MUCKAMORE ABBEY HOSPITAL INQUIRY

SITTING AT CORN EXCHANGE, CATHEDRAL QUARTER, BELFAST

HEARD BEFORE THE INQUIRY PANEL

ON TUESDAY, 21ST MARCH 2023 - DAY 29

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

GWEN MALONE STENOGRAPHY SERVICES

29

APPEARANCES

CHAIRPERSON:	MR. TOM KARK KC
INQUIRY PANEL:	MR. TOM KARK KC - CHAIRPERSON PROF. GLYNIS MURPHY DR. ELAINE MAXWELL
COUNSEL TO THE INQUIRY:	MR. SEAN DORAN KC MS. DENISE KILEY BL MR. MARK McEVOY BL MS. SHIRLEY TANG BL MS. SOPHIE BRIGGS BL MR. JAMES TOAL BL
INSTRUCTED BY:	MS. LORRAINE KEOWN SOLICITOR TO THE INQUIRY
SECRETARY TO THE INQUIRY:	MS. JACLYN RICHARDSON
ASSISTED BY:	MR. STEVEN MONTGOMERY
FOR ACTION FOR MUCKAMORE & SOCIETY OF PARENTS AND FRIENDS OF MUCKAMORE	MS. MONYE ANYADIKE-DANES KC MR. AIDAN MCGOWAN BL
INSTRUCTED BY:	PHOENIX LAW SOLICITORS
FOR GROUP 3:	MR. CONOR MAGUIRE KC MS. VICTORIA ROSS BL
INSTRUCTED BY:	O'REILLY STEWART SOLICITORS
FOR BELFAST HEALTH & SOCIAL CARE TRUST:	MR. JOSEPH AIKEN KC MS. ANNA MCLARNON BL MS. LAURA KING BL **MS. SARAH SHARMAN BL** **MS. SARAH MINFORD BL** **MS. BETH MCMULLAN BL**
INSTRUCTED BY:	DIRECTORATE OF LEGAL SERVICES

FOR DEPARTMENT OF HEALTH:	MR. ANDREW MCGUINNESS BL MS. EMMA TREMLETT BL
INSTRUCTED BY:	MRS. SARA ERWIN MS. TUTU OGLE DEPARTMENTAL SOLICITORS OFFICE
FOR RQIA:	MR. MICHAEL NEESON BL MR. DANIEL LYTTLE BL
INSTRUCTED BY:	DWF LAW LLP
FOR PSNI:	MR. MARK ROBINSON KC MS. EILIS LUNNY BL
INSTRUCTED BY:	DCI JILL DUFFIE

COPYRIGHT: Transcripts are the work of Gwen Malone Stenography Services and they must not be photocopied or reproduced in any manner or supplied or loaned by an appellant to a respondent or to any other party without written permission of Gwen Malone Stenography Services

INDEX

PAGE

THE INQUIRY RESUMED ON TUESDAY, 21ST MARCH 2023, AS FOLLOWS

CHAIRMAN: Yes, Mr. Doran?

MR. DORAN KC: Yes, Chair, this morning's speaker is Professor Roy McConkey, who is giving a presentation by video link. The presentation is on Module 1, Bamfard and Mental Health Law in Northern Ireland, Topics A to C -- A: Overview of Bamford Review and Subsequent Developments; B: Analysis of Different Models for Learning Disability Services; and C: Focus Study of the Equal Lives Learning Disability Review from September 2005. I've had the opportunity of speaking to Professor McConkey this morning. The link seems to be working reasonably well. There is also a PowerPoint presentation which the technical team will be operating from the room, and I explained to Professor McConkey the procedure that we followed yesterday whereby the speaker gave the presentation and the Panel put questions as the presentation proceeded, as appropriate. He was content that we adopt the same approach today. 10:00 10:01 10:01 10:01

I can say, Chair, Professor McConkey is also agreeable to returning on a future occasion, if necessary -- perhaps when he's actually in the jurisdiction on this occasion -- to deal with any follow-on questions that might arise. You'll recall that I mentioned yesterday that we will invite all Core Participants to provide 10:01

any follow-up issues or questions that they may have after the presentation today.

So I don't think I need to say anything further, Chair. You, in fact, gave a full introduction to Professor McConkey yesterday. So I think we're ready to proceed with the presentation now.

CHAIRMAN: Yes, indeed. Good evening, Professor McConkey. Thank you very much for joining us. I know you watched part of proceedings yesterday and I hope I didn't misdescribe your background or your qualifications. But, if I did, you're obviously very welcome to correct anything that I said. 10:02

Please let me know when you would like a break. I know it's late evening there for you, so I'm particularly grateful for you assisting us. But just let me know. We would normally go for just under an hour, but if you need a break before that, just say. Thank you. 10:03

10:03

PRESENTATION BY PROFESSOR McCONKEY

PROF. McCONKEY: Thank you. Well, thank you very much for the invitation to be with you. I'm sorry I can't be with you in person. When I get an invitation to spend an Irish winter in Australia with my son and family, it's very hard to turn it down! So all being well, I'll be back in Northern Ireland in time for an Irish summer in the hopes that it competes with an 10:03

Australian one!

Can I also apologise for my dress. I noticed people yesterday were well dressed by comparison to the relaxed look that I appear to you. It's simply because 10:04
I don't have a jacket and tie with me! I assure you these are not my pyjamas -- I am still dressed and ready to go!

I might also have to apologise for yawning from time to 10:04
time, particularly as the time goes on. And there might be the danger that I might actually be the first witness that falls asleep while addressing the Panel! So please wake me up if that happens -- and your questions would be a good way of doing that! 10:04

CHAIRMAN: All right. I'm sure you won't, okay!

PROF. MCCONKEY: Well, thank you again. Can I have the next slide please?

CHAIRMAN: Can you see the slides yourself Professor McConkey?

PROF. McCONKEY: I'd like to pay tribute to three people who were really instrumental when it came to both designing the way the Review was undertaken, managing the organisation of the Review, and the ethos that underpinned it. David Bamford was certainly an 10:05
inspired choice of Chair. His background was in social work. He had worked as a field social worker, had worked his way up through various managerial positions and ended up as Professor of Social Work at Ulster

university. His death was a sad loss to us. He was replaced then by the Vice Chair, Professor Roy McClelland, who you will be meeting, I gather, next week; Siobhan Bogues, sadly, also died some years back. Siobhan headed up the Equal Lives Working Group and she really was an inspiration. She had that very unique ability to be able to relate to people, whether they were service users, carers, professionals, senior administrators and even ministers within the Department. She was a pleasure to work with, an inspirational leader and her loss is still very much felt to this day. 10:05 10:06

At the conclusion of the Bamford Review, the Northern Ireland Executive made a response to it in which they said that: 10:06

"The far-reaching vision for a radical reform and modernisation of mental health and learning disability law, policy and services." 10:06

It was, indeed, a far-reaching vision that was portrayed over the years of the Review. The Executive then went on to say that they accepted the thrust of the recommendations by the Review. It was classic civil service language, arguably. The thrust was never really defined, but certainly we took heart from the fact that they did see that it was a radical reform of what had gone before and, in many people's opinions, as 10:06

you'll hear as my talk continues, saw that that was really very needed at Northern Ireland at that moment in our history. Next slide, please.

I gather you have had copies of the presentation that I'm making to you now. But if I could follow my eminent predecessor yesterday, Mr. Alex Ruck Keene and give you some further reading should you really want to delve deeper into some of the reports that I've mentioned in my synopsis. You can get an overview at the Bamford Review link that's presented here. And if you're linked to the computer at any time, you can use those links to take you straight to the materials that are listed. 10:07 10:07

The full copy of Equal Lives Report is also available at a separate link, and that was followed by an implementation plan headed up by the Northern Ireland Executive encompassing all the departments of the Government at that time. And that implementation plan gave you some indication of how Government was taking forward the recommendations that had been in the Bamford Review. 10:08 10:08

However, life went on beyond the Review and there were a number of other significant reports, two of which I have highlighted there for you and which I make mention in my report -- an RQI Review of Community Services in 2016, and then a very exhaustive but very 10:08

illuminating and detailed account of the whole resettlement process that had happened -- or some, sadly, didn't happen, in the Northern Ireland context, certainly within the time frame that was envisaged. So there's a wealth of written documents backing up some of the information I'm, in the course of today, only able to skim over. Next slide, please. 10:09

Well, we're following a 27-year timeline as I come before you this morning. And it's beginning to make me feel my age. I wanted to take you through some of the pre-Bamford activities that had happened. When I came back to Northern Ireland in 1997 there were already in hand a number of important developments that laid a good foundation, certainly for the Equal Lives Review that was going to take place. And those pre-Bamford activities are noted on pages 2 and 3 of the written submission. 10:09 10:09

I'll give you a brief overview of the Bamford Review. It took place between 2002 to 2007. So it spans a six-year period. And that's briefly summarised on page 3. The Equal Lives Report, which was one of eleven reports that emerged from the Bamford Review, is looked at in a bit more detail, particularly given the Terms of Reference of the Inquiry, and that takes up pages 4 to 6. And then post-Bamford, in two sections, from 2008 through to 2016, there were a series of action plans produced by the Northern Ireland Executive 10:09 10:10

designed to implement the recommendations from Bamford. Then from 2017 to 2023, up to the present, there have been other reviews of progress that I've alluded to in my written submission. So that's the outline of what I want to cover in this particular presentation. 10:10
And can we go to the next slide, please?

The most significant document in the 1996 period that I was familiar with was produced by the Eastern Health and Social Services Board. At that time in Northern 10:11
Ireland, we had four different commissioning boards, imaginatively titled "North", "Eastern", "Western" and "Southern" and we had eleven community health trusts. Now, this is for a population of about 1.7 million at that time in the 1990s. However, the Eastern Health 10:11
and Social Services Board had decided to produce their own commissioning document which they entitled "A Model of Community-Based Services". Now, to our great regret, neither I or other colleagues who were around at that time, we have not been able to source a copy of that 10:12
original document. It in some ways probably predated PDF. Those initials probably weren't even known at that time. So we have no actual physical copy of that particular document. But John Richards, who was a recently appointed director of social services who came 10:12
over from England, John had no prior history with Northern Ireland and he was the epitome of an English gentlemen, when the emphasis on the word "gentle". But he actually had this manner that masked a very much

determination that the services in Northern Ireland were outmoded and were outdated and that we really did need to move towards a new model of community-based provision. That would, of course, mean the resettlement of people from very long-stay institutions.

So as part of the model of learning disability that they wanted to promote, they had the concept of having a joint appointment at the University of Ulster and the Eastern Health and Social Services Board. I saw the ad for it, I was very attracted to the prospect of coming back to Northern Ireland, but particularly coming to work, having spent the last 20 years of my career working in services directly -- first of all, in Dublin with an organisation called St Michael's House, I was 11 happy years there. Then I moved to the Scottish Border and worked there for another religious order called the Brothers of Charity, and there we were developing community-based services for adult persons with learning disability who previously had lived in long-stay institutions.

So the joint appointment meant that I had a foot in both camps. In one sense, I had the foot in the University or academia that provided me with evidence from international as well as GB and Irish studies, but also the other foot was very firmly planted in service delivery, and particularly innovative service models.

So there was quite a harmony then between what the skills that I had acquired in the service world and now being extended into a much more academic-led post as well.

10:14

In consultation with John and other colleagues, we then developed up a research programme that would start to gather evidence about what service life was like for people with learning disabilities in Northern Ireland at that time. One of the projects that we happened -- 10:14
were happily negotiating, particularly with the Medical Director of Muckamore Abbey Hospital at that time, a rather formidable consultant psychiatrist called Dr. Caroline Marriott, and Dr. Marriott was someone who could be quite forceful in her arguments and didn't 10:15
really want to get -- well, she was very keen on research but, equally, very protective of the hospital. But it took, with a bit of negotiation, we did manage that she would become co-director of a project with myself and at that time a doctoral student, who has now 10:15
become Professor Laurence Taggart at Ulster University. But we formed a research team in which we were able to monitor all the admissions and discharges to Muckamore Abbey Hospital over a two-year period. Now, this was using the in-patient database that all the 10:16
hospitals in Northern Ireland were using at the time. So it was a piece of software that was readily available and, to our surprise, had never really been interrogated in terms of analysing just what does this

data tell you cumulatively over the period of time, the two-year period that we had chosen to do this monitoring.

But four of the findings really stood out from that particular study. The first one was that there was this revolving door of the same people coming in for admissions, being discharged, and then coming back in for admissions again. Very often, the arrangements in the community where they were discharged to were pretty fragile. There was not much support for people in the community and, hence, they ended up back in hospital again. 10:16 10:16

The second striking finding was that quite a number of these people would be what you would call mild or borderline learning disabled. They weren't the people with the more severe disabilities that Alex Ruck Keene had mentioned yesterday in terms of that whole intention of when the mental health order would be applied and under what circumstances it would be applied. So there certainly were people being admitted to Muckamore who were at that more mild borderline sense. 10:16 10:17 10:17

The third big outcome was the treatment that people were given was largely medication-focused. There was very little evidence of any other forms of therapy being applied. And because people often had

behavioural difficulties, and these were manifested in the community situations in which they were living, very often they didn't have the support in those situations to help change their behaviour. So although their behaviour may have improved in the hospital context, which was much more tightly supervised, and with the addition of medication, once they come back to their situation again they ended up showing some of these same behaviours. 10:18

The fourth thing was that many of the people who did come into hospital were coming in from nursing homes or residential homes, congregated settings where people were having to live amongst other people that maybe they didn't particularly get on with. And they were noisy places, given the numbers of people that were there. Some people were in shared bedrooms and they certainly had to share a lot of bath and shower-type facilities. 10:18

So the information that we had gleaned in that period started to question just what the role of the hospital might be. It wasn't the only project that we did at the time, but we also looked to see just how much the services were -- money that were available to services in Northern Ireland, and there certainly seemed to be an underfunding compared to what was happening in GB. 10:19

CHAIRMAN: Can I just ask you to pause for a moment? Sorry to interrupt you.

PROF. McCONKEY: Not at all.
CHAIRMAN: I've had a look at your presentation, but can you now remember the two years that were analysed?
PROF. MCCONKEY: To be honest, not precisely, but if I took up appointment in '97, I guess we're talking about 2000 and 2001. 10:19
CHAIRMAN: Yeah, okay. If that's wrong, could you just drop an e-mail to us and let us know in due course, if you do find out?
PROF. MCCONKEY: I haven't the papers with me - I have them in Northern Ireland - but I can certainly do that. 10:19
CHAIRMAN: Sure, thank you. It's just so that we can pinpoint more accurately.
PROF. MCCONKEY: No problem. And Dr. Taggart's doctoral thesis would also help confirm that, so there won't be an issue in getting that information to you. 10:20

I should point out that in terms of the overall health and social care budget, around the 1990s, moving into the early 2000s, the proportion of the health and social care spend on learning disability services was around about 7 or 8 percent of the total budget. Mental health was actually slightly less at that time, but together they constituted about 16 percent of the total health and social care spend in the Northern Ireland budget -- which sounds an impressive enough figure until you realise that that was the only source of funding that was available to service provision in Northern Ireland, whereas in GB you have local 10:20 10:20

authority funding matched going into -- not necessarily matching, but alongside what was available from central government. So there was the possibility, and although it was difficult to get the actual hard data, it did seem very likely that there was an underfunding of services and that was reflected, for example, in the proportion of people who were living in what you would call supported accommodation, living away from their families, which we were able to benchmark, both in the Republic of Ireland and to figures from England, Scotland and Wales. We, in Northern Ireland, at that time, we had 50 percent fewer people living in supported accommodation compared to the other parts of the jurisdictions. But that meant, effectively, that a lot of people were having to live with family carers for far longer than might have been the case elsewhere in these islands. And those families, other than maybe their relative attending a day centre, really got very little by way of other forms of support.

10:21
10:21
10:22
10:22

And, as I alluded to earlier, there was also within Northern Ireland at that time -- and it wasn't just peculiar to Northern Ireland because in the Scottish Border we also had taken advantage -- there was a period of time when social security payments were made available to facilitate people moving into some form of out-of-home care. They were called "board and lodgings" and this was a way in which people could move out of long-stay establishments and the social security

10:22

payments were sufficient to enable them to live in community settings. But in terms of costs, it was much easier to put those people into nursing homes or residential care homes, homes for the elderly -- modelled on homes for the elderly. And a lot of the services that had started to develop in Northern Ireland as a community alternative was located in these larger homes. The median was 19 different residents, but that could extend from something like a small home of 10 persons right up to 80 people living in one registered accommodation. And in many ways, the social security payments were, indeed, successful in one sense in that it enabled people to move out of the long-stay accommodation, but at no real expense to the health and social care budget. So if you were going to provide an alternative model of care, you would have to find monies separate from this board and lodging arrangement. But in Northern Ireland in the '90s through into the 2000s, this was the main economic vehicle for people leaving long-stay places. 10:23 10:23 10:24 10:24

The other thing that was also facilitating the development, these congregated models of residential care, was that the people who had been patients in Muckamore Abbey hospital were deemed to be under the care of the consultant psychiatrist, who had to sign off their discharge to a place that the psychiatrist considered to be suitable to that person's needs. So we ended up with a very high, compared to other 10:24

jurisdictions, numbers of people living in nursing homes where there had to be nursing staff, often waking night staff. So, in many instances, we had the development of a model of care that was skewed both for, if you like, financial reasons, but also for the whole medical model that was really dominating the discharge of people to what was considered to be a suitable place in the community.

10:25

So, much of what I'm describing was starting to be debated and talked about. In that sense, the Bamford Review was already an opportunity to try and explore and develop many of these issues a step further. However -- if we can move on to the next slide -- the Bamford Review, when it was set up, was not originally going to include learning disability. It was conceived initially -- and it hadn't the title "Bamford" at this stage, I hasten to add -- it was known as "A Review of Mental Health". Now, at that time, Northern Ireland was under direct rule from Westminster, but one of the ministers, who is an MP for Kilmarnock, I think, Des Browne -- and I think, if my memory serves me right, he was the father of a young man with learning disabilities, and he championed the addition of learning disability as part of this review of mental health.

10:25

10:26

10:26

10:26

Now, there was some angst at the time amongst myself and amongst others that this was potentially quite a

confusing amalgam of what might be two very different conditions. Subsequently to Bamford, as you'll hear from the people who come to talk to you about service structures, subsequent to Bamford, they have now often created a joint directorship of mental health and learning disability. But pre-Bamford, these were very distinct programmes of care within the health and social service system. So the people who were managing the mental health side had very little liaison or contact with the people managing the learning disability side. They were two ring-fenced budgets, pretty well, that fulfilled the service requirements of those two groups. 10:27 10:27

And, of course, the needs of the two groups of people were also quite different. However, our judgement was that at this -- if this was an opportunity for the whole review of learning disability to also be undertaken, then why would we want to hold out and say nae to it? 10:27 10:28

So it was fortuitous that both David Bamford, Roy McClelland and Siobhan Bogues were heading up this particular review. And they were very sensitive and very appreciative of the distinctness of what the thrust of the Review needed to be, both in the context of mental health and the issues facing people with mental health, some of which could be subsumed -- some of that population could, of course, be considered to 10:28

be people with a learning disability. But the other didn't work -- people with a learning disability equally had very distinct needs.

So in tackling the way learning disability was to be managed, the working group model was adopted and Equal Lives became the working group on the learning disability side, and the other nine working groups were allocated different domains within the broader mental health area. And the listing that you see on the slide are the reports from all these different working groups, with a little bit of augmentation. 10:29 10:29

So you can see that the first two reports produced -- the Review started in 2002 and the first two reports were completed in 2005. A lot of activity went on in that period and, in many ways, it was a very satisfying time to actually feel that there was a real opportunity opening up and that people had a new sense of vision and a new sense of energy that we really could make things happen. So I look back on it as a really happy and productive time in my career and I was really pleased to be part of it. The people you were working with, whether they be service users, carers, professionals, health service managers, people from a whole range of disciplines, my whole, if you like, professional life also opened up as a result of that particular experience. 10:29 10:30 10:30

The other ones that came through subsequently were really focused in on a lot more mental health. And if you've got the stamina and if you really want to look and read some of these reports, you'll probably not see too much mention of learning disability in any of the other reports. And, partly, that was again the mindset that learning disability had been covered by the Equal Lives Review. So many of the other issues to do with alcohol and substance abuse -- well, I don't think learning disability got much of a mention there. 10:30 10:31

Mental health promotion, no, that was much more geared at a population-based development. Autism spectrum disorders, interestingly enough, had not been considered within the ambit of the Review, but the autism lobby were quite vocal at that time and a special working group was set up specifically to look at that. But that tended to be people who we might describe -- or who in the past might have been described as being higher functioning people with Asperger's who did not have a learning disability. We like to think that in the Equal Lives Review, people with a learning disability and autism, their needs were being considered, but the autism lobby were keen to have their own separate recognition. 10:31 10:31 10:32

The Child and Adolescent Mental Health Service Report, again because the consultant psychiatry services that were provided through the Learning Disability Programme

covered children, adolescents and adults, then ipso facto children with a learning disability were not referred to CAMHS services and, therefore, that report makes sparse mention.

10:32

Likewise, the Forensic Services Report didn't really report much there.

The Human Rights and Equality of Opportunity Report was a broader based one. Yesterday, Alex Ruck Keene did 10:32
point out how much the human rights had started to come to the fore.

Living with dementia and mental health again was much more focused on the elderly, elderly non-learning 10:32
disabled population. The legal framework did, of course, cover learning disability and some of the consultant psychiatrists in learning disability were part of that particular review.

10:33

The final report, strangely, came at the very end when, in some ways, some of us would have thought that would have been the one that we might have been putting a lot of energy in from the outset, but it was probably one of the more disappointing reports and somewhat rushed, 10:33
I think, towards the end.

So those -- that's a very quick overview, Chair, of the whole breadth of the Bamford Review. As I say, I have

made the judgement that maybe I could focus more on the Equal Lives Review, in particular, partly because I've little experience in the mental health services, even less contact with the mental health aspect of the Bamford Review, and, if I may suggest that Roy McClelland, when he is with you, he would be the best person to field the questions. We began to be known in the Bamford -- in the post-Bamford era as the two Roys who often turned up at particular events. And Roy McClelland was very gracious in letting me speak to the learning disability side of the Review, and I graciously and relievedly let him talk about the mental health side of the Review. So there's no better man to ask him about some of the mental health side.

10:33

10:34

If you're happy, I'd like to move on to the Equal Lives Review. Is that okay?

CHAIRMAN: Yes, sure. Please do. Thank you.

PROF. MCCONKEY: Next slide. So the Equal Lives Review mention a real reappraisal of the whole lifespan of a person with a learning disability, starting from birth going right through to old age and death. And the way in which it was chosen to work, modelled in somewhat the way in which the overall review was conceived, and that is that there would be a series of working groups who would look in detail at the different models of care and support that might be required throughout the life of a person. And the six working groups that Siobhan had convened was, one, looking at children and

10:34

10:35

young people and their families, although I should say that families were -- or family carers, in particular, were a constant theme throughout the whole of Equal Lives, but they are mentioned in that particular regard; the whole issue of accommodation and support, and that brought in, of course, people living in long stay hospitals and re-settlement. 10:36

Day opportunities covered post-school provision and this was a health and social services review. So there was little attention given to special schools, per se, and even, although health and social services staff such as therapists would be located within special schools, that didn't really get that much attention. So day opportunities was very much more focused on adult persons. 10:36 10:36

Aging was another working group. And then a working group on mental health, which could also and did also include people with more complex needs, challenging behaviours, people who may be in the criminal justice system and so on. And physical health. 10:36

So each of those working groups had a mixture of people involved in them. There would have been in all the working groups people with a learning disability; family carers; a range of different professionals; people who were involved in managing services from both the statutory side and the nonstatutory side, 10:37

particularly voluntary organisations. Siobhan was quite keen that the whole opportunity should be totally open, transparent, and participatory. And that was a really good strategy and it was pretty -- it was really novel in a Northern Irish context. It all seems so 10:37
obvious now with our 20/20 vision, but this was the prime example of public patient engagement and co-production. Because alongside the working group, the steering group for the Equal Lives Review, there was an advisory group of people who used services and 10:38
they actually called themselves -- the advisory group called themselves the Equal Lives Group, and that's where the name of the report came from. It was chosen by service users who said they want a life that's equal to other people's lives. And there was also an 10:38
advisory group of family carers spanning that age range that I mentioned earlier.

So, in addition to having the two advisory groups and having this mix of people within each working group, 10:38
there was organised six public meetings around Northern Ireland so that people could access them relatively close to their own homes. Six were aimed particularly at people who use services. Six of those meetings were primarily for carers, but often that got intermingled. 10:39
There was a free-phone help line, information line, that was set up where people could also, if they couldn't get to a meeting, could phone in a comment or write in a comment. And twelve different conferences

were organised at different points to really profile new styles of services that were being implemented not just in the Northern Irish context, but also with invited speakers coming in from, for example, Sweden, Kent Eriksson; from Scotland, Lisa Curtis, who was working in the Scottish development projects at that time; and a number of people from other parts of GB, and also a civil servant who had been involved from Ireland, who'd been involved in the review of services in the Irish context. So it was quite an eclectic and a very novel thing for people in Northern Ireland at that time to have the opportunity to really think through in a collegiate way how services could look at some point in the future. And, as I say, the whole thrust of the Equal Lives Report was to represent as much as we could the voices and aspirations and needs of the people for whom the service was going to be provided. 10:39 10:40 10:40

Out of all of that gathering of information, and I have to give Siobhan real credit for this because, in addition to all her skills as communicator in a verbal and social way, she was the primary author of the Equal Lives Report and brought to it the structure and the clarity of language that you can read in it. 10:40 10:41

Five key values were identified; twelve objectives for remodelling services and sports; and seventy-four recommendations for actions that were needed to model

and extend learning disability services across the lifespan. Seventy-four was probably too many, but when you had that whole lifespan -- because I often say, you know, when you have a topic like learning disability, all human life is there in terms of the span of age, the variety of people, the heterogeneity of their life experiences. So it's very hard to just narrow it down to "just let's concentrate on a few recommendations". But those recommendations were really, as much as we could make them, to be quite concise, precise, ones that we could see that were realistic in the time scale available, although we did admit that it might take up to 15 years for all of these recommendations. This was a long-term, radical reform that we were hoping would be instituted in Northern Ireland -- 10:41 10:42 10:42

CHAIRMAN: Could I just ask this: You had five working groups --

PROF. MCCONKEY: Six.

CHAIRMAN: Is it six working groups -- yes.

PROF. MCCONKEY: Yes. 10:42

CHAIRMAN: Of those, which would have had input into your recommendations in terms of the ability to make them real or, to use a horrible word, operationalise them? So did you have anybody who was able to advise you on the reality of putting into effect your recommendations, because sometimes that's pretty crucial. 10:43

PROF. MCCONKEY: I agree, yeah, absolutely. We certainly did because we had health service managers

who were already delivering services and they knew what some of the constraints were going to be. You had professional people like therapists, psychologists, psychiatrists, who also from a professional point of view were able to see. But they were all challenged by 10:43
service users saying, "We don't want more of the same, we want something that's different." And it was through that dialogue approach that -- you know, we talk about the Good Friday Agreement quite a lot in Northern Ireland and when you've been through some of 10:44
the negotiations that were involved in trying to find the wording of these recommendations, you get a sense of what it means to negotiate. So, yeah, there were times when the boat was pushed out in terms of the recommendations, and I'll allude to some of those as 10:44
we move on to the next section, and there were others that were so obvious that you think, well, why isn't this happening, because this is something that could actually start tomorrow. And, ironically, in some parts of Northern Ireland it was already happening 10:44
because there was a great deal of variation and people not really learning from each other.

CHAIRMAN: Yes. Sorry for interrupting. Thank you.

PROF. MCCONKEY: Not at all. So, can we go to the next slide? Oh, sorry, just to say what, obviously, this 10:44
resulted in, because we had all these different working groups looking at different aspects of the people's life, it has to be said that there's no one model of learning disability services. It's an amalgam of a lot

of different models that are very much more aimed at particular needs and aspirations that people hold and that are more suited to certain parts of their life than other parts. So there isn't, if you like, a model per se, but you could say that there is an overarching ethos or some sort of end vision that you have. And David Bamford, in his preface to the Equal Lives Report, wrote this as the overarching aspiration underpinning Equal Lives -- he said. 10:45

"Progress needs to be accelerated on establishing a new service model which draws a line under outdated notions of grouping people with a learning disability together and their segregation in services where they are required to lead separate lives from their neighbours." 10:45 10:46

Every word in that was very carefully crafted. He went on then to say -- next slide -- he went on then to say -- oh, sorry, I've --

CHAIRMAN: Yes, I think we've...

PROF. McCONKEY: You've got --

CHAIRMAN: Yes, it's one more.

PROF. McCONKEY: Okay, go one more. So he went on then to say, as you probably can read it: 10:46

"The model of future needs to be based on integration, where people participate fully in the lives of their communities and are supported to individually access the full range of opportunities that are open to

everyone else."

So, there, he contrasts that segregated, congregated model of people living and not having the same opportunities as others, with this model, which -- and 10:47
if Alex Ruck Keene were here he would probably point to the UN Convention of Rights of People With Disability -- and Equal Lives anticipated the publication in, if you like, and I'm not sure that we take any credit for that, but certainly it shows how much the tenor of 10:47
people's aspirations had developed not just internationally, as the UN convention embodied it, but, here locally, we had an affirmation, if you like, from an international perspective of what we needed to be doing to move away from an outmoded model into this 10:47
rather different model. And people said, "Yeah, that's exactly what we need." So there was almost this sense of, well, we've really achieved something now, of building this coalition of people with like-mindedness -- from service users, through carers, through health 10:48
service managers -- this sense of, gosh, we've done it, we could really make something happen. It was, though, with some caution in the sense that, although this was not overly emphasised because there was no time scale per se to any of the recommendations, because, as you 10:48
rightly say, Chair, the whole process of implementation requires another set of skills and opportunities to know and to plan and to make sure you have the resources, both human and financial, to let you do

that. So we guessed that, in 2005, by, maybe, 2020, we would have done it in terms of not just a perfect vision but, equally, in the year in question.

Are you okay still for time or would you like to take a break? 10:49

CHAIRMAN: I was just thinking, because you're just about to move on to your recommendations, aren't you?

PROF. McCONKEY: Yes, equalised recommendations, yeah.

CHAIRMAN: And I think you're just a bit more than halfway through? 10:49

PROF. McCONKEY: A bit more than halfway, I would say, yes.

CHAIRMAN: Would you mind then if we took a short break now? 10:49

PROF. McCONKEY: No, I'd welcome that.

CHAIRMAN: All right, let's take a short break now. We'll say fifteen minutes, because people need to get out and grab a cup of coffee or tea. You can do the same. Thank you very much, indeed. The normal rules 10:49 don't apply. You can talk to who you like, but you may not have many people to talk to at your time of the evening!

PROF. McCONKEY: They're all in bed! Fast asleep.

CHAIRMAN: We'll see you in fifteen minutes. Thank you 10:49 very much indeed.

PROF. McCONKEY: Pleasure.

THE INQUIRY ADJOURNED BRIEFLY AND RESUMED AS FOLLOWS:

CHAIRMAN: Welcome back. Thank you. So we're moving on to recommendations?

PROF. McCONKEY: We're on Slide 10. Chair, I have chosen to highlight recommendations that are, maybe, particularly pertinent to the Inquiry. I can obviously talk to other recommendations as well, but I'll leave you to ask those questions, if I may. But I did want to highlight this set of recommendations in as much as they relate to people in long-stay hospitals or in hospital-based assessment and treatment. 11:07 11:07

This issue had been bubbling up in Northern Ireland, as I alluded to earlier in the pre-Bamford years, but also there was accumulating international evidence that what we were about to propose could be well-evidenced from experience in other countries -- and, indeed, we had examples of them being implemented in Great Britain. We also had examples, albeit on a smaller scale, within Northern Ireland. We, as part of the research programme with the Eastern Health and Social Services Board and one of the other consultant psychiatrists at Muckamore, we had done a follow-up of people who had been resettled from Muckamore Abbey into accommodation in the community, and that was a story of great success. There was very few people that needed to be readmitted to the hospital because of a placement proving unsuitable. 11:08 11:08 11:08

But the people that we spoke to -- we interviewed all the new residents in their new settings -- we spoke to quite a proportion of the family carers, a number of who said they were quite opposed to the idea of their relative moving out of the hospital initially but now that they'd seen them in these new surroundings, they were really pleased and felt that it really had made a big difference to their lives as carers, as well as to their relatives' lives. So we had this growing evidence based. 11:09

Then, sad to say, we also had a growing awareness that there was a higher risk of abuse happening in these types of long-stay hospitals, and that goes back quite a number of years in England and in Wales, and, indeed, I remember a colleague of mine in the past working in Wales had said to me, "Do you know, maybe the only way we'll ever close long-stay hospitals is when there's abuse proven to have occurred and on a systemic basis." I thought at that time that was a bit of an exaggeration, but, sad to say, I think his words were quite percipient in that way. 11:09 11:10

Although the heightened risk of abuse, I think, to be honest, wasn't really recognised that much in the whole context of the Equal Lives Review, in fact I went back into the Equal Lives Review to do a search on how often the word "abuse" appeared in the whole document, and there were only six instances of the word "abuse" 11:10

appearing and two of those was in the context of schoolchildren and being bullied and the others were more general -- to do with risk assessment around the potential for abuse. So it didn't get a heightened profile at that time, but obviously subsequent revelations have shown that to be true. 11:11

So when we came to write the Equal Lives recommendations in regards of people, their living arrangements outside of a family care setting, we were brave enough to put in that by June 2011 -- and remember this was being written in 2005, so we were talking about a five/six-year programme of resettling people from the hospital. Now, at that time there would have been over 400 people in the hospital, so we're talking about having to resettle people in the order of 70 to 80 a year to meet that particular target. But we did think that was doable because we had the evidence from other resettlement programmes in the UK that people had visited under the auspices of Eastern Health and Social Services Board, and there was also the precedent that that number of people had been resettled, albeit over a slightly longer period from Muckamore in the preceding years. So that seemed to us to be a way of achieving this ambition. 11:11 11:11 11:12

The other reason that I alluded to earlier about this number of people coming in to the hospital on short admissions and then being discharged and then coming

back again, it's pretty clear that you needed some form of emergency support and accommodation for individuals where their actual placement has become unsafe either for themselves or for another person. So the hospital was fulfilling a function that could well be filled if there were local arrangements to enable the person to be removed from the situation which they were finding quite difficult at that moment in time, whether it be a family home or a group home or a nursing home; that the person could live temporarily for a week/two weeks or whatever, get back on an even track again, if you like, and then return to their home, whatever that home would be. 11:12 11:13

Now, we didn't have that form of provision within Northern Ireland. So the hospital, by default, became that place where people went to when they needed that break if they lived within the eastern and northern areas of Northern Ireland. So that was a recommendation. 11:13 11:13

The other recommendation that in some ways was a bit of pushing the boat out that I alluded to earlier was that all new housing that needed support workers, either people sleeping in, waking night staff or visiting staff during daytime hours, should be for no more than five individuals within the same household. This recommendation, we were encouraged to include, having talked to Swedish colleagues for whom this had become 11:13

very much a legal requirement within certainly one of the cities of Sweden -- and Kent Eriksson, who had married a Northern Irish girl and was a frequent visitor to Northern Ireland, was quite to the fore in that movement and helped influence and support us in making this particular recommendation. 11:14

Why five, you may ask. Well, the idea was that people could then live in ordinary housing. You didn't need to build new accommodation with grandiose numbers of bedrooms, bathrooms and so on and so on. Also, it was more likely that a group of three people, who themselves wanted to live with one another, could then be accommodated, and maybe their circle of friends could grow up to five. But having up to fifteen/twenty people that you don't know -- and why would you want to live with them -- there was no choice given to you. This was a much more viable model -- 11:14

CHAIRMAN: Sorry to interrupt you again, but just to ask I understand that worked in Sweden, but did you have buy-in from your patient groups to whom you were speaking in relation to that number? 11:15

PROF. McCONKEY: Very much. Very much. That was their aspiration, to have their own house. And they wanted to be with their friends, though. Now, some people aspired to having their own accommodation and that was accommodated. This was particularly in relation to housing where support was going to be provided. But if people could get by with just minimal amounts of 11:15

support, then we would certainly support them to be in arrangements where they had their own flat or their apartment that they could live in. But this was the idea of people would still be living in smaller groups and, for economic reasons, there's other arguments from that point of view. But the model was actually working. One of the trusts in the Eastern Health and Social Services Board had embraced this model and it had worked very successfully for them. So, again, we could see examples of how it could become a reality and was becoming a reality, with a good evidence base that this really produced better outcomes for individuals in terms of their quality of life. 11:16 11:16

The other point we went on to stress, and this is the boat being pushed out even further, was that, by 2013, all accommodation for people under 60 years should be for no more than five people. Now, effectively, this was flagging up a new form of resettlement of people moving out of these nursing homes and residential care homes that I've mentioned earlier were the dominant form of provision, in which people who were not in those settings said they didn't want to go to those settings, nor did their carers want them to go to those sorts of places. Ironically, the people living in those places, because they actually knew nothing different, I guess, to some extent, were okay. They didn't see that as being particularly something that they were clamouring to move from those places. 11:16 11:16 11:17

However, some people who did do it were really pleased that they had done that. But I guess here we were putting down a marker that if we were going to be true to this notion of people living fuller lives in ordinary settings, then we had to start to think ahead 11:17
to a period when maybe this congregated form of housing -- the under 60s was particularly chosen because we did recognise that that model of care, nursing homes and residential homes, could well suit some people who were older and who were less able and wanted to enjoy simply 11:18
the company of other people. And, for them, that was much more in a normative sense what was happening for older people in Northern Ireland anyway. And particularly in rural areas where it would be very difficult for people to necessarily access that type of 11:18
accommodation, they may well be accommodated within an existing nursing home or care home if the regulatory authority was willing to recognise that as a suitable placement. So the notion was really to really try and appreciate that the model of residential care needs to 11:19
be tailored to the needs and wishes of the people who are going to be in it. So it was by no means a diktat that only group homes was the only model -- there would be a range of different alternatives within that.
CHAIRMAN: Did you explore as part of this whether that 11:19
would require considerable funding of new housing?
PROF. McCONKEY: At this time, Chair, there was the development of the housing associations, whose remit was to develop what you might call social housing, not

just for people with learning disabilities but people with other social needs. And there was, therefore, money coming through -- in Northern Ireland terms, the Housing Executive, which was a non-governmental body that was the source of capital monies for people in rented accommodation -- and there was other means whereby the housing could be found for people.

In the bigger scheme of things, of course, learning disability housing was not going to need a whole lot of houses. So if you take, for example, the people moving out of Muckamore Abbey as part of that long-stay population, 400 odd people, you might need 80 homes or 100 units to accommodate. But in the social housing programme, each year you might be talking about having 1,000 units as part of that programme. So we didn't ever think that was an unattainable objective. In fact, there were organisations actively doing that, joining with housing associations to source housing.

11:20

11:20

11:20

11:21

One of the other things that the housing associations were able to do was to buy existing properties so that they owned the house they bought but then they put tennants into those houses that had been bought. So you didn't even have a capital programme to think about, a capital bill programme with all the lead-in times that would be required from that.

11:21

So we were seeing examples already in place across

Northern Ireland of housing associations and voluntary providers doing this. And, indeed, some of the trusts also used a similar approach.

CHAIRMAN: Can I just interrupt you for a second? I think Dr. Maxwell wants to ask a question. 11:21

DR. MAXWELL: Yes, can I ask did you also look at staffing costs, because some of these places did need support staff. There's an economy of staffing costs in having larger facilities; did you actually look at whether the ongoing revenue costs of staffing would be 11:22 an issue?

PROF. McCONKEY: No, we didn't. And I think that's one of the implementation issues, Dr. Maxwell, that -- and, in fact, in retrospect -- I was reflecting today -- if you were to ask me what were some of the shortcomings 11:22 of the Equal Lives Review, certainly I think there was insufficient attention paid to value for money. In that respect, the costs of the long-stay hospital, any evidence that we could gather on those costs -- and, indeed, it was very hard to extract from the trusts how 11:22 much money was being spent in the long-stay accommodation -- the information, although on the face of it, if you like, the staff/resident ratio might be 1:6, just as an example, and in a group home you might be talking about a ratio of 1:2, but, of course, what 11:23 was happening in the hospital context was you were paying nursing staff and higher managerial costs because you had all the layers of management that invariably come with the larger institutions, whereas

in the group homes, you were very often employing what you might call care assistants. Now, these were talented people in terms of their personal qualities and often when the NVQ system was up and running, they were getting a lot of extra training and well able to 11:23
provide good-quality care in those settings. And they are still, to a large degree, an exploited workforce with, if you like, minimum pay often being offered to them because the Commissioners have often been trying to drive down the costs. 11:24

But if you look at value for money in terms of, well, what quality of life are you buying for the money you're spending on staff, that changes the agenda considerably. But I'd be the first to admit that we 11:24
could do with a lot more of that value for money appraisal and, if it does cost more to have people in group homes of the smaller scale that we're talking about here, or more individualised arrangements, the quality of their lives might be so much better than 11:24
what would happen in a long-stay hospital. But that certainly is an issue that -- implementation would be one that that's where the next phase would take that, I hope.

DR. MAXWELL: I mean, we see this in all community 11:24
services and it's actually the double running costs of the transition that are the problem, because you don't move the money on the same day out of the hospitals to the community. And, actually, unless you budget for

double running of both the hospital and a community service, you can't make it happen.

PROF. McCONKEY: That's right. And the bridging costs are well documented for all the resettlement schemes, for example, in Great Britain. And, of course, in the Great Britain context, those monies were then recouped from the sale of the land and the buildings that formerly created the long-stay hospital. So Gogarburn Hospital in Edinburgh, which I would have known well through the resettlement programme when I was working in the Scottish Borders, that was sold off to the Royal Bank of Scotland and the Lothian Trust had a windfall in terms of the amount of money they got for that site, which more than compensated for the spending that they put in. 11:25 11:25 11:26

Now, Muckamore Abbey is going to be a difficult scenario to sell that land because, for all intents and purposes, it was supposed to revert to be an agricultural land if it ever closed as a hospital. So that option wasn't available. But, again, it would have been a case of the Government saying, "Well, how could we redeploy that site in a way that would save us the capital costs that would be involved if we were doing another new build for another service user?". 11:26 11:26

CHAIRMAN: That was something that I wanted to ask you. Was using the Muckamore Estate itself ever looked at in cost terms? Because it's a very large estate when you look at its footprint.

PROF. McCONKEY: Absolutely, yeah. And a lot of the money that was going into the hospital wasn't on direct patient care either, but we could never get to the bottom of how, as it turned out to be, the North -- at this point in time, we're talking about a health and social service trust called North and West Belfast Trust, and there was a South and East Belfast Trust, both of whom became amalgamated into the Belfast Health and Social Care Trust -- a slight change of name. But, if you like, at that moment in time, Northwest Trust was the only trust in Northern Ireland, I think I'm right in saying, that didn't have a hospital. All the other trusts had a general hospital or whatever, and Muckamore Abbey Hospital came under this North and West Belfast Trust. And the benefit of having a hospital trust was that you probably had more income coming to supplement your HR functions, your finance functions and other functions of the Trust. Now, I don't have evidence for that. This is -- I must admit this is from my experiences of dealing with people within the Commissioning Board through my joint appointment, but those financial arrangements were always very opaque. It was very hard to actually suss out how much money was being spent on direct patient care and how much was being spent to run the plant, if you like, and keep North and West Belfast Trust subvented in its other functions. But that's something that you might ask some of the people who are going to appear before you.

11:27 11:27 11:27 11:28 11:28

CHAIRMAN: Thank you. We've interrupted you.
PROF. MCCONKEY: Not at all.

The second dimension to the Equal Lives recommendations that related then again to hospital provision was looking at where -- if people do need to have a time of assessment and treatment, whether it be on the short-term basis or a long-term basis, is there an alternative to doing that within a hospital setting? And certainly we felt and the evidence was accumulating from experiences in GB, in particular -- I should say at this point the Republic of Ireland, where I had worked and had ongoing contact with, they did not have any hospital-based assessment and treatment services. They were often managed within the existing service provision that people were using, although there was some move to trying to create specialised assessment and treatment units of the sort that you might have seen developing also in Great Britain through the private hospital-type arrangement. But the model we were looking to tended to be happening around England and in Scotland and this had been promoted through a lot of evidence that was being gathered, not least by the Tizard Centre, which Prof. Murphy and her colleague, Jim Mansell, would have been quite to the fore in. So the recommendations that we made here was that many more people with a learning disability should be actually accessing mainstream mental health services, either on a community basis or an in-patient

11:29 11:29 11:29 11:30 11:30

basis. We were particularly attracted to the model where, if you like, the people with a learning disability might have some beds within a unit attached to a general hospital. I had seen this model evolve in the Scottish Borders and that meant that your services then could be much more localised, in the west of the province, for example, you could have it so that people would not need to go to Gransha Hospital in Derry, which would be some 70/80 miles away, but if there were beds available in the South and West Hospital -- or at that time it was located in Omagh -- that would have also meant that people had the option of having -- it still would have been in the context of hospital, but it would also have been in the context of a wider mental health service provision occurring in those places. 11:31 11:31 11:31

But the other thrust of the argument was the need for multi-disciplinary, community-based assessment and treatment services. And some of the trusts, the Northern Trust, in particular -- and I gather you're going to have Dr. Petra Corr talk to you at some point -- she was involved very much with the setting up of that type of model within the Northern Trust and diverted a lot of patients who previously might have gone to Muckamore Abbey Hospital, were now being successfully being seen by these community-based assessment and treatment services. 11:31 11:32

This was a different model to what was happening at the moment by -- the consultant psychiatrists and their senior house officers, their registrars and so on would do outpatient clinics in the community trusts, but it was very much modelled on the type of review, the 11:32
hospital-based type review. There wasn't a great deal of multi-disciplinary working going on. It was much more the consultant psychiatrists or one of the doctors reviewing the individual that was still under the care of the consultant. They may well have had some 11:33
involvement with psychology or possibly with therapies, but there wasn't, if you like, one particularly coherent assessment and treatment plan that we could see evidence for. That model of outpatient reviews seemed to still be very dominant. So the idea was to 11:33
try and build up the expertise within the community so that people did not need to be admitted to hospital; they would have the opportunity of getting support where they lived. And if we link that with that emergency support accommodation in the community that 11:33
I referred to, it would mean that the community trust providing the services would still keep responsibility for the person while they were in this emergency support accommodation, but certainly also when they were actually working with individuals in their own 11:34
homes or in their place of residence.

There was another type of peculiar double funding going on here because what happened if a person was removed

from the community into the hospital, then the hospital costs were then incurred, but their costs in the community were still needing to be covered until such time as they came out of the hospital. Now, there were some arrangement that after a period of time there might be some adjustments made, but very often there was no great incentive for the community people to actually divert any resources if the person is taken out and goes to the hospital because then the hospital is going to be bearing the costs of their assessment and treatment. 11:34 11:34

CHAIRMAN: And otherwise, presumably, they'd lose their place. Sorry to interrupt you --

PROF. MCCONKEY: ...to prevent that type of dichotomy and no continuity, really, between people's needs in that respect. 11:35

CHAIRMAN: Professor, sorry, we lost you for a moment. I think the collection is less good than it was. It's showing as unstable.

PROF. MCCONKEY: Oh, sorry. 11:35

CHAIRMAN: No, it's not your fault. We'll carry on.

PROF. MCCONKEY: Well, in fact, those were the two -- that latter two, the model of service to replace hospital-based assessment and treatment. I should say at this point -- you asked me earlier about how much unanimity there was regards of that. One of the things that we were struck by when we were taking evidence was that, in the midst of all of the information-gathering that we were doing as part of the Equal Lives Review, 11:35

we had a presentation from the Eastern Health and Social Services Board, but that was largely the North and West Belfast Trust who had responsibility for Muckamore Abbey, and from the Western Health and Social Services Board who were responsible for another hospital in Derry called Gransha Hospital, and these presentations were telling us about the new capital improvements that they were going to be making at both Muckamore Abbey Hospital and at Gransha Hospital -- a new capital development to create a new assessment and treatment service centre for up to 110 people, I think it was, at Muckamore Abbey, and a similar -- not as big a development at Gransha -- I can't actually recall the number of beds there. 11:36 11:36

Now, this struck us as really very odd that this development was being planned at the same time when a review was moving towards the point of saying "We actually don't need new capital development, we want to get people off these sites." But, unfortunately, that message never got heard and I can speculate on various reasons why it didn't. But you will know if you've visited Muckamore Abbey Hospital that capital development went ahead and that associated revenue costs with that, not just in terms of the medical staff -- because, remember, we had staff doctors, as well as the senior house officers, registrars and consultants. We had also additional psychologists going and working from there. So a lot 11:37 11:37

of the money that could have been made available for community-based assessment and treatment services, or for new capital developments, at a moment in history it was spent in perpetrating a model that this review a few years later was going to say something very different. Can we move to the next slide? 11:38

PROF. MURPHY: Roy, can I ask you, before you go on, can you tell us whether at the time when you were doing this -- so around 2005 -- were there community-based multi-disciplinary teams of any kind around Northern Ireland for people with learning disabilities? 11:38

PROF. MCCONKEY: Not in the same sense as you would have had it clearly delineated in England, I think, Glynis, or at least places within England. The whole movement -- and I suppose part of this was this medical model dominated development or evolving services that was very much led by consultant psychiatrists, who then, over time, had in the hospital, at least, recruited psychologists -- a few psychologists used to work there -- some speech therapists, some physios, but no occupational therapists. And I can tell you an anecdote about that, but anyway! That model hadn't really got replicated in the community. Although those individuals were there in their single professional capacities -- so you did have psychology doing assessments, you did have therapists doing assessments, but they weren't necessarily working as a team, not even co-located within a team. There was embryonic development starting to happen, but I would say much of 11:38 11:39 11:39

that happened post-Bamford, rather than during the time we were reviewing in 2005. And I think what I've just told you there about the redevelopments in Muckamore and at Gransha rather was evidence that there wasn't much interest from those constituents -- people managing the hospital and working in the hospital -- to actually explore the notion of multi-disciplinary working. And so the outpatient model of reviews was still the dominant thing, in my perception. 11:40

But I think there was another group of psychologists -- and Petra Corr's name I've mentioned -- there were others coming off the training courses who had been more widely read, who were much more involved with the British Psychological Society, started to attend the learning disability section of that, and I think they started to draw in much more of an interest in and engagement with the whole concept of multi-disciplinary worked. It required very careful negotiations, as you might guess, trying to marry that to a very strongly, medically-led model. But they succeeded in places and I think it's taken root very much more in the Northern Trust area, rather than in, arguably, in the West, North Western part -- less so in the Belfast Trust. 11:40 11:41 11:41

PROF. MURPHY: Thank you.

PROF. MCCONKEY: If we go to the next slide, we'll move on to post-Bamford, maybe? So the Equal Lives Report was completed in 2005. Now what, I think, in our

innocence we hadn't really appreciated --
CHAIRMAN: Stop, hold on one second. I think we might have missed a slide. I don't know if you want to go back?
PROF. McCONKEY: Did you? 11:42
CHAIRMAN: Yeah, the 2008 to 2016 Action Plans.
PROF. MCCONKEY: That's the one I want to come on to now.
CHAIRMAN: Exactly, yeah. We were on the next slide.
PROF. MCCONKEY: Oh, were you? Sorry. Okay, thank you 11:42
for that. So the Equal Lives Report was submitted in 2005 and what we had underestimated was that really nothing was going to happen by way of taking forward any of the recommendations until all the Bamford Reviews were in. Now, we didn't -- I suppose at some 11:42
level we thought that seemed to be a waste of time and, in a sense, it comes back to the notion of learning disability being tagged on to a wider review of mental health and, in our innocence, we thought that we were masters of our own destiny and we could have taken the 11:43
whole thing and run with it. But that wasn't to be. In fact, until the last report was submitted -- and by this time Northern Ireland had its own executive -- so for much of the period of time over the Bamford Review, it was direct rule ministers who were actually the 11:43
policymakers within the Department, if you like, and any meetings that we had with ministers, it was with the direct rule ministers.

I attended a few of those meetings. I think the thing I found most interesting was that the direct rule minister was keen to tell us about the problems they were having in their constituency with learning disability services and didn't really, I think, have a 11:43
grasp of what it was we were trying to tell them about the problems we were having. So it was with some -- well, you know, you hope that local politicians would have a better understanding, shall we say, of the context in which we were operating. 11:44

So we had to wait until 2007/2008 until the Executive were up, and I've already quoted to you that the Executive had appreciated the radicalness of what was being proposed. And one of the -- the First Minister 11:44
of Health in the new Executive was an Ulster Unionist politician by the name of Michael McGimpsey, and he had appointed what he called a Board of Experts, a small number of his -- and I accepted his invitation to be part of that Board of Experts who were meeting around 11:44
2007 for a two-year period, 2007/2008, and this was to prepare for the implementation of Bamford. But it was made very clear to us that our role was advisory; that this was going to be the responsibility of the Department of Health as the lead agency, but it would 11:45
be a cross-governmental department action plan and that was something we felt was really helpful and necessary because housing came under one, transport came under a different department, education, further education and

so on. So it made a lot of sense. Although I do remember the Permanent Secretary or the Head of the Civil Service in Northern Ireland, who I happened to know personally because he had trained at Queen's with me when I was doing psychology there, saying, you know, it's the kiss of death if you set up an inter-departmental committee, and I hadn't appreciated what he meant by that until, as you'll hear, this is how it unfolded. 11:45

11:46

So the Government then did produce an action plan, which was to cover the years 2009 to 2012. That action plan was a fairly substantial document. I've given you a link to it. There was 43 pages devoted to learning disability and all the different actions that the various departments were going to take in relation to implementing. It was hard sometimes to track where the Bamford recommendations sat with relation to this action plan that had been produced by the cross-departmental steering group and the teams that were involved in it. Nonetheless, it certainly seemed a good action plan and in terms of an intent to make a start on the whole implementation of the Bamford recommendations. 11:46 11:46

11:46

However, in 2012, when they did a review of it and the action plan was being renewed then for another three years, this action plan only had two pages devoted to learning disability and, among the actions

they were proposing in the new action plan would be a 25 percent reduction -- only a 25 percent reduction in the number of long-stay patients in learning disability by 2013 -- you recall that we thought the whole place could be cleared by 2011 -- and anybody would be promptly and suitably treated in the community and no one would remain unnecessarily in the hospital. 11:47

That, again, sounded to be very much in line -- broadly in line with what -- was hoping. But when 2016 came and there was a consultation over the action plan, it was pretty apparent that these targets were not being met at all. And that consultation was done very widely. There was a lot of information gathered through focus groups, through individual responses, and so on. So we waited with bated breath to see the next action plan, which, of course, would have covered the years 2016 through to 2019, and nothing happened. The consultation and the reports of the consultation were never published and haven't yet been published. So we assumed that the inter-departmental initiative just withered away. 11:47 11:48 11:48

However, the Department then had got this idea of service frameworks and the Chief Medical Officer was particularly keen that we should move towards a set of service frameworks that would guarantee to individuals that if you're a user of health and social care services, that there was three big standards: they 11:48

would keep you save; there would be a minimal risk of harm to service users and staff; they would be effective because they'd be informed by an evidence basis and commissioned and delivered in an efficient manner; and that they'd be person-centred. 11:49

Now, the service frameworks had originally been designed more for cardiac, respiratory, and cancer. But the concept that the Department came up with was that these could be extended to mental health, to 11:49 learning disabilities, to children services and care of the elderly. So these were going to be transposed onto social -- what was essentially social care social services, even though their origins were very much within the medical framework. But, again, as Siobhan 11:49 Bogues bravely took on chairing the Service Framework for Learning Disability, which was good continuity with Bamford, I got an invitation to be part of that framework as well, and the idea was there would be these service standards against which all services for 11:50 people with learning disabilities could be judged with key performance indicators. I've highlighted three standards from the Learning Disability Standards that I think are particularly relevant, I think, to your interests. 11:50

The first, of course, was that: "People of all ages are safeguarded from harm through abuse, exploitation or neglect." Standard 26: "All people with a learning

disability who has behavioural challenges should be able to get support locally." And Standard 28: "Health carers should work in patternship with a variety of agencies in order to ensure that the accommodation needs of people with a learning disability are addressed."

And some of the key performance indicators, for example, for Standard 28 was that the number of -- proportion of people living in accommodation with less than five other unrelated people, coming directly from the Bamford Review, would have been one of the key performance indicators.

So, again, a lot of effort was expanded in developing these service frameworks. They were largely, if you like, a desktop exercise in general. They weren't necessarily tested. The idea was that the working party would develop these service frameworks and then they would be handed down for services to implement. But that stage didn't really ever seem to happen and, indeed, when it came to a review of progress -- if you move to the next slide now...

CHAIRMAN: Can I just ask, sorry, the working groups that you've just described, how often were they meeting?

PROF. MCCONKEY: This is for the service frameworks, Chair?

CHAIRMAN: Yes.

PROF. MCCONKEY: I would have thought monthly. It was fairly intense work again and it was a mixture of people. Like, because Siobhan had taken on the chair, she modelled it very much on the way the working groups in Bamford had done. So there was service users, carers, as well as different professionals. And they reported -- there was a project board chaired by the Chief Medical Officer and each of the working groups on the different frameworks would report into that project board. 11:52

CHAIRMAN: I was going to ask were the working groups reporting effectively to the Department of Health through the CMO?

PROF. MCCONKEY: Yes.

CHAIRMAN: So there's nobody from the Department of Health actually on the working groups? 11:52

PROF. MCCONKEY: Yes, there would have been. So, yes, and, as it happened, one of the officials was a parent of a young man with Down's syndrome. Again, I've known him from Queen's University and, his son, I would have known through the services that he used. So, yes, there was that personal involvement and engagement in that respect. 11:53

CHAIRMAN: So you had that advantage. And how easy did you find it to understand what the DoH were actually doing about the recommendations that were coming out of your working groups? How did you keep track of what was actually happening on the ground? 11:53

PROF. MCCONKEY: The information went up rather than

any coming down, I think, would be my honest answer to that, Chair. So that Siobhan, through our working group, for example, she would report to the project board of what was progress and how the things were going. But we didn't ever get a strong indication as to what then was going to happen. Rather vaguely, it was hoped that the then Health and Social Care Board, and there now just was one for Northern Ireland, that the Health and Social Care Board replacing the four health and social service boards that previously had existed, would somehow monitor how these service frameworks were operational within the social service model and/or the public health agency because Minister McGimpsey had this notion that we also needed to have a public health agency, as well as having a commissioning board. So we had this -- it was very hard to suss out then whose responsibility was it going to be. Certainly, the Department saw themselves as producing the policy, if you like, and then it would be up to other people to implement that policy when it was handed down.

11:53 11:54 11:54 11:55

CHAIRMAN: Yes. And, of course, by this time, sadly, David Bamford had died some time ago. You were effectively chairing the Bamford Review. And did you have a key point of contact in the DoH to whom you felt you could speak freely so that you could find out what was going on?

PROF. MCCONKEY: At the time when the Board of Experts was set up, it was the Permanent Secretary who had

taken a particular interest in that and, subsequently, the Director For Learning Disability would have been the main point of contact, would have been the lead. And I think you're going to meet the current lead for learning disability within the Department. But you have to remember that the Department of Health has its primary concern and interest in acute hospital provision. It's no coincidence that they changed the name back to Department of Health when it used to be the Department of Health, Social Services and Public Safety. And I think in some ways it always was a Department of Hospitals. And the Department of Social Services, in particular, and because learning disability was very firmly within this social services side of the house, as it were, was not seen as a particularly high profile and there was quite a turnover of personnel working within that section.

CHAIRMAN: Yes. No, I understand that quite well. Thank you.

PROF. MCCONKEY: There were some others reviews of progress happening in that period, 2016 to 2022. And, in 2016, the RQIA often undertook what they call topic reviews, and they chose to do a review of adult community service, adults with learning disability and community services. And I accepted an invitation to be the independent reviewer alongside two RQIA staff, in which we met with the what were now five community trusts. We previously had eleven, but with amalgamations they were now whittled down to five.

We met with each of them to review the range of services that they had done. And the conclusion that they came to, which I have mentioned in the report, was that the resettlement was still ongoing. It was not going to even meet the target that had now been set originally of 2017. The admission of people with a mild learning disability to mainstream mental health services remained very low. And the behaviour support teams that were starting to be set up by the trusts didn't really have an evidence base for the models they were doing and very little, bar one trust, the Northern Trust, had any evidence of impact and what outcomes they had achieved for the people that they had dealt with. 11:57 11:58

There were other aspects of the review which were very positive. I've only highlighted those that link in close to the recommendation, as I've said. We could see changes that were happening in terms of some of the accommodation needs. There was a growing development of people living independently, people living in smaller group home accommodation, better family support services, new types of employment services, further education opportunities were opening up. So other models were starting to take route, and that was, really, despite any implementation plan coming from the Department, but more individuals within the non-statutory sector, in particular, because they had access to other sources of funding, were able to 11:58 11:58

instigate on a model basis new forms of services. And some of the trusts themselves were also beginning to create some of these new services that people needed. But the progress that we had envisaged happening within the context of long-stay and hospital-based assessment and treatment was still quite sporadic. 11:59

The Minister commissioned an independent review of resettlement in November 2001. I've referenced this document as well because it's an extremely well-written document and gives you a very detailed historical record of all the attempts that had been made at trying to get resettlement completed, particularly from Muckamore Abbey Hospital, and I would commend that to you. But again, their recommendation was that a lot of the failure was due to a lack of performance management. There was much more of an emphasis on monitoring, rather than actually managing the process. 11:59 12:00

Another development, of course, is yourselves -- oh, sorry, the other development in 2021 was that the Health and Social Care Board instigated the development of what they called a regional learning disability model. There was some concern that the five trusts had developed very diverse models of provision into things like day opportunities, in types of accommodation and so on. And it was a bit of a bemusement to us that, having had the Equal Lives Review, that there was the need to do what almost seemed to be a repeat of the 12:00 12:00

Equal Lives Review. And the report that they have submitted to the Department has not been made public, as yet, but it was widely consulted by the Board and the people leading that review and they came up to all intents and purposes that there would be the need for a much more coherent model of service provision so that the people, wherever you lived in Northern Ireland, you would have the opportunity of having the same type of supports that you would get if you were living in another part. That seemed to be the big intent behind this particular model -- 12:01 12:01

CHAIRMAN: I'm so sorry to interrupt. You said it wasn't made public, but did you get a copy of it?

PROF. MCCONKEY: No, I haven't had a copy. I was to have -- they were to consult with me at one point to hear my views, but that never happened in the end. I can't now recall the reason for it. So they were consulting fairly widely. But, no, I think they felt it had to be approved by the Department before it could be made public. This is another instance of the information going up. But it still hasn't been made public, so we're no nearer getting a regional learning disability model. And now that the Board is gone and it's replaced by an SG group, I'm not quite sure what its status is going to be. 12:02 12:02 12:02

And then yourselves in 2022. And then the Minister also, shortly after announcing the Inquiry, has had a consultation going on the closure of Muckamore Abbey

Hospital in 2022.

So that's where we are at the moment, nearly bang up to date. And I suppose if you were to ask me for some conclusions, I think I would pinpoint these particular ones. There are plenty more, but I think I certainly do need to be concise here. I would say the great success of Equal Lives was the fact that it really was visionary in terms of creating a person-centred and human rights-centred model of service provision. And, as you heard yesterday from Alex, it's really rooted within international best practice and, therefore, for us in Northern Ireland, who really do want to acknowledge the rights of everyone that lives in this small part of the island, that everyone has a right to equal opportunities. 12:03 12:03 12:04

I think for me -- and, again, in retrospect, it's hard to really appreciate just how much of a model it provided of public patient involvement and co-production at a time when those words weren't even buzz words at all. We didn't realise we were doing what now seemed to be best practice. So I think, in that sense, those process elements. 12:04

And I think if new community-based services have been established, it may not have spoken to what we might say transformations within the system, per se, but it certainly spoke to the people and gave them aspirations

if you were a carer or if you were a service user that, yes, this is something that we could be doing and need to be doing for people. And I mention the non-statutory sector because I've worked in the voluntary sector over the years... 12:05

CHAIRMAN: Sorry, we lost you for a second. You said you had worked in the voluntary sector and then we lost you --

PROF. MCCONKEY: I'd worked in the voluntary sector, both in Dublin and then latterly in Scotland and I've been a trustee for voluntary organisations in Northern Ireland, and I can see how quickly that sector can respond flexibly, locally, and in a person-centred way, and also draw down funding from organisations like the Big Lottery or from the European Social Fund when we had that available. 12:05

So, very often, the developments that were promoted within Equal Lives were being implemented by people on the ground at the grassroots. So while we may not have influenced as much as we would have liked to have done the systems, per se, I think it made a big contribution in changing people's mindsets as to what was attainable for people with a learning disability. 12:06

I think I also have to realise I've learned a lot about how the lack of commitment to implementation there was within statutory systems. The status quo seemed to be something that they valued -- it needed to be protected

more than what implementation of new things could offer -- and make life easier for everyone, in the end. So your question earlier, Chair, when you said about implementation, I think I now appreciate how, maybe, any review needs to be really conscious of right at the outset thinking: Well, how are we going to change the system? How are we going to make that happen? And I've already said that I think the value for money has been rarely considered and we didn't do sufficient attention to that element. And the economics and the financial arguments that now are so topical within the Northern Irish health and social care system, that value for money. And, yet, we've had the Bengoa Report, we've had the Transforming Your Care Report, and those equally have met similar fates to the Bamford Review. 12:07 12:07 12:07

So I think there's a lot of lessons that we can draw for future reviews and inquiries in Northern Ireland about all the effort that we expend and all the talent we bring together and all the great minds that we, hopefully, try to address pressing issues, can easily, apparently, not come to very much. So I hope you are spared that outcome from your particular inquiry. 12:07

CHAIRMAN: Can I thank you, first, for bringing the Bamford Report to life in a way that you simply can't get if you just read it, which, of course, we have, certainly the Equal Lives part of it. Also, I think your comments on the difficulties of implementation 12:08

are, I have no doubt, pertinent to this and every other inquiry because, as you well know, governments are always very good at commissioning reports and inquiries; sometimes they are rather less good at implementing the recommendations. So certainly we will take your advice very much on board. Thank you. 12:09

I don't know if there are any questions from my Panel members or from counsel?

MR. DORAN KC: Not at this stage, Chair. As I indicated, there may well be a follow-up to the sessions that we've had today and yesterday. 12:09

CHAIRMAN: Yes. Certainly. Yes, indeed. And if we're lucky, we will have Professor McConkey actually with us in -- or at least in the jurisdiction on the next occasion. 12:09

PROF. MCCONKEY: I very much hope so.

CHAIRMAN: Professor McConkey, can I thank you very much, indeed. It is pretty late for you, and we are just about to stop and have lunch here in Belfast. But thank you very much for a really enlightening delivery and presentation of your report. So, thank you. 12:09

PROF. MCCONKEY: Thank you very much for your attention. Much appreciated. And thank you for your kind words. 12:10

CHAIRMAN: Thank you very much, indeed. We'll close the link.

PROF. MCCONKEY: Good-bye.

CHAIRMAN: All right. I think the next witness is next

Wednesday?
MR. DORAN KC: That's correct, Chair. It's Professor Roy McClelland, who has been mentioned in dispatches over the last couple of days. I should say, Chair, he is in a different position from the two speakers from whom we have heard on Module 1. They have given essentially expert presentations on the developments that have brought us to where we are today. Professor McClelland will be giving evidence on behalf of the Trust -- 12:10
CHAIRMAN: So he's more of a witness, as it were, rather than a presenter.
MR. DORAN KC: Yes, indeed. And he has, indeed, provided a detailed witness statement with exhibits, and those materials have been circulated to all Core Participants. 12:11
CHAIRMAN: Yes. And there's a fairly significant amount of it, I think.
MR. DORAN KC: Yes, indeed.
CHAIRMAN: All right, thank you very much, indeed. We will stop now and reconvene on Wednesday next at ten o'clock in the morning. 12:11

THE INQUIRY WAS THEN ADJOURNED TO WEDNESDAY, 29TH MARCH 2023 AT 10:00A.M. 11:58