Ms Maeve McLaughlin MLA
Chairperson, Committee for Health, Social Services and Public Safety

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15 January 2014

As you will be aware, the Committee for Health, Social Services and Public Safety has identified the implementation of Transforming Your Care as one of its strategic priorities for 2013- 2014.

The Committee has determined to undertake this piece of work by focusing on a number of programmes of care. The first programme of care which the Committee has examined is learning disability.

The TYC Strategic Implementation Plan states that one of the key objectives of the entire TYC future service model is the reduction of health inequality. As you know, the Committee previously carried out a review on health inequalities which was published in January 2013. In order to build on that work, the Committee agreed to consider the issue of health inequalities in the context of learning disability.

Given that the TYC Strategic Implementation Plan sets out the future service model for learning disability, the Committee decided to examine that service model, in terms of how effective it might be in tackling the health inequalities experienced by people with a learning disability.

In undertaking this piece of work the Committee took evidence from departmental officials on the Department’s current and planned approach for reducing the health inequalities experienced by people with a learning disability (Appendix 1). It also commissioned a research paper on the relevant issues from Assembly Research Services (Appendix 2). In addition, the Committee held a stakeholder event in order to obtain the views of representatives from learning disability charities, families and carers, and people themselves who have a learning disability (Appendix 3).

The Committee has agreed a set of findings and recommendations based on the evidence it has gathered. These are attached to this letter.

The Committee hopes that the Department will find this information useful, and I look forward to your response to the recommendations within the usual 8 week period.

In the interim the Committee intends to bring a motion to the Assembly in order to highlight the issues, and I look forward to your participation in that debate.

Maeve McLaughlin MLA

Committee Chair

Findings and recommendations

1. The Transforming Your Care framework

The Committee wished to understand how the service model for learning disability, as set out in the TYC Strategic Implementation Plan, will reduce the health inequalities experienced by people with a learning disability. The Committee took evidence from departmental officials on this issue on 16 October 2013 (Appendix 1).

Officials advised that there are a number of policies in place which are aimed at addressing these health inequalities. However, it emerged that these are all existing policies which pre-date the publication of Transforming Your Care. For example, the official stated:
"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".

While the Committee sees the merit in building on existing policies and programmes, and the need to avoid duplication of work, it does take the view that an opportunity may have been missed to use Transforming Your Care as a vehicle to set out more wide-ranging and ambitious proposals for tackling the health inequalities experienced by the learning disability population.

During the evidence session, officials primarily focused on only two approaches for tackling health inequalities:

- The annual GP health checks; and
- Future work to be undertaken by the Public Health Agency to create health promotion campaigns specifically for people with a learning disability.

Very brief mention was made of the problems which people with a learning disability have in terms of accessing secondary care services, and in particular, treatment at Emergency Departments. However, the care provided by hospitals was a major area of concern for the various participants who attended the Committee’s stakeholder event (Appendix 3).

It may be the case that work is ongoing to improve the care and treatment which people with a learning disability receive at hospitals in Northern Ireland. However, at present the Committee is not aware of that work. **The Committee therefore requests a written update from the Department on work it is undertaking with the HSC Trusts in this respect.**

2. GP annual health checks

Officials advised the Committee that GP annual health checks for people with a learning disability have been operating in Northern Ireland since 2010. This policy is based on evidence that shows that people with a learning disability are not as likely to access primary care as compared to the rest of the population. This results in poorer health outcomes for them, as a result of delayed diagnosis and treatment.

Officials explained that while all GP practices have been invited to take part in the annual health check programme, only 76% of them are currently offering the service. This means that almost a quarter of GP practices are not offering health checks to patients registered with them who have a learning disability.

The Committee notes that the Department intends to approach the non-participating GP practices again, to try to persuade them to take part in the service. If they will not do so, the Department will aim to make alternative arrangements for their learning disability patients to access a health check with another GP practice.

The Committee was disappointed to learn that a significant number of GP practices are not participating in the annual health check programme. It is of the view that this leads to further inequalities for an already disadvantaged population.

Recommendation 1: The Department should make alternative arrangements for people with a learning disability, who are registered with a non-participating GP practice, to receive an annual health check with another GP, as a matter of urgency.

The Committee's discussions with representatives from learning disability charities, carers and people with a learning disability themselves, revealed that people were in favour of the idea of annual GP health checks. However, there was the feeling that their existence was not widely known across the learning disability charity sector, and that more needed to be done to reach people who were unaware that they, or the person they are caring for, are entitled to an annual health check.

Recommendations 2: The Department should consider a range of measures to advertise the existence of the annual GP health check programme, and make use of the existing communication networks within the voluntary/community sector.

3. Health facilitators

Officials advised the Committee that there are nine whole-time equivalent health facilitators across the Trusts. Their role is to assist with the GP annual health check programme. They do this by accompanying patients who do not have a carer to the appointment, by following up on patients who do not attend their appointment after receiving an invitation, and by assisting patients to proceed with further work that is required after the appointment, such as a secondary care referral.

However, the Committee's discussions with learning disability charities revealed that very few organisations were aware of the existence of the health facilitators and the services they provide. The Committee believes that this is of major concern.

The charities stated that they would like the opportunity to signpost people to the health facilitators. Furthermore, they also saw themselves as having the potential to work in partnership with the facilitators to identify people who may need an annual health check, but who are not currently known to services.

Recommendation 3: The Department should direct the health facilitators to make contact with the learning disability charities/groups in their area to advise what services they offer, and to develop partnership working arrangements.

4. The need for "reasonable adjustments" - GPs

A paper commissioned by the Committee from Assembly Research Services made reference to the "Equal Lives" report of 2005. One of the recommendations of that report was that each GP practice and acute hospital within Northern Ireland should have formalised arrangements to facilitate equity of access to services (Appendix 2).

During the evidence session, departmental officials recognised that the health service should make reasonable adjustment to accommodate the needs of people with a learning disability:

"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" (Appendix 1).

The issue of reasonable adjustments was of key concern to the participants at the stakeholder event (Appendix 3). People had a range of ideas about adjustments that could be made to make it easier for people with a learning disability to access health services, both in primary care and secondary care settings.

In relation to GP appointments, there are a range of barriers which can potentially prevent people from accessing good care. These include:

- Long waiting times in the waiting room, which can be distressing for people with a learning disability;

- Appointment slots being too short to allow people to adequately communicate with the GP;
- The perception that some GPs do not listen to the patient, but simply take note of what their carer says; and
- Use of technical language and medical jargon by GPs, with the result that patients do not comprehend what the GP is saying or what treatment they are going to receive.

Given the importance of GPs in terms of spotting the early signs of illness and disease, the Committee believe it is vital that GPs provide a service to people with a learning disability that meets their particular needs.

Recommendation 4: The Department should engage with the BMA NI to consider options to provide effective training for GPs on the reasonable adjustments that may be required for people with a learning disability, and how best to communicate with these patients – before, during and after appointments.

5. The need for “reasonable adjustments” – hospitals

In relation to attending a hospital for care, participants at the stakeholder event relayed a range of problems commonly encountered by people with a learning disability (Appendix 3).

Some of the key concerns articulated were:

- The fact that attendance at hospital often involves the patient having to interact with a number of different staff – a receptionist, a triage nurse, a doctor. People with a learning disability often find it difficult and stressful to have to repeat their personal details, medical history and current symptoms to more than one person.
- Long waiting times in an unfamiliar and often noisy environment, particularly in Emergency Departments, can be stressful for people with a learning disability.

- The perception that staff are not skilled or experienced in terms of communicating with patients with a learning disability, and are not aware of their particular needs.

As noted in section 1 of the Committee's findings and recommendations above, very little information was provided by departmental officials during the evidence session on what work is being done to improve the experience and treatment received by learning disability patients when they need to access secondary care.

It may be that work is ongoing in this regard, but the discussions with stakeholders clearly indicated that further improvements are required.

Recommendation 5: The Department requests baseline data from all the HSC Trusts, regarding the reasonable adjustments provided at each of the hospitals for patients with a learning disability who require elective care (inpatient and outpatient appointments), and who attend at Emergency Departments.

Recommendation 6: The Department identifies examples of good practice in relation to reasonable adjustments provided at hospital settings, and communicates these examples across the HSC Trusts.

6. Health promotion

During the evidence session, officials advised the Committee that the Public Health Agency will be undertaking work to provide health promotion campaigns specifically targeted at people with a learning disability.

The Committee welcomes this commitment. During the discussions at the stakeholder event, it was apparent that there is great need for people with a learning disability to be able to access relevant and suitable information about how to keep healthy and avoid preventable diseases.

The point was made by a number of participants that public health messages are only effective if they can be understood by the target audience. In relation to people with learning disabilities, the traditional communication tools such as leaflets and television campaigns are not often the most appropriate.

Recommendation 7: The Public Health Agency should ensure that it involves representatives from the learning disability charity sector, people with learning disabilities, and carers in relation to developing public health information and campaigns.

7. Data collection

The Assembly Research Services paper revealed that there is no central register of the total number of people with a learning disability in Northern Ireland (Appendix 2). While some people are known to certain services, other people have never been diagnosed or come into contact with services.

While the Committee does recognise that the creation of a central register would be a complex task, it does take the view that without any centralised data it will be difficult for the Department to assess need and to effectively target resources to reduce the health inequalities experienced by this section of society.

Recommendation 8: The Department conducts some preliminary research into the potential systems which could be developed in order to create a central register of people with a learning disability in Northern Ireland.

Appendix 1

Hansard of evidence session with departmental officials

16 October 2013

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

Committee for Health, Social Services and Public Safety

Transforming Your Care — Learning Disability Services: DHSSPS Briefing

16 October 2013

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.

Appendix 2

NIA Research and Information Service – research paper

“Health inequalities and people with a learning disability”

1 November 2013

Northern Ireland
Assembly

Research and Information Service
Research Paper

1 November 2013

Dr Lesley-Ann Black

Health inequalities and people with a learning disability.

NIAR 769-2013

This paper examines the evidence relating to the health inequalities faced by people with a learning disability. It also considers policy developments from the Department of Health, Social Services and Public Safety (DHSSPS) in terms of addressing health inequalities in the learning disability population.

Key Points

- Health inequalities are described as preventable and unjust differences in the health status between groups, populations or individuals. They exist because of unequal distributions of social, environmental and economic conditions within societies. These conditions determine the risk of people getting ill, their ability to prevent sickness, and opportunities access to the right treatments.
- People with a learning disability are a vulnerable group who experience health inequalities. They have diverse needs; often they will experience multiple health problems and have difficulties communicating. This can lead to challenges in terms of identifying health issues.
- Research shows that people with a learning disability are more likely to experience poorer health outcomes and have shorter life expectancies than the general population.
- Even though people with a learning disability have a right to access healthcare services in the same way as everyone else, they are less likely to get some of the evidence-based treatments and checks they need, and more likely to face barriers when accessing services.
- Whilst GPs act as the gatekeepers to the healthcare system and are usually the first point of contact, people with a learning disability make far less use of their GP than the general population. This can also lead to delays in diagnosis and treatment.
- A range of inquiries conducted elsewhere in the UK have stated that healthcare services are failing to meet the needs of people with learning disabilities, resulting in poor health outcomes and premature death. There are also problems with 'diagnostic overshadowing' a lack of 'reasonable adjustments' being made (such as longer appointment times), and disjointed working practices with other parts of the healthcare system.
- Local policies and legislation have attempted to address the issue of health inequalities and people with a learning disability in Northern Ireland. The main driver for change was the Bamford Review. It made a series of recommendations to improve the lives and address the unmet health care needs of people with a learning disability.
- Despite two Bamford Action Plans and a Service Framework for Learning Disability, progress to reduce the health inequalities faced by people with a learning disability, whilst commendable, has been slow. At times, it appears that details of actions have been vague and targets have not always been met.
- Currently, there is no central register detailing the actual number of people with a learning disability in Northern Ireland. This makes it difficult to target services at this group and to monitor the state of their health in terms of health inequalities.
- Evidence would indicate that continued action is needed on several fronts. Identifying people who are not known to services, collecting appropriate learning disability population data, ensuring all GPs are involved in the health check scheme, and improving health promotion/screening are just some steps that will start to close the gap in terms of the health inequalities experienced by people with a learning disability.

Contents

1. Introduction

In 2012 the Committee for Health, Social Services and Public Safety undertook a *Review of Health Inequalities*.[1,2] After a series of evidence sessions with subject experts, the Committee learned that, although life expectancy and the general health of the population in Northern Ireland is improving, the rate of improvement was not equal; for example, outcomes were less favorable for some people over others.[3] Since then, the Committee has sought further research regarding health inequalities for one particularly vulnerable group, namely people with a learning disability. This paper provides an overview of the evidence regarding this issue and the current situation in Northern Ireland.

2. What is a learning disability?

Internationally, various terms are used to describe a 'learning disability'.[4] In Northern Ireland, a learning disability (or intellectual disability) is a lifelong condition which can vary in severity. It replaces the degrading and outdated term 'mental handicap'.

2.1 Classification of a learning disability

Having a learning disability is not easy to define. There is often widespread confusion and debate about the term learning disability which is sometimes confused with 'mental health problems' or 'learning difficulties' like dyslexia.[5]

Irrespective of the wording of the various definitions, the *Valuing People* White Paper[6] published by the Department of Health in England states that a learning disability includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence)[7], with;
- a reduced ability to cope independently (impaired social functioning[8]);
- which started before adulthood[9], and has a lasting effect on development.[10]

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[1] See: Committee for HSSPS (2012) Review of Health Inequalities Report. Available online at: http://www.niassembly.gov.uk/assembly-business/committees/2011-2016/health-social-services-and-public-safety/reports/review-of-health-inequalities-report/

[2] The purpose of the review was to examine health inequalities and various approaches to tackling health inequalities in other countries which could feed into the DHSSPS's draft public health strategy, 'Fit and Well: Changing Lives 2012 – 2022'.

[3] Committee for HSSPS (2012) Review of Health Inequalities Report, p3.

[4] McConkey, R. (2006) Accessibility of healthcare information for people with a learning disability. p5.

[5] Unlike learning disability, dyslexia does not affect intellect. In addition, mental health problems can affect anyone at any time and may be overcome with treatment, which is not true of a learning disability. Unlike mental illness, having a learning disability is a permanent, non-treatable condition.

[6] Department of Health (2001) Valuing People: A New Strategy for Learning Disability for the 21st Century.

[7] This is often based on psychometric assessment and an I.Q. of under 70.

[8] Social functioning relates to a person's performance in coping on a day-to-day basis with the demands of their environment; daily living tasks.

[9] This can occur because of maternal illness, accidents and chromosomal abnormalities such as Down's syndrome. Other causes include prematurity or complications during childbirth, such as a lack of oxygen to the child's brain. Onset after birth is typically the result of early childhood illnesses or physical accidents.

Learning disabilities can be classed as mild, moderate or severe, and as such, people with a learning disability are not a homogenous group; their needs are diverse. They can also have additional diagnoses, for example Down's syndrome, autism, challenging behaviours or other physical, sensory or mental health conditions.[11] Many will also have communication difficulties. Sometimes the learning disability will be apparent, but in other cases, it is not always possible to tell by appearance that a learning disability is present. These factors can make a person with a learning disability particularly vulnerable.

A learning disability is a diagnosis not an illness. It may be discovered early in life. For others, it may take longer, and for some, they may never receive a diagnosis. This can mean they are excluded from various forms of support.

2.2 Prevalence of learning disabilties in Northern Ireland

There are no exact figures on the number of children and adults living with a learning disability in Northern Ireland. Various figures have been suggested, and it is thought that up to 2% of the population may be affected.[12] Data from the DHSSPS suggests that around **26,500 people in Northern Ireland have a learning disability**, with half of these falling into the 0-10 age group.[13] The DHSSPS states:

> *"This figure [of 26,500] was estimated by taking an accepted prevalence rate from national and international studies – which varies from 1% to 2% of the population".*[14]

As there is no centrally collected data on the total number of people living with a learning disability in Northern Ireland, this creates difficulties in terms of assessing and monitoring healthcare needs and mapping appropriate levels of support. In addition, not all people with a learning disability are known to services - such as GP services or social services. This has huge implications in terms of targeting support where it is needed most.

2.3 Changing models of care and support

Over the last 40 years, models of care and support for people with a learning disability have changed radically. Historically, care for people with a learning disability was provided in the family home, or by the state in long stay hospitals in what was called 'institutional care'. People with a learning disability were often stigmatised, denied choices and excluded from mainstream society.

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[10] This criteria is similar to that outlined by the World Health Organisation (1992) The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines. Geneva.

[11] Mencap website: Learning disability and other conditions http://www.mencap.org.uk/all-about-learning-disability/about-learning-disability/learning-disability-and-other-conditions

[12] McConkey, R. et al, (2004) Audit of Learning Disability in NI, p6. Report commissioned by the DHSSPS.

[13] DHSSPS (2008) Delivering the Bamford Vision, p15.

[14] Correspondence between E. Murphy (NI Assembly RAISE service) and the DHSSPS, August 2013.

During the 1970s, the care and treatment of people with a learning disability centred around the 'medical model of disability' which focused on the individual's impairments or problems.[15] However, a shift in societal perceptions about disability led to the replacement of the medical model with the 'social model of disability'.[16] This changed how people with disabilities, including those with learning disabilities, would be viewed and treated. The social model focuses on equality and sees people with disabilities as human beings and holders of rights – with a right to full participation in society.[17]

In tandem, numerous international human rights instruments have since been created to promote inclusion and to protect the rights of people with disabilities.[18] The advent of anti-discrimination legislation[19] and more recent government policies have also recognised that people with disabilities should be included in society and able to lead full and valued lives.

Today, the vast majority of children with a learning disability live with family carers, as do around 60% of adults; the remaining live in long stay hospitals, residential homes, supported living schemes and a small number live independently by themselves.[20] Whilst there have been clear improvements in terms of care and support services, many people with a learning disability still face widespread discrimination, marginalisation and barriers to opportunities.[21] Some of the barriers include:

- The majority of children with a learning disability attend special schools or special units and many adults with a learning disability attend day care centers; both can result in separation from mainstream society;
- Only one in ten adults is in some form of paid employment;[22]
- People with a learning disability can have speech or communication problems, illiteracy, and for some, comprehending information is difficult. This can lead to them being misunderstood and to social isolation in terms of developing friendships, participating in social activities and accessing services/benefits. **From a health perspective, this could also result in medical problems being undetected until they become more serious**.

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[15] Disabled World website. The definitions of the models of disability.

[16] The social model of disability sees the issue of "disability" as a socially created problem and a matter of the full integration of individuals into society.

[17] Disability Action website: What do we mean by disability?

[18] For example, the United Nations Convention on the Rights of Persons with Disabilities which was ratified in the UK in 2009; or the Human Rights Act (1998).

[19] For example, the Disability Discrimination Act (1995) http://www.nidirect.gov.uk/the-disability-discrimination-act-dda. The DDA emphasises the need for service providers to make 'reasonable adjustments' to accommodate the needs of persons with disabilities.

[20] McConkey, R. (2006) Accessibility of healthcare information for people with a learning disability, p8.

[21] Bamford Review (2006) Promoting the mental health of people with mental health problem or a learning disability. Consultation report.

[22] McConkey, R. (2006) Accessibility of healthcare information for people with a learning disability, p12.

3. Health inequalities

3.1 A recap

As this paper focuses on the health inequalities of people with a learning disability, it is useful to recap what this actually means. The World Health Organisation explains that '*health inequalities are systematic differences in health status between different socio-economic groups'*.[23] These inequalities are observed along a social gradient. The lower a person's social status, the worse their health is likely to be. In other words, the better a person's social circumstances, the greater their chances of enjoying good health, and a longer life.[24]

3.2 Causes of health ineqaulites

The causes of health inequalities are complex and multi-faceted. They are driven by social, economic and environmental conditions, or what are called the 'social determinants' of health. In a very simplistic sense, social determinants of health are risk factors that can have an adverse impact on health. For example, poverty, social exclusion, poor access to health care services, a lack of education, poor diet, poor housing, unemployment, and limited social supports are social determinants that can lead to health inequalities.[25]

According to a review conducted by Marmot in 2010,[26] health inequalities are **avoidable and socially unjust.** Marmot argues that a fairer distribution of good health is needed across society. In order to reduce the steepness of the social gradient in health, Marmot suggests that actions must be universal, but with a scale and intensity proportionate to the level of disadvantage. Therefore, policies and strategies should target action at those experiencing greater social and economic disadvantage. This approach is termed '*proportionate universalism*'[27] and it requires multi-agency working across local and central government, and the voluntary and private sectors.[28]

4. Learning disability and health inequalities

This section of the paper presents evidence concerning the health inequalities that people with a learning disability may experience.

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[23] WHO (2007) Levelling Up: Social inequalities in health concern systematic differences' in health status between different socioeconomic groups.

[24] Thompson, J. (2012) NI Assembly RAISE paper 308-12. Health Inequalities in Northern Ireland

[25] Wilkinson, R. and Marmot, M. (2003) Social determinants of health: The solid facts, p11.

[26] The Marmot Review (2010) Fair Society, healthy lives. Strategic Review of Health Inequalities in England post-2010. Available online at: http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review/fair-society-healthy-lives-executive-summary.pdf

[27] The Marmot Review (2010) Fair Society, healthy lives (Executive Review) p 10.

[28] The Marmot Review (2010) Fair Society, healthy lives (Executive Review) p 12.

People with a learning disability have a right of access to healthcare needs in the same way as any other citizen.[29] However, a person with a learning disability is more likely to have a range of needs and require support from a variety of health professionals. They are also more likely to be exposed to the social determinants of health (i.e. poverty, unemployment, social exclusion)[30] and have poorer health outcomes. A report on *Health Inequalities* (2009) by the House of Commons' Health Committee stated that:

> *…Health inequalities are not only apparent between people of different socio-economic groups - they exist between different genders, different ethnic groups, and the elderly and people suffering from mental health problems or learning disabilities also have worse health than the rest of the population."*[31]

The report also indicates that access to healthcare is not equal:

> *"Access to health is also uneven. The old and disabled receive worse treatment than the young and able-bodied."*[32]

4.1 Summary of UK and International Evidence

A comprehensive review of UK and international evidence entitled *Health inequalities and people with learning disabilities* was published in 2010.[33] The main findings in the report were that:

- People with learning disabilities have poorer health than their non-disabled peers, that are to an extent, avoidable;
- Despite the fact that life expectancy is increasing, people with a learning disability have shorter life expectancy;
- Health screening of adults with learning disabilities registered with GPs reveals high levels of unmet mental and physical needs;
- Health inequalities start early in life and result from barriers to accessing timely and appropriate care;
- Existing patterns of care are insufficient, inequitable and likely to be in contravention of legal requirements under the Disability Discrimination Acts and the UN Convention on the Rights of Persons with Disabilities.

The report provided evidence of specific healthcare issues which affect people with a learning disability:

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[29] DHSSPS response to NI Assembly Question AQW 2490/11-15 Mr Pat Ramsey to ask HSSPS Minister how he will ensure that robust arrangements are in place so that future needs and wishes of people with a learning disability and their family carers are identified, planned for and delivered when required.

[30] Emerson, E. and Baines, S. (2010) Health inequalities and people with learning disabilities in the UK, p6.

[31] House of Commons Health Committee, Health Inequalities, Third Report of Session 2008-09, p26

[32] House of Commons Health Committee, Health Inequalities, Third Report of Session 2008-09, p9. Available online at:http://www.publications.parliament.uk/pa/cm200809/cmselect/cmhealth/286/286.pdf

[33] Emerson, E and Baines, S. (2010) Health inequalities and people with learning disabilities in the UK.

- Gastrointestinal cancer is proportionally higher, and there is increased risk of stomach cancer. Children with Down's syndrome are at higher risk of leukemia;
- Coronary heart disease is a leading cause of death in this group;
- Respiratory disease is much higher than the general population;
- Increased incidence of psychiatric disorders, schizophrenia and challenging behaviours; anti-psychotic medications administered have serious side effects;
- The risk of dementia is greater (and occurring at younger stages of life);
- Epilepsy has been reported as 20 times higher than in the general population;
- Increased incidence of sensory impairments (e.g. hearing or vision);
- Oral health is generally poor;
- Difficulties eating, drinking and swallowing (dysphagia) increases the risk of recurrent respiratory infections. This can also lead to poor nutrition;
- A lack of knowledge about healthy eating; increased risk of obesity, which is associated with an increased risk of diabetes;
- Over 80% do not engage in the recommended amount of physical activity, and those in restrictive environments are at increased risk of inactivity;
- Barriers to accessing sexual health services/information; and low uptake of health promotion/screening (e.g. breast, cervical, dental checks).

The report also identified issues around 'diagnostic overshadowing'- whereby medical problems can be overlooked because of the learning disability;[34] consent;[35] the use of the Mental Capacity Act (used in England and Wales); and the lack of collaboration amongst care providers (between primary/secondary care).

The report recommended action on several fronts:

- ➢ reducing the exposure of people with learning disabilities from the common social determinants of health;
- ➢ Improving early identification of illness (e.g. health checks and screening)
- ➢ Enhancing 'health literacy' of people with a learning disability / their families
- ➢ Making reasonable adjustments (e.g. longer appointment times)
- ➢ Monitoring progress towards the elimination of health inequalities faced by people with learning disabilities.

A number of other reports have also highlighted the issue of health inequalities and people with a learning disability. These are now briefly considered.

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[34] Diagnostic overshadowing – this occurs when reports of physical ill health are viewed as part of a mental health problem or learning disability, and therefore not investigated or treated.

[35] In Northern Ireland, under common law, if a person is deemed to have capacity, they should be allowed to consent or refuse treatment and have that decision respected. The DHSSPS is currently developing a Mental Capacity Bill to provide for this in statute.

4.2 Closing the Gap report (2006)

In 2006 the former Disability Rights Commission[36] in England investigated the issue of health inequalities in the learning disability population in its report *Closing the Gap* (2006).[37] Findings demonstrated that people with a learning disability die younger than the general population and that they have greater health needs, often because they have multiple, complex health problems. The report criticised what it described as the "fatal complacency" within the NHS that people with a learning disability "just die younger".[38] The report stated:

> *"The acid test of a national health service is not whether it works for people who are generally healthy but whether it benefits those with the shortest life expectancy, the greatest problems accessing services and the biggest risk that poor health will stop them taking part in society."*[39]

The report continued by saying that, in terms of primary care, people with learning disabilities were less likely to receive some of the expected, evidence-based checks and treatments than other patients, and efforts to target their needs were far too ad hoc:

> *"There is little or no evidence that information on the physical health needs of people with learning disabilities is either regularly collated or used locally by commissioners to develop improved services…. There is also extensive evidence that primary care services are not generally making 'reasonable adjustments' (such as providing treatment information in alternative formats, allowing longer times for appointments) required by the Disability Discrimination Act."*[40]

The report makes a series of recommendations including a call for the government to target and monitor programmes to tackle the health inequalities faced by people with a learning disability.

4.3 Death by Indifference reports (2007 and 2012)

In 2007, 'Mencap' - a learning disability charity in the UK, published *Death by Indifference*.[41] The report, written following the deaths of six people with a learning disability in NHS care in England, highlighted many failings in the NHS, and exposed what it called the unequal healthcare and institutional discrimination that people a learning disability often experienced in the healthcare system.[42] *Death by Indifference*

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[36] This is now known as the Equality and Human Rights Commission. This is a non-departmental body for England, Scotland and Wales.

[37] Nocon A. (2006). Disability Rights Commission. Equal Treatment - Closing the Gap: Background evidence for the DRC's formal investigation into health inequalities experienced by people with learning disabilities or mental health problems.

[38] House of Commons Written Evidence by Mencap (HI 51) – The contribution of the NHS to reducing health inequalities.

[39] Nocon A. (2006) Disability Rights Commission. Equal Treatment - Closing the Gap, Executive Summary, p3.

[40] Nocon A. (2006) Disability Rights Commission. Equal Treatment - Closing the Gap, Executive Summary, p6.

[41] Mencap (2007) Death by Indifference http://www.mencap.org.uk/campaigns/take-action/death-indifference

[42] Mencap (2007) Death by Indifference, p2, p5.

triggered an independent inquiry of the six cases by the Parliamentary and Health Service Ombudsman.[43] The recommendations of the inquiry included actions around:

- staff training;
- the collection of data to allow people with a learning disability to be identified by the health service and their care pathways tracked;
- the establishment of a Public Health Observatory to promote good practice;
- a detailed confidential inquiry into premature deaths in people with learning disabilities (this was published in 2013 and is discussed in section 4.4);
- improving regulation of the disability equality duty; and
- improving primary care commissioning to include regular health checks.

The government in England accepted all the recommendations of the Inquiry and included them in their updated strategy for people with a learning disability, *Valuing People Now*.[44]

Following the publication of the initial *Death by Indifference* report, other families contacted Mencap to highlight concerns about their family members. This resulted in a subsequent report entitled "*Death by indifference: 74 deaths and counting*"[45] published in 2012. Whist the report acknowledged examples of good practice concerning health authorities in terms of learning disability, it also affirmed that:

> *"people with a learning disability are dying prematurely and experience serious inequalities when accessing the NHS is not in dispute…. Equal healthcare is a legal obligation that should be embedded in the everyday running of the NHS, in every GP practice and in every hospital ward, not an exercise in identifying pockets of good practice."*

The report described the 74 cases it considered as "just the tip of the iceberg".

There have also other critical reports and inquiries in England which have highlighted the poor care individuals with a learning disability have experienced by healthcare staff,[46] such as the abuse by staff of patients with learning disabilities at the Winterbourne View private hospital in Bristol which was revealed in 2011.[47]

4.4 Confidential inquiry: premature deaths of people with learning disabilties (2013)

The most recent investigation examining the unexpected deaths of people with a learning disability was known as the '*Confidential Inquiry into premature deaths of*

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[43] Parliamentary and Health Service Ombudsman website: Healthcare for All: The Independent Inquiry into Access to Healthcare for People with Learning Disabilities (The Michael Inquiry)

[44] DoH Valuing People Now (2009) http://www.salford.gov.uk/d/valuingpeoplenow-summary.pdf

[45] Mencap (2012) Death by indifference: 74 deaths and counting, p29. http://www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference%20-%2074%20Deaths%20and%20counting.pdf

[46] Other inquiries are listed in the Royal Colleges of Nursing guidance "Meeting the health needs of people with learning disabilities" p4-5.

[47] BBC News (December 2012) Winterbourne view scandal: Government rethinks use of hospitals http://www.bbc.co.uk/news/uk-20669741

people with learning disabilities' (2013).[48] The inquiry investigated the deaths of 247 people with a learning disability aged four or older in South West England between 2010 and 2012. Those included in the study had multiple health conditions. The main findings from the inquiry were that:

- Men with learning disabilities died 13 years earlier than men in the general population, and women with learning disabilities died 20 years earlier.
- The main reason for these deaths was a delay or problem in their treatment.
- **37% of the deaths of people with a learning disability in the inquiry could be prevented and were avoidable.**

Like other inquiries, it also concluded that there was considerable evidence of fragmented care that failed to take account of the needs of people with a learning disability:

> *The quality and effectiveness of health and social care has been shown to be deficient in a number of ways. Despite numerous previous investigations and reports, many professionals are either not aware of, or do not include in their usual practice, approaches that adapt services to meet the needs of people with learning disabilities.*[49]

The report made a series of 18 recommendations, the first of which was for:

> Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems.[50]

Other recommendations included: annual audits of 'reasonable adjustments'; the establishment of a named healthcare coordinator for people with complex healthcare needs; and improved systems for collecting standardised mortality data for people with a learning disability. The full list of recommendations is provided in Appendix 1 of this paper.

5. What is the situation in Northern Ireland?

Unlike England, there have been no wide scale independent inquiries into the lives of people with a learning disability who may have died unexpectedly or prematurely. In addition, there is no standardised monitoring of the life expectancy of this group. The Public Health Agency[51] in Northern Ireland is a key agency tasked with improving the overall health and well-being of the Northern Ireland population (for example, through

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[48] The inquiry was funded by the Department of Health in England. It also compares the cases of the learning disability population with the health of 58 people who did not have a learning disability.

[49] Heslop, P. et al (2013) Confidential Inquiry into premature deaths of people with learning disabilities, p5.

[50] Ibid p109.

[51] Public Health Agency website: http://www.publichealth.hscni.net/

health screening) as well as reducing health inequalities and tackling the social determinants of health.[52]

For the majority of people, the first point of contact when they feel unwell is likely to be their GP. Yet people with a learning disability in Northern Ireland utilise their GP significantly less often than the general population.[53] This has implications in terms of diagnosis and treatment – which are likely to be delayed. Furthermore, evidence, whilst not to the level of investigation that has occurred in England, would suggest that locally, people with a learning disability do experience health inequalities.[54] One example is a study carried out by the Equality Commission (NI) in 2006 about of access to health information by people with a learning disability.[55] In 2013, a review of progress since the initial Equality Commission study suggested that, whilst health information had improved, further improvements - such as having more information in 'easy read' formats, longer appointments, and better staff training were needed.[56]

6. DHSSPS policies relating to health inequalities

It is perhaps useful to outline the Department of Health, Social Services and Public Safety's (DHSSPS) policies that attempt to address the health inequities faced by people with a learning disability. The DHSSPS shares many of the UK policy positions concerning the treatment and care of people with a learning disability. One of the earliest departmental policies, from 1995, relating to learning disability stated that:

> *Government policy for people with a learning disability should be inclusion ... which stresses citizenship, inclusion in society, inclusion in decision-making, participation so far as is practicable in mainstream education, employment and leisure, integration in living accommodation and the use of services and facilities, not least in the field of health and personal social services.*[57]

Several strategies and policies have since been developed and these are briefly considered.

6.1 Investing for Health (2002)

The original strategy to tackle health inequalities in Northern Ireland was entitled *Investing for Health* (2002).[58] However, a criticism of the strategy was that there was little mention or attention focused on people with a learning disability.[59]

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[52] NI Assembly Official Report (4 July 2012). Health inequalities. Evidence from Departmental Officials. It is understood that work is underway to include public health initiatives for people with a learning disability (in areas such as diet, obesity and so forth).

[53] http://www.niassembly.gov.uk/Assembly-Business/Official-Report/Committee-Minutes-of-Evidence/Session-2013-2014/October-2013/Transforming-Your-Care---Learning-Disability-Services-DHSSPS-Briefing-/ p12.

[54] See for example, McConkey, R. (2006) Accessibility of healthcare information for people with a learning disability.

[55] This study included the views of 74 people with a learning disability and 178 carers

[56] Equality Commission NI (2013) Has health information for people with a learning disability got better?

[57] DHSS (1995) Review of policy for people with a learning disability.

[58] DHSSPS (2002) Investing for health http://www.dhsspsni.gov.uk/index/phealth/php/ifh.htm

[59] Equal Lives (2005) Review of Policy and Services for People with a Learning Disability in Northern Ireland p72.

6.2 The Bamford Reveiw and Equal Lives (2005)

After the publication of *Investing for Health*, the key driver for reforming and modernising law, policy and services for people with a learning disability in Northern Ireland was the *Bamford Review of Mental Health and Learning Disability*, commissioned by the DHSSPS between 2002 and 2007. One of the outputs of the Bamford review was the *Equal Lives* report (2005) – which focused specifically on people with a learning disability. *Equal Lives* highlighted the inequalities faced by people with a learning disability (see Appendix 2) and stated:[60]

> *There is ample evidence to demonstrate that people with a learning disability do not have access to the same range of services and opportunities as other people in Northern Ireland… Their families frequently suffer high levels of social disadvantage and their caring responsibilities can place them under almost unbearable levels of stress.*

Equal Lives echoed much of the research on health inequalities faced by people with a learning disability in the UK literature. It made several recommendations, such as employing health facilitators, and creating robust medical records and individual health plans:[61]

- The DHSSPS should produce a **Regional Framework for Health Improvement** of people with a learning disability providing direction, targets and timescales.
- All generic health strategies published should **make specific reference** to the needs of and impact upon people with a learning disability.
- Resources should be made available from within primary care to appoint within primary care a **Health Facilitator** for each 110-120,000 population.
- A **Health Action Plan** will be developed, which is to be set in place for all those with a learning disability in contact with health and social services agencies.
- Each GP practice and acute general hospital within NI should have **formalised arrangements** to facilitate equity of access to services.
- Each GP practice should establish **robust medical records** and health data about people with a learning disability on their practice register.
- Each GP practice should have an identified **link person within their local Community Learning Disability Team** with whom they work collaboratively to facilitate better access for people with learning disability in primary care settings.
- Equipment and wheelchair provision **budgets should be increased** to meet significant additional demand. This will require an increase of the proportion available to people with a learning disability.

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[60] DHSSPS Equal Lives (2005) Review of Policy and Services for People with a Learning Disability in Northern Ireland p6.

[61] DHSSPS Equal Lives (2005) Review of Policy and Services for People with a Learning Disability in Northern Ireland, Chapter 7.

6.3 The first Bamford Action Plan (2009-11)

Following the Bamford Review – which made over 700 recommendations in total, the DHSSPS launched a consultation document known as *Delivering the Bamford Vision.*[62] *Delivering the Bamford Vision* was superseded by the *Bamford Action Plan* (2009-2011). The Action Plan set out how changes to reform services for people with a learning disability would occur.[63] It contained 67 actions pertaining to learning disability to be taken forward under five themes by a number of government departments, and a timetable for delivery.[64] The plan acknowledged that learning disability is a lifelong condition and that this group are living longer; and as such, clients require more sustained life-long and integrated services, not just individual episodes of care and treatment.[65] Frequent reference to equity of access to health services was made:

> *commissioners and service providers need to actively ensure that there is equity of access to the full range of healthcare provision enjoyed by the general population. This includes improved and supported access to primary care services (GP, dentistry, optometry and the full range of health screening), secondary care services (particularly in-patient acute services), mental health services, sexual health services, and end of life services, if necessary.*[66]

The first action within the Bamford Action Plan addresses health inequalities:

1) "*ensure that persons with a learning disability have equal access to the full range of services to improve* ***physical and mental health inequalities*** *experienced by them.*"

   It also states that a directed enhanced service (DES) will be created, which includes annual GP health checks and individual health plans.

   The resulting output of the action is that:

"*the directed enhanced service will be rolled out regionally for* ***adults with learning disabilities*** *and provided in* ***90%*** *of GP practices.*" (see Appendix 3)

The DES GP health checks were originally intended for people with severe learning disabilities,[67] however they have included people with mild learning disabilities if it was judged there was a clinical need.[68]

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[62] DHSSPS (2008) Delivering the Bamford Vision. The response of the NI Executive to the Bamford Review of Learning Disability

[63] DHSSPS (2009) Delivering the Bamford Vision. Action Plan 2009-2011

[64] An interdepartmental monitoring group, and the Bamford Monitoring Group (established by the Patient and Client Council) which included the voices of service users were established to monitor progress on actions. A Health and Social Care Taskforce comprising of the Health and Social Care Board and the Public Health Agency was also established, including a regional commissioning team and subgroups.

[65] DHSSPS (2009) Delivering the Bamford Vision. Action Plan 2009-2011, p91.

[66] DHSSPS (2009) Delivering the Bamford Vision. Action Plan 2009-2011, p96.

[67] This DES was introduced initially for people with a **severe learning disability**. However, there was debate about the eligibly and the prevailing view is that people who may have a mild learning disability who have a

6.3.1 Evaluation of 2009-11 Bamford Action Plan

In 2012, the DHSSPS conducted an in-house evaluation of the 2009-2011 Bamford Action Plan. The evaluation stated that '80% of the actions had been achieved'.[69] It also outlined progress on several fronts, but acknowledged that more needed to be done.

There are some points of note about the evaluation. Firstly, the 67 actions concerning learning disability in the Action Plan do not describe 'outcomes' in detail and baseline data is limited. Progress is marked 'red' for action not achieved, or 'green' for actions achieved, so it is impossible to fully gauge what has been a success or not and how this has been measured.[70]

Secondly, important areas that have not been achieved include the mapping of learning disability services so that new services could be better targeted[71] and oral health initiatives. The plan also states that people with a learning disability reported difficulties in assessing and communicating with their GP, and there were also issues with them using general hospitals.[72]

Thirdly, the target on access and health inequalities, which the evaluation notes as 'green' (i.e. achieved) should be treated with some caution. DHSSPS officials at the Health Committee meeting on 16 October 2013 reported that around 75% of GPs (not the 90% required by the target) had actively taken part in the DES health checks scheme in the last two years. Whilst progress has been made towards this target, it has not been achieved. This raises the question, therefore, about how successful other actions in the Plan which are marked as 'green' (i.e. achieved) have been.

6.3.2 Evaluation of DES Health Checks (McConkey, 2013)

Notable improvements have been made regarding the Bamford Action Plan, such as the appointment of Health Facilitators and the introduction of health checks – (as recommended in the plan's first action under learning disability) which will undoubtedly improve access to healthcare. Nevertheless, an independent evaluation of the DES health check scheme across the province which was conducted by Professor McConkey (2013)[73] indicates that further work is required. According to McConkey's evaluation, around 7,000 adults with a learning disability in Northern Ireland are listed on GP registers. The evaluation states that the overall proportion of adults with a learning disability who received a health check in Northern Ireland was 69% of those

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clinical need that otherwise may be unmet should receive the DES. The DES enables GP's to claim £75 for each patient who has a learning disability who has a health check.

[68] Personal correspondence with author and Professor R. McConkey on 28.11.13.

[69] DHSSPS (2012) Evaluation of the 2009-2011 Bamford Action Plan, p49.

[70] DHSSPS (2012) Evaluation of the 2009-2011 Bamford Action Plan. Pp76-126.

[71] DHSSPS (2012) Evaluation of the 2009-2011 Bamford Action Plan, p49 and p77 and p80.

[72] DHSSPS (2012) Evaluation of the 2009-2011 Bamford Action Plan, p28.

[73] McConkey, R. (2013) Evaluation of the enhanced service specialising in health care for adults with a learning disability provided by GMS practices and of health facilitators provided by five HSC Trusts.

currently known to GP practices.[74] This means that a number of people both known and unknown to services (given the overall estimated number of people with a learning disability) have not had a health check.[75] The evaluation also identified other anomalies: people with a learning disability were more likely to receive a health check if they were older, living in residential accommodation and in areas of less deprivation; and less likely to have a health check if they were younger and living in more deprived areas.[76] This finding would indicate that other ways would be needed to identify and target people with a learning disability in more deprived areas. Furthermore, the evaluation showed that there appeared to be few individual health plans to ensure health issues were addressed, and that this would require further attention.[77]

Since GPs act as the gatekeepers to healthcare, evidence would suggest that more action is needed to ensure that all GPs sign up and partake in the DES programme; and that all relevant people with a learning disability are identified and have access to health checks/screening/health plans. In addition, there needs to be better ways to marry up the health check forms to computerised GP records as this is currently not possible.

6.7 The second Bamford Action Plan (2012-2015)

In 2012, the DHSSPS published a second Bamford Action Plan (2012-2015).[78] The new plan highlights areas of achievement, but acknowledges that change has been slower than anticipated and that funding constraints continue to be a challenge.[79] The new plan does however provide a much 'tighter' set of quantifiable targets and 'outcomes' (rather than outputs) compared to the original Bamford Action plan (2009-11). It also includes a series of outcomes created by service users. Several healthcare actions of note included in the new Plan are:

> **Action 5** – equal access to the full range of primary care services by March 2015 with the "full implementation of the DES across NI".
>
> **Action 51** – to complete a map of learning disability services across NI by December 2013.
>
> **Action 57** – to improve the experience of people with a learning disability using acute general hospitals (based on the GAIN guidelines) – implement staff training, reasonable adjustments, co-ordinated links between hospital and community services by March 2015.[80]

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[74] McConkey, R. (2013) Evaluation of the enhanced service specialising in health care for adults with a learning disability provided by GMS practices and of health facilitators provided by five HSC Trusts, p13.

[75] The appointment of 9.3 WTE Health facilitators has helped to identify people eligible for a health check (as was originally recommended by the *Equal Lives* report).

[76] Although the evaluation acknowledges that the NI uptake rate is higher than in the rest of Great Britain.

[77] McConkey, R. (2013) Evaluation of the enhanced service specialising in health care for adults with a learning disability provided by GMS practices and of health facilitators provided by five HSC Trusts, p13.p23.

[78] DHSSPS Delivering the Bamford Vision Action Plan 2012-2015.

[79] DHSSPS Delivering the Bamford Vision Action Plan 2012-2015, p12

[80] DHSSPS Delivering the Bamford Vision Action Plan 2012-2015, p32, p 54, p56.

6.4 Transforming Your Care

One of the most important policy developments in recent years, and an area of interest to the Committee, concerns the department's proposals for reforming the health and social care system in Northern Ireland, known as *Transforming Your Care* (TYC).[81] Again, one of several aims in this policy is to reduce health inequalities across the whole population.[82] Whilst the proposals are wide ranging, a central feature is the "shift left" from hospital-based care towards an integrated model of care that is delivered in local communities, closer to people's homes. In addition, increasing emphasis will be placed on primary care, and GPs will be given more responsibilities. This may have implications for the services they provide to people with a learning disability.

In addition to the TYC document, a *draft* Strategic Implementation Plan (SIP) has been developed.[83] In terms of learning disabilities, the SIP focuses efforts on resettlement, delayed discharge from hospital, access to respite for carers, individualised budgets, day opportunities, the DES service, advocacy services and so forth.[84] In the recent Committee meeting in October 2013 on learning disability, Departmental Officials stated that "there is nothing 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*." As the implementation plan is in draft form, the full impact of the proposed changes will not be known until the final plan is published and the proposals have had time to have an impact.

6.5 Service Framework for Learning Disability (2012)

In September 2012, following delays, the DHSSPS *Service Framework for Learning Disability* (2013-16) was published.[85] Its aim is "*to promote social inclusion, reduce inequalities in health and well-being and improve HSC quality of care for people with a learning disability*" by setting out 34 standards. This document includes a range of targets (with more details about 'how' things will be achieved), performance indicators and what baseline data is to be collected (see Appendix 4 of this paper). Standards about accessing healthcare, health promotion initiatives such as reducing smoking, healthy eating, and physical exercise, are included. As baseline measures are not expected to be collected until 2014/15, it is not possible to comment on the current performance against the standards.

6.6 Fit and Well (2012-2022)

In 2012, the DHSSPS also developed a new *draft* public health strategy entitled *Fit and Well – Changing Lives* (2012-2022).[86] Its overarching goals are 1) to improve health

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[81] DHSSPS (2011) Transforming Your Care.
[82] Health Social Services and Public Safety website. TYC explained http://www.dhsspsni.gov.uk/index/tyc/tyc-timeline.htm
[83] DHSSPS (2012) Transforming Your Care; Draft Strategic Implementation plan, pp39-40.
[84] DHSSPS (2012) Transforming Your Care; Draft Strategic Implementation plan, pp39-40.
[85] DHSSPS (2012) Service Framework for learning disability.
[86] DHSSPS (2012) Fit and Well Changing Lives 2012-2022

and 2) to reduce health inequalities in collaboration with other government departments. The draft strategy identifies two strategic priorities for tackling health inequalities, both of which have relevance to people with learning disabilities:

- Early Years; and
- Supporting vulnerable people and communities

Indeed the strategy recognises that people with a learning disability are an “at risk” group, but the document appears to base its evidence largely on evidence from the UK, and provides only a small section specifically on learning disabilities as follows:[87]

> *People with a learning disability are more likely to experience major illnesses, to develop them younger, and die of them sooner than the population as a whole. UK reports indicate they have higher rates of obesity, respiratory disease, some cancers, osteoporosis, dementia and epilepsy. It is estimated that people with learning disability are 58 times more likely to die prematurely.*
>
> *Even with such a dramatic health profile, the learning disabled population is less likely to get some of the evidence-based screening, checks and treatments they need, and continue to face real barriers in accessing services. Information on, and activities in, health promotion can be difficult to access. These factors contribute to **preventable** ill health, poor quality of life and potentially, premature death.*

Some of the targeted actions for people with a learning disability in the strategy include:

- Mental and physical wellbeing of children/young people and adults with a learning disability improved through implementation of the Mental Health and Learning Disability Service Frameworks and the Bamford Action Plan.
- Increased number of young people and adults with learning disabilities participating in sport and recreation and leisure activities.[88]

7. Conclusion

Health inequalities are complex and are influenced by a number of factors such as poverty, social isolation and a lack of access to healthcare services. People with a learning disability are a particularly vulnerable group who experience greater health inequalities than the general population. Research shows that they die at a younger age and experience poorer health outcomes. In many instances, these poorer health outcomes are avoidable.

An estimated 26,500 people in Northern Ireland have a learning disability – yet no accurate register of actual numbers exists, meaning that some people with a learning disability are ‘hidden’, not known to services, and missing out on appropriate

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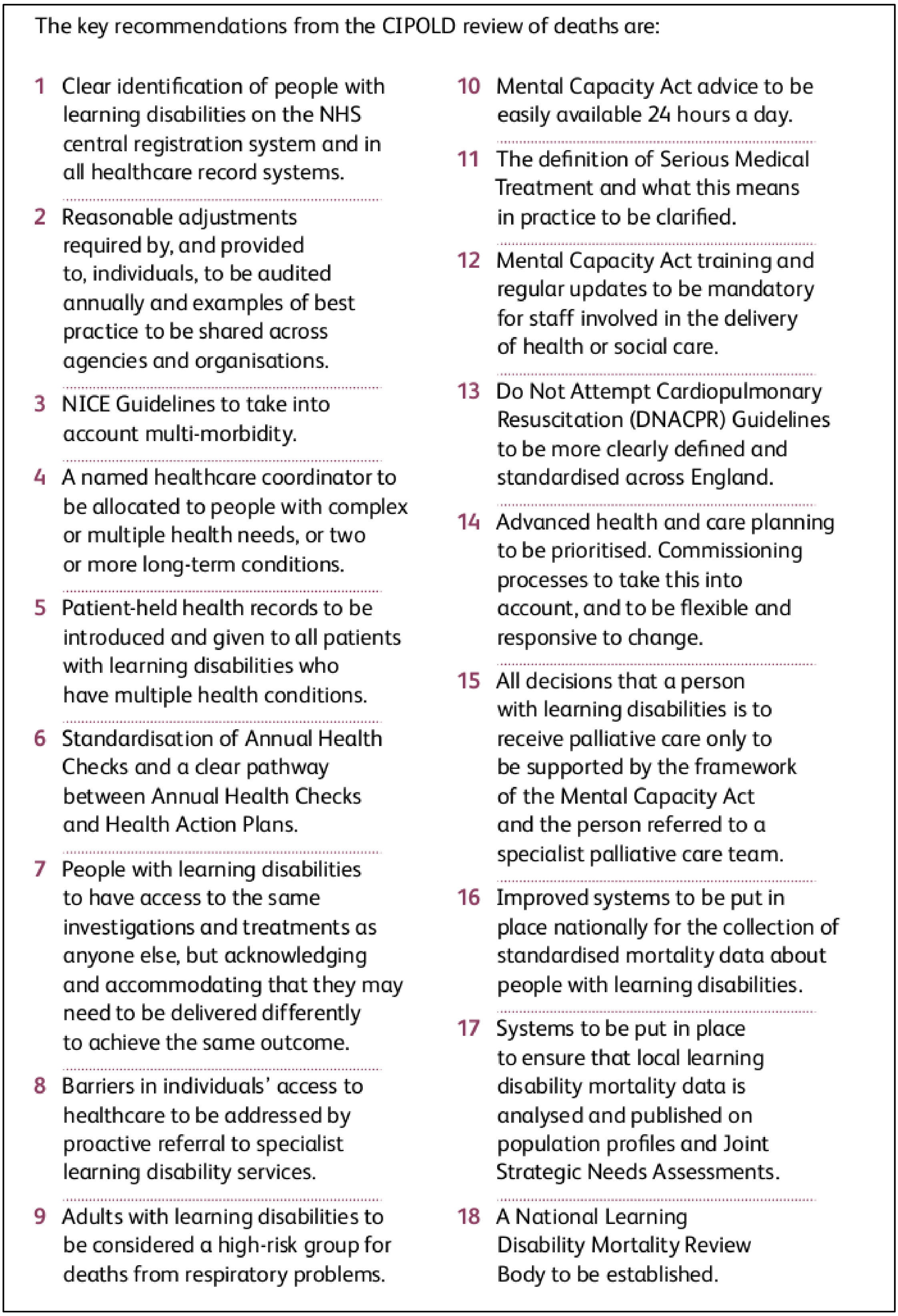
[87] DHSSPS (2012) Fit and Well Changing Lives 2012-2022 p 48.
[88] DHSSPS (2012) Fit and Well Changing Lives 2012-2022 p 60.

healthcare services. Collecting accurate data on the learning disability population would be a useful starting place to establish baseline data on service users and their health. It would also fulfill the repeated recommendations by various UK based inquires about the importance of collecting and monitoring data about this group.

Several policies, such as the DHSSPS Service Framework for Learning Disability and the latest Bamford Action Plan (2012-15) place responsibility on the department to identify and address the health inequalities of people with a learning disability. Whilst the overall intention of the DHSSPS to deliver on the Bamford Vision and the associated strategies are commendable, the time taken for many areas to be implemented has been long. Given the slow pace, it is too soon to sense any real change in terms of health inequalities.

Evidence would also indicate that more needs to be done - not just to improve access to primary care through the DES, which is only one facet of care, but to ensure that needs are met through secondary care; through health promotion and screening; in terms of legal obligations and reasonable adjustments; and in terms of identifying and monitoring the health of people with a learning disability throughout the life course. In tackling the wider social determinants of health for this group (such as poverty and unemployment), continued targeted action is required across all government departments.

Appendix 1 Recommendations from the Confidential Inquiring into the premature deaths of people with learning disabilities



The key recommendations from the CIPOLD review of deaths are:

1 Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems.

2 Reasonable adjustments required by, and provided to, individuals, to be audited annually and examples of best practice to be shared across agencies and organisations.

3 NICE Guidelines to take into account multi-morbidity.

4 A named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions.

5 Patient-held health records to be introduced and given to all patients with learning disabilities who have multiple health conditions.

6 Standardisation of Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans.

7 People with learning disabilities to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome.

8 Barriers in individuals' access to healthcare to be addressed by proactive referral to specialist learning disability services.

9 Adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems.

10 Mental Capacity Act advice to be easily available 24 hours a day.

11 The definition of Serious Medical Treatment and what this means in practice to be clarified.

12 Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care.

13 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Guidelines to be more clearly defined and standardised across England.

14 Advanced health and care planning to be prioritised. Commissioning processes to take this into account, and to be flexible and responsive to change.

15 All decisions that a person with learning disabilities is to receive palliative care only to be supported by the framework of the Mental Capacity Act and the person referred to a specialist palliative care team.

16 Improved systems to be put in place nationally for the collection of standardised mortality data about people with learning disabilities.

17 Systems to be put in place to ensure that local learning disability mortality data is analysed and published on population profiles and Joint Strategic Needs Assessments.

18 A National Learning Disability Mortality Review Body to be established.

Appendix 2: Inequalities linked to learning disability (Equal Lives Review, 2005)[89]

	Equal Lives Review (2005) Inequalities faced by people with a learning disability
Children and Young People	Many children are unable to access mainstream play and leisure activities. Access to preschool facilities is curtailed. Mothers are likely to be unemployed and more likely to report ill-health. The burden of caring is more likely to fall on the mother. Financial burdens due to reduced income, families more likely to experience social deprivation. Siblings may also face inequalities - many having less contact with friends; increased anxiety compared to other children. Transition from school to adult services is a concern for parents. Lack of career guidance, further education, work experience and vocational training.
Adult Life	Lack of opportunities in employment, further education, leisure, social life and personal relationships. Poverty contributes to some of these. Fewer people with a learning disability achieve accredited qualifications.
Health and Wellbeing	High levels of unmet health needs among people with a learning disability in NI. Some may have a higher incidence of physical health problems. People with challenging behaviours are more likely to be socially isolated not only because of their behaviour, but because of barriers to their social interaction skills. Those with the most severe behavioural problems are also more likely to be excluded from day opportunities such as day care or school. People who challenge services are more likely to be the last to leave institutional care and more likely to be admitted to hospitals for specialist assessment and treatment. People who commit offences may not come before the courts but will have to live in more confined and highly supervised settings, often long-stay in hospitals.
Growing Older	Many older people with a learning disability are at particular risk of neglect, poor access to health care and marginalisation within society. Some people with Down's Syndrome age prematurely and life longevity is reduced for many people with severe and profound disabilities.

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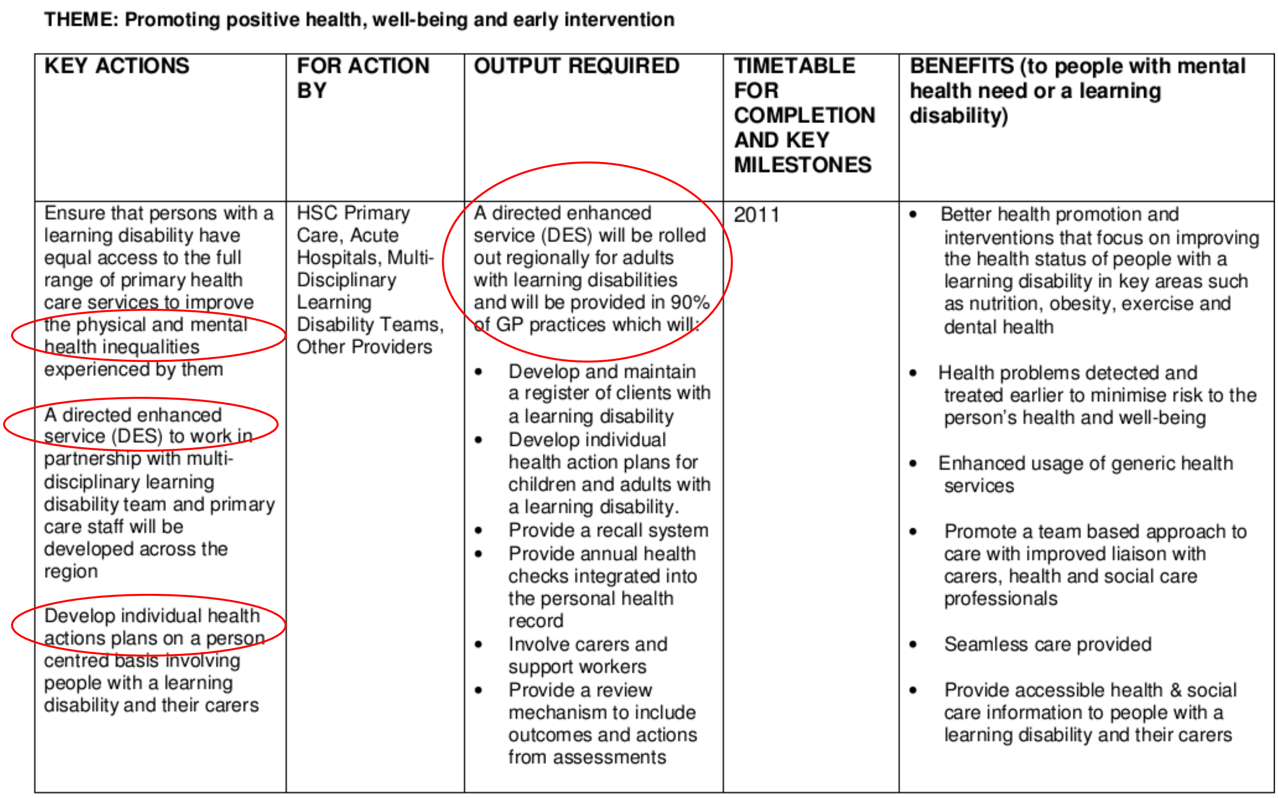
[89] Equal Lives (2005) Review of Policy and Services for People with a Learning Disability in Northern Ireland p29.

Appendix 3: Bamford Action Plan (2009-11); Key action to address health inequalities

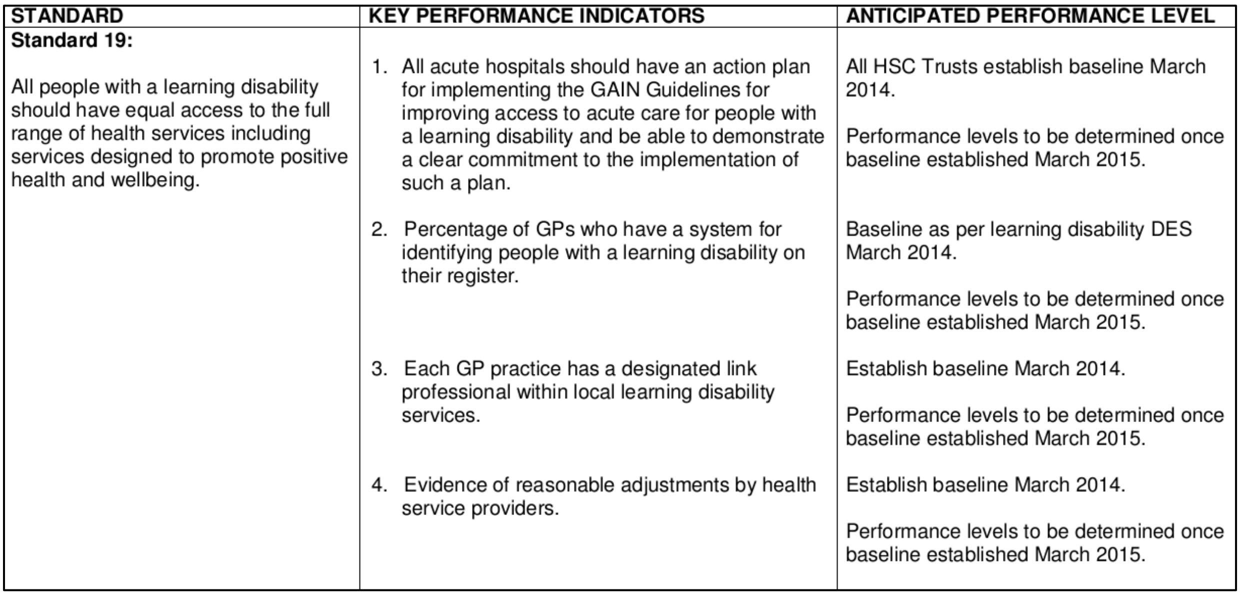


THEME: Promoting positive health, well-being and early intervention

KEY ACTIONS	FOR ACTION BY	OUTPUT REQUIRED	TIMETABLE FOR COMPLETION AND KEY MILESTONES	BENEFITS (to people with mental health need or a learning disability)
Ensure that persons with a learning disability have equal access to the full range of primary health care services to improve the physical and mental health inequalities experienced by them A directed enhanced service (DES) to work in partnership with multi-disciplinary learning disability team and primary care staff will be developed across the region Develop individual health actions plans on a person centred basis involving people with a learning disability and their carers	HSC Primary Care, Acute Hospitals, Multi-Disciplinary Learning Disability Teams, Other Providers	A directed enhanced service (DES) will be rolled out regionally for adults with learning disabilities and will be provided in 90% of GP practices which will: • Develop and maintain a register of clients with a learning disability • Develop individual health action plans for children and adults with a learning disability. • Provide a recall system • Provide annual health checks integrated into the personal health record • Involve carers and support workers • Provide a review mechanism to include outcomes and actions from assessments	2011	• Better health promotion and interventions that focus on improving the health status of people with a learning disability in key areas such as nutrition, obesity, exercise and dental health • Health problems detected and treated earlier to minimise risk to the person's health and well-being • Enhanced usage of generic health services • Promote a team based approach to care with improved liaison with carers, health and social care professionals • Seamless care provided • Provide accessible health & social care information to people with a learning disability and their carers

Appendix 4: DHSSPS Service Framework for Learning Disability (2013-16)

Standard 19 - All people with a learning disability should have equal access to the full range of health services, including services designed to promote positive health and wellbeing.



STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 19: All people with a learning disability should have equal access to the full range of health services including services designed to promote positive health and wellbeing.	1. All acute hospitals should have an action plan for implementing the GAIN Guidelines for improving access to acute care for people with a learning disability and be able to demonstrate a clear commitment to the implementation of such a plan.	All HSC Trusts establish baseline March 2014. Performance levels to be determined once baseline established March 2015.
	2. Percentage of GPs who have a system for identifying people with a learning disability on their register.	Baseline as per learning disability DES March 2014. Performance levels to be determined once baseline established March 2015.
	3. Each GP practice has a designated link professional within local learning disability services.	Establish baseline March 2014. Performance levels to be determined once baseline established March 2015.
	4. Evidence of reasonable adjustments by health service providers.	Establish baseline March 2014. Performance levels to be determined once baseline established March 2015.

Standard 21 - All people with a learning disability should be supported to achieve optimum health and well-being.

Appendix 3

Report on stakeholder event

20 November 2013, Carrickfergus Town Hall

The event was structured into two sessions.

During the morning session, Committee members held discussions with representatives from organisations that provide services to people with a learning disability. The organisations which attended are listed below:

- ARCUK
- Castleview Nursing Home
- Cedar Foundation
- Destined
- Mencap
- Post 19 Lobby Group
- Playboard
- Faculty of Learning Disabilities (South Eastern Trust)

During the afternoon session, members met with people with a learning disability and their carers, to gain their perspective on access to health services.

Summary of discussions with learning disability service provider organisations

Discussions on GP annual health checks

Q1 Is the fact that people with a learning disability are entitled to an annual check-up with their GP widely known by people and their carers?

- Some GPs inform patients, while others do not
- There is an uptake of 75% of those who know about it, but only those who know, so there is a tremendous amount under the radar.

Q2 Do GPs know how to communicate properly with someone who has a learning disability?

- Some GPs now see patients as people, their training is different than it was 30 years ago
- The language used by GPs is difficult for patients to understand
- GPs need to take the role of parent into account as they are experts when it comes to their kids
- Surgeries need to treat those with learning disabilities first and not have them sitting in the waiting room as it can be stressful.

Q3 Are GP surgeries geared up to deal with people with a learning disability? For example, are there any adjustments made in terms of getting a longer appointment?

- No
- It depends on the GP
- Some GPs provide an early appointment which is good
- There have been improvements with GPs receiving training, but GP Out of Hours is a major problem
- GP surgeries need to treat those with learning disabilities first and not have them sitting in the waiting room as it can be stressful.

Q4 Are you aware of the work of the health facilitators?

- No
- As learning disability organisations, one of our functions is to signpost people to this type of information, yet no one has informed us about it.

Q5 Do you think annual GP health checks could be effective in improving the health of people with a learning disability?

- People with learning disabilities also have associated medical symptoms, so an annual health check would identify not only the physical underlying issues, but the mental ones to, such as loneliness, isolation, depression.

Discussions on access to hospital and A&E

Q1 What are the barriers which people with a learning disability face when they are admitted to hospital?

- Lack of experience when dealing with people with a range of learning and health disabilities
- Information gets lost between doctors and nurses (having to retell their story to every member of staff that comes in)
- Difficult for the doctors to receive previous information/records quickly
- Waiting for long periods of time
- Lack of information on what is happening or what they are going to do with the patient
- Doctors and nurses aren't trained in disabled people's needs
- No communication or patience from doctors
- Starts with a brush-off approach because they have no understanding of the needs of the patient. Usually carer needs to explain and try to help with the situation – families are the experts on how to deal with the patient, for example, not all disabilities are immediately obvious e.g. autism
- Lack of staff in hospitals – funding issues
- Lack to time to understand person – to sit and talk to them – build a relationship
- Fear and lack of understanding from doctors and nurses
- If patient is from supported living they may be with staff member from the accommodation (rather than family) and the staff member is not always kept up to date with the medical history of the patient as the family don't always keep them fully informed.

Q2 What are the most common problems people with a learning disability face when they attend an A&E?

- Waiting for long periods of time – particular patients find it hard to deal with waiting out of a routine they are in or being told that they will be seen in 10 minutes and it is actually 30 minutes or an hour. Fast tracking is needed.
- Short concentration with a lot of mental health disabilities – hard to keep entertained if waiting in a small waiting room with lots of other noisy people – easily distressed
- Too many staff seen in one visit – better if one member of staff was with them from the beginning through to the end
- Better administration needed behind the scenes
- Lack of communication between front desk staff and all other staff
- Lack of interest and patience because they are busy
- Lack of support in the hospitals for people without carers/family
- Getting the triage right in A&E is crucial – so triage nurses must be well trained in dealing with different disabilities
- It would be useful to have a set of mobile staff trained in learning disability that could be called to assist such patients wherever in the hospital they find themselves.

- On-Call doctors/out-of-hours tend to instantly refer such patients to A&E as they don’t want the responsibility of dealing with them.

Q3 Do hospital staff have the necessary skills or training to know how to deal with a patient who has a learning disability?

- No training or skills across the whole of NIs health service
- Training and refresher needed in all hospitals/A&E/health professionals/GPs
- Enthusiastic and helpful staff with motivation needed
- Would be useful if disability groups give the training and staff had interaction with disabled patients
- Carers/advocates are essential in most cases to help health service/GPs communicate during appointments etc. with patients
- Lack of understanding for patients if doctors/nurses use fancy terms
- Lack of tools available to communicate
- Lack of common sense with health service staff - a reasonable adjustment would be just to allow more time in appointments for such patients
- Difficult for doctors to balance rights of patient with learning disability gains listening to the carer (the patient has become a victim of the successes achieved in equality – for example one carer was not listened too even though she knew that everything the patient was telling the doctor was incorrect)
- As TYC progresses and those with learning disabilities move into the community – good use should be made of the staff who have worked in the institutions – they have a wealth of expertise.

Q4 Are there any reasonable adjustments that hospitals should be making, to make things easier for patients with a learning disability?

- Better training and refresher training to keep doctors and nurses up-to-date with mental health/physical health issues.
- Additional administration needed behind the scenes
- Visual information – signs/pictures to explain things better
- Identified person in each hospital/Health centre to help with eg autistic patients etc.
- Information not passed on between A&E and ward
- Extra resources are needed
- A lack of services causes health issues for carers / families – need more services in place

Q5 Do you think a central register of people with a learning disability which would be accessible to all health professionals be a good thing?

- People are still under the radar as regards to disabilities so even if there was a register, everyone wouldn’t be on it that needed to be
- Encouragement is needed to get patients onto the register
- People fall through the net if their disability is not seen to be severe – those with mild/moderate LD are the ones struggling in mainstream

schools, don’t attain good education and go on to struggle as adults – find it difficult to get or hold down employment, often social service involvement as the demonstrate poor parenting skills as adults.
- Registrar would be good as there is a lack of communication between health service staff
- Would be hard to know if it would be even possible to do this – a community audit through the health service and other areas e.g. support groups and disability organisations
- Only disabilities that are diagnosed are would appear on it
- There is a need for a provision of services first
- Good to help all services that, that patient would approach
- People may be offended to be on the list, labelled

Q7 How could people with a learning disability be better involved in making decisions about their healthcare?

- Accessible information for all of the health service
- Doctors nurses talk to patients and their families who help
- The person with the disability having a chance to get involved at appointments as well as advocates
- Making sure advocates have all the information before going to a doctors or hospital appointment with person
- Doctors meeting with the person and their carer or families – who are involved to get more information

Discussions on health promotion

Q1 Who educates PLD about health promotion/healthy eating?

- For children with a learning disability, health promotion messages come from mainly from parents and/or from teachers. However, there is a growing worry for parents that when the child turns 19 years of age, they will not get the same level of support about health promotion if they are living away from home or at day centres. When young people with a learning disability leave school, their only structured options are day centres with older people; they cannot freely do what young people do, i.e. run about/play. When the structure and control of school or supported accommodation is taken away, the health of people with learning disabilities can go down-hill rapidly. Increased anxiety levels can lead to overeating in people with learning disabilities.
- Carers or parents of people with learning disabilities may also not be aware of health promotion messages. They may be illiterate or have a learning disability too, or be living in more socially deprived areas and living on low incomes, and therefore unaware of the consequences of poor health choices, eating low nutrient diets, which can impact on all the family.
- At day centres, staff said there was a gap about health promotion, there is no formal training, but that staff were probably educating people with learning

disabilities about healthy eating in an ad-hoc or informal way as part of their role in caring for the person. However, it was identified that more formalised staff training would be required to get health promotion messages across better.
- For people who have never had a formal learning disability diagnosis, it was unknown who - if anyone - would educate them about healthy lifestyle choices. Participants agreed that those 'hidden' people with learning disabilities needed to be targeted and supported.

Q2 How effective are public health campaigns?

- Any campaign is only effective if it can reach its audience. Health promotion puts an onus on the individual to take the information and make more healthy choices. However, people with learning disabilities often do not have the capacity to understand. Wider campaigns, like eating your '5 a day' of fruits and vegetables are only good for those who understand it and can make changes. Many people with a learning disability have no understanding of what a healthy lifestyle or healthy eating is, or how it might have an impact on them. It is unlikely they will make healthier choices based on current public health campaigns unless it is contextualised for them in a way they can comprehend. They also can get into a pattern of eating badly or becoming sedentary, thus leading to obesity and this can be very hard for support staff/family carers to change these behaviours.

Q3 What format should health promotion messages be delivered?

- There is a large proportion of the learning disability population for whom written health promotion material will not be appropriate. Therefore, messages should be accessible and given in a sensitive and individualised way, appropriate to the person's needs/level of understanding. One size does not fit all as this group have very diverse needs. It is also important that the person does not feel singled-out as this can lead to further stigmatisation. Other formats should be considered like the use of technology, using pictures, cartoons, boardmaker, DVDs, signing/makaton to get the message across. Staff should be trained on the key messages to support the person in making healthy choices.

Q4 What assistance could be provided to PLD to help them live more healthy lifestyles?

- Health is currently delivered on a model that reacts to when people get sick whereas more emphasis should be placed on being proactive and on prevention. There needs to be a holistic, connected approach to well-being, with not just one department being involved. There needs to be more joined-up working on health promotion with the DHSSPS, the Department of Education and others. In addition, the government needs to take a more targeted approach - specific pathways, healthy eating plans and working with dieticians should be explored. The DHSSPS should consult and engage with families and carers about how to best deliver health promotion initiatives to the learning disability population.

- The health service needs to conduct research about the health of this population and start to measure it. Trusts need to be consistent in their approach and in the systems they use.
- There needs to be an increase in the public health budget.
- There also needs to be a cultural shift (change in mind-set) in attitudes so that people with learning disabilities are more widely included in life.
- Initiatives like ‘Cook it’ and others (such as helping people with learning disabilities go to the gym) that are often small scale programmes not widely available to everyone with a learning disability. Often eligibility criteria are strict, and there is a lot of bureaucracy in applying for funding for such initiatives. Furthermore, once these programmes end, the danger is people go back to their old habits - such as eating fast food or not keeping active. The DHSSPS should tap into the knowledge and expertise of the voluntary sector who know who the learning disability population are and who have the skills to help them live healthier lives. Good practice local schemes should be rolled out nationally.
- There also needs to be more mental health messages getting out there for people with learning disabilities as many will suffer mental health problems which can impact on health.
- There needs to be more assistance around the area of resettlement – sometimes the new residence does not always work out. The vulnerability of people with learning disabilities who live in the community leads to issues around capacity, consent and who will advocate for them; not all people can manage their care/health in the same way as it would have been looked after in hospital, and the level of care may differ or be more fragmented.
- In addition, there appears to be a lack of awareness of the annual GP health checks scheme and for some parents, they might need more support from other medical professionals (e.g. a psychiatrist rather than a GP health check). Care should be tailored to the individual, and be consistent.
- There needs to be creative solutions like a “health passport”, so that doctors can treat people with learning disabilities quickly and have some background information to hand – for example if someone is allergic to certain substances. These types of solutions should be widely adopted amongst the medical profession.
- Some specialist services are required but are not available to assist people with learning disabilities to cope with and navigate their way through mainstream health system.

Q5 What else can Public Health Agency/DHSSPS do?

- Parents often have to fight for resources therefore making their child a ‘job of work’ rather than allowing them time and peace of mind to enjoy them; this has a knock on effect to parents health and well-being, thus creating another strain on resources. The Public Health Agency should focus on the environment around people with learning disabilities, and include their families in any health promotion initiatives.
- Alter the information to suit the target group; use more pictures, easy reading format, symbols, DVDs, vox pops, social media.
- Promote play time early on in life to encourage exercise.
- Parents need to be told sensitively what to look out for.
- Health promotion should not be a one-off communication, it needs to be re-enforced.
- Consult people with learning disabilities when making adverts/flyers.
- Planned one-to-one or group education programmes; use resources in organisations that already exist and work with people with learning disabilities to rollout programmes.
- Start at an early age and include in school education programme.
- Educate health care professionals in how to communicate with people with learning disabilities, during initial training and refresher courses. Teach Makaton.
- Have pathway appointments with no waiting times.
- Include modules in initial doctor training courses.
- Not every GP conducts annual health checks, and more training is needed.
- Have person centred plans around healthy living.
- The Public Health Agency should also lobby supermarkets about healthy eating packaging - more needs to be done in this area.
- The Public Health Agency should include people with learning disabilities in policy change/development.
- The health and social care service needs to plan for future. People with learning disabilities can end up requiring emergency assistance when it could have been planned for. e.g. when main carer dies. In addition, services are not equipped to deal with the growing number of older people with a learning disability; this should be planned for. Gaps in services are more apparent now as there are less people with learning disabilities in care and more living in the community.
- There should be a central register of people with learning disabilities. If accurate mapping is completed planning for future resources can be allocated where it is needed most.
- Have a programme for a personal assistant to show people with learning disabilities how to shop, cook, access exercise and develop an understanding as to what is good for them.
- Research is required into early intervention studies; Randomised Control Trials need to target people with learning disabilities to see what interventions work.

- Examples of Projects etc. currently in operation – however these are sporadic and not available to all PLD
- ‘Lost for Words’ - Project designed by MENCAP to show public how to communicate with individuals who do not speak, using snapshot videos.
- ‘Cook it’ – run by Destined to show independent living PLD how to shop & cook healthily.
- ‘Lifestyle Support Project’ – Helps to tap PLD into existing services for diet/exercise and day-to-day living. Needs can change over time but this service will still be required.
- ‘Charter for Social Inclusion’ – Destined are in discussion with Derry/Londonderry City Council to get organisations and service providers to sign up to this charter.
- Utilises a ‘train the trainer’ technique to educate the public, organisations etc. in the anticipation this will make changes in the community via a ripple effect.
- ‘Market Place’ - Event run by Belfast Trust to explain the Health care services available and engage with PLD service providers.
- ‘Learning Disability Liaison Nurses’ – provided by Southern Trust to care for PLD whilst in hospital and explain everything to PLD.
- Website http://www.gmc-uk.org/learningdisabilities/104.aspx designed by GMC & MENCAP to show healthcare professionals how to communicate with individuals with LD, using videos and guides.
- ‘Live Net’ online interactive tool around healthy eating.
- Queen’s University have developed a traffic light system for making food content easier to understand for people with learning disabilities:
  - Green includes info such as likes and dislikes
  - Amber includes on-going medical info
  - Red urgent crucial info, allergies etc.

Summary of discussions with people who have a learning disability and carers

General comments

Health is the one area where people with a learning disability are treated differently.

The GP Annual Health check is not widely advertised and not widely known about. This service is a postcode lottery and reliant on individual GPs taking part- not all of which do. People with a learning disability often find the language used by the GP difficult to understand and to remember. Medical letters contain a lot of text which is difficult to understand.

GPs often talk to family members rather than to the person with the learning disability. They also use a different voice when they do talk to the person with the learning disability. Sometimes there is not enough time at the GP appointment.

People with a learning disability feel that some GPs get frustrated with them. Some feel that GPs often don't know where to signpost the person for further help as there may be lots of people involved in the care of the person with the learning disability.

GPs do not explain the benefits of health promotion at appointments.

There is also a lack of consistency amongst Trusts – e.g. regarding healthcare 'passports'.

People with a learning disability also feel that care is not joined up if they have to go to hospital and they receive little information when they get there from staff directly. There is no consistent level of care across hospitals, it is better in some hospitals over others.

Some families said that medical staff in hospitals feel that the person with the learning disability is exaggerating their pain and they do not take them seriously. People with learning disabilities do not want to go back to hospital if they are treated like this repeatedly.

In hospital, staff often do not take the time to explain procedures to the person with the learning disability and this can make them anxious and frightened (e.g. if getting an anaesthetic or having to wear a mask). Pictures could help make this better. More information needs to be made available in easy read format.

GPs, doctors and nurses are under pressure; training about caring for people with a learning disability should be given before their medical training is completed and refresher courses should be on-going.

Often the worst medical experience is with dentists – many of whom are not equipped in dealing with people with learning disabilities, especially those with challenging behaviours.

There are also issues for families of people with learning disabilities living in rural areas in terms of how they can access care.

Some solutions:

- Medical information should be delivered with pictures, using clear language. Utilise technology innovatively by using video call, face time or skype.
- An assistant or carer who is not a family member should be available to assist a person with learning disabilities if they do not want their parents to attend with them at their GP.
- People with learning disabilities should make better use of the ‘purple card’ scheme – which they can hand to a GP if they feel their care was substandard.
- It is important that care is delivered in a strategic fashion, not just in a piecemeal approach which can be very ‘hit and miss’.
- All medical staff should be trained in communicating with people with a learning disability, not all people with a learning disability are the same so no one method fits all, and communication must be tailored.

Q1 What are the main barriers which you face when you are feeling unwell and need to see a GP?

GP rarely trained in communicating or dealing with people with learning disabilities.

GP talks to parents and not people with learning disabilities.

GP doesn’t give enough time for appointment. Different practices have different procedures, in some place lines are busy and the procedures regarding emergency appointments need to be looked at as 5 minute slots are of no use to those with learning disabilities as it can take 5 minutes just to get them through the front door and make take another five to get to the GP’s office door.

GP can get impatient or frustrated.

GP can go too fast in explanations, gives no time to process information.

GP doesn’t explain what they are doing to the person.

Jargon is used in verbal & written communication, too hard to understand. Should use easy read format.

Person with the learning disability doesn’t always remember everything they wish to discuss. Requires advocate (not always appropriate to be family member) to assist with medical history etc.

Annual checks should be used as an ‘MOT’ & sign posting to other services.

Delayed action from GPs.

GPs should visit patients with learning disabilities more readily.

Doctors refusing to come out and see patients that cannot leave the house

GPs don’t take carers with learning disabilities seriously – doctors need to remember that those with mild/moderate disabilities are often living in the community with responsibility for children and other relatives and are carers in their own right, and may need help themselves.

People tend to seek help from community centres if anything is wrong rather than GPs – as GPs don't take the time to listen.
Check-ups for patients need to be flagged up so they remind people

Trust is a big issue – building relationships – continuity of care.

Difficulty with getting a same sex doctor.

Staff are aware, or rather should be aware of the patient's disabilities. There has to be a way of identifying those with learning disabilities. Some dementia sufferers wear a purple band to identify themselves. If it was voluntary it would be a good idea.

Q2 What sort of problems do you face when you have to go to hospital?

Doctors in hospitals are worse than GP -very poor at communicating, no time for people with learning disabilities.

They are strangers - so no rapport built up.

Don't take time to explain treatment, equipment, process etc.

People with learning disabilities have no time to take in surroundings.

People with learning disabilities require step-by-step talk through of treatment, equipment explained etc. as experience is frightening and frustrating.

Doctors can be dismissive of symptoms if they see a people with learning disabilities.

Hospital visits can be a sensory overload to people with learning disabilities.

Hospitals can have staff that are eager to help and make the person feel at ease

- Some staff are good at explaining what will happen next and how long they have to wait etc.
- People with learning difficulties need to feel they can trust the health service staff
- People with learning difficulties feel more at ease if they have a carer/family member or someone with them who understands their own disability and needs
- People are more relaxed if the doctors/nurses are patient and relaxed
- Hospital staff need to be more understanding if the person

'JAM' cards are useful when in hospitals etc. to ask people to be patient and wait

There needs to be a joined up approach for appointments. Instead of having four separate appointments in one week, they could have all taken place in one day.

Poor communication between the Trusts whereby information gets lost.

Q3 How do you find out how to keep healthy?

Healthy food is not advertised enough, mainly junk food is.

Reliant on leaflets - this is a poor format for people with learning disabilities.

Independent advice from an advocate not parents would be helpful.

Group education programme designed for people with learning disabilities.

Information comes from community groups, family centres.

There is a need for this through TV/videos and radio on buses.

Information that is discussed at a session will be passed onto other people in their support group / network.