We just accepted it and learned to live with dealing with these things, but people outside the house didn't understand. I always tried to protect him as he was my brother. 14:08

It was around this time that our mother had to go into hospital for an operation and our father was travelling for work. My mother did not tell me what was happening at the time, but I was later told by my sister and by 14:09 our mother's friend that the GP said that there was no choice but to put John in Muckamore. She said if he did not go in the strain would kill our mother. I think that John was brought in for assessment, but I was not made aware of what was wrong with him and I do 14:09 not believe that the family was informed. I have not seen that assessment.

My mother took a nervous breakdown when John went into Muckamore and found it difficult to deal with 14:09 everything. My father couldn't accept it either and found it very difficult.

John was admitted to Muckamore on the 20th May 1961, when he was five years old. I do not recall John going 14:09 into Muckamore. I just remember he was not there one day. Years later, after my mother passed away, I found the committal papers in my mother's belongings. It was probably the only thing she didn't destroy. I got a

shock when I found them and was very tearful. I refer to the form of consent to special care signed by our mother at Exhibit 2. John was taken to Muckamore and admitted for special care in the form of institutional care. 14:10

I was quite young at the time John was admitted, about nine years old, but I remember going to see John in Muckamore and being told that he would only be there for a while. 14:10

There was a specific bus that went from Smithfield to Muckamore on a Saturday. It stayed until 4:00pm and brought you back again. I grew up around Muckamore. I went once per week with my family until my grandfather 14:10 paid for my mother to have driving lessons, and then she got a car, after which we no longer needed to take the bus.

Our mother would bring John fresh clothes and food that 14:10 he liked. We would also bring him treats and always sweets. Our mother also brought sweets and cigarettes for other patients. Many patients did not receive visits from anyone. Our mother's church group collected money and gave it to our mother and she used 14:11 it to buy treats and sweets for John and for other parents. John has a sweet tooth and I still bring John a bag of sweets when I visit him.

Following John's admission to Muckamore, and after a period of time had passed, our family would bring John home on a Friday and he would go back to Muckamore on a Monday. It was very difficult to look after him at home as someone had to be with him 24-hours per day. He was active and could run around. He would try to feed himself, but he had a habit of storing sweets in his cheeks, which was not good for his teeth. 14:11

When we visited John at Muckamore, the staff would bring him to see us in a visitor room. We would take him out to the grounds and we would also go to a cafe in the grounds. We never really mixed or interacted with other families a lot. My mother did speak to a few families in the villas at Muckamore. 14:11 14:12

As a child, John was a voluntary patient, and this remained the position throughout John's time in Muckamore. He was not detained, as our mother had provided her consent. Our parents were entitled to apply to bring John home for a period of leave if they gave written notice, but we were not told why John could not come home permanently. Our father really did not want John to be in Muckamore but there was never any question otherwise. 14:12 14:12

At some point the weekend visits stopped because we were told they destabilised John as when he went back to Muckamore he was out of routine. I can remember

John showing resistance when going back to Muckamore after visits, and I remember him trying to stay in the car by putting his feet up against the seats and holding on to the handles to prevent himself being taken out. 14:12

In or about 1972, when John was about 19 years, I was asleep and hurriedly woken by our mother. She asked for my car keys. It turned out John had broken his leg, which she had been told by the police who came to 14:13 the family home door. This is the first time John broke his leg while he was a patient in Muckamore. My mother was away for a week looking after John, and I think that our mother stayed with our cousin whilst John was admitted to the Waveney Hospital in Ballymena 14:13 being treated.

I subsequently learnt from our mother that the staff informed her a patient was involved in John's leg being broken. Apparently he had driven his wheelchair into 14:13 John. I have never seen anything to suggest that this incident was investigated, even though it clearly happened when John was in Muckamore.

There were two patients who regularly harassed John." 14:13

- and you name them.

"I used to go in and I would have seen how those two

patients treated John. I do not know what, if anything, was ever done about this, as our mother would always impress on us not to make a fuss or complain. She deferred to the experience and authority of those looking after John. 14:14

In 1980 John was in Ward C8. I learned from my sister there was an incident where one of the staff was sexually interfering with patients. My sister knew this as our mother had confided this to her. My mother 14:14 asked my sister to promise her that she would not tell me, I think she would have worried about me causing a fuss. The person was a male staff member who then disappeared. Our mother enquired where the staff member had gone, and it seems the person may have been 14:14 suspended. Our mother was told that the person did not have anything to do with John, but I am now no longer sure that I can believe this. I am aware that our mother would not have questioned things and would not have looked behind an explanation given to her by the 14:14 staff. She was of that generation that tended to believe what a professional person said.

John could walk around on his own, he should have been supervised, but he did use to wander around the ward. 14:15 I remember that John always had bruises throughout his time at Muckamore and he often had stitches.

In the late 1990s I felt that John was sustaining a lot

of bruises. When something used to happen and John would have stitches, our mother would be told about it when she next visited. Our family did not have a telephone in the early days, so this was presented as the easiest way of letting her know. I remember asking our mother what happened, and she would say that John had a seizure, or he fell, or he hit something. As far as I am aware she was passing on what she had been told by the Muckamore staff. 14:15

It seemed to me that John had stitches every few weeks, but I am aware that John could fall off the toilet. John needed help with personal hygiene. He would indicate that he needed to go to the toilet, but if he was left there he could fall off, especially if he fell asleep on the toilet, as he did sometimes. At this stage I trusted the staff at Muckamore and assumed that John's injuries were from falling in some way. 14:16

When John would come home at the weekend when he was a child, he did not sustain bruises or end up needing stitches. We all made sure that John was constantly supervised to keep him safe. 14:16

I had built up a relationship with most staff at Muckamore for a period of 12 to 15 years, and I trusted them, but in or around the early 2000s, I started to ask questions about the adequacy of care, because I noticed that there were times when the staff changed 14:16

and there would be few staff available. This was around the time of John's resettlement in 2012.

H507 was introduced to Muckamore and work started to build up to resettlement. One week all the staff had changed. I was upset, so I telephoned the main office. I had a good relationship at that time with the staff in the office. I was told, I think by H359, that it was the policy of the Belfast Health and Social Care Trust to move staff about. I could not accept that, but there was a culture of trust at that time. Our mother trusted people in positions of authority and did not want me to challenge it, and I respected that. She also thought that if I confronted the staff then it would make things worse or that the staff would pick on John. 14:17 14:17 14:17

Before that time when I would have visited John, I would have sat in the canteen in Rathmullan and I would talk with staff over our week and discussed how John was getting on. After the staff change, I noticed during visits there would be less staff around who you could speak to. Most days then when I went to visit John, I would find him in the TV room not doing anything. It was as if there was not enough staff do anything with him. 14:17 14:18

On the occasions when I did ask questions about injuries, I would be told that John had a seizure, or

that someone had nipped out, or that John was on his own. I was always given excuses. I would report this to our mother, but I stopped after a while as it troubled her. She did not want me to make a fuss, but I was becoming more concerned. I was becoming increasingly unhappy with the explanations that I had been given by staff about John's injuries." 14:18

CHAIRPERSON: Could I just ask you to pause for one second. That word in the second line in paragraph 32, should it be "nipped him"? 14:18

A. Sorry?

CHAIRPERSON: So you see "I would be told that John had had a seizure or that someone had" - should it be nipped out or nipped him? 14:18

A. Nipped out. Gone. Left him on his own.

CHAIRPERSON: It is "nipped out". Oh, left on his own. I see what you mean.

A. Nipped out. It's an Irish term.

MR. McEVOY: It's another idiom. 14:19

CHAIRPERSON: That's why I misunderstood it. Sorry, Mr. McEvoy.

MR. McEVOY: Okay:

"I saw a big change in John from the last time he broke his leg in 2013. We were told by staff in the Royal Victoria Hospital, Belfast, that he took a spiral seizure, and we accepted that, but I would have thought Muckamore staff would have contacted my mother 14:19

themselves and said this is what happened, but in hindsight they never did. There was no investigation over what happened. I attended the hospital and the injury was horrendous. His tibia snapped and came through his skin. The doctors had to put a screw in each end of the bone to join them together. My sister and I sat with him in the hospital as he went nuts if the RVH staff came in as I think he associated them with pain. There was a member of staff..." 14:19

14:19

- who you name from Muckamore:

"...who knew him very well who used to sit with him. If there were problems and he was on duty he would come up and assist, and even if he was off duty he would come up, as he lived nearby. He was a super guy. I still have his number in my phone. I held him in very high regard. 14:20

Staff told us John had a fall off the toilet in Rathmullan Ward and split his head, so they had a special toilet built for him. It cost tens of thousands of pounds, and then, two weeks later, management closed the Rathmullan Ward. The Belfast Trust said it had to be closed because of a heating issue, as referred to in the letter dated 17th May 2013, which I attach at Exhibit 3. 14:20 14:20

We had been led to believe it would close down the

line, but two weeks later they closed it. A year or two later there were really bad floods in the area and they were going to move a nursing home from Antrim to Rathmullan so contractors were sent in to get it ready, but RQIA did not permit it. These are examples of decisions I saw that were being made by management without consulting frontline staff and to me made no sense. 14:21

Belfast Trust moved everyone from Rathmullan to Greenan and had themselves on a deadline that they still have not met. The resettlement staff management were ruthless about the process of resettlement. 14:21

When I was going to visit, there was another patient in a wheelchair who had also been in Rathmullan with John who had now been moved him into a small room. He had no family in his care and he had tears running down his cheeks. This is an example of the impact on the patients of being moved to Greenan. They crammed all the patients into a small area, took away their dignity and their privacy. They were like eggs in a box. The reason that patient was crying was because he had nowhere to go in his wheelchair, he was totally restricted. I informed the RQIA about the Greenan move and things slightly improved. Some of the female patients were moved and therefore that patient and the other patients had more space to live in. 14:21 14:22

There was an occasion on or about 19th October 2010 when John was taken to Antrim Area Hospital with difficulties mobilising and bearing weight on his right-hand side. Hospital staff said they could not x-ray him because he was agitated and uncooperative. I think he may have been sent by H223 because he had chest or stomach pains. I did not know about this until the next morning when H223 telephoned me at home and told me what had happened. H223 told me that Antrim Hospital had sent John back to Muckamore but that he was now sending John back again. 14:22 14:22

I went straight to Antrim Hospital and arrived before John. I went to the sister in charge of A&E as I was not happy John had been in and sent back to Muckamore and was now on his way back again. She gave me a complaint form to fill in. She then went and got the consultant who informed me what had happened and that John had been uncooperative. I was not happy with the consultant's explanation. I asked why a learning disability nurse had not been called? I pursued a complaint about this incident. John was subsequently x-rayed on 21st of October 2010, when no bony injury was found to his ankle, knee or pelvis, and the diagnosis of John's musculoskeletal pain was inconclusive, with simply the suggestion to return promptly if the condition deteriorates. A week later I met with the Director of Clinical Medicine from Antrim Hospital who apologised to me and sent a letter of 14:23 14:23

apology to John.

John's clothes often went missing. When we asked about this, we were told that the clothes were brought to the laundry and were boiled and the clothes could get ruined in the process. 14:24

I wondered if different things that were happening, like John requiring stitches, would be happening to other people as well. I wanted to become involved in what happened in the hospital, so I went to a meeting of the Society of Parents & Friends of Muckamore Abbey Hospital (SPFM) which were initially held in the old nurses home at Muckamore. 14:24

Before this point the only time that our family would have met other families would have been at a Christmas dinner that was held at the Ramble Inn, Antrim.

At SPFM meetings I heard people saying different things that were happening, such as reports of loved ones being assaulted by other patients. This happened in other wards such as Finglas. Sometimes there were issues about how patients were being treated by management. I became interested and wanted to help with SPFM. 14:24 14:24

As of the 13th January 2009, I was recorded as John's practical next of kin, as our mother was suffering with

Parkinson's disease, and so all correspondence about John was to be sent to me. When I took over the role of John's next of kin from our mother due to her ill-health, I started taking her up to visit John and dealing with Muckamore. By about 2012 our mother was no longer able to visit John due to her ill-health. 14:25

In or around the 1st of December 2012, John was referred to Antrim Area Hospital with an injury to his right ankle, having apparently got his foot trapped under the door of a toilet cubicle having fallen off when he was on the toilet. Once again it was claimed in the hospital that they could not properly examine John due to his challenging behaviour, and the radiology report records that within the limits of the examination no acute bony injury was identified. 14:25 14:25

I also noticed that when John took out and he had a seizure, he was a bit lethargic. He seemed different to me. Then on one occasion John had three massive seizures during one visit. I went in to the office and found out that John's medication was being experimented with. 14:26

After this, in 2014, I attended the first yearly review since I had taken over from our mother looking after John. John's prominent nurse, a ward sister, a doctor whom I had not met before, and a social worker SW16, were there. The social worker started telling me about 14:26

John and I told him not to tell me how to deal with my brother. The social worker said that John needed medication, which I said was a matter for John's consultant to decide, and not him. I said that John should not get any more medication than what was prescribed by the consultant. This was when I changed my approach to Muckamore. So far as I was concerned the social worker's recommendation did not fit with what John's consultant was saying. 14:26

I took over John's finances as controller on 17 October 2013, pursuant to a full controller order made on that date. Before then Muckamore collected John's benefits, which our parents had authorised. Our parents did not receive reports about how the money was used. 14:27

Throughout their lives everything my parents did was for John. Financially, everything they had was sent to Muckamore for John's account. If John needed anything, our parents bought or paid for it. There was no money ever taken out of my brother's account by the family. 14:27

Someone told me to ask for a financial report around the time I took control of John's affairs. When I received the information in the first yearly document from Muckamore, I found that £400 had been spent from John's account on flameproof pyjamas. I could not understand why he would need those. I confronted the sister on the ward (now deceased) about it, and she 14:27

gave me a spiel, and we fell out over it. Since then, every year I requested a financial report from the personal secretary to the manager who ran Muckamore day-to-day.

14:28

I had no problem in the first and second year when I requested these financial reports, I got them within a week. Then the third year I was stopped from getting them and was told I had to send a formal request to headquarters in Knockbracken for the financial report. 14:28
I noticed that from that first incident and when I started querying and keeping an eye on John's finances, then his money in Muckamore went up and up each year.

I tried to get financial reports for years prior to 14:28
H351 being in charge of the finances, but I never received them. H351 was the financial controller for Muckamore. I couldn't believe this. I did not make a formal request for them as I thought I knew him well enough that they would be sent to me. I couldn't see 14:29
why they wouldn't give them to me. Any time I asked about them they would say they were too busy or that it would be looked into, but I never got them.

Belfast Trust gave John £28 a week whilst in Muckamore. 14:29
I have no knowledge of how Muckamore accounted for John's money all the time he was a patient there or how carefully the accounts relating to the use of his money was scrutinized. I did not get reports nor did my

mother. I was shocked when I got the first report to see that John had very little money accrued. I would have expected that a patient such as John would have had much more money in his account. I refer to the only financial documentation I have from Muckamore at Exhibit 4. 14:29

When John was in Muckamore, I did not get receipts about how money was spent, even when I became John's controller. I get this now that John has been resettled. 14:30

I am required to provide a financial report to the Office of Care and Protection in November of each year. The Office of Care and Protection audit the financial report. I think that there is greater protection for John in every respect now that he has been resettled, compared to when he was in Muckamore. 14:30

I cannot understand and want to find out why John was not safe in Muckamore when he had been placed there and kept for "institutional care". 14:30

I would like to see the financial records for the previous years to when I have been able to receive them. Considering how many people were in Muckamore, and yet there was only one person who dealt with finances, H351. 14:30

From in or about February 2014, I was engaged in discussions and meetings in relation to a potential resettlement placement for John. I refer to the minutes of these meetings at Exhibit 5. This culminated in him being placed in a care home for a trial period starting on or about 27th October 2014. John was subsequently resettled to a bungalow as part of that care home..." 14:31

- in a place which you name. 14:31

"Our mother died after this, but because of her illness she did not know that John had finally been moved out of Muckamore. 14:31

John was still walking when he was resettled. Now he is older and since he has broken his leg twice he has been less mobile and is in a wheelchair. He still has seizures, but his seizure rate has not increased and he has not had any injuries since he went into his resettlement. 14:31

I beat myself up about this. When John had cuts and stitches in Muckamore they would say it happened when John had had a seizure and I would have accepted it. 14:32

I would like if the Inquiry could get the information from the day books for the incidents when John suffered his broken legs, fingers, and other traumas he went

through. I would also like the Inquiry to see his hospital records for the attendances he had about those incidents.

I think the RQIA investigation report about the closure of Rathmullan and patients moved to the Greenan Ward, as well as any management information about this would be relevant to the Inquiry. 14:32

Over the years I found that Muckamore had a great art of isolating everyone, as in patient's families from one another. They would never try to bring everyone together. It seemed to be an attitude of divide and conquer. Even though we went up on a regular basis we would never see many other people. I always told the staff in Muckamore when I was coming up, as a courtesy. I think now this was giving staff a heads up and that this hid from us poor treatment of John. 14:32 14:32

By trusting the Muckamore staff in the way we did, it then took us much longer to trust the staff in John's new placement. 14:33

Not everyone in Muckamore was bad. There was real good people. But, unfortunately, the good staff are hammered and there was no-one to advocate for them. There was very little family involvement and, again, this seemed as though it was part of a divide and conquer mentality. Management treated good staff badly 14:33

putting them in wards where they were not comfortable working and so senior staff had enough and left.

I can remember many things that at the time over the years caused me concern when John was in Muckamore. There are things I have buried and I don't want to be reminded of them."

So, Billy, that concludes the statement that you've provided about your experience with your brother and his time and, indeed, your time in dealing with Muckamore. 14:33

One of the topics that you mention in your statement is your involvement with the organisation known as "The Society for the Parents and Friends of Muckamore", and that society has been mentioned of course in the course of the Inquiry, but you're one of the first sort of main representatives of the organisation that has come to the Inquiry. Could I start by asking when it was that you first became aware of the Society? 14:34

A. Vaguely going back to I suppose about 20-odd years ago. Again, my mother took everything to do - she would never really discuss anything about my brother, to be truthful. The likes of -- again, as I've said, we never knew anything even about his diagnosis. It was just we did what we did and we went up to Muckamore. Mother never - my mother should have worked for MI5, to tell you the truth. She was very secretive. But then 14:34

that generation were. It was just when my mother took Parkinson's, my father died, we moved my mother in with my kid sister, we sold the family home, to look after her, because she couldn't cope. And then I started to take more and more activity about John. My sister would have went up then. I would have went up. My I would have -- my niece was a nipper at the time and she would always have come with me, she was like my second daughter. But it's later on that sort of, when I sort of realise - I can't even remember exactly when I seen the meeting "I'll have to go to that", and then that started, and I met Malcolm, and I met Jack. Now my mother used to talk about a lady called Greta. Greta was, I think, the first Chairman at the time, or Chairperson at the time. You've got to be very careful now what you say! But I never really had any dealings with Greta. Greta was gone by the time that I went to the first meeting. And, as I say, Malcolm was the secretary, Jack was the Chairman, and then things basically was discussed. 14:35 14:36 14:36 14:36

142 Q. Okay. So really to summarise then, there were sort of changes in your own family circumstances and the arrangements in terms of who could really look out for...

A. Yeah. 14:37

143 Q. -- your brother's welfare?

A. It probably was. I maybe neglected him in going up to see him for a while, because I found it, like my father, very very hard to accept.

144 Q. Yes.
A. I was brought up in the church.
145 Q. Yes.
A. That's a story in itself!
146 Q. Yes. 14:37
A. And I couldn't understand about people breaching at me about this, that and the other thing, and yet I had a brother who never done anybody any harm and was in the position he was, because he was my brother and I loved him. And I just couldn't - it just wouldn't, you know, 14:37 it's hard to explain unless you're in that situation. But then, and as I say later when I did start to go and -- well I am his daddy for all intents and purposes now, and I have been for many years. And as I say, I've been very active until, well, over recent years 14:38 things has dwindled, as you can expect. I think there's only about 30 left in Muckamore now, considering when we were there it was 300 or 400.
147 Q. Yeah. Yeah.
A. And we tried to help, just basically everywhere, 14:38 because in Muckamore, sad to say, about 10 or 15% of families just, no involvement.
148 Q. Yeah.
A. They just - they were just dumped there really, you know, and that -- it's a terrible thing to say, but 14:38 unfortunately society, and anybody who deals with the public will know that there is some hard people who just, if it interrupts with their lives they just don't want to be bothered.

149 Q. Yeah. Those weren't the kind of people that were involved in the Society then, it's safe to assume.

A. No. No. The more we become involved in it, I was, for the want of a better word, very vocal.

150 Q. Yes. 14:39

A. So this is maybe the more people then would have come and spoke to me...

151 Q. Yes.

A. I would have tried to help. And then --

152 Q. When you sort of joined, or maybe if I put it this way, 14:39 when you sort of first started attending, can you think back to how many people, just like in terms of numbers, we don't necessarily need names, but how many people you would have seen on a regular basis?

A. You could have anywhere from 20 to 40, you know. But 14:39 in saying that, maybe husband and wife, or brother and sister.

153 Q. Yeah.

A. So in -- it wasn't really a whole lot, you know. But we tried to reach out to as many as possible, and 14:40 people would have come to you after meetings and "Look, I've got this problem. Can you help me?"

154 Q. And is that, just picking up on that, is that what the, you know, where the society's work really involved, as you say people sort of informally mentioning an issue 14:40 to you?

A. Well, yes, in a sense. We would have tried to advocate for people, tried to help people.

155 Q. Yeah.

A. But also when resettlement come, we had a seat on two boards, and the decisions - there was obviously a resettlement team, which was a considerable team in Muckamore, and then they were the ones that sort of suggested what to do, which Bridgeen and I were members on the Board, and then they kicked it up to Linenhall Street, which then all the directors from all the Trusts in Northern Ireland would have sat there.

156 Q. So when you say you had a seat on two Boards, can you remember what the two Boards were then? There's that one that you've just described, which was like a Board with the resettlement team?

A. Both Boards were all about resettlement.

157 Q. Okay. Okay.

A. Because the ones used to suggest things, and then they kicked it upstairs to the ones, the movers and the shakers.

158 Q. That did things.

A. The ones -- and then they moved that up then into the Health Board.

159 Q. Right.

A. Now, as we well know, the Board doesn't exist anymore.

160 Q. Yeah.

A. But they're a big part of what you should hear, as you'll find out later. But they're a big part of what should be involved in this Inquiry.

161 Q. Okay. And thinking back then to the role of the Society. How did it's representation work then in those Boards?

A. Well, they would have put forward proposals to do things.

162 Q. Yes.

A. I'll give you an example. We put forward for a facility outside of - well it was within the grounds of Muckamore, but there was about 14 acres, and they could have put a facility for the people that they found very hard to resettle. 14:42

163 Q. Yeah.

A. And there was certain people, one of them a director in the Belfast Trust, was adamant, big time, that this was not going to happen. You know what I mean. All they were concerned about was statistics and targets. 14:42

164 Q. Okay.

A. Every villa they closed they retained money. So that's all - they were just absolutely ruthless. 14:42

165 Q. Okay.

A. There was no care involved in it.

166 Q. So there was that advocacy and representation role then in relation to resettlement that the Society would have played, and was that in relation to individual cases/patients or was it on a more kind of a policy level? 14:43

A. Yeah. There would have been patients would have asked you to sit in on their interviews. 14:43

167 Q. Okay.

A. Which we travelled near and far, and you tried to help them.

168 Q. Yes.

A. But sometimes, you know, you just can't help everybody. And maybe you'd advised them to do something and they would have done the opposite.

169 Q. Okay.

A. But, you know, we were in it because - and we still are, I still am involved... 14:43

170 Q. Yeah.

A. Simply because I want to be. I've got to see, especially this Inquiry, it's got do the right thing.

171 Q. Okay. 14:43

A. It has got to show the people who are responsible for why I'm sitting here.

172 Q. Okay. On that score. As you know, the Inquiry is looking at not just the running of the Hospital, but it's looking at other organisations and other agencies, 14:44 and it would be helpful, you've mentioned one of them in the course of your statement, which is the RQIA, and it might be helpful for the Panel to hear something, if you can, in terms of the society's interaction with, we'll start with the RQIA perhaps, if you can? 14:44

A. Well, I don't know where you would start with that one. We went to Manion House, several occasions. We tried to put things across to them.

173 Q. When you say "things" can you give us an example?

A. Well, about the way they operated. 14:44

174 Q. The RQIA?

A. Yeah. They would have, what do you call it, they would have let them know that they were coming up.

175 Q. Okay. When you say "they", you mean the RQIA?

A. Oh, aye. They'd give them the nod that we were coming to do an inspection, basically. I don't know what way you want to put it, but...

176 Q. Yes.

A. But in my eye they should just have been able to walk in, close the doors and say "Right, we're doing this." Put the phones off type of thing. 14:45

177 Q. Were you, as a society, ever made aware that an unannounced inspection was going to take place?

A. They say they did it, and quite possibly they might have, but we were never, I can honestly put my hand on my heart and say we were never happy with what they did. 14:45

178 Q. Okay. There was also a Health and Social Care Trust's process for complaints. Did you ever have any involvement in the operation of that process, as a Society? 14:45

A. To be truthful with you, over the years the different people who have tried to have complaints, they, you know -- I have an incident going on at the minute and I don't want to change things, but I reported an incident to Muckamore, for instance four weeks ago, and the person who was running the Inquiry went on holidays after two weeks, and she has still to come back to me to tell me what's happening. 14:46 14:46

179 Q. That's a person in the Trust?

A. That's in Muckamore now.

180 Q. In Muckamore now. Okay.

A. And her boss, I phoned her boss about another incident

and I left an urgent message on his answering machine two weeks ago.

181 Q. Okay.

A. He's still to come back to me.

CHAIRPERSON: Sorry, was this all on behalf of members of the Society? 14:46

A. Sorry?

CHAIRPERSON: Was that all on behalf of members of the Society.

A. Yes. I was contacted about an incident ongoing at the minute in Muckamore, and we tried to liaise, as you do. First you go to the first person in charge and try to pass that on. 14:46

CHAIRPERSON: Yeah.

A. And there's nothing. 14:47

182 Q. MR. McEVOY: Is there a sort of - it might not necessarily be the most formal process in the world, Billy, but is there a kind of a, you know the way people use the phrase "custom and practice", is there a sort of a practice of what you would do when a relative, a family member of a patient, for example, or a patient even indeed, him or herself, might raise an issue with you, is there sort of something that you would do almost instinctively in terms of contacting management at Muckamore, and can you give us an idea about that? 14:47 14:47

A. Yeah. It was -- you used to phone the, what is it they call them, the safety officer, and you would have phoned them up and you would have said, "Right, this is

an incident happened such and such a place".

183 Q. So it would be a safety officer then? They would be the first point of contact?

A. The safety -- this would be the person. So you would always go up the line. 14:48

184 Q. Yes.

A. So you would phone them. And I would say, for instance - her name is in this list too, on my list - well, that's another list compared to your list. But, "Yeah, okay, thank you very much." I says "Well, you'll come back to me?" "Oh, sorry, confidentiality, I can't", and that's the way you would be cut off. 14:48

185 Q. Okay.

A. So in other words that they would deal with it in-house, but you didn't know whether they dealt with it at all. 14:48

186 Q. Yeah. Okay. But you would still be able to alert somebody to an issue, albeit that you might not hear anymore about it?

A. Well, it got to the point then you ignored that and you went up a stage. 14:48

187 Q. Okay.

A. So you would have went to the service manager.

188 Q. Yeah.

A. And then it got to the point where the service manager - I don't know why I can even say it here, because I might end up swearing - she was useless, and it got to the point she told that many lies that I couldn't even deal with her! 14:48

189 Q. Okay. Well, are you giving that based on your experience, are you giving that evidence based on your experience of just one person?

A. Well, that was the service manager.

190 Q. Yeah. 14:49

A. Talking --

191 Q. One person in that role, in other words, as opposed to --

A. Yeah, you'd have went to try to talk to them, and nothing was ever, you know, you sort of felt that 14:49 nothing was ever done.

192 Q. Yeah.

A. You were -- sometimes you were beating your head against a wall.

193 Q. Was is that because you were dealing with that one 14:49 particular individual? Were any other service managers better?

A. No, no, no. Over the years it was just - as we've found out, you know, hindsight is a wonderful thing - as we have found out over the years that it was all 14:49 dealt with in-house, it didn't go outside, you know.

194 Q. Okay.

A. And I suppose, you know, if we'd had known then what we know now, this is why we've been fighting for the Inquiry all these years. 14:50

195 Q. Right.

A. For all this to come out and the people who are responsible, and who made the decisions, and who kept things in-house, they need to answer the question

"why?".

196 Q. Okay. Well no doubt the Inquiry will be moving on to ask those sorts of questions in a short space of time. Thinking back, Billy, to the interactions that you might have had with other organisations. We talked about the Trust's complaint process, and we talked about the RQIA. Were you aware PCC, the Patient Client Council? 14:50

A. Yeah. We went to -- well, I did, I went to a couple of seminars, but I didn't find them any better. 14:50

197 Q. Okay. Had you any dialogue with them on an ongoing basis?

A. Not -- to be truthful, on a few occasions maybe we sent people to them, but they came back very unhappy too. You know, it didn't really - no. 14:51

198 Q. When you say "unhappy", what were they being --

A. They just never got anywhere.

199 Q. Yeah. Okay. In what sense? What was it that they were bringing to the PCC that made them come away feeling unhappy? 14:51

A. Well, if it was sort of -- with the likes of us, we could only take something so far.

200 Q. Yeah.

A. Because then it was like opening a door and somebody standing there and saying, "Sorry, you can't come in." 14:51

201 Q. It became an issue about a particular patient?

A. The famous word from the Belfast Trust is "confidentiality".

202 Q. Right. Okay. And in terms of your overall - I mean

the organisation, the Society, it's been going for quite some time, hasn't it? I mean it is not a comparatively new organisation?

A. No.

203 Q. Can you give us an idea of how long it's been around? If you don't know, that's okay, but maybe even a rough idea? 14:52

A. 60, you know, about 60. You know 58/60.

204 Q. Okay. So it's been around for decades?

A. It's been there to try and do the best that we could for the patients. 14:52

205 Q. And I know you have only been involved on an active basis in more recent decades as opposed to all of those decades.

A. Yeah. 14:52

206 Q. But, you know, you were, as you've told us in your statement, you were the relative of someone who was there for a long portion of that time?

A. Yeah. I grew up in Muckamore, yeah.

207 Q. Do you recall the Society, although you weren't an active member, but do you recall the Society having better relations with management at Muckamore in past times, if I can put it that way? 14:52

A. I had better relationships, or we had better relationships before resettlement. 14:53

208 Q. Right.

A. With I think the director was - her name is not even - no, hold on. Her name actually isn't there.

CHAIRPERSON: If you want to write the name down and

pass it to the secretary and then we'll have the name and we'll work out if there's a cipher.

MR. McEVOY: Don't worry.

A. You may forgive my bad spelling, I am dyslexic. And her assistant. And we had, if we had phoned up about an issue, the director there. But the service manager, as she was then, she would have - I could have phoned up and said certain issue, "Billy, I'll deal with that", and she would have phoned me back the next day. 14:54

209 Q. And let you know the outcome or given you an idea? 14:54

A. And then I would have relayed it to whoever had asked me about the issue. And there was never really, I can honestly say I don't think I ever, because if it was something she couldn't deal with she kicked it upstairs to the director. 14:54

210 Q. Yeah.

A. And then the director would have came back to me. There was none of this "Confidentiality, I can't come back to you." This all really started, you know, we had more reaction then. This all started from the beginning of resettlement. 14:54

211 Q. Yeah. So is that...

A. These two people left, you see.

212 Q. Yeah.

A. Now, I'll not go into it now, but I know why these two people left. 14:55

213 Q. Well I mean you were -- you seemed to be pinpointing a few minutes ago, the time when things started to change to around when resettlement became a topic?

A. Yeah.
214 Q. Would that be your evidence? Is that when you think that things...
A. Big time.
215 Q. -- things started to go -- 14:55
A. Yeah. Don't get me wrong, Muckamore wasn't perfect.
216 Q. Yes.
A. No institution is. But things from resettlement went north.
217 Q. So roughly when was that, Billy? Can you give us an idea when that would have been? 14:55
A. You're talking in and around 2012.
218 Q. Yeah.
A. The new -- they brought in a new service manager.
219 Q. Yeah. 14:55
A. H507.
220 Q. Yeah.
A. She was just there for, shall we say -- she was evil.
221 Q. Okay.
A. That's the word I can only -- I can only use that word. 14:56
222 Q. Okay. Okay. Well, in terms of how things are now, in terms of the dealings that the Society has with Muckamore, can you summarise whether things are in a good or a bad or sort of a middling position? How would you describe them? 14:56
A. Things are on the wind, you know. We, obviously with Muckamore, they'd give a date for to close it.
223 Q. Yes.
A. So once they close Muckamore the Society will not exist

basically as an organisation. Anybody whoever phones me, myself and the Society, our phone numbers are in every ward, and if anybody phoned me and they had a problem. I have phone calls from patients.

224 Q. Yeah. 14:57

A. I have phone calls from staff, even yet.

225 Q. Do you have any interaction with organisations such as - and this is by way of example, but patient advocacy services like Bryson House?

A. Does anybody? 14:57

226 Q. Okay. That's a "no", is it?

A. Not very good.

227 Q. Okay.

A. Even I'll give you an example, they were going to transfer a young lad and he didn't want to go, for 14:57 resettlement, didn't want to go.

228 Q. Mhm-mhm.

A. He sent for his advocate from Bryson House.

229 Q. Mhm-mhm.

A. And she says to him, "But you have to go. They're 14:57 closing Muckamore." Now bear in mind we're not talking this year, we're talking a couple of years back.

230 Q. Mhm-mhm.

A. And the patient phoned me and -- sorry, I'll get that right. He asked another patient to phone me because he 14:58 had a communication problem, and he says "Could you phone Billy?", and I got it stopped, or the Society got it stopped because of -- it was unreal, you know. And that's not the first one. There's been umpteen where

we have intervened and stopped it, you know. There's things going on even at the minute, there's patients in places they don't want to be.

231 Q. In terms of resettlement?

A. Resettlement. 14:59

232 Q. Yeah.

A. And it was always the understanding in Bamford that if a patient went - it's like you and me buying a house, you go and you buy a house, you stay there for about six months and you don't like it . You say "Nah, I'm going to move". They can't. 14:59

233 Q. Yeah.

A. And this is why so many of them have taken their own lives. They've died of broken hearts.

234 Q. Yeah. 14:59

A. Now in Muckamore, as I say it wasn't perfect, but they had company. So they're putting them into residential areas, they're putting them into associated living, they're supervised from nine to five and then they go home and they're stuck in a room on their own. They've nothing! 14:59

235 Q. Billy, in contrast to that, those sorts of experiences, you've told us in very moving detail your family's experiences around John and then what has worked out to be I think on balance what we can say was a positive experience of resettlement eventually. Would that be fair to say? 15:00

A. My brother's experience of where he is now, he's two hours journey away from where I live.

236 Q. Yes.
A. And I wouldn't care if it was four hours journey.
237 Q. Yes.
A. I picked it and went to look and got the vibes from the manager and deputy manager and the head nurse, and when we moved him there, I never signed him off for a year. I had to make sure -- it was the biggest decision that I have ever made in my life, because I had never told my mother I moved him. 15:00
238 Q. Yeah. Yeah. It's a big responsibility. 15:01
A. Tell me about it!
239 Q. Yeah.
A. But I had -- it got to the point -- I was against resettlement! I can tell you that now. Totally!
240 Q. In principle, or what was the objection that you had? 15:01
A. My objection was because they were taking people, and there's residents in Muckamore at the minute who don't want to leave.
241 Q. Yeah.
A. You know, they've been there 30/40 years. I mean if you live in a house that you're happy in and somebody says to you "Right, you're out." No, it's not right. 15:01
242 Q. Yeah.
A. And then they're talking about moving them -- the rumour is they're talking about moving them into Knockbracken. Now we all know with Knockbracken - well if you don't, you should go and find out what Knockbracken is! 15:01
243 Q. So, Billy, what I wanted to ask you about was, I mean

you've obviously described the experiences that you've heard sort of anecdotally, and maybe even more strongly than that in terms of where it has gone wrong for people, very wrong in some cases in, and in contrast I suppose it would be fair to say that your experience and your brother's experience, your family's experience has been on the more positive side, shall we say, in terms of resettlement?

A. In Muckamore --

244 Q. Let me just sort of come to the question that I would like you to think about. How could - based on your experience, how could things be fixed so that more people, when it comes to the question of resettlement, more people could have an experience like yours and your family's? In other words, an outcome that is better. How do you think things could be fixed, based on what you've been through? 15:02

A. First of all you've got to get a place. I mean the whole thing about resettlement is Bamford.

245 Q. Yeah. 15:02

A. The thing about it is, it is moving somebody from an institution into a family environment, a home environment.

246 Q. Yeah.

A. Now, to move somebody from Muckamore, who are living in their own room and then they move them to a nursing home and put them in to a room with somebody else. 15:03

247 Q. Yes.

A. It's not what you would call a family environment or a

betterment. For where my brother is, they have six en suite rooms in one bungalow. They have a ratio of, what shall we say, five, sometimes? Aye, I would say four care workers, I don't even like to call them care workers, because they're better than that. 15:03

248 Q. Yeah.

A. And a Staff Nurse.

249 Q. Yeah. And when you say that about you don't like to call them care workers because they're better than that... 15:03

A. They are better than that because they...

250 Q. Yeah. Is there something -- when you say that, is there something in that for the future and for the Inquiry to think about?

A. Yeah, yeah, there really is. Because for instance 15:04 there's two of the girls who are married with a family, and one of them in particular has to work in a chip shop three nights a week. There was a guy we've just lost who lived -- he spent £15 a day in a taxi from where he lived. Think about this one. 15:04

251 Q. To come to work?

A. On care workers wages! £15 a day! Broke my heart when he left. And I hugged him. But he got a job, and apparently they've been chasing him in this particular home where he lives to come and work in the dementia 15:04 unit, and it's only walking distance from his house. Do you know something, I can't blame him.

252 Q. So when you describe somebody like that, and I'm going to go back to what I asked you about, which is sort of

maybe fixing things or making something better for the resettlement process, does a clue lie in making sure that you get the best people working in those resettlement places?

A. But you see the resettlement system, they're not -- what's the word for it? They don't care about where they put them. All they're concerned about is getting them out. 15:05

253 Q. Yeah.

A. You know. This word they use to -- and I used to always laugh at them -- personal centred planning. 15:05

254 Q. Yeah.

A. So they go in -- well you all know what personal centred planning is. So you'd take -- just exactly what we've been saying... 15:05

255 Q. Yeah.

A. You take the person and you'd say "Right, what's his needs?".

256 Q. Exactly.

A. Right. I don't know where that has happened. In all the resettlements, there has been very very few. It was a case of Rathmullan, when they come to Rathmullan, I think there was only three family involvements out of 28 patients. They actually moved one patient on a bank holiday because I was going to advocate for him. 15:05 15:06

257 Q. So the resettlement, when they say -- when they talk about -- when they talk about person centred planning, one thing you would strongly assert then is that that should mean person centred planning. It should

genuinely be...

A. I'll tell you what I mean now. You see every person that's been resettled....

258 Q. Yeah.

A. They need to go and investigate every one. 15:06

259 Q. Yes.

A. And I mean investigate. And I don't mean going and saying "We'll have to send a team there". You need to select your team, but you need to select them outside the Trust. 15:07

260 Q. Yeah. Yeah.

A. They need to come from outside.

261 Q. Yeah.

A. So that nobody - same as us as a Society...

262 Q. Yeah. 15:07

A. We used to go and argue, and I said what I -- well you'll know me from the past.

263 Q. Yeah.

A. If I've something to say, I'll say it. Because nobody was paying my wages! You know what I mean? 15:07

264 Q. Yeah.

A. I wasn't scared. And you mentioned a certain advocacy service, that's the reason why...

265 Q. Yeah. Yeah.

A. They cow-towed to the Trust. And anything I say in 15:07 this Inquiry, I will stand by. And they, what do you call it, they were scared of losing, because they had them on the short contract - I think they still do. But they should never have been involved. The people

concerned should have been given a contract and guaranteed on what they did, and judged on what they did. Not a particular thing, how could you put it? You know, every three months we'll review it, or every six months.

266 Q. Yeah.

A. And the staff were the same, and there was good staff got -- actually, one in particular, they didn't renew his contract. Do you know why? Because he fought for the patients. 15:08

267 Q. Yeah. So better quality staff, less of a, I suppose a lottery if you want to put it that way in terms of what people are coming out to in the resettlement. More places should be like where your brother now is. That's really what you're saying? 15:08

A. Yeah. To bring that point up too, the likes of my brother, the staff should not have to go and do two jobs.

268 Q. Yeah.

A. They should be -- the money that they're being paid -- I pay my gardener more! You know what I mean? And that's what, they should be paid more, because the only way you're going to get good people -- now, I know it's a special person that does what they do, but they need to be able to live. The price of their loaf is the same as yours and mine, you know. That's the important thing. 15:08 15:09

269 Q. Billy, that's been very helpful from the Inquiry's team point of view, but it may be now that the Panel have

questions. So thank you very much for your time this afternoon.

CHAIRPERSON: Professor Murphy.

QUESTIONED BY PROFESSOR MURPHY 15:09

PROFESSOR MURPHY: It sounds to me like, and I think you said this, that you object to resettlement on principle.

A. Sorry, you need to speak up just a little bit. 15:09

270 Q. It sounds like, and I think you said exactly this, that you object to resettlement on principle. Have I understood you right?

A. That's right, yeah. Because we had gone through different places, nursing homes, facilities. I mean if 15:10 you're going to put somebody out in resettlement, the personal centred planning which they were driving as a leader, you've got to make the facility - should you have to build it? You have to build a home for somebody to bring them into society. Now, as we well 15:10 know in reality, society doesn't want people like my brother. They would walk to the -- if you went down the road, they'll walk to the other side of the street, an awful lot of people. So if you're going to move somebody out into resettlement to go have a home, is 15:10 what they always said, a home in the community, then you have got to give them a home that suits them and is built round them.

Now, the resettlement situation that we were involved in, I don't know many. They either put them in facilities, nursing - the majority of them are in nursing homes. So they went from an institution into an institution, and I think everybody would agree that a nursing home is an institution. And that's really what happened. So unless they done it right.

Now we were told that money wasn't an object. At all the Board meetings "Money is no object". Money was an object. All they were concerned about was retention, closing villas and moving them out. And another thing they did, we told them -- and this is -- if you look back at statistics about assaults, both patient on patient, patient on staff, they moved people who weren't compatible. They just "Oh, there's two beds there. Right, move them two in there." They weren't compatible to be around.

15:11

15:11

15:11

271 Q. Aren't you saying really that you don't think the process of resettlement was right?

15:12

A. Yeah.

272 Q. Not the principle, but the process. And they are two different things?

A. Well, if you want to sort of nit-pick. Basically, yeah. But if they'd of done it right and put the facilities -- plus you need staff. It's just an example, the EV at the minute. They're trying to put electric cars in here. They have no chance because they haven't got the facilities to charge them! The

15:12

same things with residents. When they tried to move them out, the facilities out there, they're still not there. And I'll tell you now, about 70% of the patients who has been resettled are not happy where they are. And, hopefully, this Inquiry will show that. 15:13
But as to what I said to what do you call it, to Mr. McEvoy, that we need to actually go back and inspect where all those residents are and see how happy they are.

273 Q. So has SPFM done a survey of that? 15:13

A. Sorry? I'm a wee bit...

274 Q. Has SPFM done a survey of people who have been resettled to ask them whether they're happy?

A. They were supposed to. The Trust, through Bryson House, were supposed to do -- I'm trying to remember 15:13
what they called it. After they were resettled, to see how happy they were, a questionnaire, and we still never got the report of that. I've never heard of it. And that was -- also the Trust were supposed to investigate the amount of people who died, and I've 15:14
mentioned her name there -- where are we? H507. She was told by the Board to go and investigate why so many people died, and how they died, and why they died. Never seen that report either. It never came about. So it was just -- and to this day it's the same, just 15:14
push them out, you know. And that's -- one other is what I brought up there about the safeguarding issue, that I had to report it. They're going to move somebody who an incident happened when they lived

together in Muckamore, and they're going to move them next door to where this other person is. Why? But yet, they won't respond to me, so I don't know how you get them to respond.

275 Q. Okay. 15:15

A. Maybe after this they might.

PROFESSOR MURPHY: Thank you?

QUESTIONED BY THE CHAIRPERSON

15:15

CHAIRPERSON: I just want to understand a bit more about SPFM and the structure, because even when you were taking complaints on behalf of people, you were more recently meeting the objection "Well, we'll take your complaint on board, but what happens hereafter is 15:15 confidential", that's what you were told?

A. That's basically what we did, we took it so far and then you were just...

276 Q. But if you were acting on behalf of people and you had their authority, were you not able to get through that 15:15 barrier of confidentiality?

A. No! No.

277 Q. So that, I suppose, comes down to what sort of organisation SPFM is. You're currently Chair?

A. Yeah. 15:16

278 Q. And can you just explain a bit about - do people join SPFM, or do they just contact you? How does it work?

A. In a sense now, you know in times gone by they had a little card and they subscribed, but we cut that out.

People come -- basically if you had a resident in Muckamore Abbey, you were entitled to come to the meetings and join in with the Society. So there was no like the Masonic joining or swearing allegiance, no, no, no. And as I say, in certain circumstances, people - we would have brought the Director of the Board wanted to speak to the members, sorry the co-director who was in charge of resettlement wanted to speak to the resident or the family members, so we set up a special meeting for him and (laughs) the reason I'm laughing, he actually asked me half way through it to end the meeting because it got very vocal and he thought that he was going to get assaulted. So things like that. We tried, we tried to help in other ways, you know, we would have supplied things, we would have bought things for the patients, and tried to help in any way that we possibly could. 15:16 15:17 15:17

279 Q. Where does your funding come from?

A. Well, funding is non-entity. We don't take anything. Occasionally people would leave us money in their will, not a fortune, but we used the money, the few pound that we have left, we use it wisely. An incident: One of the residents had an issue with the courts and he needed instant money. We supplied it. Due to his -- there was a mix up and the case had to go ahead and, amazingly, which funny enough when I talk about that particular patient, he got it back. Now that happened about two years ago, maybe three, and he actually got it back in a cheque about six months ago from the 15:17 15:18

Department, and he phoned up and told me that he got the money and donated it back to the Society.

280 Q. Right. And are you registered charity?

A. Not now.

281 Q. It was, wasn't it? 15:19

A. We were. Yes, we were. We were. But it was really - there was no point from then on because things started to dwindle a lot, and the fundraising end of it, we had enough money to do what we needed to do.

282 Q. Right. So if we looked at the organisation of SPFM now, it's you and who? 15:19

A. It would be me, Bridgeen, Aidan, my wife is a treasurer.

283 Q. Right.

A. And we would sort of be -- you know the meetings, there's really no point in holding a lot of meetings now. As we say, we're on the wane. Things is going once Muckamore goes. 15:19

284 Q. Yeah. And I suppose that's the last thing I wanted to ask you about. The relationship between you and the current management of Muckamore. Do you speak to those in charge now? 15:20

A. Yeah. Oh, aye.

285 Q. So there is still dialogue?

A. We have bi-monthly meetings. 15:20

286 Q. Right.

A. And we have been promised that if we have an issue it would be dealt with. Well, the first couple were. But this particular incident, she had two weeks to deal

with it, and then I phoned up again and was told that she had went on holiday.

287 Q. Yeah.

A. And then I phoned up the next week and she had gone on the sick. So. 15:20

288 Q. All right. All right.

CHAIRPERSON: That's all that I wanted to ask, Billy. Can I thank you very much for coming along and telling us primarily about John and what's happened to him, but also filling us in a bit on the work of SPFM. So can I 15:21 thank you very much for coming to assist the Inquiry, and you can now go with Jaclyn, the secretary. Thank you very much.

A. Thank you.

CHAIRPERSON: And thank you Bridgeen as well. 15:21

THE WITNESS WITHDREW

CHAIRPERSON: Right. Tomorrow, have we got a 9:30 or a 10:00 o'clock? 10:00 o'clock tomorrow. Okay. 10:00 15:21 o'clock tomorrow. Thank you very much indeed.

THE INQUIRY WAS THEN ADJOURNED TO THURSDAY, 28TH SEPTEMBER 2023 AT 10:00 A.M.