



Northern Ireland
Assembly

Committee for Health, Social Services and
Public Safety

OFFICIAL REPORT (Hansard)

Transforming Your Care — Learning
Disability Services: DHSSPS Briefing

16 October 2013

NORTHERN IRELAND ASSEMBLY

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Members present for all or part of the proceedings:

Ms Maeve McLaughlin (Chairperson)
Mr Jim Wells (Deputy Chairperson)
Mr Roy Beggs
Mr Mickey Brady
Ms Pam Brown
Mr Gordon Dunne
Mr Samuel Gardiner
Mr Kieran McCarthy
Mr David McIlveen
Mr Fearghal McKinney

Witnesses:

Dr Maura Briscoe	Department of Health, Social Services and Public Safety
Mr Aidan Murray	Health and Social Care Board

The Chairperson: Maura and Aidan, you are welcome to the meeting. I invite you to give a 10-minute presentation. Following that, I will invite questions from members.

Dr Maura Briscoe (Department of Health, Social Services and Public Safety): Thank you very much. Good afternoon, everyone. My colleague Aidan Murray is assistant director of mental health and learning disability in the Health and Social Care Board. The purpose of what we have sent you is to outline the content for service transformation in respect of learning disability in the context of Transforming Your Care (TYC). You asked particularly about health inequalities, and we have taken that, largely, on board. That will be the focus of our presentation.

It has to be acknowledged, of course, that the strategic implementation plan for TYC has not yet been published by the board. I think that you have a draft plan from earlier this year. It is fair to say that TYC, in general, is a transformation model to improve overall health and well-being, and that includes placing individuals at the centre of care with the focus on prevention, protection and improved integrated care provision.

Drilling down into learning disability, then, we acknowledge that those living with a learning difficulty have a shorter life expectancy and are at increased risk of premature death, compared with the general population. We also acknowledge — and, as you know, Bamford acknowledged — that the promotion of social inclusion in terms of better health and well-being is very important. Equally, it has to be highlighted that many people living with a learning disability have associated co-morbid conditions, such as physical and mental health conditions, including epilepsy and autism. Mental health conditions, certain specific syndromes are associated with other physical conditions and,

indeed, challenging behaviour. Therefore it is very important that those with a learning disability have access to the same range of services as the general population. That is particularly necessary to promote better health outcomes for those with a learning disability.

We acknowledge that 'Equal Lives' and Bamford were pivotal reports in respect of learning disability, and that the Government's response was 'Delivering the Bamford Vision' and the associated action plans that were produced 2009-2011 and 2012-15. You will have seen the Bamford action plan that was produced in January 2013.

'Delivering the Bamford Vision' and the Bamford action plan are all about health inequalities for mental health and learning disability, and recognising that there are a number of social determinants of poorer health outcomes, such as employment, education, housing and poverty. All of those things are covered on a cross-departmental basis within the Bamford action plan and 'Delivering the Bamford Vision', which you will have received.

Just to drill down, then: it is fair to say that Transforming Your Care is about person-centred care, but in many ways that was no different. There is nothing, really, in TYC on the wide range of issues to be addressed that was not identified previously, either in 'Equal Lives' or 'Delivering the Bamford Vision' and associated action plans. So, for example, if you look at it — and you will have seen this in the January 2013 Bamford action plan that scopes 2012-15 — the emphasis across mental health and learning disability was on early intervention and health promotion; a shift to community care; promotion of a recovery ethos, largely in respect of mental health; personalisation of care; resettlement; service user and carer involvement; advocacy; provision of clearer information; and short break and respite care.

In addition to the broad range of stuff that is covered in the Bamford action plan, you will be aware that one of the actions that relates back to 'Equal Lives' and was in the previous Bamford action plan relates to GP health checks for people with learning disability. It recognises that there are particular issues in relation to the health and well-being of individuals with learning disability. I will hand over to Aidan in a couple of minutes to conclude this presentation by saying something specific about those health checks in respect of health inequalities and the role of health facilitators in each of the trusts. There are just over nine whole-time equivalents for learning disability health facilitators across the trusts, and that is very much a regional approach.

The paper's last paragraph relates to the learning disability service framework. It is no accident that there is such a framework, because the methodology used in the development of service frameworks looked at issues that, in terms of the general population, impacted on morbidity and mortality in the population. Therefore, the sequencing of the service framework programme, if you like, was in relation to cardiovascular disease first, then cancer, mental health conditions and the learning disability service framework that was produced in 2012. There was then, of course, a respiratory conditions service framework as well. So the sequencing was cardiovascular, cancer, respiratory conditions, mental health, learning disability service framework and then, more latterly, the older people's service framework. The next service framework, which is imminent really, is on children. So there was a particular logic in looking at that approach to service framework development.

In conclusion, in respect of health inequalities for learning disability, we recognise that there are health inequalities. Some of them are similar in respect of the social factors and determinants, such as poor housing, poverty, economics, education and all of those things. We supported those in developing actions in the Bamford action plan. We recognise, of course, that there are specific conditions in the learning disability population. Some can mitigate the outcome of those conditions, others not necessarily so. There are particular syndromes, etc, and other links to other co-morbid conditions that it is very difficult to mitigate the circumstances around. We recognise very much that there are particular concerns about poor communication and understanding of health issues. Suitable, reasonable adjustments have to be made in the health service in respect of people with learning disability. There are issues in respect of individual lifestyles for people with learning disability and, indeed, the way healthcare is delivered. As I say, reasonable adjustments are key issues in that respect.

If I may, Maeve, I just want to hand over to Aidan, who will talk about the annual health checks, which are a regional approach to a directed enhanced service for those with learning disability, and what the outcome of that is likely to be, because I think that it is a very important, pivotal aspect of taking forward the Bamford action plan. Just to emphasise that, I brought with me some documentation — easy-read versions — on annual health check information for people with a learning disability, just to highlight to you what reasonable adjustments are made in respect of the way that is presented to

individuals. I am happy to pass that up if you would like it. I also have with me an adapted letter of invitation to a health check to an individual with a learning disability. Again, the way the invitation is structured makes reasonable adjustments for people with learning disability. I am happy to hand that up. If colleagues would like any other copies, I have a couple more. That is fine. Maeve, to inform the discussion, I think that it would be helpful if Aidan could say a little bit about the particular aspect of health checks for learning disabled people and the potential outcome of the evaluation that is being done, if that is OK with you.

Mr Aidan Murray (Health and Social Care Board): Thank you very much. As Maura said, health is, obviously, vital to everybody. It was one of the early and very big messages that came out of the Bamford planning process a number of years ago. It was very obvious that health outcomes for people with a learning disability in Northern Ireland were not the same as the rest of us enjoy or hope to enjoy. Accordingly, when the board and the agency came into being back in 2010, one of the things that we set about finding out was, "Well, we know that, but how do we address it? How do we actually do something about it?" I will explain briefly what we have put in place.

Although it is not published and is yet to go through the Bamford approval structures through the board, I can give you details of the evaluation of the scheme, which I will describe. As Maura said, it is referred to as a "directed enhanced service". That simply means that it has a status in primary care. We pay doctors an additional sum. In a minute, I will talk about how much it costs to actually provide this service. It is based on international research. As you are probably aware, there is a lot of evidence for and against screening certain populations for certain conditions. There is a well-established international evidence base for the efficacy and benefits that are to be derived from screening adults with a learning disability. It very much bears out the research that was carried out in GB a number of years ago by Mencap. Some of you may remember the report 'Death by Indifference', which showed that people were not actually getting the ordinary primary care assessment. Accordingly, the ordinary problems that each of us would go to our GP to seek attention for were not being picked up adequately by that group of people.

So, what we did was take a twofold approach. GPs in every practice were approached and had the training and the packs for themselves and their practice staff to facilitate an annual appointment being sent out as per one of the letters that, hopefully, some of you have in front of you to invite someone along who is over 18 and has a learning disability. That is across all of Northern Ireland. At the very least, those people are getting an annual health check. That annual health check is a regionalised one. It is picked up from the Cardiff screening tool, which is also used in GB. Therefore, we get a consistent picture of people's health and how it is being addressed.

As well as the annual health check, the important thing is, obviously, what happens as a result of it. I will tell you a little bit about the evaluation. We know that it leads to better uptake of appointments into secondary care. Doctors are actually referring people through to secondary care for very important and serious conditions which, formerly, were not being picked up. Increasingly, as part of the paperwork, there is a health action plan, so that each individual, after they have had the annual assessment, actually takes something away with them which gives them and their carers and families advice and help with what can be done to improve their health in the intervening time until they are next seen by the GP.

That is one stream of it. That is paid for through primary care. A doctor is paid £75 for each appointment of the nature that I have described. In the past two years, 5,000 of those appointments have been carried out. In terms of a percentage of people whose lives that actually touches, 69% of all of those adults in Northern Ireland have had such an appointment in the past year — bearing in mind that it is something that we knew we would be starting from zero with whatever families would have been in contact with GPs back in 2010.

As Maura said earlier, the other track has been to employ through the trusts 9.3 whole-time-equivalent health facilitators. That is just the way they are distributed across the trusts. It is just the aggregated figure. Health facilitators are, essentially, nurses with a background in learning disability who work alongside each of the GP practices and follow up on the work that needs to be done after the assessment and appointment. They are also pivotal in following up if someone does not attend. Often, the situation in the past was that a number of people with learning disability would not have been in regular contact with their GPs, especially when they did not have much family or carer support in the community. Those nurses actually follow up when appointments are sent out and, if someone does not attend, try to ensure that they do come along to see the doctor. Critically, they, obviously, then follow up with the health action plan and secondary care referrals.

That has now been in operation for two years. It has grown as the money has allowed, from a smaller beginning to the position that we are in at the minute. Recently, the board and the agency commissioned the document that I referred to earlier, which will be available after the December meeting of the Bamford project board if it is approved there, which I am sure that it will be. It is an independent report from Professor Roy McConkey at the University of Ulster on the efficacy of that. Very briefly, it outlines what I have said to you about the reach of the programme into the lives of 69% of those people to date. It recommends that we continue with the scheme because it is bearing results in terms of people being followed up into secondary care. It details the types of conditions that are being found and referred on.

The cumulative effect of that, obviously, will not be felt immediately in terms of health outcomes. However, it is a very important part of the work that we are doing at the minute. The other big recommendation from it is that now that it is in place and up and running, the group that has been overseeing its development and monitoring it should now move its focus on to health promotion. In partnership with the Public Health Agency, we will launch campaigns specifically for people with learning disability based on the messages that are coming out of this, to look at areas such as improved diet and tackling obesity and, where required, drugs, alcohol and tobacco misuse. So, a whole other raft of work in health promotion will come from that.

In summary, I would just say that, as we go along, we know that there is still a severe problem between people with learning disability and the rest of the population in terms of the mismatch in health outcomes and the health conditions that people live with. We are determined to minimise those gaps and disparities, while acknowledging that there are some conditions — for example, epilepsy — where, unfortunately, if you have a learning disability you are 20 times more likely to have it than if you do not have a learning disability. Obviously, the health consequences of having epilepsy are well known from some tragic cases, and so there are some things that are very difficult to mitigate. Within those confines, we are determined to drive down those health inequalities for people with learning disability.

The Chairperson: Thank you both for that. Members, as a director of Destined, a learning disability charity in Derry, I should have declared an interest at the start of this discussion. I am not sure if any other members have any interest to declare. Okay, we will move into questions. Quite a number of members have questions. We will be moving on to the stakeholder event around learning disabilities in the next number of weeks, but my question is around the fact that the Department is putting a huge focus on learning disabilities, and carers of children with learning disabilities. How can the Department justify the fact that the mental capacity Bill will exclude under-16s? It would seem, on the face of it, that that will exclude children with learning disabilities from some of the same rights and entitlements that would be expected. It seems to be at odds with — I welcome your thoughts on that.

Dr Briscoe: We have a whole programme on the mental capacity Bill. I think that we have explained this in great detail in our previous policy papers. There is a difference between mental capacity and child development. For example, any child of 12 may not have the development to make an informed decision, whereas that is very different from legislating for mental incapacity as a consequence of a disorder or whatever. I am happy to come back, Maeve. This is a very complex issue. We have engaged heavily, and we met the Children's Law Centre last week. We are conscious that it is one of the main proponents of what you describe. We think that we have a way forward on this, but we are still in the policy development stages. If you do not mind, I will be happy to come back at a later date to discuss that specifically with the Committee. We have taken a wide range of views, and, generally speaking, we believe that the age of 16 and over for the specific mental capacity Bill is correct. That is not to say that there can be other ways of dealing with informed decision-making in respect of all children, and it does not mean that they have a mental incapacity. It may mean that they are just not mature enough to make a decision. That is quite a different thing.

The Chairperson: OK. Thank you for that. We will take you up on that offer of discussing that at a later date.

Dr Briscoe: As I said, we are still in the policy development stage. A considerable interface on that is between the civil and criminal justice systems. Therefore, while we have a very active reference group and stakeholder group, and all that has been discussed with the wide stakeholder group that we have, our policy will be out to consultation, but that will not be until early next year.

Mr McKinney: Thank you both for your presentation. You started off and concluded with the fact that people with a learning disability have a shorter life expectancy. You also dealt with other inequalities

towards the end. Can you expand on what other health inequalities are experienced by people with a learning disability? What are those other health inequalities?

Dr Briscoe: As I said, work from the UK in particular reflects a gap in life expectancy for people with a learning disability. I think that it is about 13 years or so, and the top three common causes are cardiovascular disease, cancer and respiratory conditions. I will emphasise that that is why the emphasis is on access to health checks, but also through health facilitators that individuals with a learning disability access the common screening programmes — for example, cancer screening programmes, mammograms, etc. That is part of the role of the health facilitators.

Mr McKinney: I think that you were referring maybe more to housing and things like that.

Dr Briscoe: Yes. I mentioned those in respect of the social determinants of health inequalities, my point being that it is much wider than health service provision. That is why the Bamford action plan takes a global approach, in collaboration with the Department of Education, promoting special educational needs through the Department for Employment and Learning in respect of those who are not in education, employment or training. All the other things — education, employment, housing, etc — contribute to health inequalities for people with a learning disability, as with the rest of the population, I have to say. They are not exclusive to people with a learning disability, but they are recognised as other important issues. That is why they are in the Bamford action plan.

Mr McKinney: Obviously, measuring all that is very important. How do you gather information on the health outcomes of those with learning disabilities?

Dr Briscoe: The annual health checks are a major start. We did not mention that we produced the Guidelines and Audit Implementation Network (GAIN) guideline a number of years ago. That is in respect of how people with a learning disability are treated in general hospital services including, emergency departments, etc. That GAIN guideline is under review at the moment, so that will be another contributing factor.

The other real element is in respect of the learning disability service framework. There are 34 standards in that. The generic standards, such as smoking and alcohol and all the rest, are embedded in all service frameworks, including the learning disability service framework. The service framework has performance indicators, and through the Health and Social Care Board, there will be a baseline audit through GAIN on the performance indicators in respect of the learning disability service framework. That is a baseline to try to measure improvement as we go on.

Mr McCarthy: Thanks very much for your presentation. I am delighted to hear that in both your presentations you mentioned the Bamford action plan, the Bamford report and 'Equal Lives'. That is very welcome. As you well know, Bamford has been falling behind in relation to delivering. Hopefully, this is a sign that we are going to deliver in the near future.

Following on from Fearghal, I have three questions to do with social inclusion. In paragraph 3 of your paper, you state that it is acknowledged that a focus on social inclusion promotes better health and wellbeing outcomes. What do you mean by social inclusion in that context?

Mr Murray: That follows on from the previous question very well. I will briefly say what those social determinants are on the basis of research. This stuff was produced to answer that question. There are no big surprises, because they are for the whole population, but the big things that were found to be making a very negative difference on people with a learning disability were poverty, unemployment, social isolation, which comes back to the social inclusion bit, less access to health information than the rest of the population, and stigma and bullying, which again is very much linked to social inclusion. We were determined to try to mitigate those factors because they are felt to be such detrimental factors for people's health. I will explain what we mean by social inclusion there. Research and people's own experience tells us that people are much happier and healthier — the two go very closely together — when they live with families who are well supported than when they live in institutional care. Sometimes, people need to be provided with care. However, a central thrust of Bamford was to move away from the fact that, traditionally, thousands of people in Northern Ireland lived in hospitals and in long-term care. We really are down to the last, small number of people who will move out into the community over the next couple of years.

People live happier and healthier lives with families, friends or people whom they choose to live with. Similarly, they are happier when a meaningful day is provided for them and when they are given

support to do activities that they enjoy in community settings. That is not just wishful thinking or a case of, "Wouldn't that be a nice world?" It actually provides better health and well-being outcomes for those people. They live healthier and longer lives. That is partly accountable for the rise in the average age of people with a learning disability; hopefully, it will approach that of the rest of society. So, there are practical examples.

Dr Briscoe: Kieran, it should be said that some of that is no different for other groups such as older people. It is well-documented that social isolation increases the risk of mental health problems such as depression. From that perspective, this is no different.

Mr McCarthy: That answers my next two questions about promoting health outcomes through social inclusion.

You mentioned — and we agree — that people are better out of institutions than in them. I always come back to my worry that, in the rush to clear Muckamore Abbey, for instance, people will go to the wrong locations. People are coming to me about that, and it is already happening. Do you support me in saying that consultation with parents or carers is the name of the game in getting people who are in institutions out into the community? They must be found the best facility, rather than be put somewhere just to get Muckamore emptied.

Mr Murray: Absolutely. If I may say so, it is ironic that you describe it as a rush.

Mr McCarthy: Well, it is to happen by 2015-16.

Mr Murray: I am putting it in the historical context. We had targets and dates before, and there was a lot of criticism that those were not met. We are talking about a long period; certainly, in my experience of work, from the 1980s to today. I worked in that hospital, and it had in excess of 1,000 patients. There has been a very slow process, in one sense.

I absolutely take your point. I am not taking anything away from it at all. I utterly agree with you. We have used that argument to explain why it takes time, because it must be done properly. At the heart of it is the principle of consultation with both the person themselves and the family or carers who are involved in their life and that people must be given choices about not just what location they live in but what type of accommodation and who they live with. Quite simply, to go back to what I said earlier, we know that it does not work unless we do that. It has the potential to create unhappy people who need to return.

Mr McCarthy: One individual had his own room in Muckamore for 40 years or more, and, suddenly, he was put into a room with eight other people. That cannot be right, and that is what we want to try to avoid at all costs.

Mr Murray: I absolutely agree.

Dr Briscoe: Kieran, I will make another point to alert the Committee. As you know, we fund the Patient and Client Council (PCC) through ring-fenced money in relation to the Bamford monitoring group. The Patient and Client Council has done some very important work on both mental health and learning disability. It did a report, in May 2013, on life after leaving hospital, which is what you are talking about. Although that report was based on a small sample, it showed that people resettled from long-stay hospitals are generally happier in their new homes in the community and, in particular, that individuals value freedom, privacy and independence.

The Chairperson: We have quite a lot to go through. I ask members to keep their questions succinct. Maura and Aidan, maybe you could agree for one of you to respond to each question.

Dr Briscoe: Yes; that is grand.

The Chairperson: It is just to facilitate today's agenda.

Mr Gardiner: On what evidence have you based your decision to invest resources in the GP checks as a way to improve the health of people with learning difficulties?

Dr Briscoe: The evidence goes back many years, Sam. As I said, there is a gap in life expectancy for people with a learning disability. That has been emphasised again in the last year with the confidential inquiry into premature death among people with a learning disability. It was a bespoke piece of research that highlighted that there were poorer health outcomes for people with a learning disability than for the rest of the population. Key issues highlighted were cardiovascular disease, cancer and respiratory disease.

Mr Gardiner: Thank you for your answer. Is there any evidence from other countries or regions that these checks result in better health outcomes?

Mr Murray: Yes. Those two questions are obviously interlinked. We did not do the original research. Earlier, I referred to the fact that we based it on the Cardiff screening tool, which was implemented by the Department of Health in England and Wales. We already had the benefit of its findings on how effective the checks are. However, the Cardiff screening tool, in itself, was not the originator. There was other international research, which we refer to in the executive summary and the detail of the evaluation. We looked at that research again to make sure that this is the most effective way of improving people's health.

As the Health Committee is probably aware, there has been a lot of debate about the relative effectiveness of screening for particular conditions. We wanted to make sure that we were not spending money on screening that would not be effective in bringing about the desired outcomes to improve people's health. There is a strong evidence base in use in other parts of the UK. The Cardiff screening tool, which we are currently using, has just been revised. One of the recommendations of our evaluation is that we adopt the revised screening tool and continue to use it into the future.

Mr Gardiner: When do you intend to implement that?

Mr Murray: The whole process is in place now. The evaluation is telling us of the activity of the last two years, when 5,000 screening appointments have been held for individuals in GP surgeries and followed up by nurses and secondary care referrals. So, it is in operation. In the evaluation, we are looking at how well it has been put in place in its first two years and asking what the outcomes are. The evaluation is recommending that we continue with it as a good investment and as an effective way of addressing the health inequalities for this group, who have specific healthcare needs that were not being addressed previously.

I will say — not as an advert for the thing but as a measure of some of its success — that, by the summer of 2011, which is the date of the last figure that I have, England and Wales had managed to reach 50% of the eligible over 18-year-olds. In our first two-and-a-half years, we have reached 69% of the adults in Northern Ireland. Obviously, we are dealing with a smaller, more compact area, and you might say, "That would be easier; wouldn't it?" However, we take some solace from the fact that we have made that much progress to date.

Mr Gardiner: But there is still room for improvement.

Mr Murray: Yes; absolutely. Our target is 100%, and there is much still to be done.

Mr Brady: Thanks for the presentation. Have other options, apart from the annual GP health checks, been considered to reduce health inequalities? Are there particular difficulties or constraints in developing policy to deal with health inequalities associated with people with learning disability?

Aidan, when talking about health inequalities, particularly for people with learning disability, you mentioned poverty. Have you factored in the fact that, if the proposed benefit cuts come in, young people with learning disabilities will be particularly affected? The youth incapacity benefit, which replaced the severe disablement allowance, is being phased out. The change from disability living allowance to personal independence payments will undoubtedly also have an effect. The proposed cut in numbers claiming the benefit is 20%, so people with learning disabilities, many of whom find it difficult to articulate their condition and have advocates who do that, will be affected to a greater extent. That will add to health inequalities for people with learning disabilities. I do not necessarily want you to go into that now. I just wonder whether that has been factored in.

Dr Briscoe: First and foremost, welfare reform is being taken forward by the Department for Social Development (DSD) and not the Department of Health, Social Services and Public Safety.

Mr Brady: I understand that, but welfare reform is going to have a direct impact. We are talking about cross-departmental issues.

Dr Briscoe: Indeed. Certainly, there is an interface between the Health Department and DSD on welfare reform. I have no doubt that part of the thinking on welfare reform issues will focus not just on individuals with learning disabilities but on people with a disability in general and on other socio-economic conditions. I understand what you are saying, but I do not feel that it is appropriate for me to comment any further on that.

Mr Brady: No, I would not expect you to.

Dr Briscoe: I will answer your broader question about health promotion. One of the roles of the health facilitators is to promote access to general health screening programmes such as immunisation and cancer screening programmes. In addition, there are contracts for a number of aspects — for example, there is a contract for sexual health education between the Public Health Agency (PHA) and the Family Planning Association — specifically for people with learning disabilities. Another example is the extension of Cook it!, which is a nutrition education programme and which has a specific learning disability module. There is a range of examples, from around the country, of inclusion of learning disability in health promotion.

As Aidan mentioned, we said that there was a regional planning group for the coordination of the directed enhanced service. That group, which is led through the PHA and the board, will be extended to have a much more global approach in order to bring back best practice and regional approaches on health and well-being for people with learning disabilities.

Ms Brown: Thank you for your presentation today. I would like more information on the GP annual health checks. When were the health checks established in Northern Ireland?

Mr Murray: We began to invest in the latter part of 2010. As members will recall, that was just at the time when the four boards were becoming one. The money began to go out through the four boards, which accounts, as I said earlier, for the fact that there is not an even distribution, as you will see when the report is published. We began in a very early, slow way, back at the end of 2010. The evaluation reports on the two years of full operation with staff being in post in each of the trusts and attempting to get the reach of the programme to 100%.

Ms Brown: OK. Are the checks available in all GP surgeries?

Mr Murray: At the moment, all GPs have been invited to take part. The evaluation report showed us that 76% have participated to date. The fact that 76% of GP practices have taken part has resulted in 69% of people being seen. We were asked earlier about work that remains to be done; we have to contact those other people, but we also have work to do with those GP practices that have not yet come on board, and we have a GP adviser member of our group. The report recommends that, if we establish that they are not going to come on board, we need to find an alternative way to provide access, perhaps through a neighbouring GP or one of the nurse health facilitators that we talked about, for the balance of people who have not been seen to date. It may be that a certain small number of GP practices choose not to take part, for whatever reason.

Ms Brown: OK. I suppose that you have partially answered my next question, which is this: what has been the uptake?

Mr Murray: It is at 69% at the minute, and we want to increase that.

Mr Dunne: On that, how has the evaluation gone? What lessons have been learned from it?

Dr Briscoe: I want to say, first of all, that it has not been published. We need to be somewhat circumspect about what we say in respect of the outcome of the report. However, we are happy to share some high-level things.

Mr Murray: There are certainly some big messages. You can look at the evaluation in different ways. There was the experience of the people who were having the checks and their families. As I said earlier, the paperwork includes not only the health action plan but a "How was it?" leaflet, through

which people have an opportunity to say whether it worked for them and if the waiting time was good and to explain the circumstances. The feedback on that is very high; it is almost 100%.

Mr Dunne: That was the customer care bit.

Mr Murray: Yes. They had an opportunity to say what their experience was.

In July, we backed that up with a workshop in the University of Ulster, which over 100 GPs and practice staff, as well as service users and carers, attended. Again, we got feedback from those people to say that, in the main, the experience was very good, both on the GP-side and on the side of the people who were using the service. However, there were lessons. One of those, which I alluded to a minute or two ago, was that we need to make sure that we bridge the gap between the 76% of GPs and the 100% of GPs out there, to make sure that everybody gets access to this.

The other big message was that it is largely in place and consolidated, but, in the next phase of the work, it is about taking the same regional approach to health promotion activities. I brought along a number of items that I can leave with you. This refers back to another question as well. They show some examples of other things that have been happening. They are good things, but they are not universally available. It depends on which trust you are in, which area you are in and which GP practice you have. The challenge is to make sure that the good practice, which we have examples of here, is extended to everyone, in the same way as we have done with the health checks.

Mr Dunne: Does the 76% who have had the service include people who were already going to their doctor regularly?

Mr Murray: Of course it does; you are absolutely right. They would not have had this format of the totally comprehensive assessment, because it is more likely that, in the past, they would have been going to their GP because they had a particular problem at a time. Perhaps, they had a pain here or a pain there. It includes people who were seen, but it is a new, improved and enhanced —

Mr Dunne: Will the people with mental health issues who go to their doctor for various reasons, very regularly, get this service?

Mr Murray: They will not get this annual check each time they go.

Mr Dunne: No. Will it be done annually?

Mr Murray: Yes.

Mr Dunne: They will get that check over and above their usual visit. Some people turn up to see their doctor every week, practically. Will those sorts of people still get this?

Mr Murray: The characteristics of people with a learning disability are unlike those of the group of people you are describing who are frequent callers to a GP. Earlier questions related to where we got this idea from; we did not just cook it up. The research showed that, unfortunately, people with a learning disability are much less likely to go to their GP. So, the problem is actually the other side. It is not that they are calling in a lot and that this is something on top of that; they are maybe not being seen by their GP for years on end. That is why these problems, some of which were quite common and, you might think, quite straightforward, were building up in this population and causing more severe difficulties.

Mr Dunne: So, you still have to reach about a quarter of the people.

Mr Murray: That is right.

Mr Dunne: How are you going to do that?

Mr Murray: Some of the recommendations in the report are about that. The other GP practices will be approached again, and, if they confirm that they are not taking part, we have to find alternative arrangements, so that those people can be seen by a neighbouring GP. Obviously, the other GP, not

the original GP, will get paid for the work. We have to negotiate that. That is one of the clear recommendations from the report.

Mr Dunne: I find it somewhat disappointing that GPs, with an attitude like that, are not rising to the challenge of Transforming Your Care. They need to change; they need to move on. They have to realise that they are there to serve the customer, and the customer is the public. They are well paid for what they do. They have the resources; if they do not, they can acquire them. They need to start to change and get into the way of working towards Transforming Your Care, where we want to see more responsibility for and more work being carried out by GPs.

Mr Murray: We are certainly hopeful, and we will continue to work with them to make sure that we get as close as possible to 100% participation. Our aim is to make sure that everybody over 18 with a learning disability, in Northern Ireland, has access to it.

Mr Dunne: Thank you for your indulgence, Chair.

Mr Wells: You say in the briefing that each trust has appointed a facilitator for people with learning disabilities and their carers. That was news to me. When were those appointments made?

Dr Briscoe: They were made in the past number of years.

Mr Murray: They commenced at the end of 2010.

Mr Wells: How would someone who is a carer have known of their existence?

Mr Murray: The appointment letter goes out to the family home, addressed to the patient, from the GP. Some of the paperwork that we have sent around shows some examples of that. The nurse health facilitator, who is a nurse with a learning disability background, is attached to a number of GP practices. If, for example, a person does not turn up at the appointment, the GP or practice manager will know that the health facilitator for that area is nurse A or nurse B, and, in turn, they will follow that person up. Similarly, if the nurse is going along with the person to the GP, because they may not have a carer or may not have family that they are living with, the nurse takes on the responsibility for ensuring, as far as possible, that the actions that are recommended by the doctor are carried out in the year ahead. It is not that they are visiting every family; they are responding to the programme. The health facilitators are linked to the programme.

Mr Wells: In addition to what you have outlined, what else do they do? What are their main roles?

Mr Murray: Their main role is promoting the health and well-being of people with a learning disability in their particular areas. The whole-time equivalent for the population of adults with a learning disability in Northern Ireland is 9.3. That is spread across the five trusts, so you will realise that that is a relatively small number of staff to do that job for the group of people. They are also doing the other job that I referred to earlier, which is approaching GP practices, talking to them about it and talking to the practice staff about getting involved with the scheme.

Dr Briscoe: They encourage people to go to secondary care and to routine screening programmes, such as for immunisation and mammograms.

Mr Wells: Do you intend to carry out any evaluation of this work?

Dr Briscoe: It has been done.

Mr Murray: Yes. That is the evaluation that I referred to a few moments ago. It has been completed, but not yet published, and that is why Maura exercised a bit of caution about it. Hopefully, it will be approved by the Bamford project board in December. After that, it will be publicly available. It is an evaluation of the past two years' operation. It was carried out by Professor Roy McConkey of the University of Ulster. It indicates how useful it has been and recommends that it should continue, with some important changes.

Mr Beggs: Will you advise us on how you engaged with professionals who are working with people with learning difficulties, to get their views on the best approach on this issue?

Mr Murray: The starting point is that the commissioning team of the board and the agency is multidisciplinary. I am from a social work background. The other people around the table are doctors, nurses, psychologists and occupational therapists. A group of other contributing professionals has been involved in —

Mr Beggs: Are they practitioners on the ground? Or, are they at a very high level?

Mr Murray: I do not know if they are high level, but they would see themselves as being professional representatives. I take the point that you are making about commissioners as opposed to practitioners. That was very much the reason for having the workshop in July, which I referred to. The key professional in the scheme is the GP. The workshop largely involved an audience of GPs and was about their participation — obviously, the ones who were taking part — in the health promotion activities. We had the evaluation, which was done by an academic. The reason for having the workshop was to have voices of people in the room telling us what it is like from their point of view. They have been very supportive of the scheme to date.

Mr Beggs: How have you engaged with people with learning difficulties and their carers to develop an approach that will work best with them?

Mr Murray: We took some account of that at the beginning of the scheme by including in the paperwork that, when screening takes place, the person themselves, if they have the capacity to give a view, or the family member or carer who is with them, is asked whether they thought that it was a worthwhile, satisfactory appointment, what they had learned from it and what they were taking forward from it. We have that bit built into the system, so it captures people's views as we are doing it. The July consultation event in the University of Ulster that I referred to included people who had used the service and carers, as well as GPs. The message from the three different groups was that they felt that they had been involved in a very worthwhile and useful scheme and wanted it to continue.

Mr Beggs: You mentioned poor communication in this area as another issue. I welcome the illustrative letter that you provided on the general health check-up. How are the Department and its agencies generally communicating with people with learning difficulties on a wider range of issues? I will give you a specific example of what I consider to be bad practice. Stress is adverse to health. Moving home is one of the most stressful times in anyone's life. As part of Transforming Your Care, the supported living chalets adjacent to a statutory residential home were to close. The same letter was delivered to everyone with learning difficulties in that situation. I have had people with learning difficulties come into my office to tell me that they have been told to apply for housing elsewhere, in a different town where they know no one and where their friends cannot easily visit. At present, they have the freedom to wander up and down the street. They can look after themselves; they just need a little support. Through what other practical engagements is the Department ensuring good practice in engaging with people with learning difficulties?

Dr Briscoe: I am surprised to hear the example that you quoted about people in supported living arrangements being given a letter that does not directly relate to them in respect of statutory residential —

Mr Beggs: Sorry; they have been told that they will close with Lisgarel.

Dr Briscoe: If you have examples of that, perhaps you will be good enough to share them with us. There is a whole project on statutory residential care homes. So, if you have examples where people, specifically with a learning disability, have been given letters relevant to the closure of statutory residential care homes for older people, perhaps you would be good enough to give them to us.

Mr Beggs: The point has been made directly to other members of your staff.

Dr Briscoe: OK. In general, from the Department's perspective, as I said earlier, we specifically fund the PCC, through the Bamford monitoring group. That is all about engagement with service users and carers. The PCC, through the funding arrangement for the Bamford monitoring group, has done a wide range of engagement programmes, reviews etc. That is one area at regional level.

Aidan will talk about the commissioning of services, in which there is a wide range of engagement with service users and carers. There is wide engagement in some of the work of the Regulation and Quality Improvement Authority (RQIA) on specific issues related to learning disability. That is at a very

high level. Clearly, all trusts have processes for person and public involvement in respect of learning disability.

Mr Murray: I will briefly add a point — I am conscious of what was said about one of us answering at a time — which I should perhaps have made earlier in answer to the question about the other professions that are involved in commissioning and making decisions: representatives of people with a learning disability and carers are at every meeting of the mental health and learning disability commissioning team. So, it is not just professionals, if you want to put it like that. Further to what Maura said, we have built in a key core membership who are members of the team in the same way as we are. We had a meeting this morning before we came here; we always get a very good turnout. People with a learning disability who sit on the learning disability committee are supported by the Compass Advocacy Network, which is based in the north-east area. A number of members are supported to participate in the meetings by advocates from that group. They have been doing that for about two and a half years, and it is working very well. I have some of their material with us; they advise us on the best way to do things, despite what we might think, from the point of view of the person who is receiving the service, or their family and carer.

Mr Beggs: One of the bullet points in your submission mentions multiagency and multidisciplinary collaboration to improve services. When will the multiagency support team for schools (MASTS) be available in every primary school?

Mr Murray: That is the MASTS scheme in the Northern Trust area?

Mr Beggs: Yes. There are equivalent schemes in every other trust area.

Mr Murray: Yes. Just to be clear, they are not all named MASTS. That money was spent in the Northern Trust area back in, I think, 2006. The investment was made jointly by the Education Department and the Health Department. Each of the other trust areas got its share, on the basis of population, and spent it in developing the same services to support youngsters, but they did not all necessarily put it into something called MASTS.

Mr Beggs: I know that they have different names, but half the primary schools do not have that support.

Dr Briscoe: The PHA is undertaking a review of allied health professional provision for special educational needs, which will contribute to what you describe. That review is just about to start, first and foremost looking at special educational needs in special schools, but it will extend to other schools.

Mr D McIlveen: The PHA has always been very good at funding general health programmes such as smoking cessation clinics and initiatives to tackle obesity. My experience is that that seems to be staggered across a number of different providers, such as pharmacies and, to some extent, GPs, as well as some voluntary groups. I would have thought that, under Transforming Your Care, it is most likely that there will be a centralisation of that; my suspicion is that it will go in that direction. Is there an opportunity to make the services more accessible and simplified for people who may have learning difficulties? I heard some suggestions about going out to social enterprise or something like that. Would you comment on that?

Mr Murray: One of the recommendations arising from the evaluation is that we move on from this specific piece of work. We have not rested on our laurels — we are trying to get to 100% — but, at the same time, the PHA and the board will be involved. Members may recall that, at the time of the Bamford review, the then Minister charged the respective chief executives of the board and the PHA separately and jointly with taking forward the actions of the review. Our work is completely in line with that. The groups that I talked about earlier include people from the board and the PHA. The group that will be set up to take over from what has been done to date will hold a workshop early in the new year to gather people together and launch the group. It will do exactly what you said; it will take some of the local examples that are happening in different areas and combine them into a coordinated plan so that everyone who needs it in Northern Ireland will have access to the same level of health promotion activity. We will do that with and through the PHA.

Mr D McIlveen: The pharmacy contract, for example, is currently being negotiated; there are a few i's to dot and a few t's to cross. Are pharmacies being considered as a delivery mechanism?

Mr Murray: I am not privy to that; the PHA will take that forward as part of its normal operational business. We may identify from this work that the evaluation shows us, for example, that smoking cessation is very important. However, if we just assumed that it was of the same level of importance for people with a learning disability as it is for everyone else, that would be a mistake. The evaluation shows that, after the first two years, there is quite a low level of smoking among people with a learning disability, for which we are very grateful. It would be foolish of us — it would be a mismatch — to spend a lot of money on a smoking cessation campaign when it is a miniscule problem. On the other side, the figures showed that weight reduction and obesity is a big problem for 43% of the people who have been through the health screening. That is a major area on which, I suspect, when we reach the new phase, we will be putting a lot of emphasis. Obviously, it will depend on what campaigns there are and who the delivery agents will be.

Dr Briscoe: Aidan mentioned the Cook It! programme as an example. Recognising what Aidan has said about nutrition and obesity etc, there is exploration of a specific module in Cook It! for people with a learning disability. It is about the balance between accessing general services and the expertise within those, including health promotion services, and establishing areas where it is necessary to target, as appropriate.

The Chairperson: OK. Thank you both. We look forward to following up on the mental capacity Bill. As I said at the beginning of the session, we are moving towards a stakeholder event, so I have no doubt that we will be back in contact with you on issues arising from that.

Dr Briscoe: I think that you recently received the timeline for the mental capacity Bill. As you will see from that, the consultation on that will be next year, rather than this year.

The Chairperson: OK. Thank you.