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Health inequalities and people with a learning disability.

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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.
- In Northern Ireland, anti-discrimination legislation and the development of local policies have attempted to address the issue of health inequalities and disability. 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.

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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 functioning⁸);
- which started before adulthood⁹, and has a lasting effect on development.¹⁰

¹ See: Committee for HSSPS (2012) Review of Health Inequalities Report. Available online at: <http://www.niassembly.gov.uk/Assembly-Business/Committees/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 disabilities in Northern Ireland

There are no exact figures on the number of children and adults living with a learning disability in Northern Ireland. Different 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.

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 legislation¹⁹ 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.**

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 inequalities

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.

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.instituteofhealththequity.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 to access to healthcare 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 namely:

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.

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 Commission³⁶ 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*

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. Whilst 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 been 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 came to light in 2011.⁴⁷

4.4 Confidential inquiry: premature deaths of people with learning disabilities (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*

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: 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 Agency⁵¹ in Northern Ireland is a key agency tasked with improving the overall health and well-being of the Northern Ireland population (for example, through

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, although 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/strategies relating to health inequalities

It is perhaps useful to outline some of 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

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/iff.htm>

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

6.2 The Bamford Review 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, the creation of robust medical records and individual health plans as illustrated below: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.

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

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 eligibility 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 targeted⁷¹ 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 first target action 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)⁷³ 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 GP 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 GP health check scheme across the province which was conducted by Professor McConkey (2013)⁷⁴ indicates that further work is required through a number of recommendations. According to McConkey's evaluation, around 7,000 adults with a learning disability in

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 By the second Bamford Action Plan, the target had increased so that 100% of GPs are signed up to the scheme.

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.

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 currently known to GP practices.⁷⁵ 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.⁷⁶ The evaluation also identified that 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.⁷⁷ This finding would suggest that other ways might be needed to identify and target people with a learning disability in more deprived areas. Furthermore, the evaluation showed that there appeared to be low uptake of individual health action plans which were designed to ensure that health issues were addressed.⁷⁸

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).⁷⁹ 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.⁸⁰ 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,

⁷⁵ 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.

⁷⁶ 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).

⁷⁷ Although the evaluation acknowledges that the NI uptake rate is higher than in the rest of Great Britain.

⁷⁸ 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.

⁷⁹ DHSSPS Delivering the Bamford Vision Action Plan 2012-2015.

⁸⁰ DHSSPS Delivering the Bamford Vision Action Plan 2012-2015, p12

reasonable adjustments, co-ordinated links between hospital and community services by March 2015.⁸¹

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).⁸² Again, one of several aims in this policy is to reduce health inequalities across the whole population.⁸³ 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.⁸⁴ 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.⁸⁵ 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.⁸⁶ 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.

⁸¹ DHSSPS *Delivering the Bamford Vision Action Plan 2012-2015*, p32, p 54, p56.

⁸² DHSSPS (2011) *Transforming Your Care*.

⁸³ Health Social Services and Public Safety website. TYC explained <http://www.dhsspsni.gov.uk/index/tyc/tyc-timeline.htm>

⁸⁴ DHSSPS (2012) *Transforming Your Care; Draft Strategic Implementation plan*, pp39-40.

⁸⁵ DHSSPS (2012) *Transforming Your Care; Draft Strategic Implementation plan*, pp39-40.

⁸⁶ DHSSPS (2012) *Service Framework for learning disability*.

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).⁸⁷ Its overarching goals are 1) to improve health 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:⁸⁸

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.⁸⁹

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

⁸⁷ DHSSPS (2012) *Fit and Well Changing Lives 2012-2022*

⁸⁸ DHSSPS (2012) *Fit and Well Changing Lives 2012-2022* p 48.

⁸⁹ DHSSPS (2012) *Fit and Well Changing Lives 2012-2022* p 60.

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 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)⁹⁰

	Equal Lives Review (2005) Inequalities faced by people with a learning disability
Children and Young People	<p>Many children are unable to access mainstream play and leisure activities.</p> <p>Access to preschool facilities is curtailed.</p> <p>Mothers are likely to be unemployed and more likely to report ill-health.</p> <p>The burden of caring is more likely to fall on the mother.</p> <p>Financial burdens due to reduced income, families more likely to experience social deprivation.</p> <p>Siblings may also face inequalities - many having less contact with friends; increased anxiety compared to other children.</p> <p>Transition from school to adult services is a concern for parents. Lack of career guidance, further education, work experience and vocational training.</p>
Adult Life	<p>Lack of opportunities in employment, further education, leisure, social life and personal relationships. Poverty contributes to some of these.</p> <p>Fewer people with a learning disability achieve accredited qualifications.</p>
Health and Wellbeing	<p>High levels of unmet health needs among people with a learning disability in NI.</p> <p>Some may have a higher incidence of physical health problems.</p> <p>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.</p> <p>Those with the most severe behavioural problems are also more likely to be excluded from day opportunities such as day care or school.</p> <p>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.</p> <p>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.</p>
Growing Older	<p>Many older people with a learning disability are at particular risk of neglect, poor access to health care and marginalisation within society.</p> <p>Some people with Down's Syndrome age prematurely and life longevity is reduced for many people with severe and profound disabilities.</p>

⁹⁰ 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)
<p>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</p> <p>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</p> <p>Develop individual health actions plans on a person centred basis involving people with a learning disability and their carers</p>	<p>HSC Primary Care, Acute Hospitals, Multi-Disciplinary Learning Disability Teams, Other Providers</p>	<p>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:</p> <ul style="list-style-type: none"> • 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 	<p>2011</p>	<ul style="list-style-type: none"> • 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
<p>Standard 19:</p> <p>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.</p>	<ol style="list-style-type: none"> 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. 2. Percentage of GPs who have a system for identifying people with a learning disability on their register. 3. Each GP practice has a designated link professional within local learning disability services. 4. Evidence of reasonable adjustments by health service providers. 	<p>All HSC Trusts establish baseline March 2014.</p> <p>Performance levels to be determined once baseline established March 2015.</p> <p>Baseline as per learning disability DES March 2014.</p> <p>Performance levels to be determined once baseline established March 2015.</p> <p>Establish baseline March 2014.</p> <p>Performance levels to be determined once baseline established March 2015.</p> <p>Establish baseline March 2014.</p> <p>Performance levels to be determined once baseline established March 2015.</p>

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