



The voice of
learning disability

Mencap NI Briefing Paper No.3

Treat me well: Equal access to healthcare for people with a learning disability

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By Mary Anne Webb with Fiona Cole



There are **42,000** people with a learning disability living in Northern Ireland.¹

A **learning disability** is a reduced intellectual ability and difficulty with everyday activities, which affects someone for their whole life. The level of support someone needs depends on the individual person and the extent of his or her learning disability. With the right support, most people with a learning disability in the UK can lead fulfilled lives.²

Introduction

Mencap's vision is a future where the health inequalities faced by people with a learning disability are eliminated, and individuals have access to the same quality of physical and mental healthcare as everybody else. This future would see an end to avoidable deaths³ of people with a learning disability, and the creation of a health system that fully meets their needs.

Unfortunately, people with a learning disability face many health inequalities. Compared to the general population, they experience markedly different outcomes in terms of avoidable deaths, long-term health conditions and life expectancy. There are a number of notable disparities in life expectancy across the UK's population, for example, a person living in poorer areas can expect to die, on average, 10 years earlier.⁴ Of equal concern, and perhaps

less well known, people with a learning disability have an average shorter life expectancy of 16 years (NHS Digital, 2019). Furthermore, of the cases reported to the Learning Disability Mortality Review (LeDeR, 2018), the difference in average age of death between people with a learning disability and the general population was 25 years.

Limited understanding about how to keep in good health and other social factors have a role to play in early death for people with a learning disability. However, research suggests they can find it more difficult to access good quality healthcare, leading to delayed diagnosis, treatment and poorer outcomes (Glover & Emerson, 2013). Health professionals often lack comprehensive training in learning disability, and reasonable adjustments are not always made or recorded. In-depth knowledge and understanding about how to support people with learning disabilities is not consistently embedded in healthcare teaching and qualifications.

¹ An approximate figure calculated using learning disability prevalence rates from Public Health England (2016) and population data from the Office for National Statistics (2017).

² Mencap (2018) www.mencap.org.uk/learning-disability-explained/what-learning-disability

³ Mencap uses the term avoidable death for deaths that could have been avoided by the provision of good quality healthcare.

⁴ ONS (2016) Health state life expectancies 2014-2016 <https://www.independent.co.uk/news/uk/home-news/life-expectancy-britain-london-liverpool-scotland-ten-years-a7445726.html>

About this paper

This paper presents an overview of what Mencap is doing in Northern Ireland as part of our **Treat me well** campaign to raise awareness about the healthcare needs of people with a learning disability. In doing so, the paper also discusses some of the main barriers to quality health provision for people with a learning disability, and makes recommendations for wider policy and practice.



Policy Context England

An estimated **1,200** people with a learning disability are dying avoidably each year in England due to a lack of good quality and timely healthcare (Glover & Emerson, 2013).

In its 'Death by indifference' reports (2012; 2007), Mencap highlighted the issue of avoidable learning disability deaths in England. Following a confidential inquiry into the premature deaths of people with learning disabilities (Heslop et al., 2013), a national Learning Disability Mortality Review (LeDeR) Programme was introduced. The Government also committed to reducing excess mortality for people with a learning disability under 60 years (Department of Health, 2014 & 2015), and to closing the health gap between people with a learning disability and the wider population by improving treatment and outcomes (Department of Health & Social Care, 2018).



In order to deliver high quality services in England, **Learning Disability Standards** were developed with associated improvement measures in four areas:

• **Respecting and protecting rights** – for example, Trusts must demonstrate they have made reasonable adjustments; and that they have mechanisms to identify and flag patients with learning disabilities.

• **Inclusion and engagement** – includes Trusts demonstrating processes that ensure they work and engage with people receiving care, their families and carers; and that they co-design relevant services with them.

• **Workforce** – includes Trusts ensuring staff have the specialist knowledge and skills to meet the unique needs of people with learning disabilities; and that staff are trained, and then routinely updated, in how to deliver their care.

• **Specialist learning disability services** – for example, Trusts must have plans for the development of community-based intensive support services; and processes to regularly review the medications prescribed to people with learning disabilities (NHS Improvement, 2018).

Other recent initiatives include a government consultation on introducing mandatory training for all healthcare staff in learning disability and autism awareness (Department of Health & Social Care, 2019). Its proposals include a common curriculum that is reflected in clinical education, training and continuing professional development. The NHS are also piloting a new ‘reasonable adjustments flag’ to be placed on patients’ records, so healthcare professionals know they need to offer adjustments.⁵



Northern Ireland

“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” (DHSSPS, 2012).

Policy implementation aimed at improving health outcomes for people with a learning disability in Northern Ireland is generally slow. While there has been some progress, further development is required in ensuring “the equity of access to, the implementation of reasonable adjustments within, and the equity of outcome from general healthcare services for people with a learning disability” (Regulation and Quality Improvement Authority (RQIA), 2018).

Positive initiatives to help counter the health inequalities experienced by people with a learning disability include the Hospital Passport, guidelines on caring for people with a learning disability in hospital (RQIA, 2018), and a Directed Enhanced Service (DES) offering them annual physical and mental health checks. There are also Healthcare Facilitators who are trained learning disability nurses supporting GPs to deliver the health checks, and follow-up any further actions.

⁵ <https://digital.nhs.uk/services/reasonable-adjustment-flag>

However, while there is scope for similar support in a hospital setting, NI lags behind in terms of introducing specific nursing roles to do this. Acute Liaison nurses in other parts of the UK help ensure the effective delivery of learning disability support in hospitals and often play a big role in training staff. While roles vary, they generally provide expert advice, professional support, guidance and education to multi-professional teams, partner agencies, patients and carers.

The Health and Social Care Board (HSCB) are also leading a project aimed at creating an Adult Learning Disability Service Model by March 2020. Notably, two of the six key themes focus on improving health and wellbeing, and assessment and treatment provisions in acute care.

What is the Hospital Passport?

The Public Health Agency (PHA) and Regional General Hospital Forum for Learning Disabilities developed the Regional Hospital Passport in line with GAIN (Guidelines and Audit Implementation Network) recommendations for caring for people with a learning disability in general hospital settings. People with a learning disability and their carers were also involved in its development.

The passport is a practical resource that aims to help improve the experience of attending hospital for people with a learning disability. Presented to staff at every hospital visit, it gives them important details about the patient's medical history, how they prefer to communicate, and any other support needs. Staff can then make reasonable adjustments in order to provide the best possible care.

Learning disability and health

■ Health needs

People with a learning disability often have additional physical and mental health needs, for example, they are disproportionately more likely to suffer from serious mental health issues like schizophrenia and mood disorders (Carey et al., 2016). They are more likely to use a wide range of general hospital services, notably dentistry, paediatrics, and psychiatry (Public Health England, 2015a). Hospital in-patient care is typically accessed for underlying physical conditions associated with Down's syndrome or cerebral palsy, and for additional physical complications requiring more extensive care.

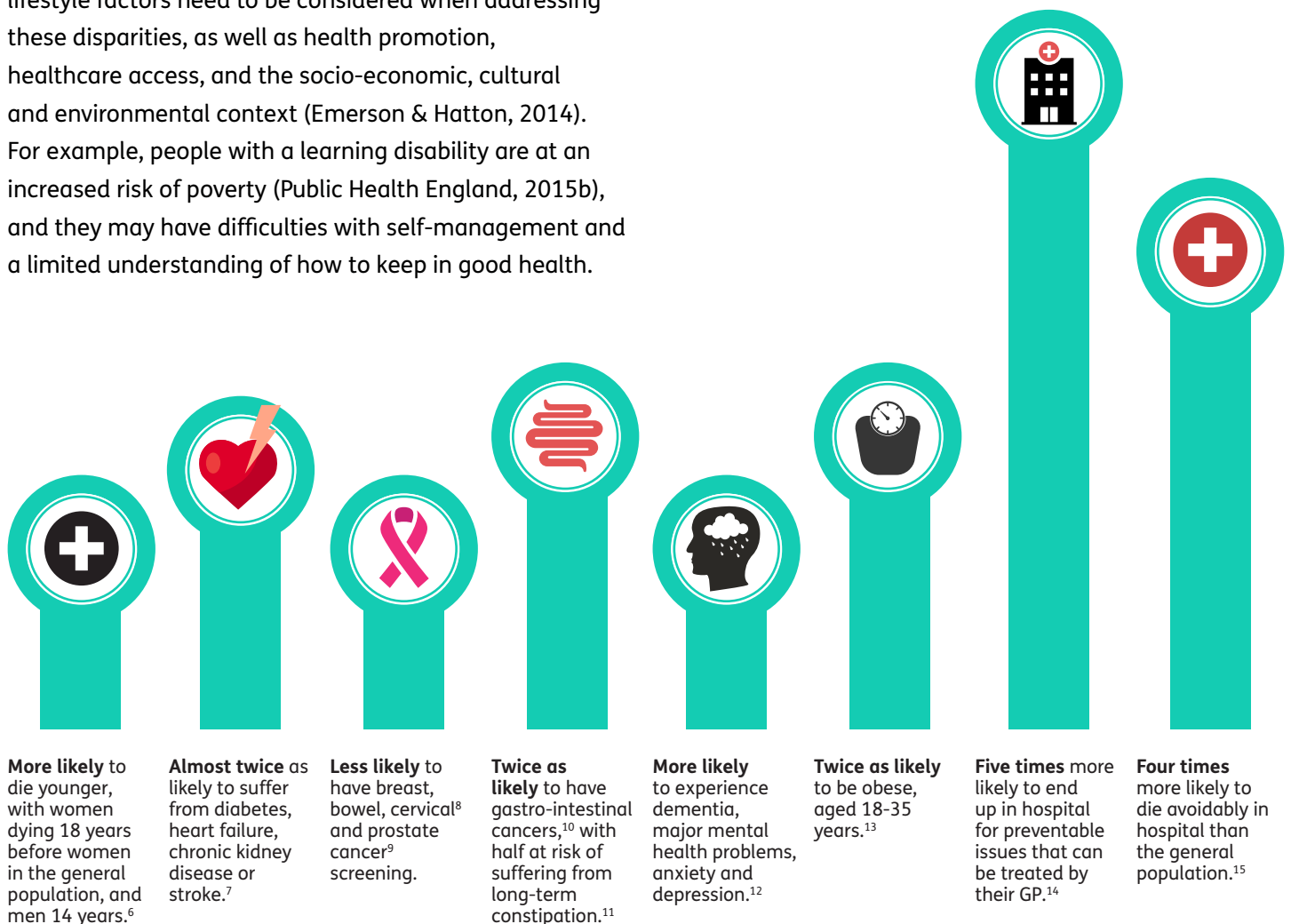
Chronic health conditions typically include epilepsy, constipation, diabetes and thyroid problems (LeDeR, 2017), while difficulties eating, drinking and swallowing (dysphagia) increase the risk of recurrent respiratory infections (Public Health England, 2016). People with a learning disability are more susceptible to constipation due to a number of risk factors including poor diet, limited physical activity, poor bowel movement monitoring and over medication (Dimensions, 2019). Cancer and coronary heart disease rates are a third lower in people with learning disabilities compared to the general population, but this may be because medical staff are missing the signs and not diagnosing those (Carey et al., 2016).

Health inequalities

Article 25 of the United Nations Convention on the Rights of Persons with Disabilities provides that people with a learning disability have a right to good health.

People with a learning disability are more likely to experience a range of physical and mental health inequalities compared to people in the wider population (See Figure 1). Various genetic / biological and individual lifestyle factors need to be considered when addressing these disparities, as well as health promotion, healthcare access, and the socio-economic, cultural and environmental context (Emerson & Hatton, 2014). For example, people with a learning disability are at an increased risk of poverty (Public Health England, 2015b), and they may have difficulties with self-management and a limited understanding of how to keep in good health.

Figure one -
People with a learning disability are:



⁶ NHS Digital (2019)

⁷ NHS Digital (2016)

⁸ British Medical Journal, 2019; Heslop et al, 2013

⁹ Osborn et al, 2012

¹⁰ Blair, 2016

¹¹ Dimensions, 2019

¹² Public Health England, 2015(b)

¹³ Ibid, n.6

¹⁴ Glover & Evison, 2013

¹⁵ Heslop et al, 2013

Barriers to healthcare

Health inequalities can start early in life for people with a learning disability and relate to a range of barriers, including:¹⁶

- Patients not being identified as having a learning disability
- Staff having little understanding about learning disability
- Communication difficulties that mean it takes time to identify that someone is unwell, delaying their access to health care
- Failure to recognise that a person with a learning disability is ill or in pain, for example, by focusing on their disability (diagnostic overshadowing)
- Failure to make a correct diagnosis, or explaining a diagnosis and treatment in a way that's hard to understand
- Lack of accessible information about maintaining good health
- Not enough involvement allowed from carers
- Inadequate aftercare or follow-up care
- Anxiety or a lack of confidence for people with a learning disability
- Lack of joint working from different care providers

▪ Lack of reasonable adjustments

Some people with a learning disability may have difficulties understanding information and expressing feelings of pain or discomfort due to reading, speech or communication problems. Standard medical appointments are often too short to allow them adequate time to communicate with the health professional, while the use of technical language and medical jargon can be challenging.

The use of reasonable adjustments can help improve people's experience in hospital and other healthcare settings. These are big or small changes that people with a learning disability need so they get equal access to healthcare, including improved rates of cancer screenings. Taking the time to explain tests and prepare someone for a procedure can help ensure cancer, or the potential for cancer, is identified early (Dimensions, 2019).

Simple changes in hospital care can make a big difference – better **communication**, more **time** and clearer **information**.



¹⁶ See, for example, <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/health-inequalities> ; & Dimensions, 2019

▪ Lack of training

Diagnostic overshadowing is the term used when health professionals overlook a patient's mental and physical health symptoms and attribute them to their learning disability, so the condition is not diagnosed and treated (Blair, 2016). Staff are not always aware about a patient's capacity to consent to treatment and care when they have a learning disability and may mistake lack of understanding or challenging behaviour as un-cooperativeness.

A skills deficit and lack of learning disability training amongst the healthcare workforce may contribute to misunderstandings about people's health (NHS Improvement, 2018), and could be contributing to avoidable deaths (Glover & Emerson, 2013). Although content on learning disability is included in most undergraduate medicine and nursing courses, teaching varies between courses and not all provide training on reasonable adjustments (Mencap, 2018; Beacock et al., 2015). As a result, some graduates may not be suitably equipped to best support people with a learning disability and their families when they enter professional practice. This is further compounded by limited opportunities for learning disability training in healthcare settings, which when it does exist may not always be available or compulsory for everyone (Mencap, 2018).

Mencap's research suggests that healthcare professionals are not always given the requisite knowledge, skills or resources to help them identify that someone has a learning disability, or to adjust their care accordingly (Mencap, 2018).¹⁷ **Over 500 healthcare professionals** reflected on what might cause healthcare inequalities and contribute to the problem of avoidable deaths:

• **50%** suggested a lack of knowledge around learning disability

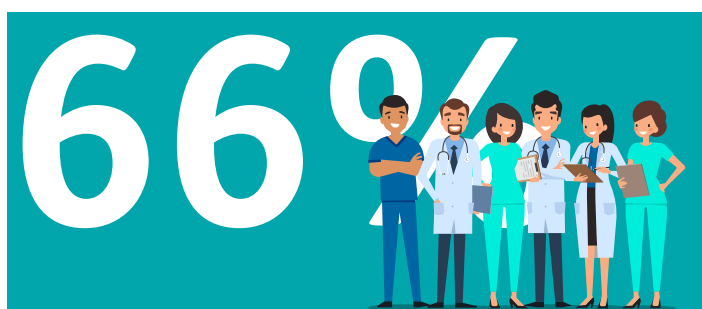
• Almost half (**45%**) thought a lack of training for nursing and medical students

• **42%** thought a lack of continuing professional development training

• Almost two-thirds (**64%**) said a lack of practical resources for themselves and their colleagues

• More than a quarter (**26%**) thought negative attitudes towards people with a learning disability.

It has been suggested that higher education provision must do more to ensure that competence in care for people with learning disabilities is reflected across all health and social care courses, supported by development of a standard competency framework (Beacock et al., 2015). Our research found that healthcare professionals would very much welcome more training on learning disability. Other research suggests that, in addition to reasonable adjustments, GPs would benefit from additional training on prescribing and assessing psychotropic medications¹⁸ to help reduce their over-prescription (Dimensions, 2019).



Two-thirds (66%) of healthcare professionals want more learning disability training (Mencap, 2018).

¹⁷ Conducted by Mencap with health professionals in England.

¹⁸ Psychotropic medication is any medication that changes the way your brain works. Common examples include anti-depressants and anti-psychotics.

▪ Lack of health promotion opportunities

People with a learning disability are less likely to engage in the recommended amount of physical activity, with an estimated **80%** affected.¹⁹

People with a learning disability are not receiving the same level of health promotion opportunities as other members of society despite being at particular risk of ill-health (Hanna-Trainor, Taggart & Cousins, 2016). They often have an unhealthy diet combined with sedentary behaviour and limited physical activity (Gephart & Loman 2013; Phillips & Holland, 2011). It has been suggested that, in addition to government ensuring that weight management groups and other health initiatives are accessible for people with a learning disability, support organisations should invest more time and resources to educate and encourage them in making healthy choices (O’Leary, Taggart & Cousins, 2017). Supported living and day opportunity services are especially well-placed to play a key role in health promotion.



▪ Low uptake of screening

People with a learning disability are **45%** less likely to be screened for cancer.²⁰

Cervical cancer screening is much lower for women with a learning disability (**30%**) than in the general population (**70%**).²¹

Regular cancer screening is a key part of public health to give individuals the best chance of positive treatment outcomes. It is particularly important for people with a learning disability who have less knowledge about checking their own body for any changes and abnormalities that need attention (Dimensions, 2019). They may lack understanding about why screening is so important and not participate due to fear, anxiety and embarrassment (Connolly, 2013). Staff may not always be aware of and use accessible resources to help people with a learning disability understand the need for screening (Taggart, Truesdale-Kennedy & McIlfatrick, 2011).

Several studies (summarised by Emerson et al., 2012) have reported low uptake of screening among people with a learning disability, including mammograms, cervical smear tests, and bowel and prostate screening; as such, they are at increased risk of late diagnosis. Cervical cancer screening rates are especially low, partly due to false assumptions that women with a learning disability are not sexually active and so do not need screened (Dimensions, 2019).

¹⁹ Emerson & Baines, 2010

²⁰ Ibid, n.8 (British Medical Journal)

²¹ Ibid, n. 15 - Cited on Mencap Health Inequalities Research Page

What is Mencap NI doing?

Working in partnership with Health and Social Care Trusts (HSCTs) and other organisations, 'Treat me well' is Mencap NI's campaign for people with a learning disability to get the reasonable adjustments they need in hospitals. This can include using simple language, allowing extra time in appointments, and providing



easy read information. It is also about ensuring health professionals get the information and training they need, particularly at the initial stages of their education as well as when they are actively working in healthcare settings.

As part of 'Treat me well' in Northern Ireland, Mencap NI has developed the following range of activities for people with a learning disability, families / carers and professionals:

▪ 'Know Your Rights' Workshops

We are working with Health and Social Care Trusts to provide 'Know Your Rights' workshops. These are aimed at improving the knowledge and awareness of people with a learning disability and their families, carers and support workers about reasonable adjustments in healthcare.



Key elements of the training include:

- **Hospital Passport** - what it is, and how to use it
- **Health screening** – why it is important, how to access it
- **Disability Discrimination Act**
- **Reasonable adjustments** - what they are, and how to request them
- **Effective engagement with healthcare professionals**
- **How to make a complaint**

▪ Embedding learning disability in training and qualifications for health professionals

Mencap has designed training resources for health professionals. These include facilitated sessions that cover areas such as learning disability awareness, the Mental Capacity Act (NI) 2016 and reasonable adjustments (practical, communication, information). Effectively piloted in England, the training was further enhanced with additional support ideas following its evaluation. The pilot also showed a real appetite and need amongst health professionals for high quality training about learning disability and related law and practice. Through the sessions, we aim to upskill professionals and inspire them to change their practice, particularly by helping them to develop a new empathy for people with a learning disability. Some examples of our practice in Northern Ireland include:

Northern Ireland Ambulance Service



Mencap NI is working with the Northern Ireland Ambulance Service (NIAS) to adapt our national professional training on the healthcare needs of people with a learning disability for inclusion in the NIAS Foundation Degree in Paramedic Practice. We have delivered the first training session in 2019 for clinical and teaching staff, with a further one scheduled.

“Can I just express my thanks for the course delivered last week. I have had some of the best feedback we have ever received. I know the staff found it of immense benefit. It was very informative and will really help to shape how we approach our course delivery”
(NIAS Manager).

We are also training all NIAS Emergency Medical Technicians, who form part of every ambulance crew, in learning disability awareness so that they can better understand and communicate with people who have a learning disability. Reflecting people’s lived experience is a core component of the training, with sessions delivered by Disability Equality Officers from our Personal Support Employment Service who also have a learning disability. We are further developing opportunities for paramedic students to gain practice experience within some of our Supported Living services.

Hospital settings

Co-delivered alongside people with a learning disability, Mencap NI is providing facilitated sessions for some hospital staff in Northern Ireland on a limited basis. We have so far delivered initial training for 45 health professionals on learning disability and reasonable adjustments so that they are more aware and able to provide appropriate support. We are keen to consider other opportunities with Health and Social Care Trusts, such as ‘train the trainer.’

Queen’s University Belfast

Mencap NI is also working with Queen’s University Belfast (QUB) School of Medicine to provide a workshop on learning disability awareness and healthcare needs. Co-delivered alongside a person who has a learning disability, the session will be for second year medical students as part of their module on Communication Skills.

It will include screening of film clips developed with QUB to highlight the importance of communication and use of reasonable adjustments when working with patients who have a learning disability, and their parents/carers or support workers. Two adults with a learning disability, two parents, and a support worker participated in making these.



■ 'Treat me well' champions

Mencap is recruiting 'Treat me well' Learning Disability Champions across the UK, including in Northern Ireland, who will represent the campaign in their hospital. The role involves health professionals receiving tailored information, access to training opportunities and campaigning resources to help them bring about change in their own hospitals. They also have opportunities to meet other hospital staff and people with a learning disability who want change locally and nationally.

■ 'Treat me well' campaign groups

Mencap is developing and co-ordinating a network of people with a learning disability to campaign on 'Treat me well' in groups at a local level throughout the UK. One group has established in Northern Ireland and is aiming to identify local health priorities and campaign for change. We will share the learning across groups and use it to influence wider policy and practice.



■ Health promotion

Mencap NI supports people in our services with their food and nutrition so that they can have a healthy and balanced diet which also reflects their personal choices, cultural and health needs. We help individuals understand the impact their diet can have upon them and work with them to develop shopping lists and menu plans with a focus on healthy options.



Recommendations

- The inclusion of people with a learning disability in the Draft Programme for Government outcome focused on improving the quality of people's healthcare experience.
- The development of Learning Disability Improvement Standards for Northern Ireland, with HSCTs legally required to monitor and improve the way they identify and support the healthcare of people with a learning disability.
- The inclusion of key knowledge, skills and competence-based learning disability training in curricula and related guidance across all aspects of professional healthcare education.
- Mandatory training for health professionals on learning disability awareness, consent, mental capacity and reasonable adjustments, supported by a 'flagging system' in hospitals that lets staff know when a patient has a learning disability. Training should be co-produced and co-delivered by people with a learning disability.
- Routine use of reasonable adjustments, such as allowing extra time in appointments, providing written information in easy read formats, and ensuring communication is accessible for all – for example, not using jargon and speaking clearly; or using communication aids such as picture cards.
- A requirement that healthcare settings should record, implement and audit the provision of reasonable adjustments.
- Better targeting of cancer screening to improve uptake from people with a learning disability, supported by additional training in this area for health professionals and greater awareness of the GP annual health check.
- Consideration by the Health and Social Care Board when developing the Regional Adult Learning Disability Service Model of the issues and recommendations highlighted in Mencap's 'Treat me well' campaign.
- A stronger health promotion focus in services working with people who have a learning disability, in order to best support them in making healthy choices and increasing control over their own health.
- Improved data collection and information about the learning disability population and their health and care across the range of general and specialist healthcare services.

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learning disability**

Mencap Northern Ireland

Mencap Centre

5 School Road

Newtownbreda

Belfast

BT8 6BT

028 9069 1351

mencapni@mencap.org.uk

www.mencap.org.uk/ni

Northern Ireland Helpline

0808 808 111

helpline.ni@mencap.org.uk