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Preventing people with a learning disability from dying too young

Jessica Morris and Sophie Julian

nuffieldtrust

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Key findings

People with a learning disability require more, and different, forms of support to ensure they stay in good health. But there are profound disparities in access to health services for this group compared with the rest of the population.

This report looks at a set of five key health care services and functions in England that people with a learning disability should have access to, to understand how well these services are working for them and whether people are able to get the support they need.

Looking across obesity, cancer screening, mental health, annual health checks and early diagnosis, this is the first report of its kind to bring together evidence across these key aspects of prevention for this group of people.

We found clear evidence that people with a learning disability are not always able to get equitable preventive support:

- People with a learning disability are more likely than the rest of the population to be obese, particularly in teenage years and in young adulthood.

- Over the past five years, there has consistently been a 15 percentage point difference in breast cancer screening rates and a 36 percentage point difference in cervical cancer screening rates between people with a learning disability and the rest of the population.

- Cancer is often diagnosed at a later stage for people with a learning disability than for the general population, and these late diagnoses are sadly often made during emergency presentation at hospital. The prevalence of cancer appears lower in people with a learning disability aged 55 and over than in the rest of the population of the same age, which illustrates the extent of missed cancer diagnoses for people with a learning disability.

- Only approximately 26% of people with a learning disability in England are on the learning disability register. This is preventing people from accessing annual health checks and Covid-19 and flu vaccinations.

- Despite a higher prevalence of mental health problems in people with a learning disability, access to effective mental health treatments is often poor. People with a learning disability are less likely to be referred for talking therapies and more likely to be prescribed psychotropic medicines for psychosis, depression and epilepsy than other people. More than 30,000 adults with a learning disability are taking psychotropic medicines even though they do not have a diagnosis of the conditions the medicines are prescribed for.

Vital opportunities for preventive forms of support that could help to avoid health problems from occurring among people with a learning disability are too often being missed as a result of disjointed care, and information and communication that are not well suited to the people they are being provided to.

We recommend that:

- Although a higher proportion of people with a learning disability have been getting an annual health check in recent years than before, the quality of these checks is variable and needs to be improved. **NHS England should conduct a national review of the quality of annual health checks for people with a learning disability**. They could make use of a pre-existing Public Health England audit tool to make an assessment of what is happening locally, to identify good practice and geographical areas needing extra support, and to encourage GP practices to improve.

- **Integrated care boards should use local data to review the number of people on GP learning disability registers and organise targeted information campaigns to encourage people to join the register**. Ensuring more people receive an annual health check is reliant on far higher numbers being on the register – only about one in four people with a learning disability are currently on the register. Some demographic groups, such as people from minority ethnic backgrounds, may also be underrepresented on registers.

- **The number of health and social care staff working in care coordination roles should be increased to improve care coordination for people with a learning disability**. Key worker, learning disability liaison nursing and health facilitator roles should be expanded, with a specific remit to ensure more joined-up and better-communicated care for people with a learning disability.

- **All providers of NHS and publicly funded social care should deliver training to staff in the use of the 'Reasonable Adjustment Digital Flag'**. This should ensure that staff understand how to record and share details of reasonable adjustments that people with a disability or impairment require to access services. Training should be used to improve awareness of the range of adjustments that can be provided, such as longer appointment times, and the flag should be rolled out across all services.

- **All local authorities should provide weight management programmes specifically tailored for people with a learning disability**. Mainstream weight management programmes are often inaccessible for people with a learning disability, and evidence is emerging that dietary advice, physical activity and behaviour change can be effectively adapted. The success of existing programmes should be assessed, adapted and rolled out across all local authorities.

1 Introduction

Prevention is better than cure, and it enables people to live longer, healthier lives.

Making healthier lifestyle choices, treating illness early on and reducing the severity of physical and mental health problems are important for everyone. But profound inequalities persist in people's ability to access timely and effective health and care services. Certain groups in society, including people with a learning disability, require more support than others to help them stay in good health and ensure that services are as accessible as they are for everyone else. Yet improvements are not being made fast enough and overall care falls short of what is being delivered to the general population.

Around 1.3 million people in England have a learning disability[1] – that is more than one in 44 people. Having a learning disability affects the way a person learns new things, throughout their life, and the type of learning disability they have will determine how much care and support they will need. People with severe or profound learning disabilities will have great trouble communicating, and many will have additional long-term conditions or impairments, resulting in complex health needs that require support from multiple different services.

People with a learning disability have higher levels of premature death compared with the rest of the population. The Learning from Lives and Deaths (LeDeR) programme, funded by NHS England and NHS Improvement, publishes an annual report each year summarising the lives and deaths of people with a learning disability and autistic people who died in England. Its 2022 report found that of deaths reported to the programme, the median age

1 Mencap (no date) 'How common is a learning disability?'. www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability. Accessed 11 January 2024.

at death for both males and females with a learning disability was 62.9 years.[2] This is an improvement on 2018 when the median age at death was 61.8 years, but is still staggeringly 20 years younger than the median age at death for the general population. Further, 42% of deaths of people with a learning disability that LeDeR reviewed were classified as avoidable, compared with 22% of deaths for the general population.

Helping people with a learning disability live longer in good health involves much more than influencing their lifestyle choices. Behaviour change, such as encouraging people to eat healthier foods and exercise, is complicated and complex. Wider socioeconomic factors, such as people with a learning disability being more likely to live in poverty and lack social networks, are linked to poor health and are much harder to influence. To prevent avoidable deaths for people with a learning disability, it is important to enable them to access preventive health care services, to train carers and staff to spot signs and symptoms early and to avoid thinking that a sign or symptom is just a part of an individual's learning disability (called 'diagnostic overshadowing') and therefore it is not addressed or investigated.

The NHS has committed to tackling the causes of ill health and preventable deaths in people with a learning disability.[3,4] The stark statistics presented above suggest that much work needs to be done to improve the picture. This report takes a closer look at what is currently happening to close the gap in health care inequalities, the barriers and challenges to making improvements, and how we could go further to improve the healthy lifespan of this group.

2 King's College London (no date) 'Learning from Lives and Deaths – people with a learning disability and autistic people (LeDeR)'. www.kcl.ac.uk/research/leder. Accessed 11 January 2024.

3 NHS (2019) *The NHS Long Term Plan*. NHS. www.longtermplan.nhs.uk. Accessed 11 January 2024.

4 NHS England (no date) 'Core20PLUS5 (adults) – an approach to reducing healthcare inequalities'. www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/core20plus5. Accessed 11 January 2024.

Box 1: What is a learning disability?

The Department of Health and Social Care defines a learning disability as 'a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood'.[5]

There are different degrees of learning disability, from mild to moderate, severe or profound. A learning disability is a lifelong condition that cannot be cured. Although a learning disability starts in childhood, some people are only diagnosed with it when they are an adult.

A learning disability is not the same as a learning difficulty, which is a reduced ability for a specific form of learning.[6] Learning difficulties encompass a broader range of conditions than learning disabilities, including dyslexia and attention deficit hyperactivity disorder (ADHD). A person with a learning disability may also have one or more learning difficulties. Some people who fit the definition of having a learning disability prefer to talk about themselves as a person who has learning difficulties.

There are also a number of impairments and genetic differences that may involve some type of learning disability, such as Down's syndrome, autism and cerebral palsy.

5 Department of Health and Social Care (2001) *Valuing People: A new strategy for learning disability for the 21st century*. GOV.UK. www.gov.uk/government/publications/valuing-people-a-new-strategy-for-learning-disability-for-the-21st-century. Accessed 11 January 2024.

6 Public Health England (2023) 'Learning disability – applying All Our Health'. www.gov.uk/government/publications/learning-disability-applying-all-our-health/learning-disabilities-applying-all-our-health#:~:text=Learning%20disability%2C%20human%20rights%20and,and%20respect%2C%20as%20anyone%20else. Accessed 11 January 2024.

Support and service provision

The amount of support required depends on the degree of learning disability. People with a mild learning disability can manage most everyday tasks with minimal support. People with a moderate learning disability might need considerable support to live and work independently. People with severe or profound learning disabilities have very limited language skills, may have complex health needs, and typically need support with every aspect of daily living.

To make significant improvements to health inequalities for people with a learning disability, it is necessary to consider both interventions that aim to prevent ill health, such as the learning disability annual health check, as well as ways to enable people to access high-quality health and care services that appropriately diagnose and treat illnesses.

Preventive health care encompasses a set of services that aim to prevent illness and detect disease early. It can include:

- primary prevention (measures to prevent a disease from ever occurring)
- secondary prevention (which detects and treats disease early before symptoms occur)
- tertiary prevention (which reduces the severity of symptomatic disease through rehabilitation and treatment).

Structure of this report and methodology

This report explores preventive health care for people with a learning disability and their ability to access effective health and care services across **five** key areas:

- prevention of obesity
- cancer screening
- annual health checks

- addressing mental health problems
- early diagnosis.

We selected the five topics based on the availability of literature and data, the publication of related policy guidance and coverage across different aspects of prevention and access to health care. The report does not therefore cover every possible topic, but is the first of its kind to bring together evidence across some major aspects of prevention for people with a learning disability, who experience significant barriers in accessing health care in the same way as the general population.

For this research we carried out a rapid literature search, reviewed policy and analysed published data relating to preventive health care and access to effective health and care services for people with a learning disability. We also held a roundtable with key stakeholders to inform this report, including people with lived experience.

For each of the five topics in this report, we summarise the evidence we found and discuss key barriers and challenges in relation to making improvements. Looking across the five topics combined, we then detail some current policy improvement initiatives before setting out our recommendations for further improving the health of this population group. We conclude this report with a discussion.

Legal and policy landscape

Before we move on to consider the five key areas, it is important to be aware of the laws and policies in place for people with a learning disability, as they cut across many of the themes discussed in this report. See the timeline below for some key moments that help set the scene.

1995 Disability Discrimination Act. This outlawed discrimination against disabled people in various areas of life, including access to goods, services and employment, and set out rights to reasonable adjustments to increase inclusion and access.

1998 Human Rights Act. This is the main law protecting human rights in the UK. It gives people with a learning disability the right to be treated and live life with the same rights, choices and opportunities as everyone else.

2001 *Valuing People*. This White Paper included government pledges to ensure that people with a learning disability have the same right of access to health services as everyone else.

2005 Mental Capacity Act. This assumes that a person has the capacity to make decisions themselves unless it is proved otherwise, and sets out rights to support people to make their own decisions wherever possible. If a person lacks capacity, a decision must be made in their 'best interests'. The Mental Capacity Act applies to people aged 16 and over and is time and decision specific.

2007 *Death by Indifference*. This is a report by Mencap that called on the government to make the NHS safe for people with a learning disability, evidencing institutional discrimination leading to avoidable deaths.

2009 *Valuing People Now*. This is the government's three-year strategy that reiterated the objectives of the 2001 *Valuing People* White Paper to improve outcomes for people with a learning disability.

2010 Equality Act. This legally protects people from discrimination in the workplace and in wider society. It replaced previous anti-discrimination

laws, strengthened legislation in some areas and established the Equality and Human Rights Commission.

2013 Confidential Inquiry into Premature Deaths of People with Learning Disabilities. This investigated the avoidable or premature deaths of people with learning disabilities across the South West of England and made recommendations to prevent future deaths.

2014 Care Act. This strengthened the rights of people with a learning disability and their carers to assessment and support for care needs, as well as setting national thresholds for eligibility.

2015 Learning Disabilities Mortality Review (LeDeR) programme. Now known as **Learning from Lives and Deaths**, this was established following a pilot that the Confidential Inquiry undertook to learn from the lives and deaths of people with a learning disability across England, aiming to improve care, reduce health inequalities and prevent avoidable deaths for people with a learning disability and autistic people.

2015 Building the Right Support. This is a national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display challenging behaviour, including those with a mental health condition.

2016 Accessible Information Standard. This aims to make sure that health and care services give people with a learning disability or sensory loss information in a way they can understand. All organisations that provide NHS care or publicly funded social care are legally required to follow the standard.

2017 Health Charter for Social Care Providers. This is aimed at social care providers and staff and provides guidance to help people with a learning disability get better access to medical services to improve their health.

2019 The NHS Long Term Plan. This sets out NHS commitments for improving the health of people with a learning disability.

2021 Core20PLUS5. This is NHS England's approach to reducing health care inequalities. People with a learning disability and autistic people are one of the 'PLUS' groups that should be considered when looking at health inequalities.

2022 *The Government's 2022–23 Mandate to NHS England*. This focuses on improving access and addressing the impact of Covid-19 on services for people with a learning disability, improving the delivery of learning disability annual health checks and reducing the reliance on specialist inpatient care.

2022 *Building the Right Support for People with a Learning Disability and Autistic People*. This is a new plan from the Department of Health and Social Care focusing on six areas to develop community services and reduce reliance on mental health inpatient care.

2022 Health and Care Act. This introduced a requirement that all regulated health and social care service providers ensure their staff receive learning disability and autism training that is appropriate to their role.

2023 Learning from Lives and Deaths (LeDeR) 2022 report. This is the latest report from the LeDeR programme, which summarises the lives and deaths of people with a learning disability and autistic people who died in England in 2022.

2 Prevention of obesity

Obesity is a major risk factor for a number of chronic diseases, including cardiovascular disease (such as heart failure and stroke), diabetes and cancer.[7] It is associated with stigma and bullying in childhood and poor mental health in adults.[8] Obesity is largely preventable through healthy eating and engaging in regular physical activity. Evidence shows that obese children and adolescents are more likely to become obese adults.[9]

Data collected from 55% of patients registered at GP practices in England (see the Appendix for more information) show that, in 2022–23, a higher proportion of people with a learning disability who had a Body Mass Index (BMI) assessment in the previous 15 months were obese (37%) compared with people without a learning disability (32%).[10] The difference was particularly stark for young adults, where the prevalence of obesity in people with a learning disability was double that of other people (see Figure 1). Among people with a learning disability, women have a much higher prevalence of obesity (44% in 2022–23) compared with men (32%).

7 World Health Organization (2023) 'Obesity'. www.who.int/health-topics/obesity#tab=tab_2. Accessed 11 January 2024.

8 Public Health England (no date) *Health Inequalities: Overweight, obesity and underweight*. Public Health England. https://fingertips.phe.org.uk/documents/Health_inequalities_Overweight_obesity_underweight.pdf.

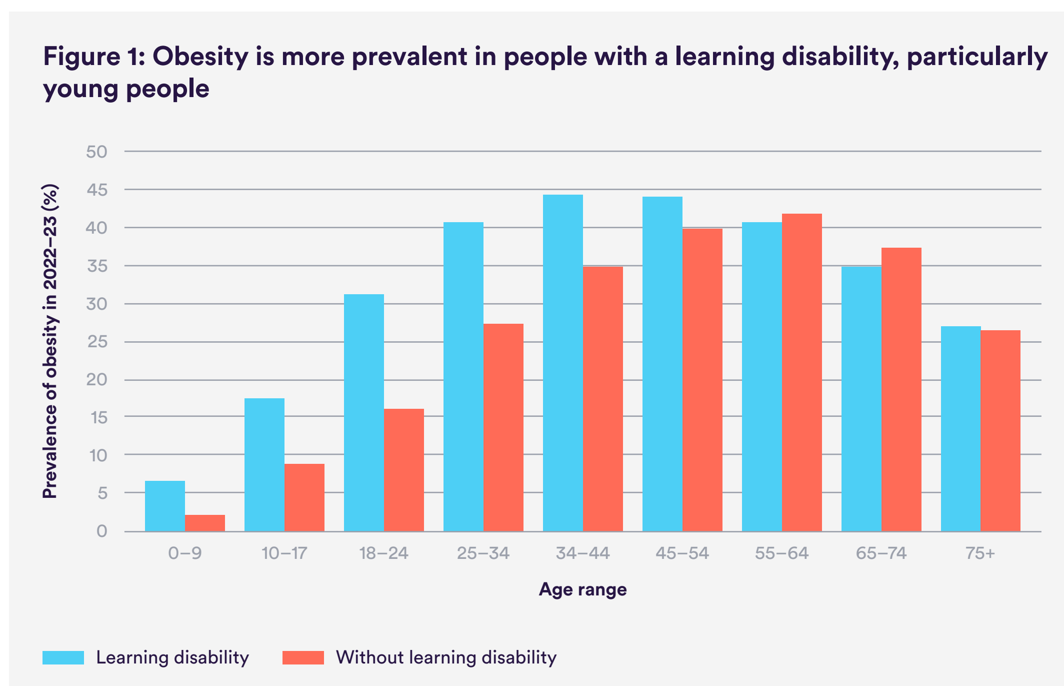
9 Simmonds M, Llewellyn A, Owen CG and Woolacott N (2016) 'Predicting adult obesity from childhood obesity: a systematic review and meta-analysis', *Obesity Reviews* 17(2), 95–107.

10 NHS Digital (2023) 'Health and care of people with learning disabilities, experimental statistics 2022 to 2023'. https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2022-to-2023. Accessed 11 January 2024.

The same dataset shows that people with a learning disability have higher rates of conditions that are associated with being overweight. For example, in 2022–23, 7.5% of people with a learning disability had an active diagnosis of type 2 diabetes compared with 5.1% of people without a learning disability.[10]

The main reasons for the higher obesity rate among people with a learning disability are poorly balanced diets and very low levels of physical activity.[11] Meanwhile, some people with a learning disability particularly struggle with weight control due to conditions such as Prader-Willi Syndrome or because of medications they take. But whatever the underlying cause, eating healthily and taking part in physical activity are the two most important ways to achieve and maintain a healthy weight.

Figure 1: Obesity is more prevalent in people with a learning disability, particularly young people



Note: Figure 1 shows the percentage of people with a learning disability whose most recent BMI classification in the previous 15 months was obese, compared with a control cohort.

Source: NHS Digital (2023) 'Health and care of people with learning disabilities, experimental statistics 2022 to 2023'[10]

11 Public Health England (2020) 'Obesity and weight management for people with learning disabilities: guidance'. www.gov.uk/government/publications/obesity-weight-management-and-people-with-learning-disabilities/obesity-and-weight-management-for-people-with-learning-disabilities-guidance. Accessed 11 January 2024.

Barriers and challenges

Prevention of obesity can include preventing people from gaining weight in the first place, as well as enabling overweight and obese people to lose weight. As Figure 1 shows, people with a learning disability are more likely to become obese when they are teenagers and young adults compared with the general population. So, clearly, obesity needs to be reduced and prevented in these age groups in particular.

Yet there is a major underlying society-level challenge in preventing obesity in people with a learning disability, in that they tend to be of lower socioeconomic status. Both obesity and physical inactivity are higher in the more deprived areas of England, and research shows that the increased risk of obesity among people with a learning disability relates to their poorer living conditions.[12] In 2021/22, only 4.8% of people with a learning disability receiving long-term social care support were in paid employment in England.[13] Financial pressures, coupled with a higher chance of experiencing poor mental health, abuse and other negative life events earlier on in life,[14] can lead to a reliance on unhealthy foods that are cheaper and easily accessible.

The majority of studies and policy documents focus on ways to support people with a learning disability to lose weight. There is currently a lack of evidence and guidance about ways to prevent people with a learning disability from gaining weight to begin with. As mentioned previously, some people with a learning disability may struggle in particular with weight control because of certain conditions. Given the level of inequality and the fact that obesity is one of the major risk factors for disease, there is a significant evidence gap that needs to be filled.

12 Public Health England (no date) 'Learning disability profiles'. *Health Inequalities: Overweight, obesity and underweight*. https://fingertips.phe.org.uk/profile/learning-disabilities. Accessed 11 January 2024.

13 NHS Digital (2022) 'Measures from the Adult Social Care Outcomes Framework, England, 2021–22'. https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-outcomes-framework-ascof/2021-22. Accessed 11 January 2024.

14 Mencap (no date) 'Mental health'. www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/mental-health. Accessed 11 January 2024.

Public Health England's guidance on obesity and weight management for people with a learning disability acknowledges that helping people with a learning disability lose weight can be more complex than for the general population.[11] Many adults with a learning disability receive no social care support, may have limited cooking skills and may lack knowledge about good nutrition; in 2019/20, only around 153,000 adults with a learning disability received long-term social care support out of a population of around 1.3 million people with a learning disability.[15] For people with a learning disability who rely on family carers or paid staff for nutritional provision, a lack of motivational or practical support can be a major barrier to healthy living. Some carers and staff lack knowledge about buying and cooking healthy food and there is a need for training and accessible information.[16] They may also make unhealthy choices themselves, which in turn means they can become unhealthy role models.

There can be a tension between capacity and choice, with carers and staff struggling to make best-interest decisions and influence food choices.[17] This can stem from a lack of adherence to or understanding of the Mental Capacity Act 2005, as well as inadequate partnership working with families. The Mental Capacity Act assumes that a person has capacity unless proven otherwise. Encouraging people to make independent choices is important but they need to be informed choices. In this case, the person needs to be able to demonstrate that they understand the relationship between diet, weight and health. People with a learning disability can be left to make poor decisions and

15 Mencap (no date) 'Social care – research and statistics'. www.mencap.org.uk/learning-disability-explained/research-and-statistics/social-care-research-and-statistics#:~:text=Over%201%20million%20adults%20in%20England%20received%20short%2Dterm%20or,main%20reason%20they%20needed%20support. Accessed 11 January 2024.

16 Doherty AJ, Jones SP, Chauhan U and Gibson J (2020) 'Eating well, living well and weight management: a co-produced semi-qualitative study of barriers and facilitators experienced by adults with intellectual disabilities', *Journal of Intellectual Disabilities* 24(2), 158–76.

17 British Dietetic Association (2021) 'Weight management for people with learning disabilities'. www.bda.uk.com/resource/weight-management-for-people-with-learning-disabilities.html?fbclid=IwAR0YsAOfrHsZoxZbqoud_hbD-1ZpMGanM3T7HkLCtXHgBqEr3cLng1qPMxM. Accessed 11 January 2024.

eat unhealthily if they do not have access to good support or do not have their capacity regularly assessed.

Many mainstream weight-loss support programmes and community exercise groups are inaccessible for people with a learning disability.[16] In addition, most promotional health materials, including healthy recipes and exercise tutorials, require literacy skills and are not tailored to the individual. There is a vast amount of information online, which can be hard to navigate, but also, people with a learning disability are more likely than others to face digital exclusion and so might not be able to access websites or apps at all.[18]

"Almost every day there is a news story about what to eat and what not to eat, and I find it very confusing. There is too much information and I don't know what source to look at."
(Person with lived experience)

There are also practical barriers to eating healthily and taking part in exercise, such as time pressure, transport issues and financial constraints.[11] Accessing supermarkets, gyms and sports centres may require carer or staff support, and depending on where the person lives may be difficult to get to and expensive.

Access to mainstream weight management groups, such as Slimming World, is often dependent on carer engagement.[19] These groups usually target individual behaviour change, but some people with a learning disability do not have the autonomy to make changes to their environment enabling them to make healthier food choices. People with a learning disability can also be subject to stigma and discrimination, which makes them less likely

18 Good Things Foundation (2022) *Digital Lifeline Fund: Evaluation summary*. GOV.UK. https://assets.publishing.service.gov.uk/media/6239c28fd3bf7f6abf0c7640/Good_Things_Foundation_Digital_Lifeline_Evaluation_Report_March_2022_v3_Accessible.pdf.

19 Croot L, Rimmer M, Salway S, Hatton C, Dowse E, Lavin J, Bennett SE, Harris J and O'Cathain A (2018) 'Adjusting a mainstream weight management intervention for people with intellectual disabilities: a user centred approach', *International Journal for Equity in Health* 17, 159.

to participate in mainstream groups that are not tailored to people with a learning disability.[20]

Another major barrier is a lack of understanding among people with a learning disability of the health risks of being overweight. Many people with a learning disability need additional support to sustain their motivation to eat healthily and take part in physical activity. Evidence shows that, for people who have access to support, a multidisciplinary and individualised approach is beneficial, with effective communication between family carers and paid staff to ensure consistency.[11]

20 Scior K and Werner S (2015) *Changing Attitudes to Learning Disability: A review of the evidence*. Mencap. www.mencap.org.uk/sites/default/files/2016-08/Attitudes_Changing_Report.pdf.

3 Cancer screening

Cancer screening is an example of secondary prevention, as it can detect signs of cancer in people before any symptoms appear. Early detection is important because it increases the chances of successful treatment and survival. In England, there are national cancer screening programmes for cervical, breast and bowel cancer.[21]

Ensuring that screening is accessible to people with a learning disability is especially important as they are more likely to encounter difficulties recognising and communicating symptoms of possible cancer, which can increase the risk of delayed diagnosis.[22] Also, people with a learning disability have been shown to have a higher risk of developing bowel cancer than the general population,[23] and the 2022 LeDeR report found that bowel cancer accounted for a higher percentage of cancer deaths among this population group.[2]

21 NHS England (no date) 'Screening and earlier diagnosis'. www.england.nhs.uk/cancer/early-diagnosis/screening-and-earlier-diagnosis. Accessed 11 January 2024.

22 Public Health England (no date) 'Learning disability profiles'. *Health Inequalities: Breast cancer*. https://fingertips.phe.org.uk/profile/learning-disabilities. Accessed 11 January 2024.

23 Gray J (2018) 'Increasing participation of people with learning disabilities in bowel screening', *British Journal of Nursing* 27(5), 250–3. https://pubmed.ncbi.nlm.nih.gov/29517317. Accessed 11 January 2024.

Box 2: Who is eligible for cancer screening?

The NHS in England offers cervical cancer screening to women aged 25–64. Screening is offered every three years to women aged 25–49 and every five years to those aged 50–64.

Breast cancer screening is offered to women aged 50–70 every three years. Women are eligible for this screening before the age of 50 if they have a very high risk of developing breast cancer.

Bowel cancer screening is offered to men and women aged 60–74, who are sent a home testing kit every two years. The Faecal Immunochemical Test (FIT) looks for blood in a small stool sample. The NHS Long Term Plan set a commitment to lower the bowel screening age from 60 to 50, and the NHS is gradually implementing this change.

People with a learning disability have a significantly lower level of participation in NHS cancer screening programmes than those without a learning disability. In 2022–23, just over half of people with a learning disability who were eligible for bowel cancer screening had the test, compared with two-thirds of eligible people without a learning disability (see Figure 2 and the Appendix for more information about NHS Digital's statistics).[10] Similarly, 47% of eligible women with a learning disability had a breast cancer screen, compared with 61% of those without a learning disability. The gap was even larger for cervical cancer screening, with corresponding figures of 31% and 66%.

Looking at the gap in cancer screening participation over the past five years, it has remained fairly static.[10] There has consistently been around a 15 percentage point difference in breast cancer screening rates and a 36 percentage point difference in cervical cancer screening rates between people with a learning disability and those without.

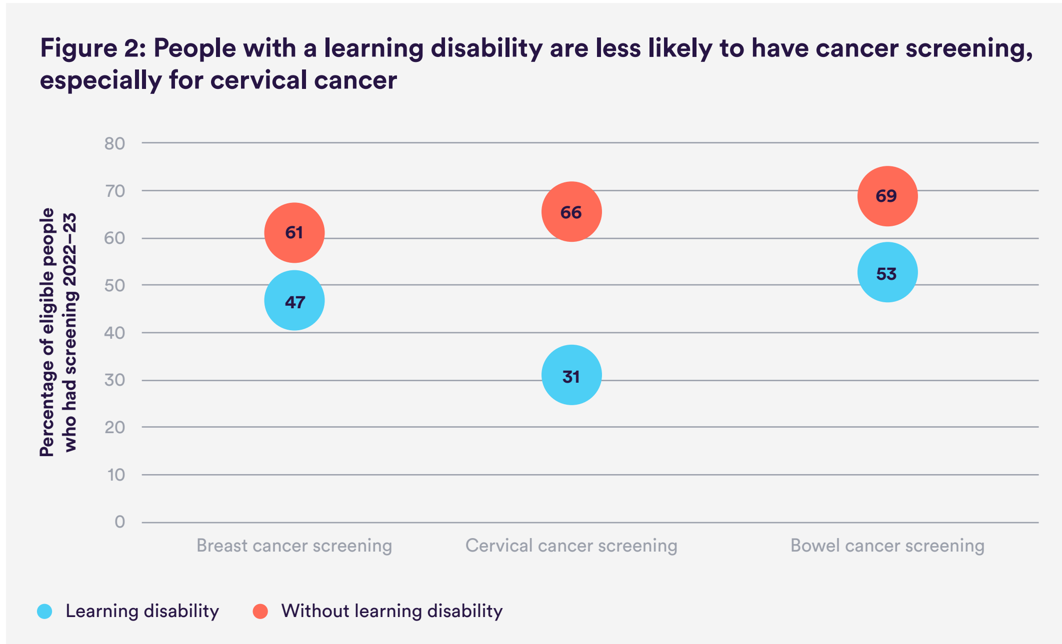


Figure 2: People with a learning disability are less likely to have cancer screening, especially for cervical cancer

Source: NHS Digital (2023) 'Health and care of people with learning disabilities, experimental statistics 2022 to 2023'[10]

Barriers and challenges

Enabling people with a learning disability to access the three national cancer screening programmes can be more difficult than for the general population. Bowel cancer screening requires individuals to produce a stool sample, use a home test kit and send it to a lab, which many people with a learning disability would need support to do. Cervical cancer screening is difficult for people whose capacity to understand and consent to the examination is limited – for people who lack the capacity to consent, a decision will need to be made in the person's best interests. And breast cancer screening often requires specialist local services to liaise between GP practices and screening services to ensure the woman's needs are met.

The lack of progress on cancer screening uptake suggests that barriers to screening are widespread and warrant attention. One major practical barrier is the lack of awareness and routine use of accessible materials, such as easy-read invitations to attend screening appointments. This is largely because of an incomplete GP learning disability register (see Box 3 on pages 25–26), which is designed to identify people who have a learning disability to

enable them to access support and ensure that reasonable adjustments are made. With cancer screening, reasonable adjustments could include longer appointments or pre-visits to look at the equipment, but these service adaptations are not always happening when needed.

Cancer screening providers and commissioners should be aware of the legal duty[24] to make reasonable adjustments for people with a learning disability, and to follow the 'Accessible Information Standard'. Acknowledging that screening inequalities exist, in 2021, Public Health England published new guidance for health professionals to help people with a learning disability better understand and access screening.[25] This explains the importance of supporting people to make an informed choice, contains links to easy-read guides and suggests interventions for how to improve access and engage primary care. There was also previous guidance published in 2016 on making reasonable adjustments to enable people with a learning disability to access cancer screening.[26]

Further practical barriers to cancer screening uptake can include:

- a lack of available carers to support attendance at cancer screening appointments
- difficulties in accessing transport
- difficulty using appointment systems
- mobility issues.[21]

24 Public Health England (2020) 'Reasonable adjustments: a legal duty'. www.gov.uk/government/publications/reasonable-adjustments-a-legal-duty/reasonable-adjustments-a-legal-duty. Accessed 11 January 2024.

25 Public Health England (2021) 'Population screening: reducing inequalities for people with a learning disability, autism or both'. www.gov.uk/government/publications/population-screening-supporting-people-with-learning-disabilities/population-screening-reducing-inequalities-for-people-with-a-learning-disability-autism-or-both. Accessed 11 January 2024.

26 Public Health England (2016) 'Cancer screening: making reasonable adjustments'. www.gov.uk/government/publications/cancer-screening-and-people-with-learning-disabilities/cancer-screening-making-reasonable-adjustments. Accessed 11 January 2024.

In particular, the roundtable with key stakeholders that we hosted to inform this report identified a lack of specialist chairs that can enable people who use moulded wheelchairs, or those who are unable to manage their posture, to be screened for breast cancer.

"There is a concern that mammography machines are inaccessible to some people with a learning disability who have additional physical needs because of a lack of specialist chairs. This may be contributing to their lower participation in breast cancer screening."
(Learning disabilities and autism liaison and health facilitation worker)

Communication barriers are also a key challenge, with screening being a complex issue that often requires discussion about sensitive topics, such as the female reproductive system. These conversations are needed to enable people to make an informed choice.[21] There are also biases such as a general assumption of a lack of sexual activity among people with a learning disability, which in the past has been used as a reason to deny women access to cervical screening.[27]

A lack of knowledge among professionals and family carers of how to support people with a learning disability to access cancer screening can also be a barrier.[21] There is a general lack of health promotion, training and information for support workers and family members, in relation to cancer prevention and detecting early signs of cancer. Also, staff and family carers may be concerned about invasive investigations that could cause distress and so participation may not be seen as a priority. For bowel screening, staff and family members may struggle with supporting the collection of stool samples. Further, despite evidence that learning disability nurses can improve the uptake of screening through their provision and coordination of support,[23] their number has

27 Heslop P, Blair P, Fleming P, Hoghton M, Marriott A and Russ L (2013) *Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD): Final report.* Norah Fry Research Centre. www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf.

decreased by 42% since 2010 (see Figure 7 in Chapter 7, and also the Appendix for how we calculated the decrease).[28]

Finally, the knowledge and attitudes of people with a learning disability can be barriers too. They may have little understanding of cancer and its signs and symptoms, and they may not know what cancer screening involves. Fear, anxiety and embarrassment can be felt, particularly in relation to cervical cancer screening, which is more invasive than other forms of screening. This can lead to a reluctance to attend screening, particularly if the benefits of the screening programme are not properly understood. Health promotion aimed at encouraging people with a learning disability to attend screening is needed, together with training and information for professionals and family carers to enable them to provide support.

28 NHS Digital, 'NHS Workforce Statistics, staff group, care setting and level'. https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics. Accessed 11 January 2024.

4 Annual health checks

Learning disability annual health checks[29] are available to people aged 14 or over who are on their GP practice's learning disability register (see Box 3). Health professionals carry them out and GP practices administer them. The annual health check features in the NHS Long Term Plan, with the ambition that by 2023/24 at least 75% of those eligible will have a health check each year.[3]

Box 3: What is the learning disability register?

GP practices have a register of their patients known to have a learning disability. Registers are open to people of all ages. They have been developed through clinical diagnoses and information gathered from learning disability teams and social care services. The Quality and Outcomes Framework (QOF) incentivises the maintenance of a learning disability register.[30] The register puts a specific code on an individual's medical record, indicating that they have a learning disability.[31]

Joining the register offers many benefits for people with a learning disability, including being invited for an annual health check and being able to access free Covid-19 and flu vaccinations.

29 NHS England (no date) 'Annual health checks'. www.england.nhs.uk/learning-disabilities/improving-health/annual-health-checks. Accessed 12 January 2024.

30 Shemtob L, Ramanathan R and Courtenay K (2021) 'Learning disability registers: known unknowns and unknown unknowns', *British Journal of General Practice* 71(705), 153–4. www.ncbi.nlm.nih.gov/pmc/articles/PMC8007252. Accessed 12 January.

31 Mencap (no date) 'Everything you need to know about the learning disability register'. www.mencap.org.uk/advice-and-support/health/learning-disability-register. Accessed 12 January 2024.

However, only approximately 26% of people with a learning disability in England are on the register (see the Appendix for how we reached this estimation). This proportion is likely to be even lower for people from minority ethnic backgrounds.[32]

Recent guidance from NHS England aiming to improve the identification of people with a learning disability has provided GP practices with a set of diagnostic codes that should automatically place some patients on the learning disability register, and other codes that may suggest the presence of a learning disability (see Chapter 7 for more information).[33]

The purpose of the annual health check is to identify unmet health needs among people with a learning disability. The check can help to detect health problems early, make sure that current treatments are appropriate and familiarise patients with their GP practice so they know how to use it when the need arises.[34] Evidence suggests that the checks can be beneficial for preventing disease occurring in the first place.[35] Research also indicates that

32 NHS Race & Health Observatory (2023) *We Deserve Better: Ethnic minorities with a learning disability and access to healthcare*. NHS Race & Health Observatory. www.nhsrho.org/research/review-into-factors-that-contribute-towards-inequalities-in-health-outcomes-faced-by-those-with-a-learning-disability-from-a-minority-ethnic-community. Accessed 12 January 2024.

33 NHS England and NHS Improvement (2019) *Improving Identification of People with a Learning Disability: Guidance for general practice*. NHS England. www.england.nhs.uk/wp-content/uploads/2019/10/improving-identification-of-people-with-a-learning-disability-guidance-for-general-practice.pdf.

34 Public Health England (2016) 'Annual health checks and people with learning disabilities'. www.gov.uk/government/publications/annual-health-checks-and-people-with-learning-disabilities/annual-health-checks-and-people-with-learning-disabilities. Accessed 12 January 2024.

35 Kennedy N, Kennedy J, Kerr M, Dredge S and Brophy S (2022) 'Health checks for adults with intellectual disability and association with survival rates: a linked electronic records matched cohort study in Wales, UK', *BMJ Open* 12(4), e049441.

they can reduce potentially preventable emergency admissions.[36] The checks are considered an important reasonable adjustment to primary care services.

The health check should include a physical check-up, including weight, height and blood pressure, and patients should be asked if they have any health concerns or worries relating to different bodily systems. The health professional should ask about health problems that can be more common in people with a learning disability, such as epilepsy or constipation. Reasonable adjustments should be considered and there should be a review of medications that the patient is currently taking. The health check should also include discussions about immunisation, screening and health promotion, with advice given about diet, exercise, smoking and more. Guidelines from the National Institute of Health and Care Excellence (NICE) state that the health check should also review the coordination of care, family carer needs and how a person might communicate pain or distress.[37] In 2017, NHS England released an electronic clinical template for annual health checks, offering a systematic approach for the check that can be accessed on GP systems.[38] There is also a step-by-step guide to health checks for people with a learning disability, published by the Royal College of General Practitioners.[39]

36 Carey IM, Hosking FJ, Harris T, DeWilde S, Beighton C, Shah SM and Cook DG (2017) 'Do health checks for adults with intellectual disability reduce emergency hospital admissions? Evaluation of a natural experiment', *Journal of Epidemiology and Community Health* 71(1), 52–8

37 National Institute for Health and Care Excellence (2019) 'Quality statement 4: annual health check'. www.nice.org.uk/guidance/qs187/chapter/quality-statement-4-annual-health-check#:~:text=Annual%20health%20check%20for%20people%20with%20a%20learning%20disability&text=A%20collaborative%20review%20of%20physical,A%20specific%20syndrome%20check. Accessed 12 January 2024. https://www.nice.org.uk/guidance/qs187/chapter/quality-statement-4-annual-health-check

38 NHS England (2017) *A Summary and Overview of the Learning Disability Annual Health Check Electronic Clinical Template*. NHS England. www.england.nhs.uk/wp-content/uploads/2017/05/nat-elec-health-check-ld-clinical-template.pdf.

39 Royal College of General Practitioners (2010) *Step-by-Step Guide to Health Checks for People with a Learning Disability*. Royal College of General Practitioners. https://dimensions-uk.org/wp-content/uploads/GP-Health-check-Step-by-Step-Guide-to-LDAHCs.pdf.

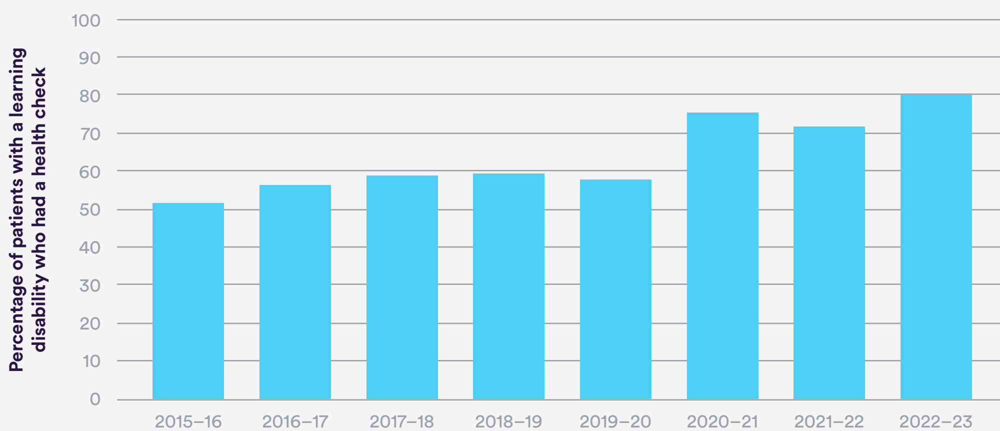
An essential component of the annual health check is the production of a 'health action plan'. The plan should include details on what support the person needs in order to look after their physical and mental health as well as actions to help them stay healthy.[37] It should cover who is responsible for each action and by when, and there should be a system in place to review whether follow-up actions have been taken. The health action plan should be agreed with the person with a learning disability and they should be given a copy of the plan in an accessible format, so that they can easily read and understand it.[39]

To help tackle health inequalities, annual health checks and health action plans are currently incentivised through the Investment and Impact Fund (IIF) 2023/24. This means primary care networks will receive funds based on the percentage of patients on the learning disability register who have received an annual health check and a completed health action plan.[40] By incentivising both the annual health check and the health action plan, NHS England hopes this will encourage better practice and help ensure people leave an annual health check with a health action plan.

In 2022–23, 80% of people aged 14 and over on the learning disability register had an annual health check, a statistically significant improvement from 72% in 2021–22. Before the Covid-19 pandemic, in 2019–20, only 58% of people had a health check (see Figure 3).[10]

40 NHS England (2023) *Investment and Impact Fund 2023/24: Guidance*. NHS England. www.england.nhs.uk/wp-content/uploads/2023/03/PRN00157-ncdes-investment-and-impact-fund-2023-24-guidance.pdf.

Figure 3: The proportion of people on the learning disability register getting an annual health check has been much higher in recent years, but more needs to be done



Note: Figure 3 shows the percentage of people aged 14 and over on the learning disability register who had an annual health check, by year.

Source: NHS Digital (2023) 'Health and care of people with learning disabilities, experimental statistics 2022 to 2023'[10]

Barriers and challenges

Invitations to attend annual health checks are dependent on people being on the learning disability register. The fact that so few individuals with a learning disability are present on the register, is perhaps the most fundamental barrier to accessing annual health checks. We know that coding for learning disabilities is inconsistent[41] and disproportionately affects people from minority ethnic groups.[32] Improving the number of people on the learning disability register is essential for enabling people to access annual health checks, which we discuss further in Chapter 8 where we set out our recommendations.

41 Wigham S, Bourne J, McKenzie K, Rowlands G, Petersen K and Hackett S (2022) 'Improving access to primary care and annual health checks for people who have a learning disability: a multistakeholder qualitative study', *BMJ Open* 12, e065945. doi: 10.1136/bmjopen-2022-065945.

GP practices have an important role to play in enabling access to annual health checks and ensuring that they are effective in meeting their aims. But it is not clear how proactive GP practices are at reaching out to people to encourage attendance at health checks and to what extent they facilitate follow-ups or referrals.[41]

Evidence suggests that although there has been an improvement in the uptake of annual health checks in recent years for people who are on the learning disability register, there is considerable variation in the quality of the checks and what they include.[36] In response to such variation in quality, Public Health England released guidance on quality-checking annual health checks for people with a learning disability. This includes setting out:

- indicators of success for what is included in the health check
- how well GP practices are doing at identifying patients with a learning disability, arranging for them to attend, putting reasonable adjustments in place and supporting follow-up actions.[42]

"It's so hard for people with a learning disability to plan, know what to expect and truly feel part of their annual health check with such variation in consistency and quality."
(Commissioning and inclusion officer)

The annual health check offers a good opportunity to have a proactive approach towards health promotion; however, studies have shown that health promotion is often not addressed.[43] Indeed, the 2022 LeDeR report found that the health check was sometimes reported to be a 'missed opportunity'

42 Public Health England (2017) *Quality Checking Health Checks for People with Learning Disabilities: A way of finding out what is happening locally*. GOV.UK. https://assets.publishing.service.gov.uk/media/5a822660ed915d74e3401ffb/Auditing_health_checks_tool_for_people_with_learning_disabilities.pdf.

43 Cooper S-A, Morrison J, Allan LM, McConnachie A, Greenlaw N, Melville CA, Baltzer MC, McArthur LA, Lammie C, Martin G, Grieve EAD and Fenwick E (2014) 'Practice nurse health checks for adults with intellectual disabilities: a cluster-design, randomised controlled trial', *The Lancet*. Psychiatry 1(7), 511–21.

for promoting health and exploring long-term conditions.[2] And health checks often focus on previously identified health needs, rather than preventive health care.[44]

As noted above, as part of the annual health check, a health action plan should be completed. Despite this being a key element of the health check, the plan is not always completed and implemented properly. Notably, 4% of people who received an annual health check in 2022–23 were recorded as not having a health action plan at all; the proportion was slightly higher for those aged 14–17 at 5%.[45]

"A check without a plan is no use. A plan without action is similarly of no benefit."
(GP)

Another routinely identified barrier is the accessibility of invitation letters to annual health checks that GP practices send out. Often, invitations lack clear, accessible information on what to expect during the health check. This uncertainty surrounding the health check creates a lot of worry for individuals.[46]

There is some variation in the demographics of people who attend annual health checks. Evidence shows that health checks are more likely to be attended by individuals who are already known to their GP practice.[44] Additionally, studies suggest that patients who attend annual health checks

44 Macdonald S, Morrison J, Melville CA, Baltzer M, MacArthur L and Cooper SA (2018) 'Embedding routine health checks for adults with intellectual disabilities in primary care: practice nurse perceptions', *Journal of Intellectual Disability Research* 62(4), 349–57.

45 NHS Digital (2023) 'Learning Disabilities Health Check Scheme'. https://digital.nhs.uk/data-and-information/publications/statistical/learning-disabilities-health-check-scheme. Accessed 12 January 2024.

46 Perry J, Felce D, Kerr M, Bartley S, Tomlinson J and Felce J (2014) 'Contact with primary care: the experience of people with intellectual disabilities' 8), *Journal of Applied Research in Intellectual Disabilities* 27(3), 200–11.

are more likely to be older and live in less deprived areas.[47,48] We know that people from minority ethnic groups are underrepresented on the learning disability register,[32] so these individuals are less likely to be accessing health checks.

47 Buszewicz M, Welch C, Horsfall L, Nazareth I, Osborn D, Hassiotis A, Glover G, Chauhan U, Hoghton M, Cooper S-A, Moulster G, Hithersay R, Hunter R, Heslop P, Courtenay K and Strydom A (2014) 'Assessment of an incentivised scheme to provide annual health checks in primary care for adults with intellectual disability: a longitudinal cohort study', *The Lancet*. Psychiatry 1(7), 522–30.

48 McConkey R, Taggart L and Kane M (2015) 'Optimizing the uptake of health checks for people with intellectual disabilities', *Journal of Intellectual Disabilities* 19(3), 205–14.

5 Addressing mental health problems

There are a number of risk factors that mean people with a learning disability are often more vulnerable to mental health problems. These range from genetic predispositions, to barriers of access to mental health services and resources. In addition, many people with a learning disability also have other long-term conditions or impairments, and poor physical health is strongly linked to mental health problems.

Moreover, socioeconomic factors play a fundamental role in a person's mental health status. People with a learning disability have lower levels of employment and are more likely to experience deprivation and poverty. And some people with a learning disability may lack social networks and receive limited support, which can lead to social exclusion and loneliness.[49] All of these social risk factors are associated with poorer mental health. People with a learning disability may also face abuse, neglect and discrimination throughout their lives, but particularly in the early years, and such experiences will make them more vulnerable to mental health problems.[14]

Population-based estimates suggest that the prevalence of mental health problems is higher among people with a learning disability compared with the general population.[49,50] In the year 2022–23, 16% of patients on the learning disability register had an active diagnosis of depression (see the Appendix for information about NHS Digital's statistics); this was disproportionately higher

49 National Institute for Health and Care Excellence (2016) *Mental Health Problems in People with Learning Disabilities: Prevention, assessment and management*. National Institute for Health and Care Excellence www.nice.org.uk/guidance/ng54/resources/mental-health-problems-in-people-with-learning-disabilities-prevention-assessment-and-management-pdf-1837513295557. Accessed 12 January 2024.

50 Joint Commissioning Panel for Mental Health (2013) *Guidance for Commissioners of Mental Health Services for People with Learning Disabilities*. Joint Commissioning Panel for Mental Health.

for women (20%) compared with men (13%). Further, 7.5% of patients with a learning disability had a diagnosis of severe mental illness.[10] NICE guidelines estimate that, in the UK, 28% of adults with a learning disability experience mental health problems at any point in time.[49]

Despite the higher prevalence of mental health problems among people with a learning disability, they have variable access to effective mental health treatments. NHS Talking Therapies (previously known as Improving Access to Psychological Therapies, or IAPT) is an NHS England service aiming to improve access to and the delivery of psychological therapies for common mental health problems. A range of different therapies are offered, with perhaps the most common being cognitive-behavioural therapy (CBT). There is evidence of IAPT being successful for some people with a learning disability, but people with a learning disability generally have poorer recovery rates compared with the general population.[51] In 2020–21, 41% of people with a learning disability who received IAPT treatment for anxiety and depression were classified as having moved to recovery, lower than for those without a learning disability.[51]

People with a learning disability are also less likely to be referred to IAPT services than the general population; the presence of a mental health problem may not be recognised, they may lack the skills to identify IAPT as an appropriate service and they may struggle to organise a referral and go through the appointment booking process.[51]

There are alternative routes to accessing mental health care that might be more appropriate for some people with a learning disability. Specialist services such as community learning disability teams can provide support, although there are access barriers for these services too and capacity is an issue.

People with a learning disability may benefit from other kinds of approaches to improve their mental health, such as creative therapies, including art and music therapy. There is evidence on the benefits that creative therapies can

51 Dagnan D, Rodhouse C, Thwaites R and Hatton C (2022) 'Improving Access to Psychological Therapies (IAPT) services outcomes for people with learning disabilities: national data 2012–2013 to 2019–2020', *the Cognitive Behaviour Therapist* 15.

have, many of which do not require language or cognitive skills, meaning that individuals with severe or profound learning disabilities are able to benefit from them.[52] However, accessing creative therapies can be difficult and varies across areas.[53]

Moving beyond talking and creative therapies, people with a learning disability, autism or both are more likely to be prescribed psychotropic medicines (including for psychosis, depression, anxiety, sleep problems and epilepsy) compared with other people. These medications are appropriate for some patients, but Public Health England estimates that between 30,000 and 35,000 adults with a learning disability are taking psychotropic medicines even though they do not have the health conditions that the medicines are generally prescribed for.[54] Research has also found that psychotropic medicines are commonly prescribed to people whose behaviour is seen as challenging.[55] These medicines can cause side effects such as weight gain, tiredness and some serious physical health problems and so these findings are concerning.

In 2016, the Stopping the Over-Medication of People with a Learning Disability, Autism or Both (STOMP) project was launched. STOMP aims to:

- encourage people to have structured medication reviews
- make sure that health professionals involve patients and their carers in decisions about medications

52 Nurturing Effective Care (no date) 'Research and evidence'. www.nacwellbeing.org/research-and-evidence. Accessed 12 January 2024.

53 MIND (no date) 'Arts and creative therapies'. www.mind.org.uk/information-support/drugs-and-treatments/talking-therapy-and-counselling/arts-and-creative-therapies. Accessed 12 January 2024.

54 NHS England (no date) 'Stopping over medication of people with a learning disability, autism or both (STOMP)'. www.england.nhs.uk/learning-disabilities/improving-health/stomp. Accessed 12 January 2024.

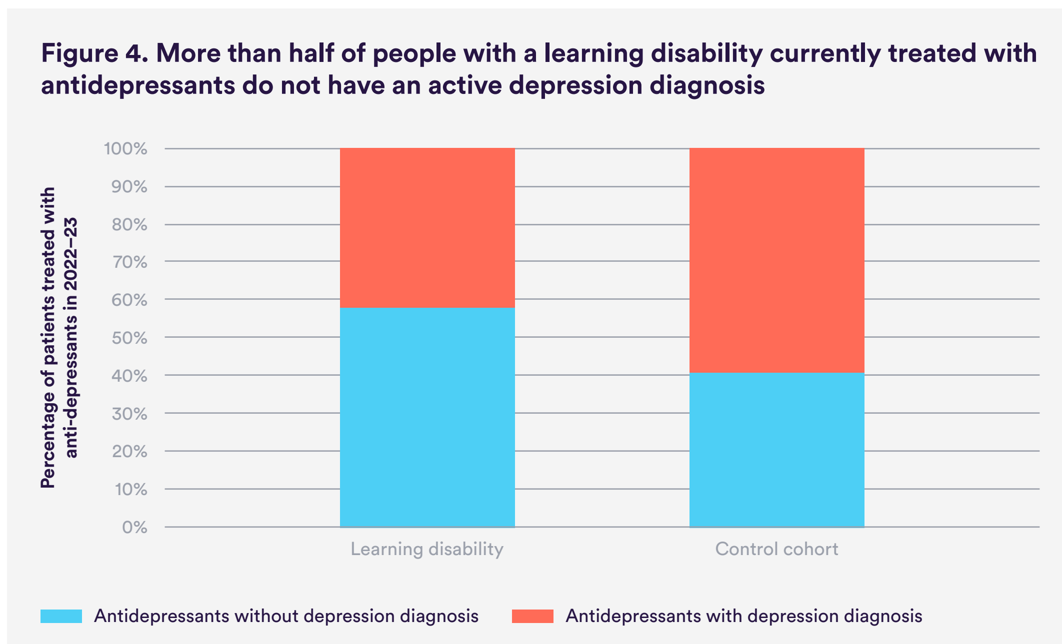
55 Perry BI, Cooray SE, Mendis J, Purandare K, Wijeratne A, Manjubhashini S, Dasari M, Esan F, Gunaratna I, Naseem RA and Hoare S (2018) 'Problem behaviours and psychotropic medication use in intellectual disability: a multinational cross-sectional survey', *Journal of Intellectual Disability Research* 62(2), 140–9.

- inform people about non-drug therapies and other ways of supporting people.[54]

The NHS Long Term Plan included the expansion of the STOMP programme as one of its actions.[3]

However, data from GP practices in England show that, in 2022–23, 14% of people with a learning disability were being treated with antipsychotic drugs, compared with 1% of people in the control cohort, and these proportions have not changed significantly over time.[10] Furthermore, 22% of patients with a learning disability were being treated with antidepressants, compared with 11% of people in the control cohort. Notably, Figure 4 shows that 58% of people with a learning disability who were being treated with antidepressants in 2022–23 did not have an active diagnosis of depression; this compared to 41% of people in the control cohort. The reasons for these large proportions, including for the control cohort, are unclear and require further research.

Figure 4. More than half of people with a learning disability currently treated with antidepressants do not have an active depression diagnosis



Source: NHS Digital (2023) 'Health and care of people with learning disabilities, experimental statistics 2022 to 2023'[10]

Barriers and challenges

Preventing people with a learning disability from experiencing poor mental health is difficult without addressing wider socioeconomic factors. As mentioned previously, there are many reasons why people with a learning disability have a higher risk of developing mental health problems, ranging from them being more likely to live in poverty, to lacking social networks. While health services cannot address these factors, recognising their impact is important as it reinforces the necessity of enabling access to effective mental health care.

Challenges in the identification of mental health problems among people with a learning disability can be a barrier to them accessing the care they need. People with a learning disability may struggle to recognise or communicate any psychological difficulties they are experiencing. They may also be reluctant to communicate troubles with their mental health because of associated stigma, or concerns about worrying friends and family.[56] Similarly, parents and carers may struggle to identify mental health problems in people with a learning disability, and to know how to support them. NICE guidelines suggest training programmes for parents or carers of children with a learning disability to help prevent or treat mental health problems.[49] However, it is unclear how widely implemented these programmes are.

56 Chinn D and Abraham E (2016) 'Using "candidacy" as a framework for understanding access to mainstream psychological treatment for people with intellectual disabilities and common mental health problems within the English Improving Access to Psychological Therapies service', *Journal of Intellectual Disability Research* 60(6), 571–82.

A fundamental challenge in identifying mental health problems in the learning disability population is 'diagnostic overshadowing', whereby mental health problems are mistaken as just being part of an individual's learning disability, thereby leaving them undiagnosed and unaddressed. It is a well-recognised challenge among health and social care professionals.[57]

Diagnostic overshadowing is a significant barrier across the mental health pathway, from identifying a concern, to accessing the appropriate support and treatment. As part of Oliver McGowan Mandatory Training on Learning Disability and Autism (see Chapter 7), health and social care staff undergo training including how to avoid diagnostic overshadowing. However, this training is perhaps not sufficient to fully address concerns about the impact that diagnostic overshadowing can have on a person's mental health care.

Knowing the individual well and recognising changes in behaviour that could be attributed to growing psychological difficulties are important. However, the high turnover in the social care workforce in particular makes this route to identification and diagnosis more difficult.

The challenges extend beyond the identification of mental health problems. Previous research with therapists suggests that those working within IAPT services do not receive enough training or support on how to adapt the therapies for people with a learning disability.[58] It is also important to note that talking therapies are not a viable option for a number of people with a learning disability as some individuals are non-verbal.[56] Notably, NICE guidelines recommends adapting cognitive-behavioural therapy to treat depression but only for people with milder learning disabilities.[49]

57 George AP, Pope D, Watkins F and O'Brien SJ (2011) 'How does front-line staff feel about the quality and accessibility of mental health services for adults with learning disabilities?', *Journal of Evaluation in Clinical Practice* 17(1), 196–8.

58 Marwood H, Chinn D, Gannon K and Scior K (2018) 'The experiences of high intensity therapists delivering cognitive behavioural therapy to people with intellectual disabilities', *Journal of Applied Research in Intellectual Disabilities* 31(1), 76–86.

Specialist mental health services for people with a learning disability tend to be based in the community. These services have faced capacity constraints in recent years, with the number of community learning disability nurses declining since 2009.[59] To account for the decline in the number of staff, the role and work of community learning disability nurses have been reduced, influencing the amount of mental health promotion and support the nurses can provide.[60]

59 NHS Digital (2023) 'NHS workforce statistics'. https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics/july-2023. Accessed 12 January 2024.

60 Royal College of Nursing (2021) *Connecting for Change: For the future of learning disability nursing*. Royal College of Nursing. www.rcn.org.uk/Professional-Development/publications/connecting-for-change-uk-pub-009-467. Accessed 12 January 2024.

6 Early diagnosis

The 2021 LeDeR report identified missed or late diagnoses of potentially treatable health problems among people with a learning disability as an area of concern in primary and community care. Specifically, it noted that there was insufficient investigation when potential problems were identified and a lack of monitoring of previously diagnosed conditions.[61]

Emergency admissions for 'ambulatory care sensitive conditions' (conditions where effective community care can help prevent the need for hospital admission) have been found to be considerably higher for the learning disability population. Beyond this, results from one cohort study showed that one in four inpatient bed days for people with a learning disability were potentially preventable.[62]

Furthermore, cancer is often diagnosed at a later stage in people with a learning disability compared with the general population. Such diagnoses are usually made during emergency presentation at hospital. Using data from the LeDeR programme in 2017–19, researchers found that 45% of individuals with a learning disability who died with cancer were diagnosed at stage IV; and 35% of individuals with a learning disability who died with cancer had their cancer identified at emergency presentation.[63] The recent 2022 LeDeR report found neoplasms (abnormal tissue growth) to be the third most common cause of death among people with a learning disability.[2]

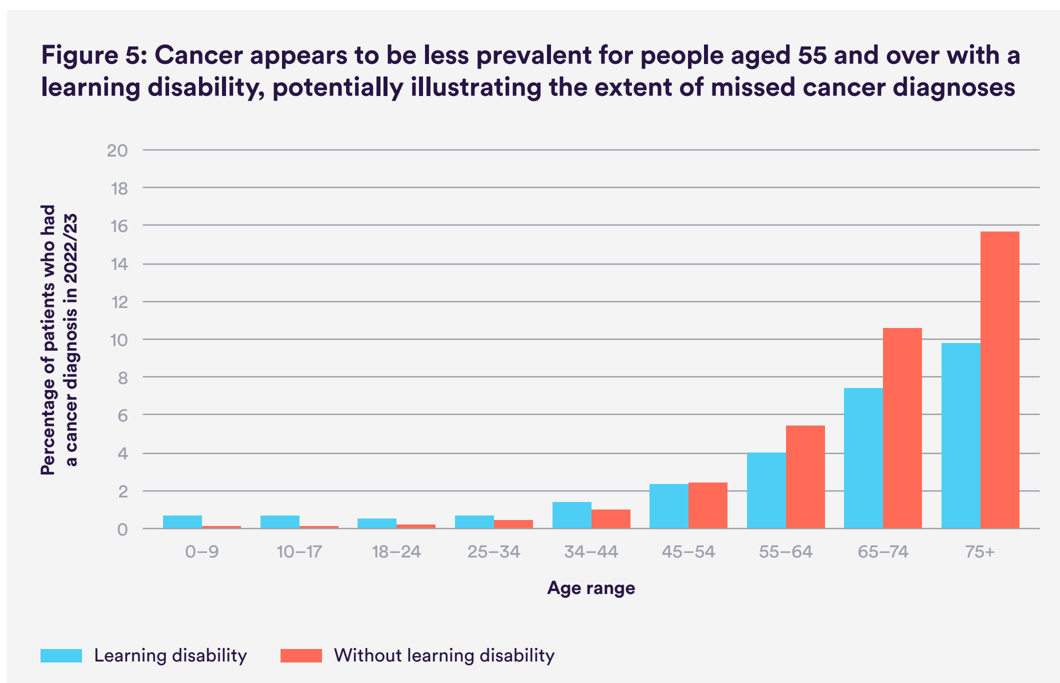
61 King's College London (2021) *LeDeR Learning from Lives and Deaths – People with a Learning Disability and Autistics People: Annual report 2021*. King's College London. www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf.

62 Glover G, Williams R and Oyinlola J (2020) 'An observational cohort study of numbers and causes of preventable general hospital admissions in people with and without intellectual disabilities in England', *Journal of Intellectual Disability Research* 64(5), 331–44.

63 Heslop P, Cook A, Sullivan B, Calkin R and Pollard J (2022) 'Cancer in deceased adults with intellectual disabilities: English population-based study using linked data from three sources', *BMJ Open* 12(3), e056974.

Figure 5 shows that for people aged 55 and over, the prevalence of cancer is lower in people with a learning disability compared with those without a learning disability (see the Appendix for information about NHS Digital's statistics).[10] This gap in prevalence perhaps illustrates the extent of missed or late cancer diagnoses among people with a learning disability. This is especially relevant to bowel cancer, a disease where people with a learning disability have a younger median age at death compared with the general population.[2] The prevalence of cancer among people with a learning disability is expected to rise alongside life expectancy, meaning that problems with missed or late diagnoses could become increasingly concerning if not addressed.[64]

Figure 5: Cancer appears to be less prevalent for people aged 55 and over with a learning disability, potentially illustrating the extent of missed cancer diagnoses



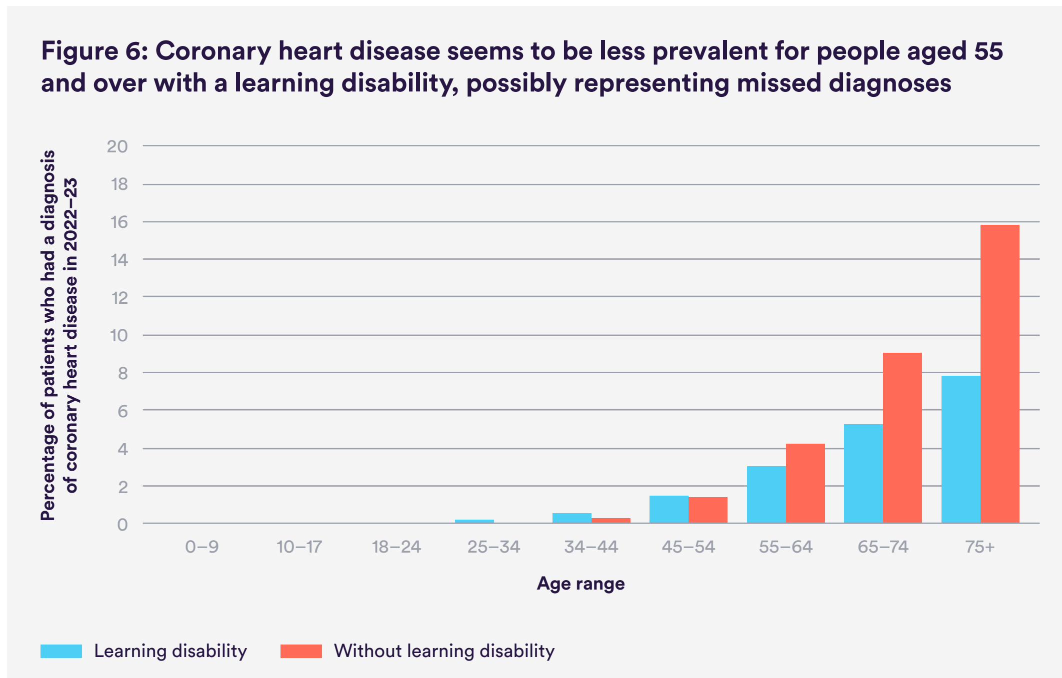
Source: NHS Digital (2023) 'Health and care of people with learning disabilities, experimental statistics 2022 to 2023'[10]

The prevalence of coronary heart disease is also recorded to be lower in the learning disability population compared with the general population (see Figure 6). But given the higher prevalence of risk factors such as diabetes

64 Hanna LM, Taggart L and Cousins W (2011) 'Cancer prevention and health promotion for people with intellectual disabilities: an exploratory study of staff knowledge', *Journal of Intellectual Disability Research* 55(3), 281–91.

and obesity among people with a learning disability, we might expect the prevalence of coronary heart disease to be greater. This raises concerns around adequate diagnosis of the condition.[65] The 2022 LeDeR report showed an increase in the proportion of deaths due to conditions of the circulatory system, including coronary heart disease.[2]

Figure 6: Coronary heart disease seems to be less prevalent for people aged 55 and over with a learning disability, possibly representing missed diagnoses



Source: NHS Digital (2023) 'Health and care of people with learning disabilities, experimental statistics 2022 to 2023'[10]

The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) from more than a decade ago, found that delays or problems with diagnosis or treatment were one of the most common reasons for deaths being assessed as premature. Notably, of people who had been identified as being unwell, 33% died with an undiagnosed significant illness, most commonly of cardiovascular disease or deep vein thrombosis.[27] This indicates that the problems of delayed diagnosis have been around for some time.

65 Carey IM, Shah SM, DeWilde S, Harris T, Beighton C and Cook DG (2016) 'Health characteristics and consultation patterns of people with intellectual disability: a cross-sectional study in English general practice', *British Journal of General Practice* 66(645), e264–e270.

Barriers and challenges

There are a number of possible reasons why diseases among people with a learning disability are diagnosed at later stages. Some people with a learning disability may find it hard to communicate how they are feeling, therefore new symptoms can present as just changes in behaviour. Additionally, it may be more difficult for people with a learning disability to understand their symptoms or to know which symptoms to look out for.

If an individual has communication difficulties, it is more likely that diagnostic overshadowing will occur.[66] Diagnostic overshadowing is therefore a significant barrier to early diagnosis for people with a learning disability. Changes in behaviour due to new physical symptoms such as pain may initially be attributed to an individual's learning disability rather than there being an exploration of possible diagnostic options.

Additionally, people with a learning disability are more likely than the general population to have multiple long-term conditions. This means that new symptoms may be attributed to an already diagnosed long-term condition rather than the possibility of a new condition being explored. Not properly exploring new symptoms will cause delays in diagnosis, and this in turn will have a large impact on the individual's health, as early intervention is essential for better outcomes.

Moreover, having multiple long term-conditions can also make the coordination of services increasingly difficult. Better coordination of care between services may help to facilitate earlier diagnosis and access to treatment.

This links to a wider issue around understanding the health system and which services to turn to for support for various health problems or concerns. Such barriers in accessing health care are considerably larger for individuals from

66 Blair J (2017) 'Diagnostic overshadowing: see beyond the diagnosis'. www.intellectualdisability.info/changing-values/diagnostic-overshadowing-see-beyond-the-diagnosis. Accessed 20 January 2024.

minority ethnic groups.[67] Difficulty navigating health services is highlighted as a barrier to achieving good health and care for people with a learning disability. Addressing care coordination can therefore help to reduce the health inequalities that people with a learning disability face.[68]

Roles such as learning disability liaison nurses can help address these challenges. Learning disability liaison nurses can work in both primary and secondary care settings, although the role is more common in hospitals. The 2021 LeDeR report highlighted the role as a valuable one for connecting care.[61] More specifically, in the 2022 LeDeR report these nurses' varied activities were described as important for ensuring the quality of care during hospital admission.[2] However, with the workforce declining in numbers, it is becoming increasingly difficult for learning disability nurses and community teams to prioritise these activities.

Annual health checks should be playing a role in the early detection of health problems among people with a learning disability (see Chapter 4). However, this depends on the extent to which people are able to access these checks and how comprehensive the checks are. As previously discussed, we know that improvements are needed to increase the number of people on the learning disability register, so that more people with a learning disability receive an annual health check, and that there is variation in the quality of the annual health checks being carried out.

67 Ali A, Scior K, Ratti V, Strydom A, King M and Hassiotis A (2013) 'Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers', *PLoS ONE* 8(8), e70855.

68 Institute of Public Care (2020) *Best Practice on Care Coordination for People with a Learning Disability and Long Term Conditions*. Institute of Public Care. https://ipc.brookes.ac.uk/files/publications/Care-coordination-report-April-2020.pdf.

7 Current improvement initiatives

Given that the NHS has committed to reducing health inequalities for people with a learning disability,[3] it is of no surprise that there is already a lot of work being done to make improvements in this area. Many current initiatives relate in some way to preventive health care, as ultimately better preventive care and support will enable people with a learning disability to live a healthier life and prevent them from dying too young. Current projects include the publication of new policy guidance, the introduction of mandatory staff training and a Reasonable Adjustment Digital Flag, workforce plans and research studies.

It is important to examine some of these initiatives before setting out our recommendations in Chapter 8 for improving access to preventive health care for people with a learning disability. They provide context about areas where progress is already being made, which are useful to be aware of when we later identify opportunities for further improvements.

The Oliver McGowan Mandatory Training on Learning Disability and Autism

The Health and Care Act 2022 introduced a requirement for regulated service providers to ensure that their staff receive training on learning disability and autism that is appropriate to their role. The Oliver McGowan Mandatory Training on Learning Disability and Autism is the training that was developed for this purpose and is the government's recommended training for health

and social care staff.[69] The National Development Team for Inclusion (NDTi) co-produced, trialled and independently evaluated this training.[70]

Tier 1 of the training is designed for all staff who require a general awareness of the support that autistic people or people with a learning disability may need. Tier 2 includes a day of face-to-face training and is for staff with the responsibility of providing care or support for these groups. It includes content on:

- avoiding diagnostic overshadowing
- communicating in accessible ways
- the law in relation to learning disability and autism
- culture
- professional behaviour
- making reasonable adjustments.[69]

In earlier chapters of this report, we identified many of these factors as being of major importance when considering barriers in access to preventive health care. Since the training is relatively new, any improvements arising from the training will not yet be visible in the data and research we have presented.

Reasonable Adjustment Digital Flag

The NHS Long Term Plan states that 'by 2023/24, a "digital flag" in the patient record will ensure staff know a patient has a learning disability or autism'.[3] The Reasonable Adjustment Digital Flag is designed to enable health and care professionals to record, share and view details of reasonable adjustments

69 Health Education England (2023) 'The Oliver McGowan Mandatory Training on Learning Disability and Autism'. www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism. Accessed 12 January 2024.

70 Skills for Care (no date) 'The Oliver McGowan Mandatory Training on Learning Disability and Autism'. www.skillsforcare.org.uk/Developing-your-workforce/Care-topics/Oliver-McGowan-Mandatory-Training/Oliver-McGowan-Mandatory-Training.aspx. Accessed 12 January 2024.

across the NHS.[71] The flag aims to identify all patients with a disability or impairment who may require reasonable adjustments (including people with a learning disability or autism) and to share key adjustments that will help an episode of care go well or happen at all.

The flag is part of the NHS Spine (allows information to be shared securely through national services) and health and care professionals can view, create or edit information from the flag using the National Care Records Service (NCRS).[72] A flag can be created in conjunction with patients and carers, to ensure best-interest decisions are made. The flag has been live since 2019 but only saw wider adoption since its inclusion in the NCRS in 2023. There is ongoing work to integrate the flag for greater use across the NHS. Social care staff are currently not able to access the flag.

Improving the number of people on the learning disability register

In Chapter 4, we explained the importance of people with a learning disability being on their GP's learning disability register, as it gives them access to annual health checks and Covid-19 and flu vaccinations, and alerts the GP practice that they might need extra support such as reasonable adjustments. The most recent data indicate that only around one in four people with a learning disability are on the register (see the Appendix for how we arrived at this estimation).

In 2019, NHS England and NHS Improvement published guidance for general practice to improve the identification of people with a learning disability.[33] This provided practices with one set of clinical diagnostic codes that should automatically ensure a patient is included on the learning disability register

71 NHS Digital (no date) 'DAPB4019: Reasonable Adjustment Digital Flag'. https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dapb4019-reasonable-adjustment-digital-flag. Accessed 12 January 2024.

72 NHS Digital (no date) 'Reasonable Adjustment Flag'. https://digital.nhs.uk/services/reasonable-adjustment-flag. Accessed 12 January 2024.

(such as Down's Syndrome), and another set of diagnostic codes that may or may not be associated with a learning disability (such as cerebral palsy). Practices were asked to make an individual assessment of these patients to determine whether they should be added to the register, which may have required a face-to-face discussion with the patient or carer.

The guidance acknowledged that 'whilst we have identified a large number of conditions and codes… as most of these conditions are rare it is likely that only small numbers of new patients will need to be added to a register'.[33]

In addition to the above, there is work being carried out nationally and regionally to encourage children and young people to join the register at age 14, to enable them to access annual health checks. A leaflet for parents and carers was publicised in the 'NHS Primary Care Bulletin' and a launch in schools was planned for September 2023.[73]

The NHS Long Term Workforce Plan commitment to increase the number of learning disability nurses

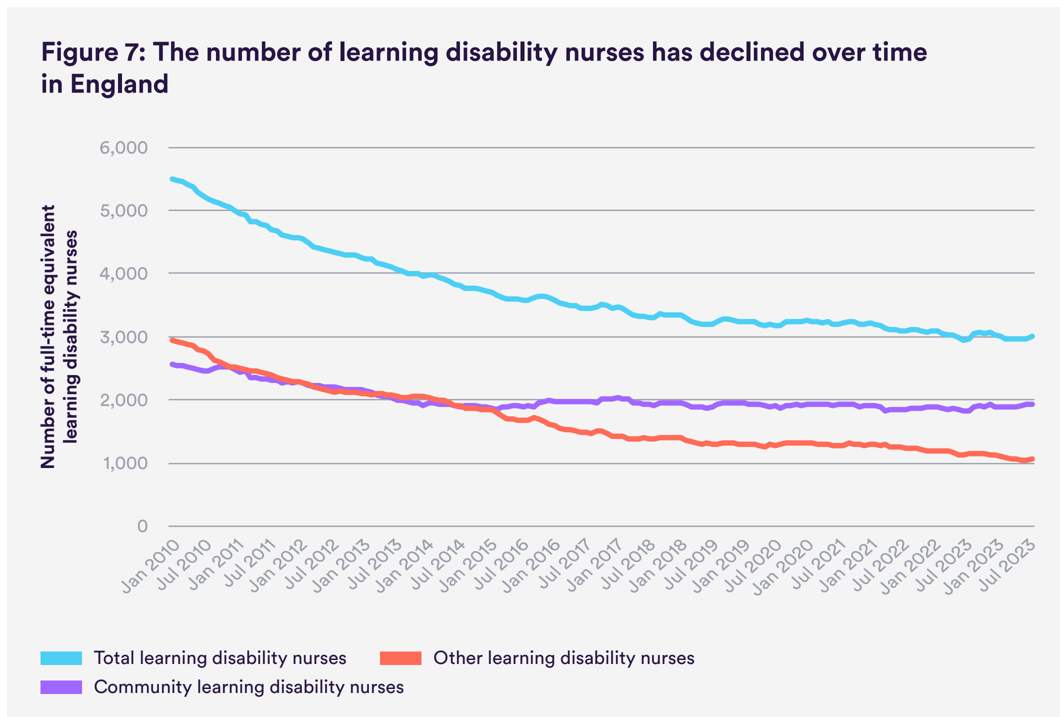
One key challenge in enabling people with a learning disability to access health care relates to the declining number of staff who specialise in supporting people with a learning disability. The number of learning disability nurses employed by NHS England has decreased by 42% since 2010.[28] This includes community learning disability nurses as well as nurses who work across other settings such as hospitals (see Figure 7).

There are other roles that have developed for learning disability nurses too, for example learning disability liaison nurses in acute care settings. However, there is little consistency between these roles as well as strong regional differences.[60]

73 UK Parliament (2023) 'Learning disability: question for Department of Health and Social Care: UIN 200470, tabled on 19 September 2023'. https://questions-statements.parliament.uk/written-questions/detail/2023-09-19/200470. Accessed 12 January 2024.

In 2016, the bursary for nursing education was cut in England. Learning disability student nurses were the most affected group and saw a decline in student applications. Additionally, applicants for learning disability nursing courses tend to be older compared with other fields of nursing.[60] This calls into question the future of the learning disability workforce.

Figure 7: The number of learning disability nurses has declined over time in England



Source: NHS Digital (2024) 'NHS workforce statistics by staff group, care setting and level'[74]

The challenges surrounding the current learning disability workforce are well recognised. Learning disability nursing features throughout the NHS Long Term Workforce Plan. This plan includes targets to increase the number of learning disability training places by 46% by 2028/29 and increase the number of learning disability nurses who qualify through the apprenticeship route.[75]

74 NHS Digital (2024) 'NHS workforce statistics – September 2023 (including selected provisional statistics for October 2023)'. https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics/september-2023. Accessed 16 January 2024.

75 NHS England (2023) *NHS Long Term Workforce Plan*. NHS England. www.england.nhs.uk/publication/nhs-long-term-workforce-plan. Accessed 12 January 2024.

However, the plan notes that the learning disability workforce may still have to rely on temporary staff, with models estimating that the learning disability nursing shortfall will grow to 1,200 full-time-equivalent staff in 2036/37.[75]

8 Recommendations

In this chapter we set out our recommendations, which are based on:

- where some of the biggest barriers and challenges are for reducing health inequalities for people with a learning disability
- understanding the scope of current improvement initiatives and where some of them could go further
- particular areas where we have identified significant gaps.

The recommendations are just some of the many ways in which quality improvements could be made. The list is not intended to be comprehensive, but includes key factors that we have identified based on our research.

1. Increase the number of people on the learning disability register

Integrated care boards should: use local data to review the number of people on GP learning disability registers; identify geographic areas, GP practices and demographic groups where the biggest improvements are needed; and organise targeted information campaigns to encourage people to join the register.

Each integrated care board has an executive lead for learning disability and autism, who could hold responsibility for this task. Some GP practices may have relatively few people on their learning disability registers compared with others. Some demographic groups, such as people from minority ethnic backgrounds, may also be underrepresented on learning disability registers. The NHS Race & Health Observatory published a report in July 2023, which found a general lack of awareness of the learning disability register among people from minority ethnic groups.[32]

There are already actions being taken to improve the identification of people with a learning disability (see Chapter 7), but they need to go further to make significant improvements. Education and spreading awareness of the advantages of being on the register, such as being able to access annual health checks, are very important. Targeted information campaigns should be co-produced with people with lived experience and be delivered in an accessible format, working with local communities.

2. Improve the quality of annual health checks

NHS England should conduct a national review of the quality of annual health checks for people with a learning disability.

As discussed in Chapter 4, evidence shows that the quality of annual health checks for people with a learning disability is variable. Invitations to an annual health check often lack accessible information, there are differences in what is included in the health check, and they are seldom used as an opportunity for health promotion.

The national review of annual health checks could make use of Public Health England's audit tool, 'Quality Checking Health Checks for People with Learning Disabilities: A way of finding out what is happening locally'[42] This includes indicators of success for how well GP practices are doing at:

- identifying patients with a learning disability
- arranging for people to attend a health check
- performing the health check
- putting reasonable adjustments in place to maximise the effectiveness of the health check
- supporting follow-up actions.

The tool suggests evidence that auditors may find helpful to gauge GP practices' performance level, including reviewing completed health action plans, getting feedback from people with a learning disability and family carers, and sourcing examples of accessible invitation letters.

The findings from the national review should be widely shared to identify good practice and encourage GP practices to make improvements where needed. The review will help to establish whether annual health checks are being provided consistently across England and to identify geographical areas that may need extra support.

3. Ensure that reasonable adjustments for people with a learning disability are more widely implemented

All providers of NHS and publicly funded social care should deliver training to staff in the use of the Reasonable Adjustment Digital Flag and raise awareness of reasonable adjustments that staff can provide.

The Reasonable Adjustment Digital Flag is a useful tool that can help health care professionals record and share details of reasonable adjustments that people with disabilities and other impairments require to access services. The implementation guidance for the flag includes training for staff in its checklist of key actions.[71]

The training should ensure that staff understand how to create, view and share the Reasonable Adjustment Digital Flag on the NHS Spine. It should include information about the Accessible Information Standard and the Reasonable Adjustment Digital Flag Standard. The training should support a workforce culture where using the flag and acting on reasonable adjustments are everyone's responsibility.[71]

Importantly, the training should be used to improve awareness of the types of reasonable adjustments that staff can provide – for example, the ability to offer longer appointment times. The training should be specific and targeted for different staff groups, as they have diverse roles and responsibilities and will be able to provide a variety of reasonable adjustments.

The success of the Reasonable Adjustment Digital Flag will depend on the ability to integrate the flag across all NHS and publicly funded social care services. Social care staff are currently not able to access the flag.

It should be noted that the flag is just one tool that can be used to identify and meet the needs of people with a learning disability – effective communication, care coordination and partnership working with families and carers are all paramount to ensuring good-quality care.

4. Improve care coordination for people with a learning disability

The number of health and social care staff in care coordination roles – including key workers, learning disability liaison nurses and health facilitators – should be increased to improve care coordination for people with a learning disability.

The 2022 LeDeR report highlighted issues with care coordination as an area of concern.[2] The care coordination role can include:

- leading the care planning process
- providing links to mainstream services
- offering support to access healthy lifestyles
- ensuring reasonable adjustments are in place.[68]

The role is especially important for people with multiple long-term conditions who require support from different services. Throughout this report, we have discussed barriers relating to these elements of care for people with a learning disability. Therefore expanding the number of staff in care coordination roles has the potential to improve access to services and quality of care for the learning disability population.

There are a number of different roles that encompass care coordination. Best practice for care coordination suggests that the health professional who undertakes this coordination role will vary depending on the individual's need.[68] Care coordination roles include key workers, health facilitators and learning disability liaison nurses.

NICE recommends appointing a key worker to someone with a learning disability. This key worker should be responsible for helping the person access

and coordinate care between services as well as being the main point of contact for the person and their family and carers.[76]

Similarly, NICE guidelines for people growing older with a learning disability recommend that in health care settings a lead practitioner should be identified. The guidelines suggest that the practitioner could be either a learning disability nurse or a member of the community learning disability team.[77]

Health facilitation teams specialise in facilitating access to health care and support for people with a learning disability. The health facilitator role can be undertaken by a learning disability nurse. Health facilitation teams aim to:

- enable improved access to mainstream services
- facilitate reasonable adjustments
- educate the workforce
- work closely with primary care to ensure annual health checks and health action plans are being carried out.

There are good examples of health facilitation teams,[78,79] however, these teams only exist in certain areas across England, meaning there is unequal access.

76 National Institute for Health and Care Excellence (2017) 'Quality statement 3: key worker'. www.nice.org.uk/guidance/qs142/chapter/Quality-statement-3-Key-worker#rationale-3. Accessed 12 January 2024.

77 National Institute for Health and Care Excellence (2018) 'Care and support of people growing older with a learning disability: NICE guideline [NG96]'. www.nice.org.uk/guidance/ng96/chapter/Recommendations. Accessed 12 January 2024.

78 Gloucestershire Health and Care NHS Foundation Trust (no date) 'Teams: Health Facilitation'. www.ghc.nhs.uk/our-teams-and-services/health-facilitation-team. Accessed 12 January 2024.

79 Lancashire & South Cumbria NHS Foundation Trust (no date) 'Health Facilitation Team'. www.lscft.nhs.uk/healthfacilitation#:~:text=The%20Health%20Facilitation%20Team%20will,with%20a%20learning%20disability%20face. Accessed 12 January 2024.

5. Improve access to weight management programmes for people with a learning disability

Local authority provision of multi-component weight management programmes tailored for people with a learning disability should be increased.

As evidenced in Chapter 2, a higher proportion of people with a learning disability are obese and it can be more difficult for them to lose weight than the general population. Many mainstream weight management programmes are inaccessible for people with a learning disability. It could be considered a reasonable adjustment to provide weight management programmes that are tailored for them.

Public Health England has stated that there is some evidence that multi-component weight management programmes – which combine dietary advice, physical activity and behaviour change – can be adapted for people with a learning disability.[11] There is currently a lack of randomised controlled trials, but some studies suggest that such programmes can be adapted in ways that are accessible and effective.[80] Involving carers or supporters has been shown to help enable access to programmes and the implementation of healthy lifestyle changes.[19]

In January 2022, it was reported that two local authorities in England – Cambridgeshire County Council and Peterborough City Council – were offering free 12-week weight management programmes for adults with a learning disability.[81] Registered nutritionists and physical activity specialists ran them. The success of these programmes should be assessed, adapted if necessary and rolled out across all local authorities in England.

80 Harris L, Hankey C, Jones N, Pert C, Murray H, Tobin J, Boyle S and Melville C (2017) 'A cluster randomised control trial of a multicomponent weight management programme for adults with intellectual disabilities and obesity', *British Journal of Nutrition* 118, 229–40.

81 Nicolle L (2022) 'Free weight management programme for adults with a learning disability'. www.learningdisabilitytoday.co.uk/news/free-weight-management-programme-for-adults-with-a-learning-disability/?highlight=weight%20management. Accessed 12 January 2024.

9 Discussion

This report has brought to attention the stark health inequalities that people with a learning disability face and the immense challenges involved in addressing them. The 2022 LeDeR report highlighted the high numbers of premature and avoidable deaths of people with a learning disability. In this report we have focused on five key areas relating to access to effective health care in England as well as preventive health care among people with a learning disability, in order to unpick some of the issues.

We have found that people with a learning disability are much more likely to be obese than the general population, that helping them lose weight can be complex and that many mainstream weight-loss groups are inaccessible to them. People with a learning disability have significantly lower levels of participation in NHS cancer screening programmes, with barriers including a lack of reasonable adjustments and support to attend screening appointments. People with a learning disability are also disproportionately affected by mental health problems, but they are less able to access suitable care and are more likely to be overprescribed medication. Uptake of the annual health check is thwarted by the fact that only around 26% of people with a learning disability are on the GP learning disability register. There are also ongoing problems with diagnostic overshadowing and people with a learning disability not receiving early diagnoses, including for cancer, which is often diagnosed at a late stage.

There are several cross-cutting themes that are worth highlighting.

First, it needs to be acknowledged that many people with a learning disability have great difficulties with communication, are more likely to have complex health needs and require support from multiple different services. They may not recognise or communicate symptoms when they feel unwell and may struggle to understand the importance of healthy living. But the barrier of communication must not be used as an excuse to disadvantage people with a learning disability. It must be overcome through the ability of carers and staff to spot symptoms of illness early and through reasonable adjustments

that make services as accessible for people with a learning disability as for everybody else.

Second, there is a lack of knowledge among health and care staff about how best to support people with a learning disability. All staff need to have a general awareness of the support that people with a learning disability may need, the importance of giving them information in a way they understand and the types of reasonable adjustments they can offer. Staff with responsibility for providing more frequent care should be trained to spot signs and symptoms of illness in the people they care for, to encourage and support them to attend screening appointments, and to be healthy role models themselves. Avoiding diagnostic overshadowing and adhering to the Mental Capacity Act 2005 are essential. It is hoped that the introduction of the Oliver McGowan Mandatory Training on Learning Disability and Autism will make significant improvements in this area – something that will not yet be visible in the published literature.

Third, the issue of poor care coordination relates to many of the matters discussed in this report. Good coordination of care enables health and care professionals from different sectors to work effectively together and provide care in collaboration with each other. This is especially important for people with complex needs and long-term conditions where care input traverses multiple specialties. It can also help to enable people with a learning disability access annual health checks and cancer screening. But care coordination is currently an area of concern, with limited focus on expanding the care coordinator role, which would be a valuable addition to the NHS workforce strategy.

Fourth, we found numerous practical barriers to accessing health and care services, ranging from transport issues, to financial constraints, to a lack of specialised chairs, the last of which is preventing some disabled women who use moulded wheelchairs from being screened for breast cancer.

Fifth, all of the topics we have discussed are happening against a backdrop of wider socioeconomic factors, such as a high rate of unemployment among people with a learning disability, and people with a learning disability being more likely to experience deprivation and loneliness. These wider factors

negatively contribute to their health and wellbeing and are much more difficult to tackle without the support of multiple sectors.

This report is not a comprehensive review of all areas relating to prevention and enabling access to health care for people with a learning disability. But it does touch on numerous themes that could, in turn, be applied elsewhere. For example, increasing the number of people on the GP learning disability register would help to increase uptake of the annual health check as well as flu vaccinations. The importance of improving the knowledge of health and care professionals about how to support people with a learning disability could in turn be applied to family carers, who often struggle to navigate the complex health and social care system.

Some areas that we have not focused on in this report include the impact of the Covid-19 pandemic on people with a learning disability. Reports have shown that people with a learning disability have an increased risk of poor outcomes if they develop Covid-19 and they had a higher rate of excess deaths compared with the general population during the pandemic. The topics we have included look more towards long-term barriers and challenges that have culminated in health inequalities for people with a learning disability for many years. We have also not touched on stigma and the negative assumptions of others; these can lead to discriminatory judgements that can affect a person's care and treatment. Further, we have not placed much focus on the improvements that could be made within social care to enable people with a learning disability to get the support they need, such as investing more in the social care workforce, which could easily justify a separate project, with this as its main focus.

Finally, we must draw attention to the fact that more research and data are needed. Many of the statistics we have presented in this report are sourced from NHS Digital's 'Health and care of people with learning disabilities, experimental statistics'. This only includes data from 55% of patients registered at GP practices in England. We recommend that it should be expanded to cover the whole GP practice population, to provide more accurate statistics. Moreover, there is a lack of research studies that focus on ways to prevent diagnostic overshadowing among health professionals, how to improve access to effective mental health care for people with a learning disability, and ways to increase cancer screening participation. Even in areas where we

did find evidence of ways to make services accessible and effective, such as multi-component weight management programmes, there is still a lack of suitable studies.

Despite the long history of policies to improve the health and care of people with a learning disability, their lack of access to effective health and care is resulting in large health inequalities that need to be addressed. The recommendations that we have highlighted in this report are just some ways to improve the health of people with a learning disability. This under-researched area is especially deserving of greater focus, given that this is a group of people who are often dying prematurely and from avoidable causes. Ultimately, people with a learning disability need access to timely and effective health and care, where care is well coordinated and signs and symptoms of illness are picked up early.

Appendix: Data notes

Many of the statistics in this report are sourced from NHS Digital's 'Health and care of people with learning disabilities, experimental statistics'[10] The dataset includes 55% of patients registered at GP practices in England. It includes data from participating GP practices using EMIS and Cegedim Healthcare Solutions, but not from practices using TPP systems. NHS Digital's publication is classified as 'experimental statistics', indicating that the data have some constraints and limitations.

Prevalence of obesity

To estimate obesity prevalence among people with a learning disability, we used data found within NHS Digital's comma-separated values (CSV) files. For the denominator, we summed the number of patients who had a Body Mass Index (BMI) classification of underweight, healthy weight, overweight or obese recorded in the previous 15 months.

Measurements of height and weight, which are necessary to calculate BMI, are not a required part of a GP visit. The learning disability annual health check scheme aims to include these measurements. Therefore, there is a higher-quality recording of BMI for people with a learning disability than for the control cohort.

Proportion on the learning disability register

To estimate the proportion of people on the learning disability register, we used the number of people on the learning disability register (338,195 people, recorded by the Quality and Outcomes Framework in 2021/22)[82] as the numerator and Mencap's estimate of 1.3 million people with a learning disability in England[1] as the denominator. This gave us an estimated 26% of people with a learning disability in England on the register. This estimation is very similar to what has been published in other sources.[30]

Percentage change in the number of learning disability nurses

To calculate the percentage change in the number of full-time-equivalent (FTE) learning disability nurses, we used the number of FTE learning disability nurses in 2010 and in 2022 – 5,274 and 3,037 respectively – giving a percentage decrease of 42%.

82 Office for Health Improvement & Disparities (various years) 'Public health profiles'. https://fingertips.phe.org.uk/search/learning#page/4/gid/1/pat/159/par/K02000001/ati/15/are/E92000001/iid/200/age/1/sex/4/cat/-1/ctp/-1/yrr/1/cid/4/tbm/1. Accessed 15 January 2024.

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- Langdon College, Edgware
- Learning Disabilities and Autism Liaison and Health Facilitation Team, East Sussex
- Learning Disability England
- Mencap
- NHS England.

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59 New Cavendish Street
London W1G 7LP
Telephone: 020 7631 8450
www.nuffieldtrust.org.uk
Email: info@nuffieldtrust.org.uk

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