Adults with Learning Disabilities in Leeds

Health Needs Assessment

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Foreword

In Leeds we have an ambition to be a healthy and caring city for everyone.

To reach this ambition, we need to understand the unique needs of our different communities by listening to their experiences and ideas.

The starkness of the inequalities that are highlighted throughout this Health Needs Assessment demands attention and action. Tackling these disparities requires a system wide approach, one that not only addresses barriers at a practical level but also challenges the social determinants that perpetuate this inequity.

There is a strong motivation in Leeds to improve this picture; dedicated teams of professionals and advocates across sectors are championing this cause, working to improve health outcomes for this group, who often face vulnerabilities. However a gap still remains. This paper was produced by Leeds Public Mental Health, with support from across the sector including people with learning disabilities and those who care for them, for whose support we are very grateful. It serves as both a reflection on existing inequalities and a call for continued efforts to ensure that people with learning disabilities have the health equity they deserve.

We would like to give thanks to everyone who has taken the time to share their views, experiences and ideas to improve health outcomes for people with learning disabilities. We are confident the data presented and recommendations made will inspire continued collective action and positive change with a greater understanding that having a learning disability is not inherently linked to poor health; rather it is the way society treats people with learning disabilities that contributes to their poorer health outcomes.

Executive Summary

The information brought together in this Health Needs Assessment provides a broad illustration of the health inequalities faced by people with learning disabilities in Leeds. It provides data around the population themselves, of their environments, living conditions and experiences, all of which impact on their health and wellbeing. It provides data around prevalence of health conditions and around treatment and care. It also provides discussion around some of the major issues that affect people with learning disabilities around accessibility, being heard and being involved, informed by voices of lived experience.

This Health Needs Assessment uses information gathered during 2023 and 2024 from a variety of sources including;

- Focus groups with people with learning disabilities and their circle of support.
- Primary and secondary care data and service access data.
- Interviews with professionals experienced in delivered services and support for people living with a learning disability.

Headline Findings

- It's believed that there are up to 12,000 people in Leeds living with a learning disability. This is far more than the 4,500 that are known to services – many people have no formal diagnosis and will live without support.
- People with learning disabilities have told us that they want to enjoy the same opportunities as those without learning disabilities, including living healthily and participating in society. Despite these aspirations, insights reveal that individuals with learning disabilities often feel they do not experience equality in these areas, telling us they feel discriminated against and even excluded, that there are fewer opportunities available for them, and they often don't feel listened to.
- People living with a learning disability are dying up to 20 years earlier than the general population, and more likely from an avoidable cause. They are more likely to live with more long-term health conditions and in generally poorer health.
- They are more likely to live in the more deprived areas of the city and with lower incomes, are therefore more likely to experience a range of associated disadvantages as a result.

A full list of recommendations can be found at the end of this paper.

Summary of Recommendations

Improvements to identification

Improvements to Identification: Address under-recording of learning disabilities on GP registers, especially among culturally diverse communities, through targeted campaigns to promote diagnosis and registration.

Annual Health Checks

Annual Health Checks: Enhance the quality and effectiveness of annual health checks by collecting detailed data, understanding communication needs, and ensuring appropriate follow-up actions.

Accessibility

Accessibility and Reasonable Adjustments: Ensure services are accessible by identifying and acting on communication and accessibility needs, raising awareness of reasonable adjustments, and integrating digital flags across health records.

Healthy Lifestyles

Supporting Access to Healthy Lifestyles: Improve accessibility of mainstream services and provide bespoke services for those with complex needs

Health Promotion

Health Education and Health Promotion: Promote healthy lifestyles with a holistic approach, involving trusted organisations, co-production, and training health champions to spread positive health messages.

Workforce training

Workforce Training: Provide quality training to health and social care workers to raise awareness of learning disabilities, improve communication, and reduce diagnostic overshadowing.

Anticipating population changes

Anticipating and Planning for Population Changes: Plan for projected changes in the population profile, including increased life expectancy and complexity of care needs, by integrating medically trained staff into supported housing.

Addressing Social determinants

Addressing the Wider Determinants of Health: Improve access to education, employment, affordable accommodation, and support for low-income individuals, while reducing stigma and improving understanding of learning disabilities.

Health protection

Health Protection: Adopt a whole-system approach to health protection priorities, such as seasonal vaccinations, and expand training around sepsis awareness.

Data collection

Data Collection: Improve data collection and separation of data on learning disabilities and autism to better understand health inequalities and inform service provision.

Contents

Introduction

What is a Health Needs Assessment (HNA)?

A Health Needs Assessment brings together data and insight around the health and wellbeing for a particular community who may experience health inequalities. The assessment can then illustrate and highlight specific issues that this group may face and consider some of the causes and factors that exacerbate these, forming conclusions and recommendations of work to address these inequalities.

The National Institute for Health and Clinical Excellence (NICE) describes a health needs assessment as a “systematic method for reviewing the health needs of a particular population, leading to agreed priorities and resource allocation, which will lead to improved health and reduced health inequalities”.

Why Undertake a Health Needs Assessment?

Adults with learning disabilities are people first, who should be valued and respected for their differences, who have the same rights as other citizens to healthcare, but who may have particular health needs.

Adults with learning disability are at increased risk of poor physical and mental health, are disproportionately affected by socio-economic disadvantage (including unemployment, poverty and social isolation) and have a significantly lower life expectancy than the general population. The failure of health and care systems to meet the complex needs of this population has been highlighted by a number of high profile reviews.

LeDeR (Learning from the lives and deaths of people with a learning disability and autistic people) programme data shows that people with a learning disability live with poorer general health, die at a much younger age than the wider population, and just under half of all of their deaths might have been avoidable. Some sub-groups of this population have even poorer health outcomes, including those from some culturally diverse communities.

There is evidence, nationally and locally, that people with learning disabilities suffer from the inverse care law and are not always able to access mainstream services whether this is in respect of general health promotion, disease prevention, screening or treatment.

In Leeds and West Yorkshire, there are considerable efforts underway to address these inequalities across the sector and this HNA is intended to support this work.

This HNA therefore aims to present data and insights to form conclusions with which to support further work to improve the health and wellbeing for people with learning disabilities in Leeds.

Scope and focus of this Health Needs Assessment

This report considers the needs of people known to have learning disabilities in Leeds, focussing predominantly on working age adults, but with the understanding that many health inequalities are present from childhood.

NHS England reports that around 29% of people with a (recorded) learning disability also have autism (compared to around 0.8% of the non-learning-disabled population) and around 30% of people with autism also have a learning disability (compared to around 0.5% of the wider population). Diagnosis of autism can often be made later in life, so these figures are averages across the ages of the population.

These are separate and distinct conditions and should be treated as such when considering data around health; despite facing comparable disadvantages, the specific needs of these two groups may be quite different- while these populations

are sometimes combined in reporting or referred to together, this HNA focusses primarily on the needs of people with learning disabilities.

Information used to build this report comes from a range of sources including local and national data; insight from people with learning disabilities, their carers and families; professionals and services who provide support and care to people with learning disabilities; as well as a range of recent reports and literature, local and national. Limitations or uncertainties surrounding data are outlined where possible.

Aim and objectives of the Health Needs Assessment

Main objectives:

- Estimate the current and future prevalence of people with learning disabilities in Leeds
- Collate data to illustrate inequalities in health outcomes for people with a learning disability
- Consider issues relating to availability, accessibility of services for people with a learning disability
- Highlight positive work and form recommendations around future opportunities.

The information included in this HNA represents a snapshot at time of publication; ideally this would be a cyclical process with data updated periodically, changes and progress noted and recommendations reviewed.

This HNA does not come with specific funding attached, but aims to make recommendations to reduce inequalities in the future.

This HNA may be of interest to anyone delivering, developing or commissioning services, especially if they are unfamiliar with the health inequalities experienced by people with learning disabilities.

Stakeholders

This HNA has been developed by Leeds City Council Public Health with support and valued input from a range of partners across the sector and those with living experience of learning disability.

National Policy and strategic context

In June 2015, NHS England commissioned the *National Learning Disability Mortality Review Programme* led by the University of Bristol, to review and learn from deaths

of people with a learning disability with the aim of improving services, care and support nationally. The Department of Health established a *Confidential Inquiry Into The Premature Deaths of People with Learning Disabilities (CIPOLD)*. The Inquiry investigated the avoidable or premature deaths of people with learning disabilities through reviews of reported deaths. The ongoing project investigates the causes of premature mortality and produces recommendations to reduce this.

The Government's Response to CIPOLD, stated that the Department of Health was committed to addressing the issues identified to improve the quality of care and outcomes for people with learning disabilities and family carers. The response set actions to be delivered by the Department of Health, NHS England, Public Health England and other statutory organisations, under each of the recommendations. Progress on these actions is monitored by the Learning Disability Programme Board.

The Government and NHS England have also committed to reducing the number of people with a learning disability placed in inpatient services. NHS England's *Transforming Care Programme* aims to improve the quality of life of those with learning disabilities by reducing the number of people placed in hospital, reducing the length of time spent as an inpatient, and improving the quality of both hospital and community settings. NHS England » Homes not hospitals

Local Policy and Strategic Context

The following strategies contribute towards improving the health and wellbeing of people with a learning disability;

The Leeds Best City Ambition – with its mission to tackle poverty and inequality and improve quality of life for everyone who calls Leeds home.

Leeds Health and Wellbeing Strategy – included as one of the '3 pillars' of the Best City Ambition with the vision that by 2030 Leeds will be a healthy and caring city for everyone, where those who are most likely to experience poverty improve their mental and physical health the fastest, people are living healthy lives for longer, and are supported to thrive from early years to later life.

Better Lives Strategy 2022 to 2027 (leeds.gov.uk): A vision that every person in Leeds that needs care and support can live in the place they call home- with the people and things they love, in communities that look out for one another, doing the things that matter most to them.

Many other organisations in Leeds will have their own learning disability strategy, for example NHS trusts.

Learning Disability and Neurodiversity Population Board

The Learning Disability and Neurodiversity Population Board brings together partners from across Leeds, to help tailor better care and support for individuals and

their carers, design more joined-up and sustainable health and care services and make better use of public resources to the benefit of people with a learning disability or who are neurodivergent.

Leeds Learning Disability Partnership Board

The Leeds Learning Disability Partnership Board meets quarterly and is made up of; councillors, commissioners from health and social care, people with learning disabilities, advocacy groups including family carers and the people's parliament, Forum Central and providers from statutory, third sector and public health services.

Purpose of the partnership board

- To make sure that people with learning disabilities are involved in making decisions which affect their lives.
- To check that people have the right services and that good quality support is in place
- To share information about the different things happening in Leeds
- Covers being well, being safe and being connected (travel, employment and social)

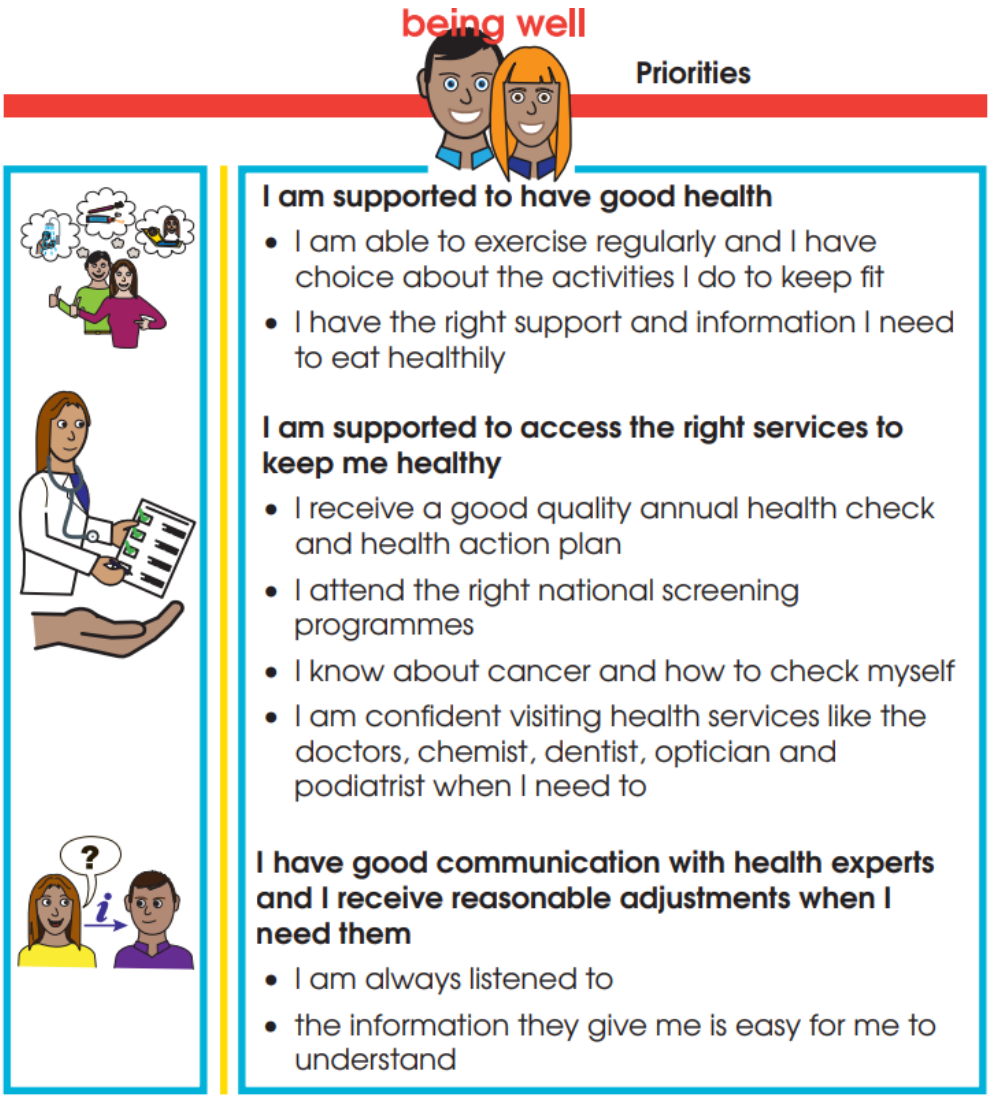
The board focuses its work around the Being Me Strategy (which is anticipated to be updated soon) and is the strategic board for learning disabilities in Leeds. The aim of the strategy is that Leeds is best city to live in for people with learning disabilities. The board supports Leeds Health and Wellbeing Board, Transforming Care Programme Board and the Being Me Project Team.

The strategic work is divided into task groups with themed leads: Being Well, Being Social, Being Safe, Employment and Travel. The Board has 2 Chairs – A Councillor from the local authority and a People's Parliament representative.

The aim is for people with learning disabilities to experience health and care that reflects these statements:

- I live well, defined by what matters to me.
- I receive high-quality, accessible, person-centred care and support.
- I am included in all decisions about my life.

The Being Well task group have identified the following priorities;



There is considerable ongoing work in Leeds to address health inequalities for people with learning disabilities; some examples are provided below however this is not an exhaustive list and does not capture the large amount of work taking place to reduce inequalities;

- The Health Facilitation Team at LYPFT work towards improving access and outcomes for people with learning disabilities, as well as providing training and resources including the useful Get checked out website which offers accessible resources and information around health.
- Improvement of accessible communication to patients, for example easy read letters around appointments, screening invitations and prescription labelling
- “Get Me Better Champions” - people with learning disabilities, employed by LTHT to support newly admitted patients with learning disabilities, ensuring that reasonable adjustment requirements are asked, understood, documented and actioned.
- Supporting and promoting the effective use of hospital passports (system-wide health passport for people with a learning disability) that is understood

and used by all services, including ambulance services, so that if a person needs to go into hospital or receive urgent treatment their main health needs and concerns can be readily understood even if their clinical notes are not easily available. The Hospital Passport (leedsth.nhs.uk))

- Surgical prioritisation support

Third sector organisations in Leeds such as People Matters, People in Action and others, as well as the Leeds and York Partnership Foundation Trust provide invaluable support for people with learning disabilities via targeted, accessible promotion of health messages and evidence-based health and wellbeing programmes, within trusted environments and by people known well to the service users. The sector also facilitates advocacy and involvement work in the city as well as a variety of other activities to enrich people's lives, helping to address the wider determinants of health discussed in this HNA.

Other health promotion work is undertaken in community settings, for example the Living Well cafes where accessible health messages are shared (for example around diabetes or vaccinations), reaching communities that might otherwise be missed.

Voices of people with lived experience

In researching this report, existing insight from people with learning disabilities was examined. Insight was also sought from people from across the sector, and people with learning disabilities as well as their carers. We are grateful for their time and expertise in supporting this report.
Clear themes emerged when talking to people about their own experiences.

What are priorities for people with learning disabilities?

- Being listened to and taken seriously, and requests acted on – many people felt they were asking repeatedly for something such as a reasonable adjustment or having to tell the same story many times to different services, and not feeling believed. Receptionists at times felt like gatekeepers to appointments, and people often reported the need to get someone else to be an advocate or to get noticed.
- Transport – buses and taxis – this is a huge issue – many people cannot travel independently. Taxis in Leeds are expensive, unreliable, and hard to get first thing in the morning. This is even harder for those who also have physical disabilities.
- Lack of opportunities for activities, fun, socialising etc. Or not enough hours with support to access them. Some service users reported to have dropped out of services due to feeling they were too expensive (Financial Assessed Charges)
- “Funding (or the lack of it) determines everything”.
- The importance of bespoke services and approaches – everyone is different and two people’s experience of a learning disability could be completely different. Easy Read is great but is not a one-size fits all solution – its far beyond the needs of some people and may feel patronising to others. Some people preferred Makaton.
- Availability of GP and dentist appointments, although a universal concern at the moment, caused significant anxiety.

What feels supportive for good health?

- People highlighted that professionals seemed to either “get” learning disabilities or they didn’t. When people received good care, or felt practitioners were listening to them, they were very positive about the experience. People shared stories of practitioners using creative methods to explain complex procedures, such as mannequin dolls, and others talked about how their GP always booked them a double appointment without asking.
- When people spoke about their health, they mentioned socialising, family, learning and being active rather than talking about a medical view of health. There was a huge enthusiasm for attending activities and groups, and enjoyed activities that were fun as well as healthy.
- The feedback around relationships with staff in support roles and third sector organisations was incredibly positive and felt to be supportive.
- There was real positivity about opportunities to feed into service design and to be part of involvement groups, and lots of passion about improving outcomes.

What doesn't currently work – what are the frustrations / barriers?

- Some people described their Annual Health checks in very inconsistent ways and people's awareness of them was very varied.
- Online systems (for example for booking appointments, or sending in photos to a doctor) including those navigated on a smartphone felt confusing and inaccessible. People wanted alternatives.
- Fear and anxiety around health options – people talked about feeling overwhelmed with messages about things being "bad for them". Others felt like they were told what to do, when they wanted to have agency over their own choices. Some health messages or the relative levels of risk appeared to have been misunderstood.
- It was striking how many people we spoke to had suffered adverse life experiences or traumatic events, including close bereavements, domestic abuse, exploitation, discrimination. Many others talked of living with complex health problems including serious mental illness such as schizophrenia that affected their day to day living.
- Diagnostic overshadowing came up a few times, for example one woman explained how she failed to have her early menopause identified for several years, her doctors apparently talked of her Down's syndrome as though it overrode all other changes in her body.
- Carers expressed concerns about the "dropping off" of services (eg those dependent on an EHCP) when the person they cared for reached an age where the services would no longer be available – there was significant concern about how to meet their needs in the absence of these services.
- Carers described feeling like a forgotten group, under-supported, isolated and with far too much sole responsibility for the complex needs of the person in their care, as well as dismayed and frustrated about the availability of meaningful / quality options and "life opportunities" for the person in their care
- Availability and quality of personal assistants and respite care was sometimes described in ways that suggested care was felt to be inconsistent, unreliable or disappointing.
- People with mental health concerns reported ending up in a loop, bounced between services because the label "learning disability" seemed to put clinicians off from referring them into mainstream support services, and ending up being referred back to where they started.
- People described frustration that they, as people with lived experience were being asked to share experiences via insight gathering exercises, and the issues being well known in the sector as a result, but then nothing improving.

Further learnings

- A significant amount of of the insight came from existing groups – it was easier to talk to people in their familiar, trusted environments where they were already meeting. To improve learning it would be good to widen the breadth of people approached.

- Many of the people we spoke to were already engaged with groups and so more likely to be articulate about expressing their needs
- People from culturally diverse communities were underrepresented in the groups we visited.

Population Data and Prevalence

Definitions and terminology

A learning disability can be described as:

> *"…a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people." (Mencap, 2022).*

The Department of Health and Social Care defines a learning disability as:

> *"A significant 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"*

The National Institute of Health and Care Excellence (NICE) states more specifically that:

> *"Learning disabilities are heterogeneous conditions, but are defined by 3 core criteria: lower intellectual ability (usually defined as an IQ of less than 70), significant impairment of social or adaptive functioning and onset in childhood"*

The above definitions lean towards the medical model of disability which view people as disadvantaged by their own impairments.

The Social model of disability sees people as being disabled by barriers in society, rather than their own impairments, and sees the world from their point of view. Third sector organisations tend to follow the social model of disability which has more positive outcomes for the people the support.

A number of things can contribute to learning disabilities including genetic conditions, labour complications, maternal infections during pregnancy, maternal lifestyle/behaviour, and early childhood infections.

A learning difficulty is not the same as learning disability. 'Learning difficulty' is often used in educational settings and refers to individuals who have specific problems with learning, such as dyslexia or dyscalculia.

The term learning disability is wide and covers a spectrum of conditions; while some people who have a learning disability may live independent lives, others may require 24-hour care.

Prevalence

There is no definitive record of the number of people with learning disabilities; data available relies on a diagnosis having been made and recorded (Hatton Emerson et al., 2013).

It is a challenge to know the exact number of people in Leeds with learning disabilities. Leeds primary care data records show that around 4,500 people are registered on GP learning disability registers, which suggests a prevalence of around 0.5% of the population. However, this "administrative prevalence" is thought to be an underestimate of the true prevalence.

Many people are not registered with a GP, while others who are, may have no diagnosis recorded, and further to this, GP records are occasionally incomplete. This picture is similar nationally. (People with learning disabilities in England 2015: Main report (publishing.service.gov.uk))

One alternative way of estimating how many people have a learning disability in a population is by examining how many people access services which relate to learning disabilities. This figure is notably higher in children (~2.5% of the population) and drops off as adulthood is reached to around 0.6%. *(IHAL, 2012).* This could potentially be due to the number of services available, and eligibility, amongst other reasons.

More evidence on the information deficit comes from the "Understanding Society Survey" (2024) a longitudinal study which followed the lives of 40,000 UK households and collected information to provide valuable evidence about 21st century life. Although it did not directly assess learning disability, the study identified a significant subgroup of people likely to have an undiagnosed learning disability through a combination of self-reported educational attainment and scores on cognitive tests.

Mencap estimate that approximately 2.16% of adults in the UK are believed to have a learning disability. How Common Is Learning Disability In The UK? How Many People Have A Learning Disability? | Mencap

[Health inequalities and the 'hidden majority' of adults with learning disabilities – UK Health Security Agency (blog.gov.uk)]

Projecting Adult Needs and Service Information (PANSI) combine information collected by government departments on the presence of learning disabilities among people using services and make overall population predictions for England and the results of epidemiological research. Projections from PANSI (Figure 1) estimate 14,925 adults have a learning disability in Leeds (ages 18+), of which around 12,327 are projected to be aged 18-64 (where the population of this comparable age group in Leeds is 500,100)

This suggests an estimated prevalence in the adult population in Leeds of around 2-2.5%.

	2020
People aged 18-24 predicted to have a learning disability	2,763
People aged 25-34 predicted to have a learning disability	3,023
People aged 35-44 predicted to have a learning disability	2,409
People aged 45-54 predicted to have a learning disability	2,217
People aged 55-64 predicted to have a learning disability	1,915
People aged 65-74 predicted to have a learning disability	1,451
People aged 75-84 predicted to have a learning disability	831
People aged 85 and over predicted to have a learning disability	316
Total population aged 18 and over predicted to have a learning disability	**14,925**

Figure 1: PANSI Estimates of numbers by age for those in Leeds with a learning disability; (PANSI [Projecting Adult Needs and Service Information System (pansi.org.uk))]

This discrepancy suggests that there are a significant number of people in Leeds who may have a learning disability, but have either not had a diagnosis, or whose diagnosis is not recorded on their GP records. The implication for the individual is that they will not be eligible for, or receiving services that could be of benefit to them (for example the Learning disability Annual Health Check or certain vaccinations).

This "hidden majority" of adults with learning disabilities may remain invisible in data collections, so services commissioned aimed at meeting the needs of this population may not reflect this need, despite that this group may still have unmet needs and face significant disadvantages in life.

There are many reasons for this under reporting. The following non-exhaustive list of potential reasons have been collated through speaking to professionals, conversations with service users and literature:

- Some people may not seek a diagnosis for themselves or for someone they care for, they may not be aware of (or may not wish to have) additional support or contact with services. Older people may have managed without a diagnosis all their life.
- There can be significant stigma around labelling learning disabilities, both for the individual and for family members, who may feel uncertain about the benefits of a formal diagnosis.
- Some patients may not have had an opportunity to disclose a learning disability to their GP or have ever been offered a diagnosis. Some people may not have had much contact with primary care, or be registered with a GP at all, this is more common in some parts of the population than others, for example recent arrivals to this country, or people from Gypsy and Traveller communities.
- Some patients living with health conditions that tend to have an associated learning disability, may have not had the learning disability separately coded – in Leeds, significant work is underway to "clean" these records. Notably the reverse can also be true, and sometimes learning difficulties can be incorrectly recorded as learning disabilities.
- Inconsistency in diagnostic methods and diagnostic overshadowing; learning disabilities can be harder to diagnose correctly (particularly in children) when accompanied by other conditions including autism, other neurodivergences, or mental health problems including particularly trauma.
- Potentially, special educational needs (SEN) identified while someone is within the education system might not always lead to a learning disability diagnosis being considered – if this is not reviewed before transition there may be a missed opportunity to identify a learning disability prior to adulthood.

This means we may lack data and insight into a large part of this population. While some may be those with mild to moderate learning disabilities who may be living fairly independently, it could also include those who are cared for by their families with little involvement of services.

When parts of the population are under-represented in learning disability data, this leads to an "identification deficit". As well as those people not receiving services or support which might impact on their quality of life, we will also have less insight into their needs.

It is important to keep in mind that people with learning disabilities who are not known to specialist services (more likely to be those with milder disabilities) may still have some significant support needs. In a follow-up of the National Child Development Study cohort (2005) to age 33, people with mild learning disabilities were significantly more likely than their non- learning-disabled peers to be still living

with their parents, be unemployed, have literacy and numeracy problems and to experience high levels of psychological distress.

While many people with a learning disability may remain unknown to health and social care, often they will only begin to access help and support when their family/carers become too old or frail to provide the support that they need.

Diagnosis

Diagnosis is often undertaken by a psychologist and is centred on the results of an IQ test. There is some movement towards a more functional skills model, as an IQ test itself may rely on the user being able to interpret the written questions and may not be considered an accessible test for everyone; however the functional skills model considers factors which could be impacted by trauma, Adverse Childhood Experience or Neurodivergence, and therefore make an isolated diagnosis more challenging.

Severity Category	Approximate % distribution by severity	Severity level based on IQ	Severity classified on the basis of daily skills
Mild	85%	Approx IQ range 50 – 69 (roughly corresponds to a child of 9-12 years)	Can hold conversations, communicate needs and live independently with minimum levels of support. May need assistance with complex issues.
Moderate	10%	Approx IQ range 36 – 49 (roughly corresponds to a child of 6-9 years)	Able to communicate socially and carry out day to day tasks with some support. Independent living may be achieved with moderate levels of support e.g. in group homes
Severe	3.5%	Approx IQ range 20 – 35 (roughly corresponds to a child of 3-4 years)	May have very basic language skills and communicate with hand gestures and words. Likely to also have some medical / physical health needs. Requires daily assistance with self-care activities and safety supervision
Profound	1.5%	Approx IQ range <20	Will have significant difficulty communicating and limited understanding. Can be non-verbal, more likely to exhibit behaviour that challenges. Requires 24 hour support/ care

Figure 2: ICD1-10 Categories of learning disability, prevalence, and IQ threshold.

Figure 2 gives the categorisations of learning disability provided by the ICD-10 (The World Health Organisation's International Classification of Diseases - a globally used medical classification used in epidemiology, health management and for clinical purposes.).

Primary care data records for Leeds (Figure 3) shows the different terminology used for different severity of learning disability, some of these categorisations are outdated and are no longer used but may remain on patient records.

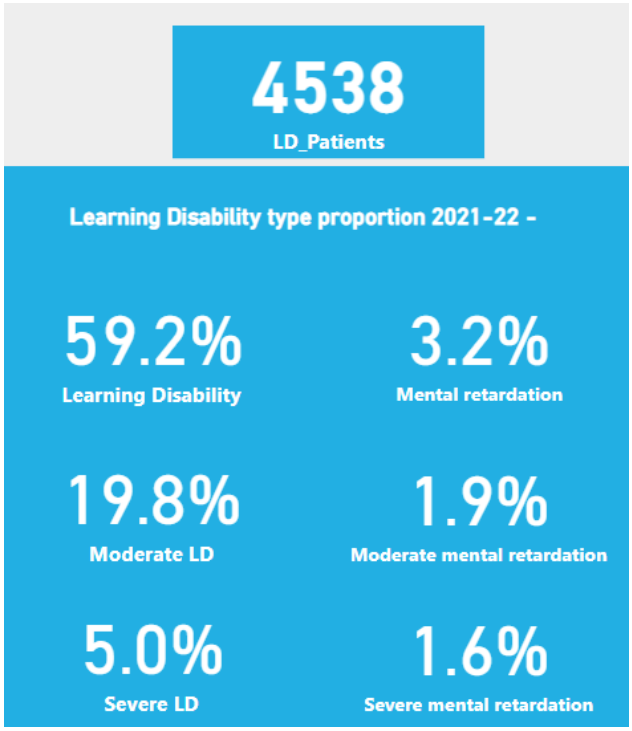


Figure 3: Prevalence of different categories of learning disability, Leeds Primary Care data, 2023

Despite the different categorisations used in Figure 2 and 3, both show that there is a significantly higher number of people living with a mild learning disability compared with moderate or severe. It is therefore likely that there are many people in Leeds who may have a mild form of learning disability but without a diagnosis and may be living independently and "under the radar" of many services.

Risk factors/ causes of learning disabilities

Learning Disabilities are caused by something affecting the development of the brain. This may occur before birth (prenatally), during birth, or in early childhood up to age 18 years.

Medical diagnoses associated with learning disabilities include Downs syndrome, Global developmental delay, Fragile X syndrome, Williams Syndrome, SYNGAP1,

and cerebral palsy. A proportion of people who have autism and Asperger syndrome or display challenging behaviour also have learning disabilities. (Mencap 2023)

Risk factors for the development of learning disabilities can include illness or infection during pregnancy, oxygen deprivation during birth, an infection such as meningitis or injury in early childhood, and certain genetic disorders.

The Leeds Best Start Plan 2015-2019 describes a broad preventative programme from conception to age 2 years which aims to ensure a good start for every baby and includes work around healthy pregnancy. The best start plan links to the Leeds Maternity Strategy 2021-25 which explains how people will work together to improve the health and care services offered to parents to be and new parents to give babies the best start in life.

With improvements in survival for pre-term babies and among infants with brain injury or illness, the prevalence of cohort with learning disabilities is projected to increase.

Learning Disability Population Data

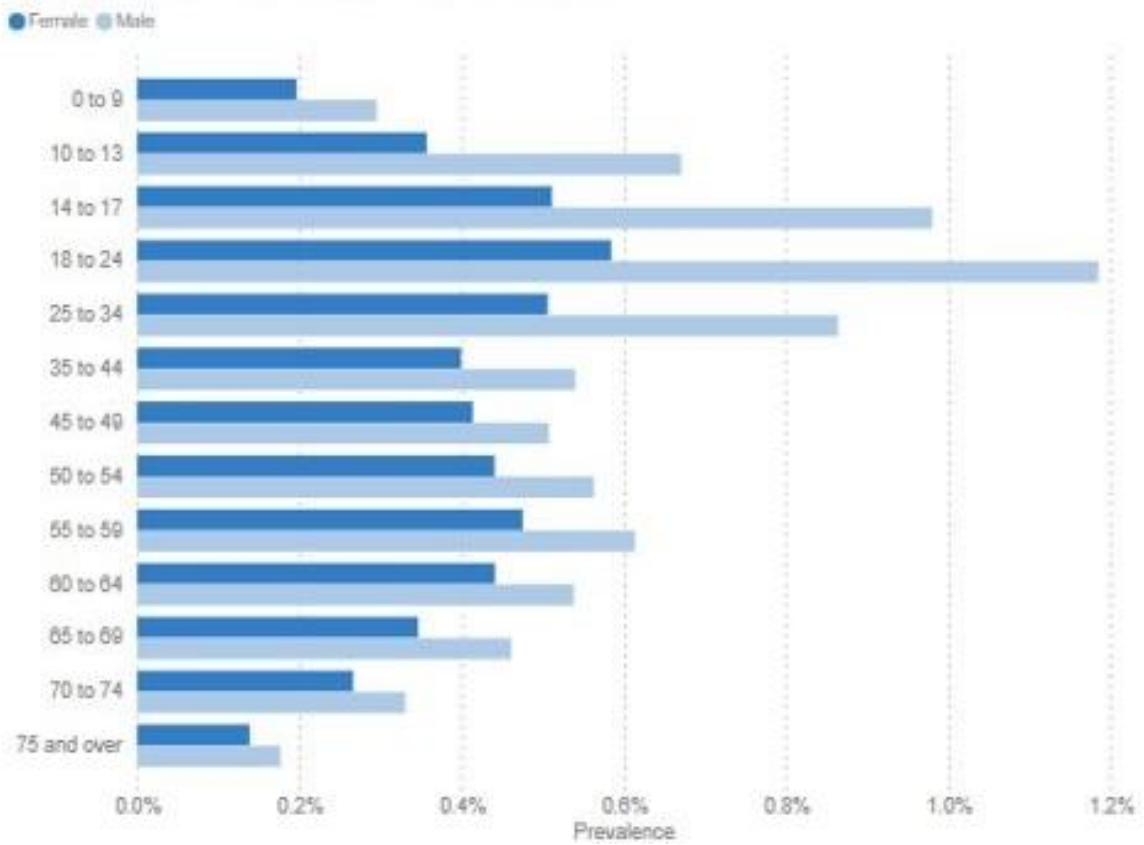


Figure 4: Percentage of patients with a learning disability by age and sex, NHSE: Health and care of people with learning disabilities – experimental data (England data, 2020/21)

Figure 4 provides population data for England whereas figure 5 provides data for Leeds- although both use primary care data, the local data in figure 5 has better patient coverage due to the GP systems from which the data is collected. The data are from one year apart but should still be reasonable comparable.

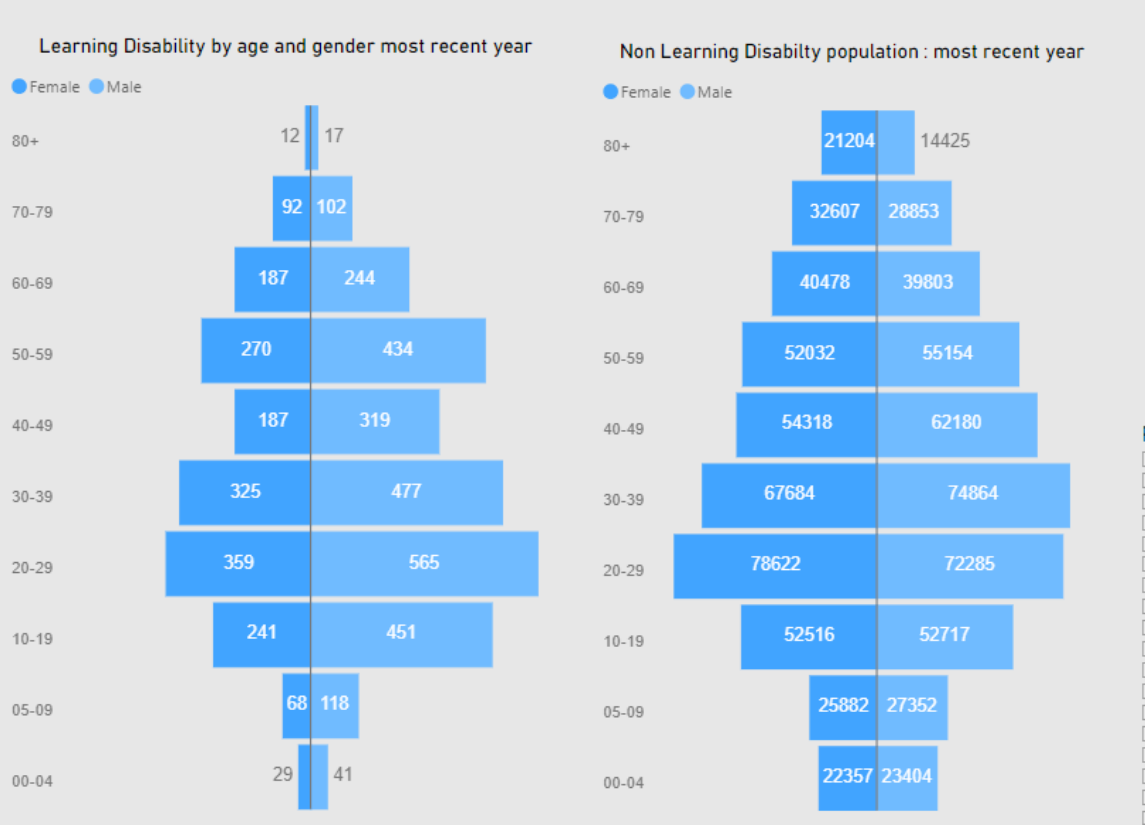


Figure 5: Number or patients with and without Learning Disability in Leeds, by age and gender (Leeds Primary Care data – December 2021/22)

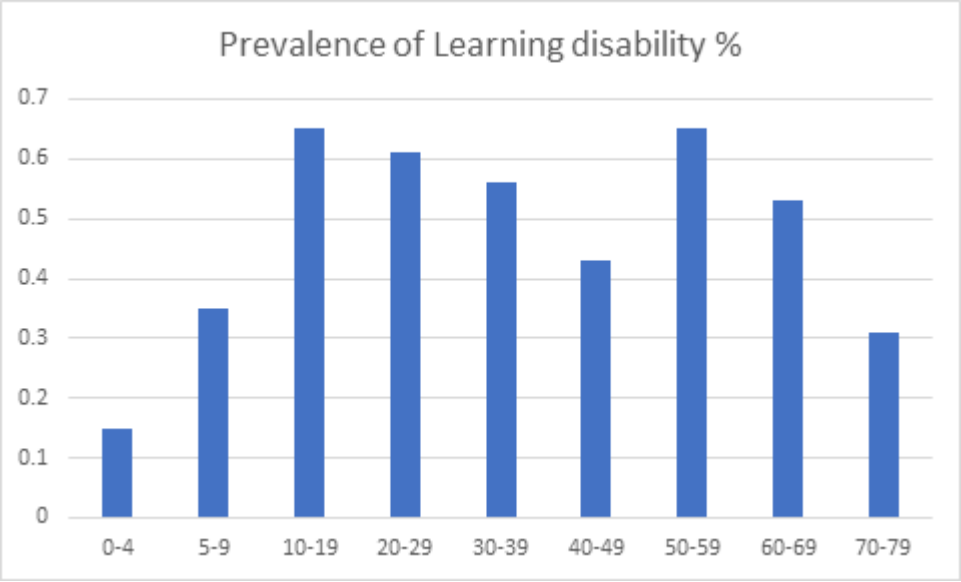


Figure 6: Prevalence of learning disability in Leeds by age band (NHS primary care data 2022)

Figure 6 shows that prevalence varies by age and is highest in the 50-59 and 10-19 age groups. Prevalence is generally higher in the male (around 0.6%) than the female (around 0.4%) population of Leeds. The age band of 80+ has been omitted due to small numbers.

Prevalence is significantly lower in younger age groups as this may be prior to individuals receiving a diagnosis. Prevalence could also show as lower in older age bands, due to the lower average life expectancy for someone with a learning disability, so this data should be viewed with caution.

Where People Live

There is not a strong correlation between geographical location and prevalence of learning disability; people live in all parts of Leeds, some with family, some independently and some within supported accommodation (located in many parts of the city); data may therefore reflect where supported accommodation is provided resulting in clusters. Prevalence of learning disabilities are higher in more deprived areas of Leeds however. This is explored further in this section.

Future Projections

There is a continuing rise in the number of people in Leeds recorded as having a learning disability, as demonstrated by figure 7. This is mainly due to considerable efforts undertaken in Leeds to increase GP recognition of patients who have a learning disability.

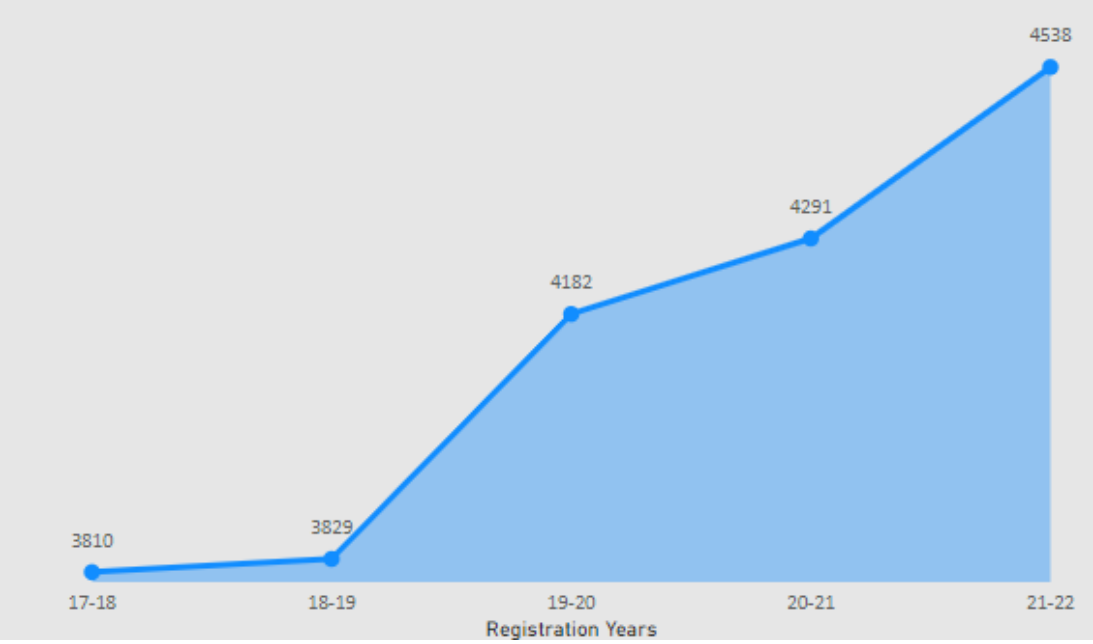


Figure 7: Learning disability population - trend by financial year: Leeds Primary Care data (December 2023)

Historically numbers have increased; the population of people with learning disabilities in England grew by 53% over the 35 year period 1960-95. These changes are largely the result of improved socioeconomic conditions, intensive neonatal care, and increasing survival, as well as increasing identification. *(BMJ, 2004* People with intellectual disabilities)

Ongoing improvements to healthcare and life expectancy will continue to change the population profile; people with learning disabilities may live increasingly longer lives, some with complex health conditions.

Figures from PANSI in Figure 8 also support the anticipated rise in prevalence in Leeds.

	2020	2025	2030	2035	2040
People aged 18-24 predicted to have a learning disability	2,763	2,816	3,141	3,215	3,033
People aged 25-34 predicted to have a learning disability	3,023	3,030	2,866	2,993	3,225
People aged 35-44 predicted to have a learning disability	2,409	2,456	2,545	2,536	2,401
People aged 45-54 predicted to have a learning disability	2,217	2,061	2,058	2,122	2,192
People aged 55-64 predicted to have a learning disability	1,915	2,001	1,915	1,781	1,786
People aged 65-74 predicted to have a learning disability	1,451	1,425	1,562	1,653	1,599
People aged 75-84 predicted to have a learning disability	831	969	1,018	1,038	1,168
People aged 85 and over predicted to have a learning disability	316	344	372	463	489
Total population aged 18 and over predicted to have a learning disability	**14,925**	**15,102**	**15,476**	**15,801**	**15,893**

Figure 8: Projected numbers of adults living in Leeds with a learning disability PANSI (2023)

The Learning Disability Observatory estimated future need for social care among adults with Learning disabilities in England, key points being:

- All scenarios suggested sustained growth in the need for social care services for adults with learning disabilities over the full time period considered, with estimated average annual increases varying from 1.2% to 5.1% (average 3.2%)
- Approximately 25% of new entrants to adult social care with learning disabilities will belong to culturally diverse communities.
- Approximately one in three of new entrants will coming from a home in which the child is eligible for Free School Meals (nationally one in six children in this age range are eligible for Free School Meals)
- By 2030 the number of adults aged 70+ using social care services for people with learning disabilities will more than double.
- Changes in demand (as distinct from need) are likely to increase faster than changes in need due to a variety of factors combining to reduce the capacity of informal support networks to provide care; networks that have primarily relied on the unpaid labour of women. These factors include:
    - Increases in lone parent families
    - Increasing rates of maternal employment
    - Increase in the percentage of older people with learning disabilities (whose parents are likely to have died or be very frail)

- Changing expectations among families regarding the person's right to an independent life

(Emerson E, Hatton C. Estimating Future Need for Social Care among Adults with Learning Disabilities in England: An Update. Learning Disabilities Observatory. 2010.)

Ethnicity

Figure 9 shows the ethnicity of people in Leeds with and without learning disabilities. This demonstrates that white British people are more likely to be recorded as having a learning disability than some other culturally diverse backgrounds.

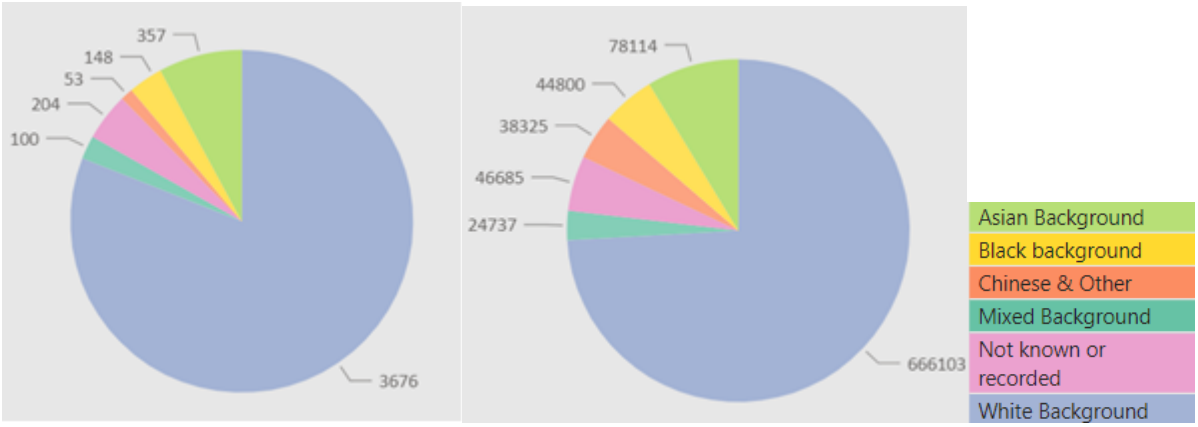


Figure 9: Population of Leeds with (left) and without (right) learning disabilities, by ethnicity (Leeds primary care data 2022)

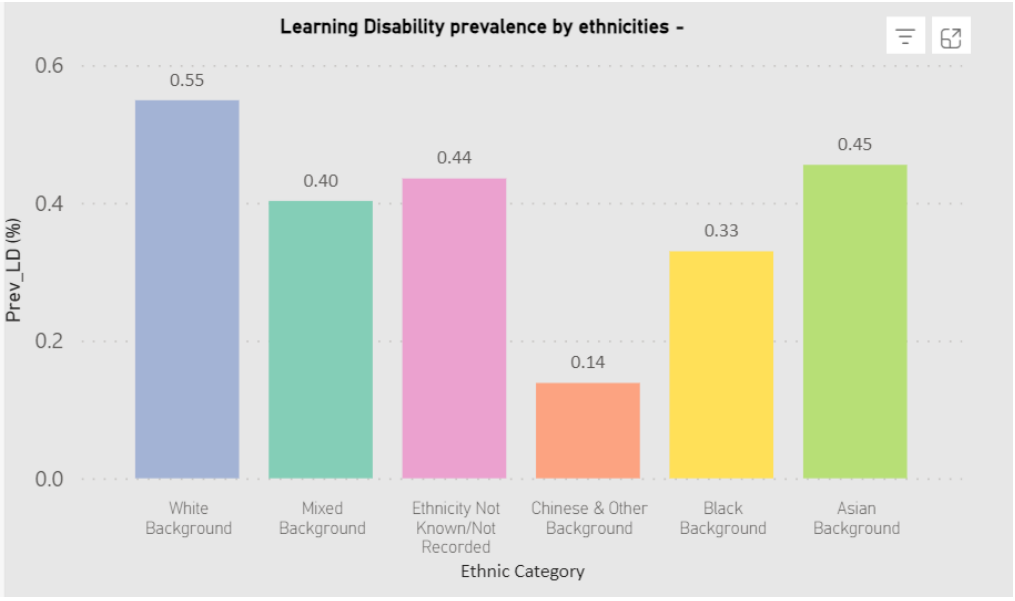


Figure 10: Learning disability prevalence by ethnicity: Leeds primary care data, December 2023,

Figure 10 presents the same data differently, demonstrating the inconsistency in recorded prevalence of learning disability across different ethnicities.

This indicates that people from certain ethnic backgrounds (notably Chinese/ other and Black) are less likely to have a learning disability recorded than their white counterparts.

This is not necessarily due to actual variations in prevalence by ethnicity, but rather could indicate an "identification deficit" for certain groups; under-reporting or under-diagnosis may disproportionately affect people from some communities, who are then under-represented in all the other data held around learning disabilities.

Those living with an unrecorded learning disability will not be offered interventions or support aimed at improving their health - from vaccinations to annual health checks, or even potentially financial support via welfare benefits, which could exacerbate inequalities further.

Around 1 in 20 people in Leeds who have a learning disability recorded in primary care records, do not have their ethnicity recorded. The issue of practice data quality is a wider issue; a recent study in Lancashire to cross reference census data with GP-held ethnicity coding for patients with learning disability, found that 8% of entries contained no code at all, but only 73.4% of those that did were valid according to the NHS data dictionary and there was a wide discrepancy in data quality between different areas. Data should therefore be used with caution.

The West Yorkshire “Learning from lives and deaths – People with a learning disability and autistic people” (LeDeR) annual report 2021/2022 reviewed 127 reported deaths. Over 100 or 85% were of White British ethnic background. The population of West Yorkshire is 76.6% White British, which suggests that those from non- white backgrounds and their health needs are less represented in this report.

The CIPOLD report similarly over-represents white British people in the reporting, which means less can be learned about those from other ethnic backgrounds*:*

> *Ethnicity; Almost all (96%) of the people with learning disabilities were of white UK ethnicity, the remaining 10 people being described as being of Irish, non-UK white, Gypsy and Traveller, Pakistani, African or Caribbean backgrounds. This is a significant under-representation of people from non-white UK ethnicity in CIPOLD, and the findings of this Confidential Inquiry should be interpreted with this in mind.*
>
> fullfinalreport.pdf (bristol.ac.uk)

This implies that we cannot accurately determine potentially what services, support and treatment programmes people with learning disabilities and from culturally diverse communities are accessing, we will have missing information regarding the health issues and barriers that are impacting them specifically; and in the case of LeDeR the causes of early death.

There are differences in the prevalence of learning disability among some culturally diverse communities, for example, higher rates of identification of more severe forms of learning disability have been documented among children of Pakistani and Bangladeshi heritage.

> *"Minority ethnic status was, in general, associated with lower rates of identification of intellectual and developmental disabilities. Exceptions to this general pattern included higher rates of identification of less severe forms of intellectual disability among Gypsy/Romany and Traveller children of Irish heritage, and higher rates of identification of more severe forms of intellectual disability among children of Pakistani and Bangladeshi heritage."*

Deprivation, ethnicity and the prevalence of intellectual and developmental disabilities (Emmerson, 2012)

There is little data available specific to Leeds around this area.

One recent LeDeR report suggests that men from an 'Asian/Asian British' background with profound and multiple learning disability had a median age at death at around 30, the lowest median age at death of all groups. This picture may change from year to year as it's a snapshot in time and the sample size is small.
In comparison, for 'White British' males with profound and multiple learning disability the median age at death was 59 (Heslop et al., 2020).

"*People with a learning disability from a minority ethnic background have a life expectancy of just 34 years—around half that of their white counterparts - who on average live to 62*" "We Deserve Better" report by the Race and Health Observatory Report, published in the BMJ.

There is a well acknowledged intersection between ethnicity and disability, two marginalised identities in society, resulting in compounded discrimination. Such discrimination exacerbates inequalities in relation to health outcomes and healthcare among people from culturally diverse communities with a learning disability.

Conclusion

Further work is recommended to gain insight into why some communities in Leeds are underrepresented in primary care data for learning disabilities, and a focus on increasing the identification of culturally diverse communities on GP Learning Disability registers.

LeDeR data shows that people from culturally diverse communities experience greater health inequalities than the rest of the learning disability population and are dying younger - the lower number of people from non-white backgrounds identified to the LeDeR programme reduces certainty about their specific health inequalities, so this is particularly important to address.

The accurate collection and coding of ethnicity data relating to people with a learning disability in health care records is essential to improve understanding of health inequalities.

More accurate data collection around ethnicity would help inform this further, particularly to help an understanding of more defined groups; for example, the umbrella category “Asian”, covers a wide range of ethnicities who may experience very different inequalities.

Studies such as LeDeR reviews should aim to reflect the demographics of the local population, so awareness of the LeDeR programme should be promoted within underrepresented communities.

Further understanding should be sought of the needs of people with a learning disability from culturally diverse communities. This should also include the range of challenges faced by their carers which may affect their wellbeing.

This connects to work in improving recognition, diagnosis and removing stigma in some communities where learning disabilities are less likely to be recorded.

The LeDeR Review - Mortality, Avoidable Death and Quality of Care for People with Learning Disabilities and Autism

The Learning Disabilities Mortality Review (LeDeR) programme was established in 2016 following one of the key recommendations from the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) in 2013. CIPOLD identified that many people with a learning disability were dying earlier than they should from preventable health conditions, and up to 30 years earlier than the remainder of the population. LeDeR is a national NHS England service improvement programme for people with a diagnosis of a learning disability, autism, or both.

In January 2022 the West Yorkshire LeDeR Programme was updated to include a diagnosis of autism; although the number of deaths of autistic people reported to the review is still relatively small.

The LeDeR review provides an illustration of the health and care of adults who died during a defined time period, had a learning disability or autism, and whose deaths were reported to the review.

As of 1st July 2023, LeDeR policy relating to the deaths of children and young people under the age of 18 has changed. There is no longer any requirement for deaths of children with a learning disability to be notified to LeDeR; these would be reviewed separately under the Child Death Overview Panel (CDOP).

The deaths reported under LeDeR may not provide a full representative picture of all the deaths of those eligible to be included. It may be more likely that deaths would be reviewed if the person was well known to services, had significant health issues or complex care needs, or if concerns were raised, than if they were someone less known to services. Not all deaths will be included in this review, due to delays in reporting, declines by family and capacity of reviewing team. Those without a recorded diagnosis would not be included.

The West Yorkshire review data is split into two parts relating to the date of the review being completed, hence comparisons are difficult. Of the 81 notifications of deaths, 33 were of deaths from 2022-23 in West Yorkshire, and the remainder were of deaths from previous years where the review was delayed. The data produced as a result therefore can vary and comparisons with other time periods should be made with caution – age at death can vary therefore depending on which reviews were considered in the review.

The last national review was 2022 (published 2023: Master LeDeR 2023 (2022 report) (kcl.ac.uk), This covered 2084 deaths.

The latest West Yorkshire review was published 2023:LeDeRWYICBannualreport22-23Report_FINAL2.pdf (wypartnership.co.uk), this covered 158 deaths.

Life expectancy and summary of health

Nationally, the average age of death in the UK is 82 years for males and 86 years for females. Nationally, the average age of death for people with a learning disability is 66 for males and 67 for females. *(National Life Tables – life expectancy in the UK – Office of National Statistics (ONS))*

The WY LeDeR report gives information on average age of death, for those people whose death was reported. The review also receives some reviews with delayed reporting, leading to two slightly different data sets.
There are therefore several different average ages of death in various data; some of the data is not comparable as it relates to different time periods, and some data sets only include adults.

Age of Death, West Yorkshire	**Gender**	
	Male	**Female**
Bradford District and Craven	48	54
Calderdale	66	61
Kirklees	63	61
Leeds	51	55
Wakefield	51	60
Total	**58**	**56**

Figure 11: Average age of death across West Yorkshire, and at place: The 2022-23 West Yorkshire LeDeR review (out of 158 deaths reported to the review). *Note that the data in this table has been corrected since the review was published, to correct the average on the bottom line from 54 to 58.* This data only includes deaths of those aged over 18; inclusion of deaths of children would bring down the average age of death.

There is a variation in the age of death across the West Yorkshire region, particularly the lowest age in Bradford District and Craven.

The numbers included in this review are small therefore comparisons should be considered with caution and recognition that figures fluctuate annually.
Despite the difficulty in ascertaining average age of death for this population, the wider picture remains that people with learning disabilities and autism die at a younger age than the wider population, even when deaths under 18 are excluded.

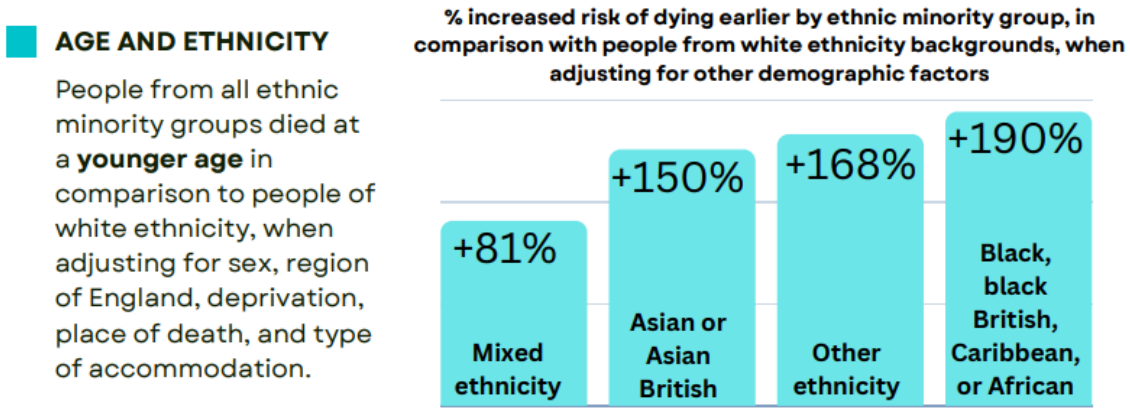


Figure 12: Age of death and ethnicity (LeDeR West Yorkshire)

The deaths examined in the West Yorkshire LeDeR review were recorded as 82.7% white British; however 77% of the population of West Yorkshire identifies as “white British”, this suggests that reviews of deaths of those from other ethnic backgrounds may be under-represented in this review.

The national LeDeR review noted that 94% of deaths it reviewed were of people who identified as white, which may also indicate an over-representation of people of white British background in the national review.

Work is under way to improve how representative the reviews undertaken are of the population; under-identification (due to under diagnosis) of people with a learning disability from culturally diverse communities remains one cause of this, another cause could be that deaths of non-white people are less likely to be reviewed. Deeper understanding around this issue may help to diversify reviewing process.

People from non-white British backgrounds have the poorest outcomes of all groups, with the life expectancy for male, South Asian, learning-disabled people estimated at under 50 years.

Significant work has been undertaken in Leeds to promote the LeDeR programme, across the learning disability and autism sectors and to Medical Examiners (who are notified of all community deaths that do not go to the coroner)

Quality of Care and Avoidable Deaths

A higher proportion of adults with learning disabilities (42%) die from avoidable causes than the general population (22%). (LeDeR 2022, National data) – this represents a reduction from the 2021 data where 50% of deaths were found to be avoidable.

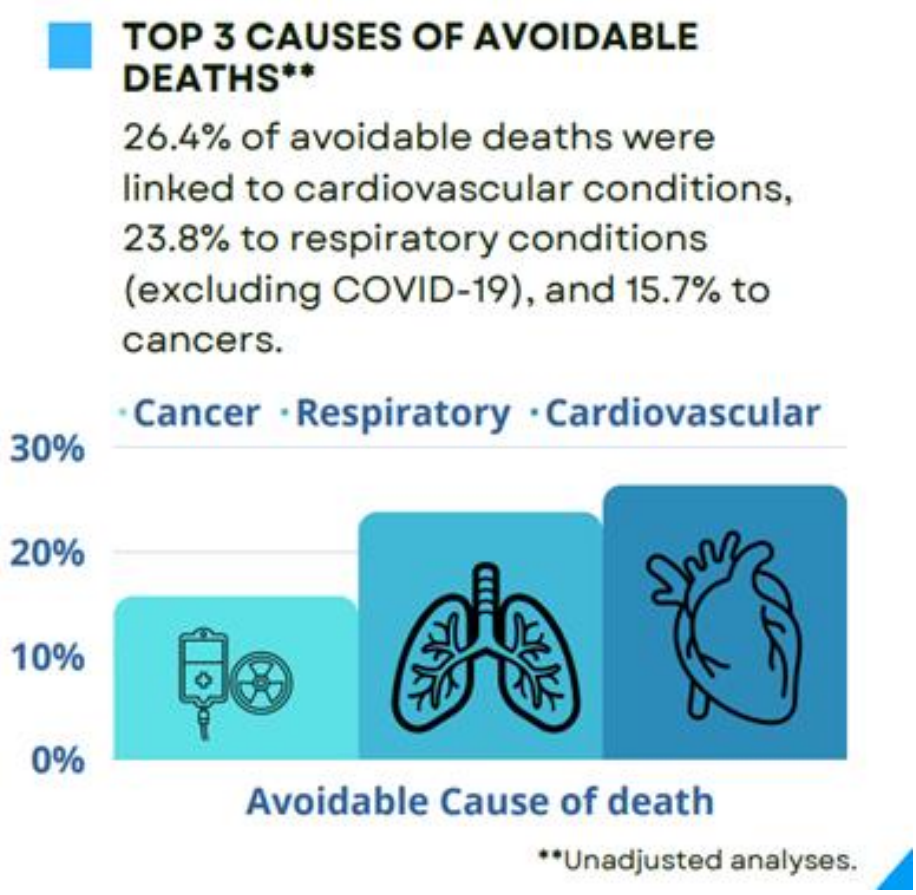


Figure 13: Data on Causes of Avoidable Deaths, LeDeR 2022 (national data)

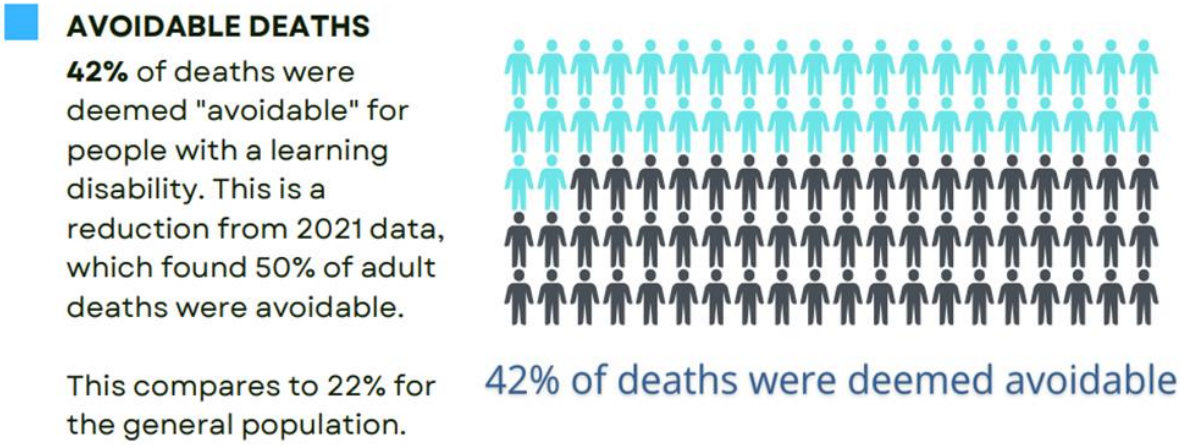


Figure 14: Data on Avoidable Deaths, LeDeR 2022 (national data)

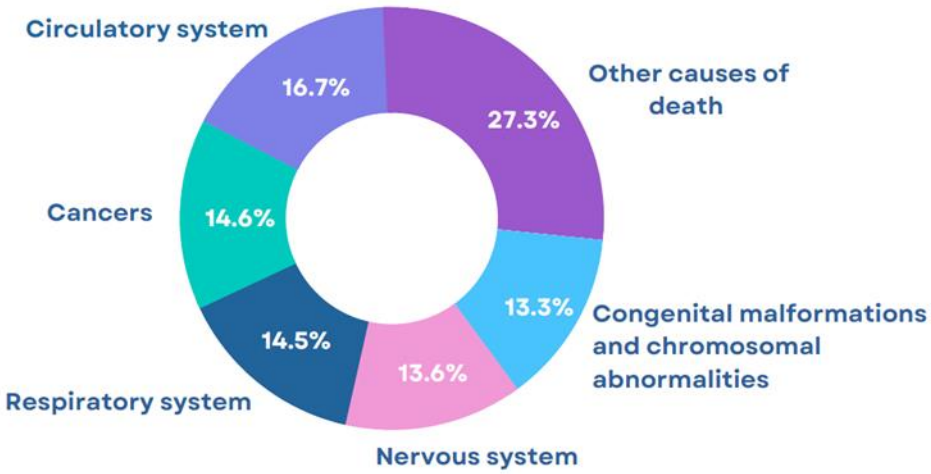


Figure 15: The five most common causes of death: National LeDeR review 2022 (2023)

Wider Determinants of Health

Wider determinants of health are a diverse range of social, economic and environmental factors which are outside of someone's control, but have an impact on their health. They're also known as social determinants of health.

These factors are influenced by the local, national and international distribution of power and resources which shape the conditions of daily life. They determine the extent to which different individuals have the physical, social and personal resources to:

- Identify and achieve goals
- Meet their needs
- Deal with changes to their circumstances

The Marmot review, published in 2010, raised the profile of wider determinants of health by emphasising the strong and persistent link between social inequalities and disparities in health outcomes. Social inequalities are widely considered as the 'causes of the causes'.

Addressing the wider determinants of health has a key role to play in reducing health inequalities. Several studies have concluded that wider determinants have a greater influence on health than health care, behaviours or genetics.

Socioeconomic

25% of the Leeds population live in the 10% most deprived deciles nationally.
The Index of Multiple Deprivation (IMD) 2015 is the official measure of relative deprivation for small areas (or neighbourhoods) in England. The Index of Multiple Deprivation ranks every small area from 1 (most deprived area) to 32,844 (least deprived area).

Deciles are calculated by ranking all of the areas in England from most to least deprived and dividing them into 10 equal groups. These range from the most deprived 10 per cent of small areas nationally to the least deprived 10 per cent of small areas nationally.

Figure 16 shows the variation in prevalence of learning disabilities across the IMD deciles– this demonstrates that people with learning disabilities are more likely to live in more deprived parts of Leeds and are therefore more likely to experience a range of associated disadvantages as a result including for example poorer air quality, less access to quality green spaces and less access to services.

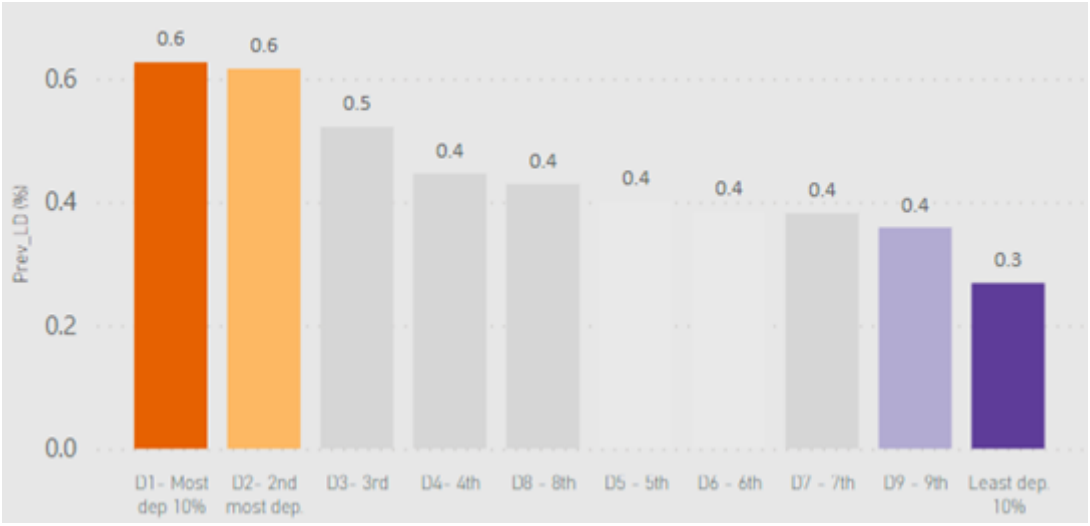


Figure 16: Prevalence of learning disabilities by decile– Leeds Primary Care Data 2023

Figure 17: Prevalence of learning disability in Leeds, by deprivation and by PCN area, 2022-23

Poorer health outcomes for people with learning disabilities also correlate with deprivation. The 2021 LeDeR report (national) shows that for all age groups, people who died were more likely to have lived in more deprived areas. This is also consistent across all age groups.

People with learning disabilities are likely to live with lower disposable income - they are less likely to be employed, more likely to be in receipt of benefits, and more likely

to be supported by unpaid carers in their household or family, which may also have an impact on the household income, social mobility and other opportunities.

The burden of caring for someone is significant and often exhausting as well as compounded by financial strain. In Leeds, a recent survey by Carers Leeds found that 52% of carers felt worried about monthly living costs and whether they could manage in the future. (The State of Unpaid Caring in Leeds. – Carers Leeds) . See also the section on carers.

There are links between familial poverty and increased rates of children with mild to moderate learning disabilities and SEND according to a report from the Joseph Rowntree Foundation.

All these factors make it more likely that people with learning disabilities live in households with lower incomes, reflecting the national picture too; people with learning disabilities are more likely to live in poverty (31% compared with 18% of the general population) according to a recent report completed by the think tank New Policy Institute.

Opportunities available to those with learning disabilities may therefore be limited by their financial means. Opportunities (including those which support health and wellbeing; from socialising to educational opportunities) may be limited to the person's assessed level of need or personal budget. Mobility needs or inability to travel independently can increase restrictions.

Employment

People with a learning disability are far less likely to be employed than people without a learning disability.
National evidence shows that:

- The employment rate for people with learning disabilities nationally is around 5.6% (Measures from the Adult Social Care Outcomes Framework, England - 2020-21 - NDRS (digital.nhs.uk)
- This compares to around 75% for the wider population (UK Labour Market Statistics - House of Commons Library (parliament.uk) .
- Of the people with learning disabilities who did have jobs, 71% of those were working fewer than 16 hours per week. (People with learning disabilities in England 2015: Main report (publishing.service.gov.uk))
- 65% people with learning disabilities would like to have a paid job. (NHS Digital, 2016)

In Leeds, the employment rate for people with learning disabilities was described by OHID in 2021 as 8.1% Public health profiles - OHID (phe.org.uk)

Another indicator is the data provided by the national Short and Long Term (SALT) return completed each year by local authorities. This estimates the percentage of working age adults (18-64) with learning disabilities in employment in Leeds at 3.1% (58 people out of 1891) in March 2024. This data is based upon individuals in receipt of long-term care from

social services and so does not take into account all individuals with learning disabilities in the city.
It is therefore hard to know the true employment figure for people with learning disabilities, nor does this give an indication as to the quality of employment, rates of pay or hours of employment.

Co-ordination of work in Leeds to improve employment opportunities for people with learning disabilities, is led by the Employment task group. Programmes such as "Developing You", sites such as Being Employed Leeds, and the Leeds Inclusive Employers Network (LIEN), work to support employers to move towards employing people with learning disabilities by improving the understanding and provision of reasonable adjustments and improving awareness of the benefits to employing a diverse workforce.

Other projects in the sector such as the LEEP1 - Café Leep offer employment linked with training so that employees gain qualifications which can help them move on to wider opportunities should they wish, and some third sector organisations offer employment support.

Some organisations in Leeds such as Forum Central, Leeds and York Partnership Foundation Trust (LYPFT) and Mencap actively recruit people with living experience of learning disability, to bring additional expertise into services.

Insight confirms that significant barriers to employment remain– such as employers having a lack of awareness and openness of the benefits of recruiting someone with a learning disability, and lack of awareness about how to remove existing barriers.

For those considering work, there can be difficulties in identifying suitable opportunities, navigating application processes, travelling to and from a place of work independently (bus and taxi reliability and availability is a frequently cited problem, especially for those that cannot travel independently) as well as concerns about loss of benefits. Appointments with Access to Work advisors may have long waiting times and appropriate opportunities with inclusive employers simply might not be available. There are also barriers around the Access to Work process - both for employees and employers.

Discrimination

People with learning disabilities can be vulnerable to discrimination and harassment.
They are more likely to be bullied and discriminated against than their peers; nine out of ten children and adults with learning disabilities report that they have been the target of bullying, almost five in ten that they have experienced verbal abuse, and one in four has experienced physical violence. Changing Attitudes to Learning Disability | www.basw.co.uk

As well as the potential to cause physical and emotional harm, this treatment can ultimately affect where people feel secure and which services they can safely use, which can limit people's freedoms and opportunities.

Over 7 in 10 people with learning disabilities have experienced some kind of hate crime in the United Kingdom. (Dimensions UK Autism and Learning Disability hate crime survey, 2016)

All this impacts on things like diet, level of physical activity undertaken, quality of life and mental wellbeing, and ability to live as full and “normal” a life as possible.

It is also possible that stigma and negative assumptions of people with learning disabilities may lead to discriminatory judgements and even diagnostic overshadowing, which can profoundly affect a person’s care and treatment.

Housing

The quality of housing that people have, as well as the level of choice, independence and proximity to services, can have a large impact on someone’s health.

Despite the significant changes in where people with learning disabilities live after the closure of large institutionalised residential homes, there are still challenges faced in finding suitable accommodation.

Care home and supported living accommodation can be in short supply. The demand for housing with support services has been rising for some time in Leeds and will continue to rise, in line with national trends.

Affordable housing is already in short supply in Leeds - people with learning disabilities are much less likely to be in employment so finding affordable accommodation can be additionally challenging. In a lot of areas, there is not sufficient independent living or supported accommodation options to offer housing of choice.

Mencap’s housing report (2016) surveyed people with learning disabilities about where they lived and what their aspirations were, the key findings were:

- Most people with a learning disability who live with family and friends want greater independence, with around 70% wanting to change their current housing arrangements to achieve this.
- 89% of parents whose child lives with them want to see greater independence for them.
- Nearly 20% of people with a learning disability known to local authorities live in accommodation that needs improvement.

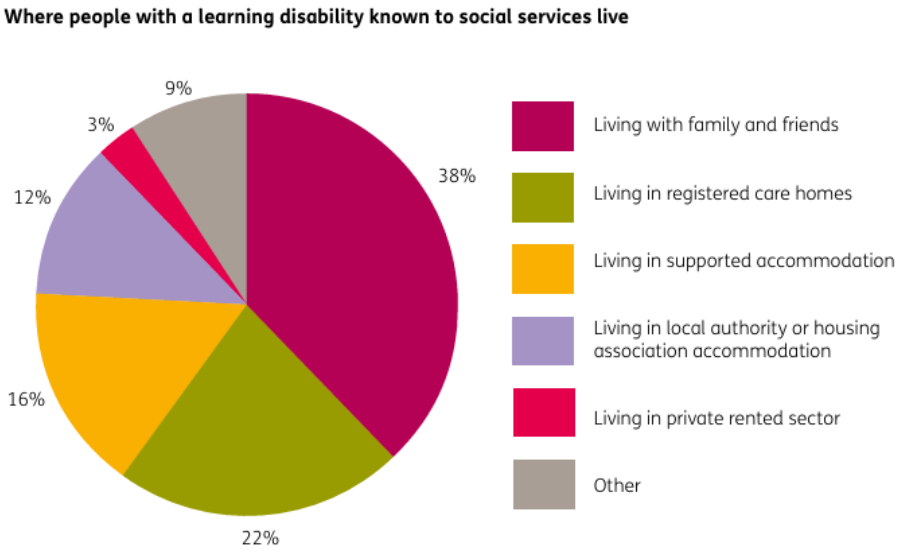


Figure 18: Where people with a learning disability known to social services live (National Data, Mencap Housing Report, 2012.

The projected increase in need for supported accommodation or other suitable options for working age adults, many of whom may have physical health problems or mobility issues alongside a learning disability, should be considered when planning housing provision.

Leeds' Housing Strategy 2022-2027 sets out the city's strategy to meet its housing needs, provide high quality affordable homes in thriving and inclusive communities, with appropriate support for those who need it.

Access to Healthcare Services

People with learning disabilities are more likely to have complex health needs, and therefore be more frequent users of, or have additional need for, health and care services, including primary care, out of hours and unscheduled care services, emergency services, mental health services, palliative care and specialist learning disability services.

A number of barriers continue to be recognised for people with a learning disability including;

- a lack of accessible transport links increasing difficulty in attending appointments
- staff having little understanding about learning disabilities
- failure to recognise that a person with a learning disability is unwell
- failure to make a correct diagnosis
- anxiety or a lack of confidence for people with a learning disability
- lack of joint working from different care providers
- complexities of involvement with carers
- patients not being identified as having a learning disability
- diagnostic overshadowing

(Heslop et al. 2013; Tuffrey-Wijnes et al. 2013; Allerton and Emerson 2012).

People with learning disabilities are also less likely to use mainstream preventative or healthy lifestyle services or activities than the general population.

Data collected from services wider than healthcare often demonstrates an underrepresentation of people with learning disabilities, relies on self-reporting, or in some cases detailed user data is not collected, leaving a lack of insight into whether people with learning disabilities are accessing and benefiting from services and activities which support healthy lifestyles.

Communication difficulties are a significant problem for many people with learning disabilities and include issues related to expression, comprehension and confidence when discussing their health. Additionally, some health professionals may lack confidence and experience in communicating with and identifying the needs of people with learning disabilities in health care settings and may require further education, training and support.

It is now mandated that anyone working in health or social care that is likely to come into contact with people with learning disabilities or autism, completes the Oliver McGowan training to improve awareness of communication barriers and how to overcome them.

With the clear evidence of the significant barriers that people with learning disabilities experience when accessing services, there is a need to ensure that services continue to review and respond to the needs of people with learning disabilities, thereby meeting their legal duty as required by the Equality Act (2010). To comply with the Equality Act, all public services, including health services, are legally required to make 'reasonable adjustments' to enable equality of health service access and help to ensure that people with learning disabilities have their health needs assessed and effectively met, to provide quality, person-centred assessment, treatment and care; and prevent avoidable harm.

Consideration of accessibility, in terms of health services, should apply to all elements of the whole journey in terms of

- Ensuring that people are aware of services, able to understand the benefit of those services and make informed choices as far as possible.
- Reasonable adjustments according to individual needs.
- Effective and clear communication prior to and during appointments, as well as in any follow up contact.
- Referral pathways and the joining up of services.
- Be able to communicate effectively with the patient to diagnose and treat appropriately, the involvement of carers, and for the service to be delivered in a way where the patient or service user is able to understand the intervention and benefit from it.

It's better for services to be focused on ability and not disability – what people can do, not what they can't. Services need to ask about what people's needs are in advance and try to adapt to meet them. They need to be clear about who they can support and how, and being flexible and positive where possible, and realistic if not; rather than either giving a blanket "no" or perhaps worse, an unrealistic "yes" which ends in the service not being helpful, and leads to frustration, disengagement, and loss of trust.

Insight from a practitioner, 2023

Reasonable Adjustments

Public Health England provide guidance on reasonable adjustments for people living with a learning disability. For example, people with learning disabilities may require:

- Clear, simple and possibly repeated explanations of what's happening and of treatments offered.
- Help with attending appointments, a quiet place to wait, longer appointments, with someone else able to attend with them to support.
- Help with managing issues of consent in line with the Mental Capacity Act.
- Support with anxiety – for example desensitisation.

- Other bespoke support; around a third of people with learning disabilities have a sensory impairment, around a fifth have a physical disability.

All organisations that provide NHS or adult social care services must follow the Accessible Information Standard by law. The standard aims to make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand with support so they can communicate effectively with health and social care services; however, in practice this does not always happen.

Figure 19 shows the proportion of reviews made by the National LeDeR review (2022) where appropriate reasonable adjustments to care were (or were not) made; this demonstrates that while improvements are seen from 2021 to 2022, a quarter of reviews still noted a lack of appropriate reasonable adjustments to the care.

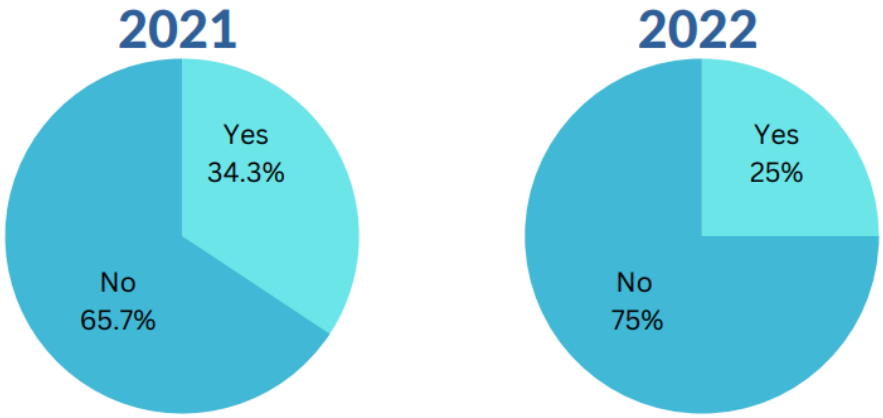


Figure 19: Proportion of reviews where reasonable adjustments to care were made (National LeDeR review 2022 – care standards)

While a person's primary care record may contain a code for a learning disability, this does not automatically flag for requiring a particular reasonable adjustment (for example a need for easy read letters, or longer length appointments).

These requirements need to be added to records, after being requested by the individual. Many people may not be aware of the ability to request communication in a different form for example. This may mean that communication could be missed or not accessible.

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.

Preventing people with a learning disability from dying too young (nuffieldtrust.org.uk)

Accessible Information Standards

The Accessible Information Standard sets out a consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

The Learning Disability Health task group "*You Can Ask*" campaign endeavours to improve awareness for patients to know they can ask to have their records amended to include their requirements.

Healthwatch Leeds has gathered useful insight around accessibility of services:

Supporting-people-to-become-active-participants-in-their-health-and-care.._.pdf (healthwatchleeds.co.uk)

Insight collected via focus groups included the following, which demonstrates how different people's needs can be, and the need for an individualised approach to communication:

> *"What helps improve accessibility for one person might not help someone else – there needs to be a more flexible, or personalised approach" (support worker, 2023)*
>
> "*The easy read information is great, but its beyond my son's level of understanding. It would be helpful if more healthcare professionals used Makaton" (Carer of a young adult 2023)*
>
> *"I don't open letters, I like getting texts but not letters" (service user, 2023)*
>
> *"One doctor said I could have a longer appointment, but another at the same place said I couldn't, he said there wasn't time as it was busy" (discussing consistency of application of reasonable adjustments) (service user, 2024)*

Health Literacy

It is important to ensure that all communication about health is as easy to understand for as wide a range of people as possible. It is estimated that the average reading age in England is around that of an 8-year-old child; considering this level of health literacy in the wider population, if all communications about health services were to

be universally more accessible and easy to read by default, the benefits will reach a wider range of people than just those with learning disabilities.

Digital Exclusion

More and more services are moving online by default including benefit claims, banking, job searches and appointment bookings. Some apps offer great opportunities for people to engage with their local community, access entertainment, transport, health and wellbeing activities, or even cheaper grocery shopping.

While for some people, apps or online services might offer more convenience, flexibility and speed, for other people this could leave them excluded and unable to access services – some people do not own or cannot use a smart phone or device, and others do not have access to data either at home or out and about.

National government has previously identified four key barriers to digital inclusion:

- Access - not everyone has the ability to connect to the internet
- Skills - not everyone has the ability to use the internet and online services
- Confidence - some people fear online crime, lack trust or don't know where to start online
- Motivation - not everyone sees why using the internet could be relevant and helpful

Easy to use and intuitive digital technology offers a range of potential opportunities; some people with learning disabilities may enjoy and benefit from using digital technology and apps, and digital inclusion training is offered by 100% Digital to support use of digital services. However no assumptions should be made that all people have access to digital technology in order to access services, this also applies to carers who may also be digitally excluded – alternate options should always be available.

Transport

Transport came up as a matter of concern and frustration in every focus group and was referenced as being a significant barrier for people with learning disabilities in terms of access, participation, attendance and inclusion generally.

People with learning disabilities are less likely to be independent travellers, they are more likely to have mobility issues or require support getting around, and are much less likely to be drivers or have use of a car. This can lead to reliance on the circle of support to facilitate transport.

This can be limited by location, proximity to services, cost of transport options, and limits to the funding or level of support received.
The need to organise activities or travel around the availability of support workers can also limit flexibility and spontaneity. This can be particularly challenging for people who live rurally or more remotely.
While some people may use taxis, these are hard to secure during school pick up and drop off hours due to the high demand for taxis at these times.
Those with a free bus pass may not be able to use the pass during peak hours (before 9.30am)

It is important to consider how to address these barriers when considering services or activities that are aimed at people with learning disabilities.

Carers and the Circle of Support

The circle of support around someone with a learning disability can include family, carers, and paid support workers.

Carers are often the people who:

- hold detailed knowledge about a person's health and history
- how this affects the person's life and the rest of their household
- the best way of communicating with the person
- have a trusted relationship with the person who may be anxious about certain situations
- will be that person's strongest advocate- supporting the person's voice and what they will or will not accept.

Caring for someone comes with considerable challenges. Carers Leeds recently published The State of Unpaid Caring in Leeds which highlights some of the areas for concerns:

- The top three concerns for unpaid carers in Leeds right now are: my own health and wellbeing; the changing needs of the person I care for; and money and the cost of living.
- 62% of unpaid carers reported that caring had a negative impact on their physical health, 73% reported it had a negative impact on their mental health.
- 62% of unpaid carers reported always or frequently feeling stressed, overwhelmed or anxious.
- 44% of unpaid carers were always or mostly missing out on time for themselves or a break.
- 31% of unpaid carers reported feeling often or always lonely.

- 52% were worried about monthly living costs and whether they can manage in the future.
- Unpaid carers have gone without essentials such as keeping their home warm (24%) and skipping meals (21%).
- 29% of unpaid carers who are not in work, would like to be in work.

Carers have sometimes felt unheard or not involved in care or decisions. They have also reported feeling instances of feeling excluded (How does it feel for me? Emma and Adam's story, 2023 - Healthwatch)

Paid support workers also build up relationships with those they support, around how to communicate and their health and wellbeing needs. However, at times, higher than average turnover of workforce in this industry and limited support hours can disrupt these positive relationships. Community learning disability teams (including health professionals and social workers) often have good knowledge about the health and lives of people with learning disabilities who are known to them and how to communicate effectively, however, many people with learning disabilities are not known to specialist services.

Subject to individual circumstances, this circle can be hugely influential in their health of the person, for example:

- The support they can offer to that person to accessing services, e.g. reading letters, supporting with transport, helping with communication at appointments.
- Providing education, information and influence around options, for example when providing or making decisions about food.
- Understanding barriers, advocating for someone and supporting them

Support is provided by a range of organisations in Leeds. While a rewarding and highly important role, the wages for support workers can be low and the hours can sometimes be unpredictable or antisocial. While some may have a high level of passion, interest and skill in the work, for others they may be balancing the work with other commitments or study, struggling to make ends meet or hoping to move onto more secure or better paid employment. It should not be assumed that those in supporting roles will have high levels of health literacy, and it should be noted that some will be subjected to health inequalities themselves.

With the huge importance of this circle of support, it may be beneficial for co-produced training, information and support (including peer support) to be made available to support their work, taking into account very busy lives and that caring is an unpaid role. This would enable the circle of support to improve understanding around health inequalities and the health needs of people with learning disabilities, health promotion and screening, and healthy lifestyles, as well as how to support positive behaviour change, to balance supporting healthy options while taking into account and respecting that person's own agency and interests.

Life Course

Children and Young People

This HNA focusses on the health inequalities for the adult population with learning disabilities. However it is recognised that many issues that affect younger people are also relevant particularly as people transition from childhood to adulthood.

In England, almost 68,000 children have a statement of special educational needs (SEN) or an education, health and care (EHC) plan and are identified as having a primary SEN associated with a learning disability. 26% of these children are educated in mainstream schools.

In addition:

- nearly 230,000 children in England identified at a broader level of SEN support have a primary SEN associated with a learning disability
- all forms of SEN associated with learning disabilities are more commonly diagnosed in boys (4.4%) than girls (2.9%)
- children eligible for free school meals or who are living in more deprived neighbourhoods are more likely to have a SEN associated with a learning disability
- higher rates of moderate and severe learning disability are more common among Romany Gypsy children; higher rates of profound multiple learning disabilities are more common among Pakistani and Bangladeshi children
- children with a SEN associated with a learning disability represent 9.2% of all looked after children (under local authority care)

Source Learning disability - applying All Our Health - GOV.UK (www.gov.uk)

The determinants of health inequities experienced by children with learning disabilities from the British Association of Social Workers (BASW) summarises scientific knowledge about the determinants of health inequities experienced by children with a learning disability in the UK.

Children or young people that are diagnosed with a learning disability should be supported by children's services until they reach adulthood. At this point, they will transition to adult services. The transitions team work closely alongside social workers (both children and adult), education providers and health professionals, as well as a wide range of voluntary and independent sector providers to develop the support for a young person's needs to be met as an adult. These plans take into account all the aspects of a young person's life, care and support needs so that they can make choices to reach their full potential and increase independence. NHS England has a full workstream committed to the improvement of services for children and young people.

GPs' recording of learning disabilities in children and young people appears to be less complete than for adults.

"A number of recent studies have shown that a 'hidden majority' of adults identified in childhood as having a learning disability are not identified as such within adult heath or social care services." Health inequalities and the 'hidden majority' of adults with learning disabilities – UK Health Security Agency (blog.gov.uk)

A potential issue may exist where children with Special Educational Needs which were identified and met (to any extent) via the education system, may not have the learning disability correspondingly recorded by their GP in their patient record. This means that when they transition to adulthood, eligibility for support via the education system would cease. This means the person may not be flagged as entitled to additional health-related support into adulthood, including annual health checks.

Some diagnosis during childhood via the education system may not be accurate- for example an autism diagnosis or even adverse childhood experiences could potentially overshadow a concurrent learning disability. Reviewing any diagnosis or coding at transition may reduce the risk that someone might enter adulthood with a missing diagnosis, unmet needs and limited support.

Maternity

Parents with a learning disability are often affected by poverty, social isolation, stress, mental health problems, and low literacy and communication difficulties.

Women and/or parents to be with a Learning Disability are more likely to first access maternity care later in their pregnancy, sometimes due to late discovery of the pregnancy, which can put them at risk of complications and poorer health outcomes.

A recent maternity health needs assessment in Leeds Leeds-Maternity-Health-Needs-Assessment-April-2020-FINAL.pdf identified that mothers with a learning disability are significantly over-represented in the cohort of women who have their babies taken into care under the age of one year old; this is known to be an extremely traumatic event for the mother, often a trigger for an escalation of her problems, but can also have profound consequences for the baby. Many people with learning disabilities also face discrimination or poor access to accessible assessments.

The Leeds Best Start Plan describes a broad preventative programme from conception to age 2 years which aims to ensure a good start for every baby, with early identification and targeted support for vulnerable families early in the life of the child.

The Leeds Maternity Care Pathway for Women with Learning Disabilities was developed in 2016. All identified pregnant women with learning disabilities have a named midwife throughout their pregnancy, who coordinates care and support for women and their families in order to navigate their personalised care, as well as appropriate reasonable adjustments.

Women with learning disabilities are a group that are referred onto the NSPCC Baby Steps programme for intensive support in the antenatal and postnatal period.

Improving identification of pregnant women with learning disabilities, earlier in their pregnancies will help improve outcomes.

Ageing Well

With gradual improvements to life expectancy, it is anticipated that growing numbers of people with learning disabilities may live into older age; by 2030, the number of adults aged over 70 with a learning disability will more than double.

As this population is much more likely to live with one or multiple long term health conditions than the wider population, they are more likely to spend a greater number of years in later life in poor health, and with increased complexity of care needs.

As well as the older population in Leeds growing in number, it is also becoming more diverse. There is therefore a need to support people to age well in an inclusive and equitable way that considers the needs of different communities.

End Of Life

It is important that all people are supported to live as well as possible until they die, and die with dignity. This includes being able to discuss and make choices around treatment escalation options, palliative care and place of death. This is equally the case for those who may need support and advocacy in expressing these preferences. However, inequalities in end-of-life care have been highlighted in recent reports.
A recent health needs assessment around end of life care in Leeds identified that some marginalised groups experience inequalities in end of life care. People with learning disabilities are not specifically mentioned within the Health Needs Assessment. It is recommended therefore that any future analysis should include people with learning disabilities.

The recent LeDeR report explores data surrounding the deaths of those with learning disabilities. Around 56% of deaths reported to LeDeR 22/23 occurred in hospital, this is higher than for the wider population which could reflect high rates of complex health conditions; in Leeds, 45% of deaths in 2019 took place in hospital.

In May 2016 the Care Quality Commission (CQC) published a thematic review into inequalities in end of life care. The review identified that;

'..People from certain groups in society sometimes experience poorer quality care at the end of their lives because providers do not always understand or fully consider their needs'

and identified people who have a learning disability as one such group. (A Different Ending - Addressing Inequalities in End of Life Care. CQC May 2016. 3. Heslop, P. et al., 2014)

The 2020 LeDeR review identifies that 64% of people who died in 2021 had a DNACPR (Do not Attempt Cardiopulmonary Resuscitation) in place at the time of death. Reviewers judged that the process for making a DNACPR decision was followed appropriately for 60% of the deaths which had the DNACPR in place. In 7.1% of those deaths however, the protocol was judged not to have been followed correctly, which was a slight increase from previous years. In 32% of cases it was not possible to determine either way with the evidence available.

CIPOLD echoes this, noting a frequent finding of:

> *"incomplete documentation that failed to record the rationale for the order not to attempt CPR. In some circumstances, such was the quality of the documentation that the assumption that the order was made because the person had learning disabilities could not be ruled out"*

Understandable concerns have been raised about patients with learning disabilities having a DNACPR decision put on their record, without the patient or family being consulted.

> *" I got really worried in covid and did a hospital passport for [my son] but was terrified of them putting a DNACPR on his file without telling or asking me. I wasn't allowed into hospital with him which was terrifying as he has such complex needs and its worse for him to be unsupported."*
> Parent carer of a young adult in Leeds with learning and physical disabilities

The LTHT recommend the use of the ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) form and process. This was developed as a result of a collaboration between CHANGE and the University of Leeds and was co-produced by people with learning disabilities. It helps structure a supportive conversation about care planning – including preferred place of death, level of interventions and escalations preferred. The objectives of this process are to ensure that the person is supported to be involved as far as possible in decisions about their own end of life planning; "No decision about me, without me". There is also an easy read booklet helping to support people to make their own decisions about end of life care.

Healthy Living

Food and Nutrition

Eating a healthy, balanced diet is an important part maintaining good health and reducing the risk of conditions such as heart disease, stroke, type 2 diabetes and some types of cancer.

People with learning disabilities may face additional barriers to eating a healthy diet. This could be due to cognitive issues, reduced awareness of healthy eating or less developed skills in cooking or preparing food. While many people with learning disabilities may live independently and shop and cook for themselves, others may be dependent on family members or carers, or have meals provided where they live, so food options would be influenced or limited by other people. In addition to challenges in eating a healthy diet faced by the general population, other barriers for people with a learning disability may include food being used as a strategy to reduce challenging behaviour by carers and add issues with swallowing which have implications for feeding.

People with learning disabilities are more likely to live in more deprived parts of the city and are more likely to live with a lower disposable income. This can lead to food insecurity and feeling unable to acquire an adequate quality or sufficient quantity of food in socially acceptable ways.

The role that advertising plays in influencing food options is considerable. People with learning disabilities may be more susceptible to advertising and commercial influence. There is a higher density of takeaways and food shops that sell more processed food compared to fresh vegetables or healthier options in some of Leeds' more deprived neighbourhoods; these are also areas where unhealthier foods are known to be advertised more heavily.

One service user explained how his diet had changed recently, indicating that unhealthier food options were the result of changes to his financial situation.

> *"It's the cost of living, I mostly just get takeaways now"* (service user at focus group, May 2023)

There is limited evidence around the dietary habits of people with learning disabilities who live independently or with families, so this was further explored through focus groups with people with learning disabilities, their family, carers and support workers. Discussions included the challenges faced by people in supporting the people in their care to eat healthily.

While most carers and support workers were well informed around healthy eating and familiar with evidence-based healthy eating messaging, others were less informed around the topic.

While some felt comfortable in promoting healthier food options to the people they supported, a significant proportion showed some ambivalence around effectively promoting healthier options. This was often due to perceptions about how the person they cared for would respond, lack of confidence in challenging unhealthy choices, knowing that a person's other carers (such as family members) did not share the same approach, and uncertainty if it was part of their role, in the limited support hours they might have with the person.

A support worker explained some of the challenges in promoting healthy options to people with learning disabilities, especially groups with a range of levels of understanding. They felt that for some people the messaging had to be simplified as well as carefully pitched according to who it was for. One challenge they mentioned was:

> *"Balance, and relative levels of risk are hard to understand. I've known people disengage from healthy eating sessions if they are told any negative things about their favourite foods, such as bacon being bad for them- it creates a lot of anxiety"* (support worker at a focus group, May 2023)

The influence of family, carers and support workers over someone's nutritional intake is potentially huge. One carer talked of having sole responsibility over her son's diet, and her concerns about what he would eat when he was not in her care:

> *"We have to have complete control over what (male, 28) eats- otherwise he would just eat biscuits"* - Insight from a carer, May 2023

Feedback from organisations in the sector stresses the need to understand the influence of the "circle of support", around a person with learning disabilities (including family, carers and support workers). They highlight the importance of working supportively with the families of people with learning disabilities to help embed learning, implement and sustain changes, understanding the many pressures that people in these roles manage - particularly unpaid carers.

Insight also highlights the importance of agreeing that part of a support role includes supporting healthier decision making for those in their care, and to improve the confidence of those in support roles to do so. This is challenging, in a very diverse sector with many different providers.

Several organisations in Leeds provide support around cooking and healthy eating to their members, either as standalone interventions or as part of wider healthy lifestyles programmes.

> *"I have made loads of changes to my diet, and I've been swapping out fast food… I have learnt to cook, now I avoid takeaways.. I know what foods are*

> *healthy and how to cook them and what foods to avoid*" (participant in focus group, talking about his learnings from a healthy lifestyles programme at People in Action 2023)

Evaluation of these programmes demonstrates that for people with learning disabilities, interventions around food and nutrition in a supportive environment can be very beneficial.

One finding was that promoting a programme around "weight management" was off-putting, and engagement was much better when the programme was designed to incorporate a more holistic healthy lifestyles approach, including cookery, mental wellbeing, gentle exercise and other topics. Key to the success of these programmes is to be delivered by people who were experienced in working with people with learning disabilities, rather than nutrition experts, and ideally familiar faces to the group, and to take place in familiar settings. This supports the widely acknowledged understanding that the messenger is often more important than the message when supporting people with learning disabilities.

Organisations also highlighted that behaviour change is more likely to be sustained when supported with ongoing peer support groups after the initial sessions finished.

People in Action highlighted the positive impact of extending the reach of the programme to the circle of support around people with learning disabilities, which helps embed sustained behaviour change more effectively.

Residential Settings

It is important that any organisation working with someone with a learning disability considers nutritional needs as part of the work they do. Any services monitored by the CQC must meet Regulation 14 – Meeting Nutritional Needs: https://www.cqc.org.uk/guidance-providers/regulations/regulation-14-meeting-nutritional-hydration-needs.

Safe Swallowing

Some conditions, particularly Downs Syndrome can be associated with Dysphagia (problems swallowing foods or liquids safely). Dysphagia can necessitate different feeding methods and therefore impact on diet and food options. Dysphagia can increase the risk of aspiration of food or liquids. Abnormal entry of material into the lower respiratory tract can carry a high risk of aspiration pneumonia. This is a dangerous infection within the lungs; up to 15% of all respiratory deaths reported to LeDeR were caused by aspiration pneumonia in 2021.

Physical Activity

Regular physical activity can lower the risk of developing many long-term conditions such as heart disease, type 2 diabetes, stroke and some cancers. Research also shows that regular activity can boost self-esteem, mood, sleep quality and energy as well as reducing risk of stress, clinical depression, dementia and Alzheimer's disease. Further benefits include an increased ability of people to contribute to society through volunteering, employment, caring responsibilities, a reduced need for intensive healthcare and voluntary service support, and improved local environments e.g. better air quality through lower car usage.

People with learning disabilities may face significant barriers to accessing physical activity – due to factors such as;

- Needing to prioritise basic needs over physical activity (for example health conditions or financial pressures)
- Lack of confidence or belief in ability to be more physically active; messaging around increasing ‘exercise levels’ can be intimidating and associated with many negative connotations (‘physical activity’ or ‘movement’ often feels more accessible and achievable)
- Reliance on the “circle of support” to promote, encourage and facilitate activities – even if physical activity is encouraged, support can be time or cost limited or inconsistent.
- Inaccessibility of provision or associated costs of organised activities; people with learning disabilities are more likely to live in deprived areas with fewer dedicated facilities, and also have fewer personal resources to support access. This means supporting people to find low-resource ways of moving such as taking the stairs rather than a lift, working with friends/neighbours to maintain a garden/green space or linking them with social prescribing or other local schemes to find free or low-cost local activities
- Lack of awareness around the specific risk factors of a less active lifestyle

Source: fingertips

A systematic review of physical activity in adults with learning disabilities found that they are ‘incredibly inactive’ with only 9% of participants across 15 studies from a number of countries achieving minimum physical activity guidelines: *(Dairo, YM and others. Physical activity levels in adults with intellectual disabilities: A systematic review. Preventive Medicine Reports, 2016. 4: p. 209-21)*

Within the most recent national activity survey by the English Federation of Disability Sport (2014), 35.8% of responders in Leeds with disabilities said they were physically inactive.

The Get Set Leeds report (Leeds City Council & Leeds Beckett university), a large-scale survey from 2020 around physical activity in Leeds, identified people with learning disabilities as much more likely to be less physically active than the wider population.

The survey found that individuals with disabilities or long-term conditions want to be physically active but may not be capable or have the social or environmental support to engage in activity. Additionally, responders with a disability or long-term condition reported significantly fewer days of physical activity a week in comparison to those without a disability or long-term condition.

Responders to the Get Set Leeds survey with a disability or long-term condition commonly discussed how they didn't feel there was enough provision of activities/opportunities for individuals with disabilities as well as facilities not always being accessible for them (e.g. at the Fearnville leisure centre, the gym is upstairs and there was no lift). This is in line with research from the English Federation of Disability Sport (2014) which found three main categories of barriers to physical activities for individuals with disabilities: logistical (geographical challenges, support from others, suitability of the activity), psychological (attitudes and perceptions of disabled and non-disabled individuals) and physical barriers (equipment, facility, health and safety).

Based on these findings, this highlights individuals with disabilities and long-term conditions as a key target group who would benefit from additional interventions to support their engagement in physical activity.

Some of the key recommendations from the Get Set Leeds Report around improving levels of physical activity;

- "Sit less and Move More"; build activity into everyday life, such as gardening, walking, taking stairs rather than a lift.
- Focus on small local-level changes which positively affect how capable people feel with being physically active.
- Focus on helping individuals feel that their first steps of becoming more active are within their immediate reach.
- Provide more supportive environments that make people feel more capable as individuals.
- Linking physical activity with opportunities to meet other people and be social.

The following year, the *"Covid-19 Rapid Review report"* (April 2021) suggested that levels of all types of physical activity decreased for all parts of the population in the previous year due to lockdown restrictions – with some parts of the population, including those with disabilities, more likely to be particularly affected.

Focus groups undertaken in Leeds in 2023 with learning disability service users, support workers and carers indicated that while some people were supported to access organised activities such as football, the gym, John Charles Centre for Sport, William Merritt Centre, and the Leeds Rhinos programme, and had largely positive views about these activities, others did very little in the way of physical activity.

Responses often recognised organised activities rather than elements of everyday living that would involve physical activity, such as active travel, walking or gardening.

When focussing on organised activities, some were frustrated at the lack of options available to them; limited in part by things like transport, the availability of a family member to accompany them or support for people with more complex needs.

> *"There is very little for adults with complex needs- he might grab someone's hair or have behaviour that upsets other people so it's hard to find a space that he can use…*
>
> *…Wheelchair activities tend to be for those that are more cognitively aware. But things for people with learning disabilities tend to be for able bodied people."* (Carer of a man with physical and learning disabilities, May 2023)
>
> *The low sensory sessions don't work for him, he likes noise and light, but potentially he can also upset people around him who might also be vulnerable– so the sensory pool session is actually not for him. There is very little for adults with complex needs, his are almost opposite to autism".*

Support workers of those using wheelchairs reported in focus groups that they felt underprepared and uncertain around how to help support the specialist physical activity needs or physiotherapy exercises for those in their care.

The focus on organised activities and lack of options available may indicate people are unaware of the variety of offers through websites such as Through the Maze and Active Leeds as well as other ways of being active in the community and at home.

Healthy Weight

Prevalence

Obesity, defined as having a Body Mass Index or BMI over 30, is more prevalent for people with Learning disabilities than the wider population. In England in 2019, 37.5% of people with a learning disability were classified as living with obesity, compared with 29.9% of those without a learning disability. *(NHS Digital, 2019).*

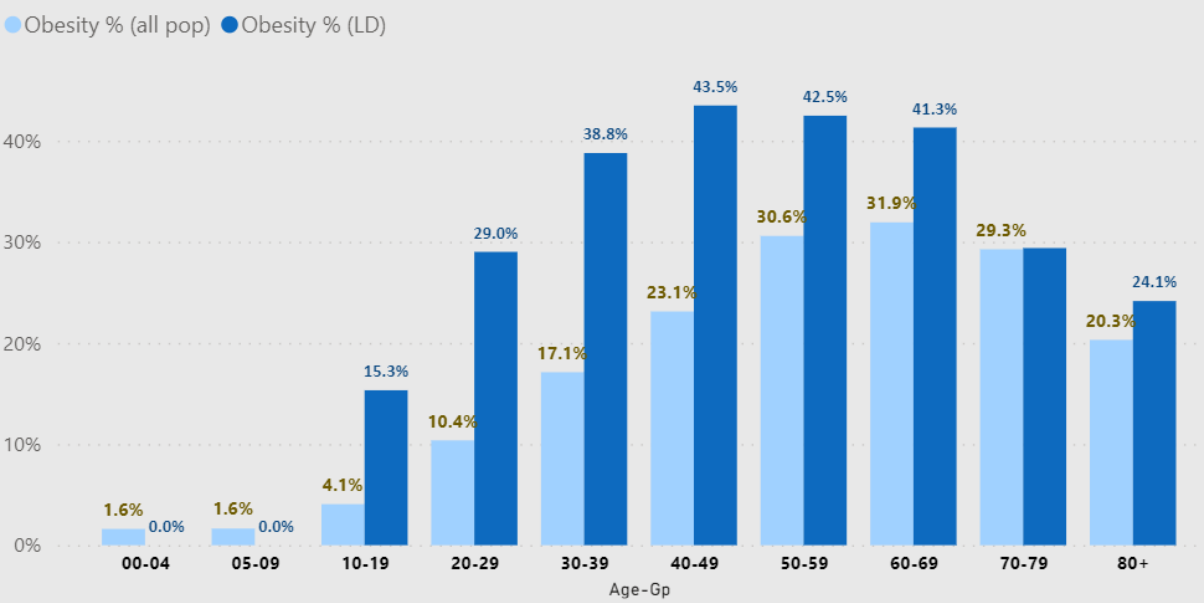


Figure 20: Percentage of patients with obesity- with and without learning disability. Leeds Primary care data, 2021/22

Figure 20 demonstrates that people with learning disabilities are more likely to live with obesity, particularly in teenage years and young adulthood.

Risk Factors

Similar to the rest of the overweight population, poorly balanced diets and low levels of physical activity are contributing factors to increased weight for people with learning disabilities. However, it is important to recognise the additional challenges and inequalities that increase this population's level of risk:

- Some antipsychotic medications can lead to weight gain.
- Downs Syndrome and Prader-Willi syndromes both cause a predisposition to being overweight.
- Inaccessibility of many mainstream health promotion, physical activity and weight management programmes
- Greater reliance on family or support workers (for those who have support) for food choices. The level of awareness, knowledge and attitude in those who support (including funded support packages) may vary according to the individual or organisation involved in care. This includes practical tasks such as shopping and cooking. Many people with learning disabilities receive no social care support however.
- Cognitive issues impacting the ability to understand new or complex information around healthy behaviours.
- Issues around balancing capacity and person’s best interest
- Practical Barriers:
    - Transport and access issues
    - Financial constraints
    - Mobility issues and other health conditions

- Risk assessment issues – eg needing supervision to use an oven or other equipment
- Digital exclusion, literacy

The impact of living with excess weight or obesity

People who are living with overweight and obesity will be exposed to additional risks of developing multiple health problems including Type 2 diabetes, certain cancers, cardiovascular diseases and strokes. Many of these conditions also have higher prevalence amongst people with learning disabilities.

This can also lead to bullying in childhood and poor mental health in adulthood, conditions which are more commonly experienced by people with learning disabilities than in the general population - although it is not clear to what extent weight contributes to these problems.

Being underweight

There is evidence that people with learning disabilities (particularly more severe disabilities) are also more likely than the general population to be underweight. Less research attention has been paid to the issue of being underweight for people with learning disabilities but is likely be due to issues around feeding and nutrition.

Being underweight is associated with health risks, for example an increased risk of infectious disease mortality, nutritional deficiencies, contribution to osteoporosis and anaemia, and a weakened immune system.

Nutritional Risk

Factors that increase nutritional risk for people with learning disabilities include physical problems such as posture and positioning, dental health problems, and difficulties with eating, chewing or swallowing may directly impact on the ability to eat well unaided. Digestive problems, such as gastro-oesophageal reflux disorder, or bowel function problems may deter people from eating. Poor sight, hearing, taste or smell or other sensory issues may reduce enjoyment at mealtimes, and some medications can reduce appetite.

Weight Management Services

It has been identified that people with a learning disability are underrepresented in data from healthy living services, which may suggest that the services do not meet their needs, that they are not aware of them or not able to access these services.

NICE 111 Guidelines state that "*Particular attention should be given to engaging people who may be less likely to participate, such as people with learning difficulties or mental health problems and those from lower socioeconomic groups*".

Quality statement 7: Referral to a lifestyle weight management programme for people with comorbidities | Obesity in adults: prevention and lifestyle weight management programmes | Quality standards | NICE

Until October 2022, One You Leeds was commissioned by Leeds City Council to offer Tier 2 mainstream weight management services for people in Leeds.

Around 1% of participants in the Tier 2 weight management service self-reported as having a learning disability.

Partner organisations involved in focus groups reported that some of the people they had supported to attend these programmes, felt they had “failed” it and subsequently disengaged, and it was felt that the course materials and pace and style of delivery were not appropriate for their needs.

Course providers’ understanding and experience of working with and supporting people with learning disabilities is crucial. It is more influential on outcomes than in-depth knowledge of nutrition, exercise science or psychology.

Smoking, Alcohol and Substance Misuse

The health impacts of smoking are well evidenced, and include chronic obstructive pulmonary disease, cerebrovascular disease, cardiovascular disease and around 15 types of cancer.

Up to two in three long-term smokers are expected to die from a smoking-related disease. Smoking is the single biggest avoidable risk factor for cancer. Tobacco smoke is estimated to be responsible for 15% of all cancer cases and tobacco causes more than one quarter (28%) of all cancer deaths in the UK. https://ash.org.uk/uploads/Smoking-and-Cancer-Fact-Sheet.pdf?v=1692800564

Prevalence

Smoking rates are declining in the general population, which has been supported with recent trends in vaping as an alternative. However smoking remains the single greatest cause of preventable morbidity and mortality for the general population.

Around 13.3% of UK adults report that they smoke Adult smoking habits in the UK - Office for National Statistics (ons.gov.uk) .

Despite this there is little research attention around prevalence and impact of smoking for people with learning disabilities.

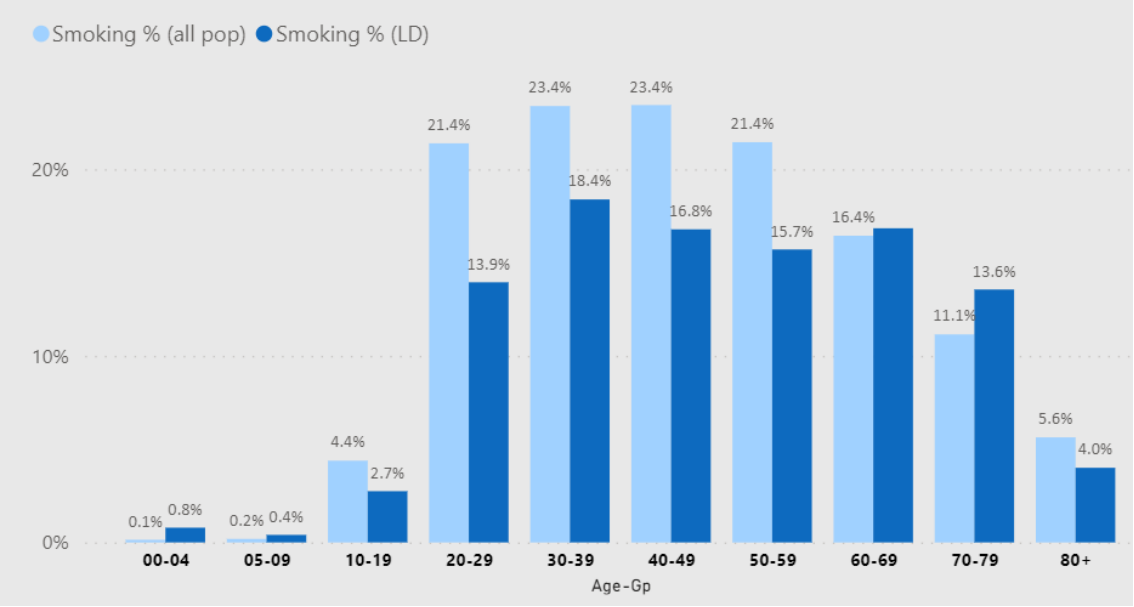


Figure 21: Prevalence of smoking (self-reported) amongst people with and without learning disabilities – Primary Care Data, December 2023

Figure 21 demonstrates that self-reported smoking prevalence in Leeds for people with a recorded learning disability appears lower than the general population in most age groups. As with all age-stratified data around learning disability, care should be taken in interpreting results around the older age bands due to shorter life expectancy and smaller numbers. Another caveat on this data is the likely difference in smoking status between those with milder and more severe learning disability- the data in this chart is combined. More granular data around smoking prevalence by varying severity of learning disability would help to understand this issue in more depth and understand if some sub-sections of this population are more vulnerable to the ill effects of smoking.

Impact

People with a learning disability who smoke are particularly vulnerable to the detrimental impact of smoking on their health, and on their financial and social wellbeing.

Smoking and People with an Intellectual Disability | Intellectual Disability and Health

The NHS Long Term Plan made commitments for the NHS on smoking and mental health stating that: "a new universal smoking cessation offer will also be available as part of specialist mental health services for long-term users of specialist mental health, and in learning disability services" (NHS, 2019). Public-mental-health-and-smoking.pdf (ash.org.uk)

Similarly, people with a learning disability are already known to be marginalised and more likely to be exposed to social determinants of poor health- such as socioeconomic deprivation, compounding the negative impacts of smoking on their health, social and financial wellbeing.

Health status and health risks of the "hidden majority" of adults with intellectual disability - PubMed (nih.gov)

Tobacco Dependency Services

Most guidance on smoking cessation is informed by studies that do not include people with learning disabilities, so their applicability and effectiveness is not well established.

People with a learning disability may face particular challenges when trying to access mainstream smoking cessation services, especially if professionals providing these services lack specific training around the abilities and needs of this group. Lawrence *et al* (*Lawrence, M., Kerr, S., Darbyshire, C., Middleton, A., and Fitzsimmons, L. Tobacco and alcohol use in people who have a learning disability: giving voice to their health promotion needs. Glasgow Caldeonian University: Glasgow, 2009)* suggest that accessing stop smoking services and attempting to quit smoking requires particular skills, which people with an intellectual disability may require additional support with, including:

- self-confidence
- planning ahead
- remaining focussed
- self-control to resist urges to smoke
- applying abstract knowledge about the harms of smoking to acute social contexts

Focus groups in the above study also highlighted the importance of regular support from family or support workers to help encourage attempts to quit, and the benefits of peer modelling – learning from other people with learning disabilities who have successfully quit smoking.

In 2023/24, the Leeds Stop Smoking Service was accessed by 26 people (2.5% of all service users) who had a self-reported learning disability.

There is little evidence on effectiveness of tobacco and alcohol related health promotion interventions for people with intellectual disability (*Kerr S and others. Tobacco and alcohol-related interventions for people with mild/moderate intellectual disabilities: a systematic review of the literature. Journal of Intellectual Disability Research, 2013. 57(5): p. 393-408)*

A more tailored approach to quit support is needed to reduce this inequality, particularly for the 40+ age group, who are usually those who engage the most in stop smoking services, ensuring that those with learning disabilities as well as their circle of support are made aware of the support available.

Alcohol and Illicit substances

There is limited evidence in Leeds about locally commissioned drug and alcohol services and their accessibility to people with learning disabilities as monitoring data is limited. One of the limitations for monitoring of these services is that service users, who may experience issues with memory as a complication of their substance misuse, may be inconsistent or incomplete in self-reporting on monitoring forms. Further understanding around use of these services may be helpful to understand the needs of this group.

Conclusions

Healthy lifestyles can have a huge impact on people's health, as unhealthier lifestyles can increase the risk factors for all the avoidable causes of ill health and death discussed in this report. Yet for this population, there are considerable barriers to accessing a healthy lifestyle.

Education around living a healthy lifestyle would ideally be a universal offer, delivered at a younger age – prior to people developing avoidable health conditions rather than a response to it.

Improving the accessibility of mainstream services is key, as is providing bespoke services to support those with more complex needs, and the range of advice, resources and activities available to help support healthy lifestyles needs to be well promoted and positively promoted via interventions such as Annual Health Checks.

As many people with a learning disability may rely on those in their circle of support to access what they need to live a healthy lifestyle or to make positive lifestyle changes, support and engagement with families and the circle of support, including organisations is essential. A collective responsibility and shared understanding around healthy behaviours, perception of risks and future health will be beneficial for the individual.

Consideration about the autonomy of people with learning disabilities around their choices should be made to help families and carers navigate the balance between an individual's right to choices, including unhealthy choices, and the responsibilities of those supporting them.

(Strategies to prevent or reduce inequalities in specific avoidable causes of death for adults with intellectual disability: A systematic review Pauline Heslop, Emily Laur, 2024, British Journal of Learning Disabilities)

Health Protection

Health protection includes the measures taken to safeguard a population from infectious diseases, environmental hazards, and other external threats to health. It includes vaccinations, disease surveillance and outbreak responses. Those with learning disabilities may be more vulnerable to these health threats due to difficulties in accessing information, communicating symptoms or understanding medical advice.

Evidence in the LeDeR reports demonstrates that those with learning disabilities are disproportionately affected by (and have worse outcomes for) communicable diseases such as Covid-19 and are less likely to receive vaccines. They are also at an increased risk of sepsis and other largely avoidable causes of death.

Effective health protection for this group requires tailored strategies, such as accessible health information, specialised support during appointments, and targeted interventions to ensure that they receive the same level of protection as the wider population.

Annual Health Checks

The Annual health Check (AHC) is a “top to toe” health check offered annually to anyone with a diagnosis of learning disability, aged 14 years and over. They are intended to reduce health inequalities by increasing the rates of general and specific health assessments and the earlier identification of risk factors and health conditions.

The check includes a wide range of prompts, questions, tests and physical examinations, covering health areas including: vaccinations, healthy lifestyles, functional life skills, sexual health, cancer screening, BMI, Blood pressure, eyesight and hearing, dental, respiratory, cardiovascular, gastrointestinal, neurological, mental health, blood tests for a variety of indicators, medication and safeguarding.

The NHS long term plan target is for 75% uptake of the check.

Under the “Being Me” strategy, one of the priorities is to ensure that people with learning disabilities are offered and supported to receive good quality annual health checks and action plans.

In Leeds, uptake is improving steadily thanks to a significant drive to promote the service by the Health Facilitation Team and others and is now at around 85%. Due to the level of achievement, it has been decided locally to increase the target to 85% in 2024/ 25.

NHS published figures March 2023			
Completed Health Checks	Register	% HC achieved	HCP
3,627	4,342	83.5%	Bradford
1,118	1,278	87.5%	Calderdale
2,225	2,871	77.5%	Kirklees
3,386	3,964	85.4%	Leeds
1,777	2,204	80.6%	Wakefield
12,133	**14,659**	**82.8%**	**WY ICB total**

Figure 22: Overall Completed Annual Health Checks – LeDeR West Yorkshire - 2023

People with learning disabilities that we spoke to in focus groups were mostly well aware of the annual health checks, and mostly very positive about them. However, some people said they were not aware of them, or uncertain if they had had a check or not in the last year.

> *"I think I have had my health check, it took ten minutes"*
>
> *(Focus group participant 2023)*

> *"My son's annual health check was at [South Leeds practice], its undertaken by a nurse and she isn't allowed or qualified to listen to his chest so the check doesn't get completed properly"*
>
> *(Focus group participant - parent carer 2023)*

It's important to consider the significant number of people who will be living with a learning disability but who do not have this identified on their primary care records and therefore will not be invited to the annual health check. This identification deficit affects some communities more than others. Improving identification and recording of learning disabilities generally, will widen the reach and impact of all health protection measures, and help reduce the health inequalities experienced. This is discussed further in this section.

Accessibility

When booking the checks, practices send out an easy read questionnaire to help the patient consider and record their health in advance of the appointment. This also invites patients to advise of any reasonable adjustments they may require. (e.g. consideration to waiting areas, support, and times).

LYPFT and the Primary Care Development Team have done significant work to promote the health checks, and also produced easy read materials that promote and explain the check.

The Healthwatch report around Annual Health Checks from 2021 provides valuable insight from those who support people with learning disabilities around additional barriers to accessing the check. These included;

> *"Everyone with a learning disability should be called for an Annual Health Check, but some aren't. There is also an issue with parents saying that their son or daughter doesn't need an annual check up"*
>
> *"Where people are in supported living or residential settings then support organisations tend to know more about medical records and the person's health. If the person is living in a family home, the support organisation often has more difficulties. Families can be quite protective, so there are more barriers in place"*
>
> Health-inequalities-report_FINAL.pdf (healthwatchleeds.co.uk)

While the improvements in uptake of the AHCs is positive, there is little segmentation in the data about which parts of the community are more or less likely to take up the AHC offer.

Work to understand uptake from health inclusion groups or further breakdown of equality characteristics would support in the targeting of future work to reduce inequalities. Further understanding around quality, completeness of the health checks, as well as patient experience and outcomes may also be beneficial to support improvements to quality. This is being explored by Primary Care and the Health Facilitation Team.

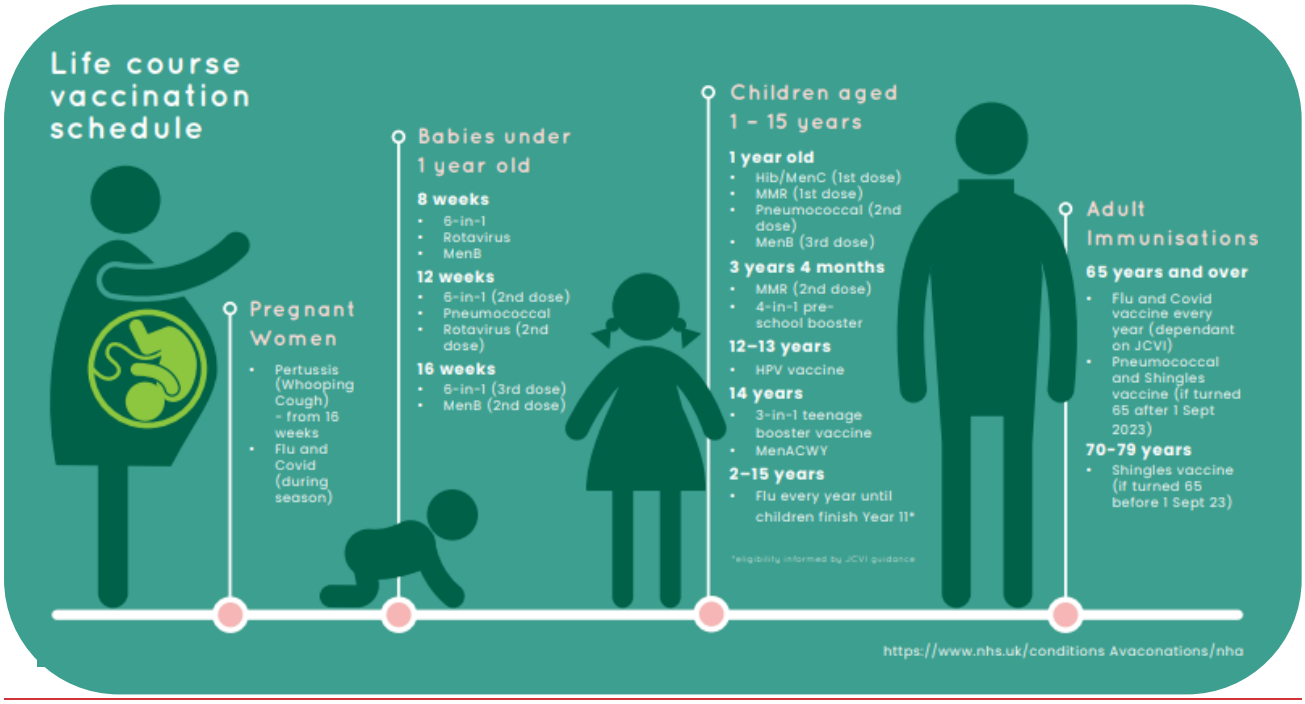
Quality resources and referral options that are embedded in templates will help support clinicians in offering support and advice to patients, where issues are identified during checks.

> *"I think they should follow up with a call six months after the health check, to find out what actually happened"*
>
> *(Focus group participant – Support worker 2024)*

Ongoing training to practice staff around how to support people who have a learning disability (such as that offered by the Health Facilitation Team) and how to complete an effective annual health check (including having good quality, supportive conversations around any recommendations) will help to improve this service further.

Vaccines and Immunisations

Vaccines and immunisations are one of the most effective disease prevention measures available to us and can offer protection against a range of diseases. The NHS has delivery responsibility for vaccinations, including the delivery of the routine immunisation schedule for infants, children, adolescents, adults and pregnant women, for those ate risk, COVID-19 vaccinations and seasonal influenza vaccinations. Some parts of the population are considered higher risk for certain diseases and thus prioritised in vaccine schedules.



Seasonal Influenza and Covid-19

People with learning disabilities are disproportionately affected by rates of respiratory illnesses such as Covid-19 and seasonal influenza, including higher morbidity and mortality rates.

Of the deaths reported to LeDeR in 2021, the highest single cause of death recorded was Covid-19 (20%). This dropped in the 2022/23 review to 6%. In a separate study, people with a learning disability were found to have had a 5x greater risk of hospitalisation with Covid and a 8x greater risk of dying from COVID-19, compared with the general population (BMJ 2021)

The reason for this is multi-factorial; people with learning disabilities are more likely to live with multiple or complex health conditions, particularly problems. It has been noted that presentations for this group are often atypical.

Due to these inequalities, people with Learning Disabilities are therefore a target for vaccine promotional work and additional support in accessing seasonal flu and Covid-19 vaccinations. Figures 23, 24 and 25 provide data around vaccine uptake.

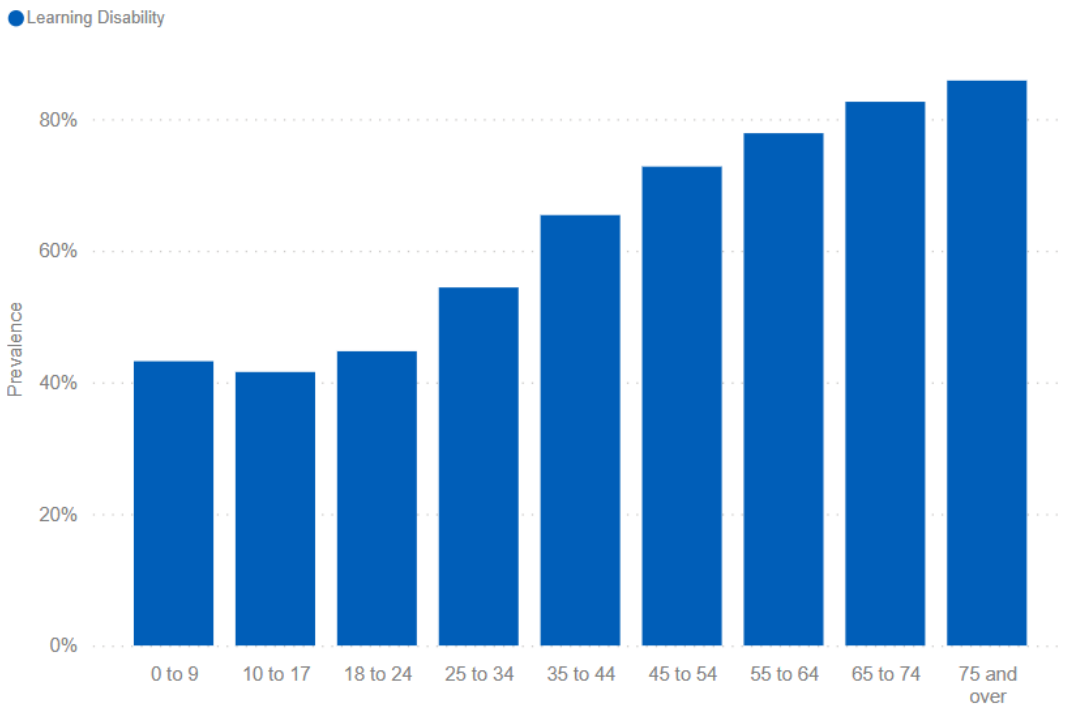


Figure 23: Seasonal Flu Vaccine: Percentage of patients who had an immunisation against seasonal influenza by age – NHSE – National Data, 2022

Flu Vaccine uptake (eligible cohorts)	% vaccine uptake for people with learning disabilities	% vaccine uptake for Leeds eligible cohort
End of season 22/23	57.7%	42.0%
End of season 23/24	57.4%	49.2%

Figure 24: Flu Vaccine: Leeds Practice data- uptake of vaccine for people with a learning disability, compared to all eligible people. The target for uptake amongst all eligible cohorts is 75%.

	Numbers vaccinated	% Numbers vaccinated
1st dose	3822	81.5
2nd dose	3638	77.6
Booster dose	2702	74.2
Autumn/Seasonal Booster eligible	1926	64.5
Spring Booster	104	21.7

Figure 25: COVID-19 Vaccine: Leeds practice data 23/5/23 for people who have a learning disability

Improving uptake for vaccinations for respiratory illness

As well as experiencing poorer outcomes for respiratory illnesses, work in Leeds on the Covid vaccine identified that vaccine uptake was lower for those with learning disabilities.

Work with local services identified barriers to vaccine uptake in this population including;

- Vaccine hesitancy or uncertainty - some people with learning disabilities can be anxious about unfamiliar, painful or invasive procedures - or healthcare services generally. This can be particularly difficult for the significant number of people who also have autism.
- Lack of awareness around where to get vaccinations – information is often not accessible.
- Issues with accessing vaccine services, difficulty traveling to clinics e.g. around transport or co-ordinating support.
- Inconsistent/ confusing offer of flu and covid at same appointment
- Consent can be withheld by parents/carers
- Vaccination availability
- Data issues, meaning target groups within this population are hard to identify and therefore target.

Ongoing work to monitor and understand uptake from health inclusion groups, further breakdown of equality characteristics, and discrepancies between PCNs will support in the targeting of future work to reduce inequalities.

An operational Winter Vaccines group was formed to monitor and co-ordinate efforts to improve vaccine uptake in this population. Significant work in the city by the Health Facilitation Team (HFT) and other partners included;

- Co-produced materials giving easy read information around procedures and the benefits of vaccinations.
- Easy Read letters sent to people with Learning Disabilities to encourage them to take up the vaccine offer.
- Desensitisation work is offered by the HFT, supporting people to understand and get used to the conditions and feeling of a vaccination to make them feel more comfortable and prepared.
- Information about vaccine services shared in an accessible way, in-person at learning disability services and groups across the city.
- Outreach vaccination clinics in trusted community settings (for example at Hamara in Beeston, this clinic reached people who might not have attended a healthcare setting)
- Offer of nasal spray alternative to injection for the influenza vaccine, as people with learning disabilities sometimes do not like needles
- Targeting certain groups e.g. those who did not attend last year via primary care records
- Increasing training and awareness to improve skills and confidence of workforce to have effective, useful conversations.

Based on the success of this work in having a system-wide approach to increasing flu and Covid vaccine uptake, it could be beneficial to explore the opportunity to expand the remit or model of this group to include other vaccination and health protection priorities (rather than working in silos to address each priority separately), and to take a life-course approach if possible (the School Aged Immunisations team engage with SILC schools to promote uptake for those of school age).

Respiratory Infections

Pneumonia, and particularly aspiration pneumonia, is a prominent cause of death in people with a learning disability. Up to 15% of all respiratory deaths reported to Learning from Lives and Death review (LeDeR) were caused by aspiration pneumonia in 2021. (https://leder.nhs.uk/)

Aspiration pneumonia, an infection caused by the inhalation of small particles, is a dangerous condition which can result in death. This condition is often secondary to dysphagia (swallowing and eating difficulties more common in people with severe learning disabilities). Other issues such as problems with posture, pathogenic microorganisms in the oral cavity, poor oral health, and conditions such as Prader Willi can also lead to increased risk of respiratory infection.

A study of death certificates by Glover and Ayub (‘How people with learning disabilities die’, 2010) found that people with a learning disability are, on average, seven times more likely to die from lung inflammation caused by aspiration than people who do not have learning disabilities.

One systematic review and meta-analysis highlighted that people with learning disabilities experience excess respiratory-associated deaths, with a respiratory

mortality of almost 11 times greater than for the general population. Clinical guidelines have contributed to a reduction in mortality from community-acquired pneumonia. Increased recognition of the link between dysphagia and respiratory disorders among caregivers and practitioners is critical to ensuring the early identification of individuals with respiratory disorders. *(Truesdale M, Melville C, Barlow F, et al. Respiratory-associated deaths in people with intellectual disabilities: a systematic review and meta-analysis. BMJ Open 2021)*

Sepsis

Sepsis is a dangerous blood infection that kill. Causes can range from a small cut to cancer to meningitis. Worldwide, sepsis is thought to affect over 30 million people every year and causes over 5 million deaths (Fleichmann et al 2016).

In England sepsis is thought to have overtaken lung cancer as the second largest cause of death after cardiovascular disease; there have been approximately 123,000 cases and 36,800 associated deaths in England (NHSE, 2015)

Historically, sepsis has been one of the 5 most common causes of death for people with a learning disability, suggesting an increased vulnerability or different trajectory within this population.

Concerns reported in deaths from sepsis within LeDeR review:

- 15% of the reviews reported concerns
- Only 47% of all deaths from sepsis had met or exceeded good practice
- 8% of deaths reviewed evidenced care that was so poor it had the potential to or actually caused harm and contributed to deaths

Most common concerns raised:

- Timeliness of diagnosis and treatment
- Inadequate support being provided to the person before they became unwell
- Delays in care or treatment adversely affected the health of people who died from sepsis in 16% of reviews where there were concerns
- Diagnostic Overshadowing
- Once a diagnosis is made of a major condition there is a tendency to attribute all other problems to that diagnosis, thereby leaving other co-existing conditions undiagnosed. (Neurotrauma Law Nexus) ‘symptoms of physical ill health are mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities’ (Emerson and Baines, 2010).

[The experiences of sepsis in people with a learning disability—a qualitative investigation - Grant - 2022 - British Journal of Learning Disabilities - Wiley Online Library]

Improving outcomes

- Sepsis is challenging to recognise, especially in this population - but is a concerning cause of often avoidable death.
- Better awareness is needed amongst people with lived experience - carers are best placed to detect when there have been changes from a person's baseline and must not be ignored.
- Improving awareness by offering training, and using easy read resources is vital to reduce avoidable deaths from sepsis among people with learning disability.

The Restore 2 mini and pulse oximetry training has been developed with support from the ICB to help provide non-clinical staff (such as carers and staff in residential settings) with a shared system of assessment tools and terminology, and the communication skills to be able to escalate care concerns appropriately to clinical staff should the situation arise. The training is intended to empower them to use their expert knowledge of the patient and help advocate more effectively for an escalation of care, and ultimately help prevent avoidable deaths.

Screening

Health profiles and age-related eligibility for screening services

Some services such as screening might be aimed at certain demographics within a population, based on risk factors and effectiveness of interventions – for example, breast cancer screening is routinely offered to woman over the age of 50 under the NHS breast screening programme.

It is important to consider the different health profile of people with learning disabilities- they are likely to live with poorer health generally, and health conditions are likely to appear at a younger age. Its therefore worth considering whether eligibility criteria for any screening programmes or other interventions should be adjusted to reflect the different health profile of this population. Data should be explored to determine if increased risk means that referral criteria should be bespoke for this population – for example reducing the eligibility age for commencement of routine screening.

This principle applies to any service where eligibility criteria are based on risk factors/ health profiles of the wider population rather than this population, and where this group may risk being excluded despite an elevated need.

See also the section on screening for cancer.

Health Conditions

1. Cardiovascular Disease
2. Diabetes
3. Epilepsy
4. Respiratory disease
5. Co-morbidity and Complexity
6. Cancer
3. Digestive Health
4. Oral Health
5. Sexual Health
6. Mental Health
7. Neurodiversity and autism
8. Dementia

People with learning disabilities are more likely to live with poorer health and develop health problems at an earlier age. They are more likely to live with multiple long term health conditions which can add complexity to care.

Cardiovascular Disease

Cardiovascular disease (CVD) is an umbrella term that describes all diseases of the heart and circulation. It includes congenital or inherited conditions and those that develop later in life such as ischaemic heart disease, atrial fibrillation, heart failure, and stroke. Globally more people die annually from CVDs than from any other cause.

Prevalence

The prevalence of CVD in adults with learning disabilities may be greater and apparent earlier in life than that found in the general population, but patterns are different for each condition and data is shown below for different conditions, where available.

Figure 26 relates to hypertension and demonstrates that hypertension appears at an earlier age in people with a learning disability, and prevalence is slightly higher. Note that reduced life expectancy impacts on patient numbers- for this reason the data should be interpreted with caution especially in the older age bands (bands over age 79 have been omitted due to identifiable patient numbers)

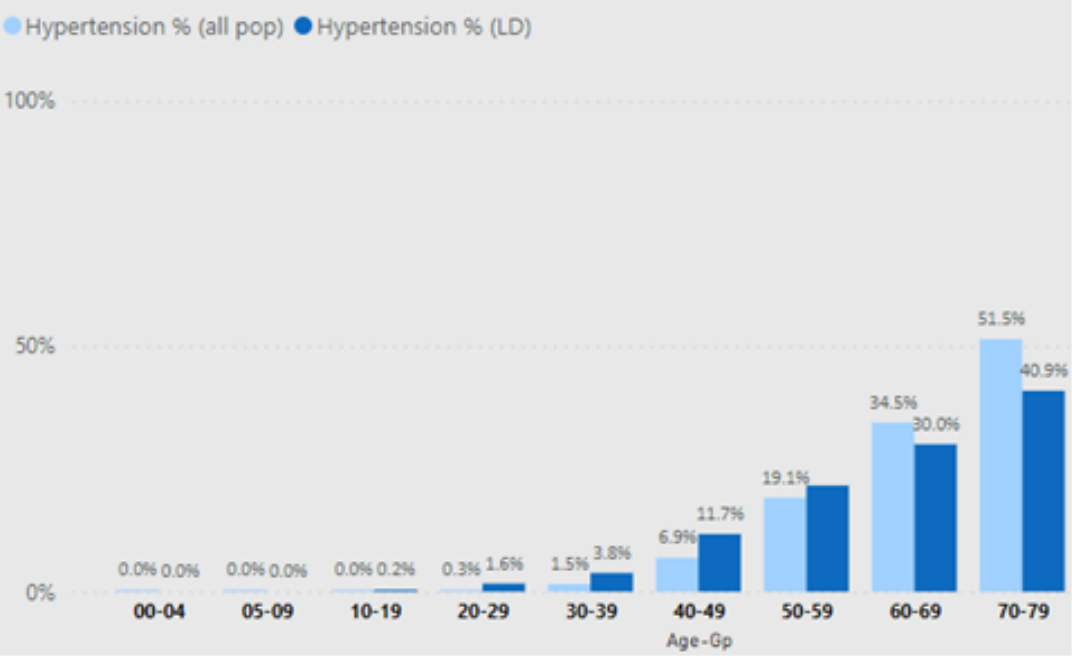


Figure 26: Patients with hypertension by age- Source: Leeds Primary Care data, 2023

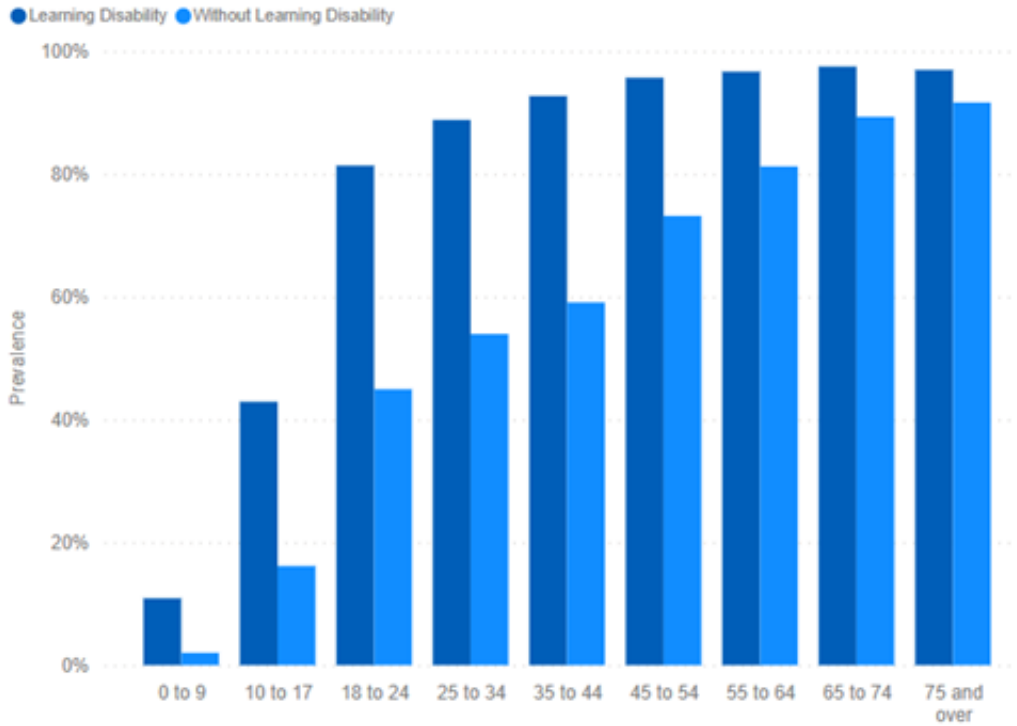


Figure 27: Percentage of patients with a high blood pressure measurement in the previous 5 years, by age band (NHSE, national data, 2022/23)

Figure 27 shows that there are significantly higher numbers of patients with learning disabilities recorded with high blood pressure at an earlier age than patients in the wider population. Due to living with obesity and having lower levels of physical activity being risk factors for hypertension, this pattern may be expected; however the higher rates of blood pressure testing offered to people with learning disabilities,

e.g. via annual health checks, may lead to better rates of diagnosis, compared to a potential underdiagnosis in the wider population.

Figures 28, 29 and 30 show different prevalence of CHD, Heart Failure and Stroke/ TIA for this population, nationally, demonstrating that prevalence is generally higher in this population and appears at a younger age. Again, data for the older age bands should be interpreted with caution due to reduced life expectancy impacting patient numbers.

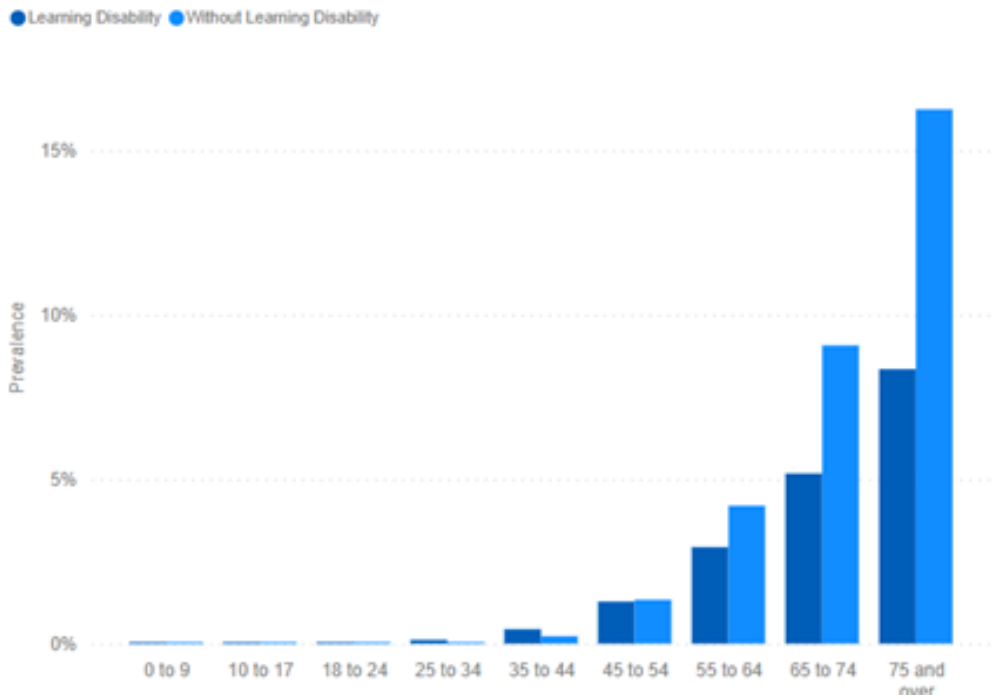


Figure 28: Percentage of patients with and without learning disability, with a diagnosis of Coronary Heart Disease, by age band (NHSE national data, 2022/23)

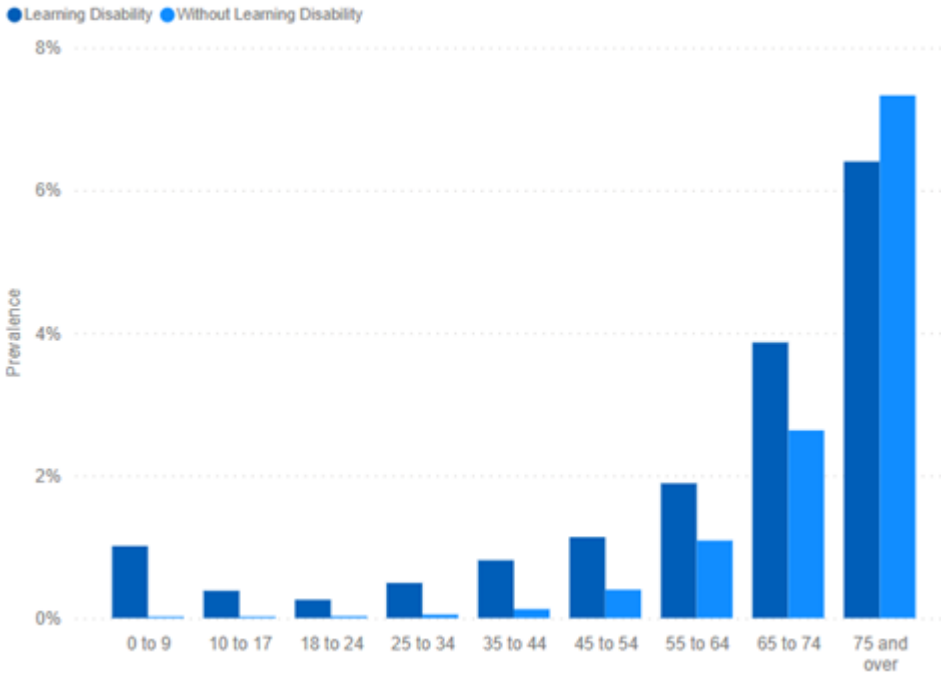


Figure 29: Percentage of patients with and without learning disability, with a diagnosis of Heart Failure, by age band (NHSE national data 2022/23)

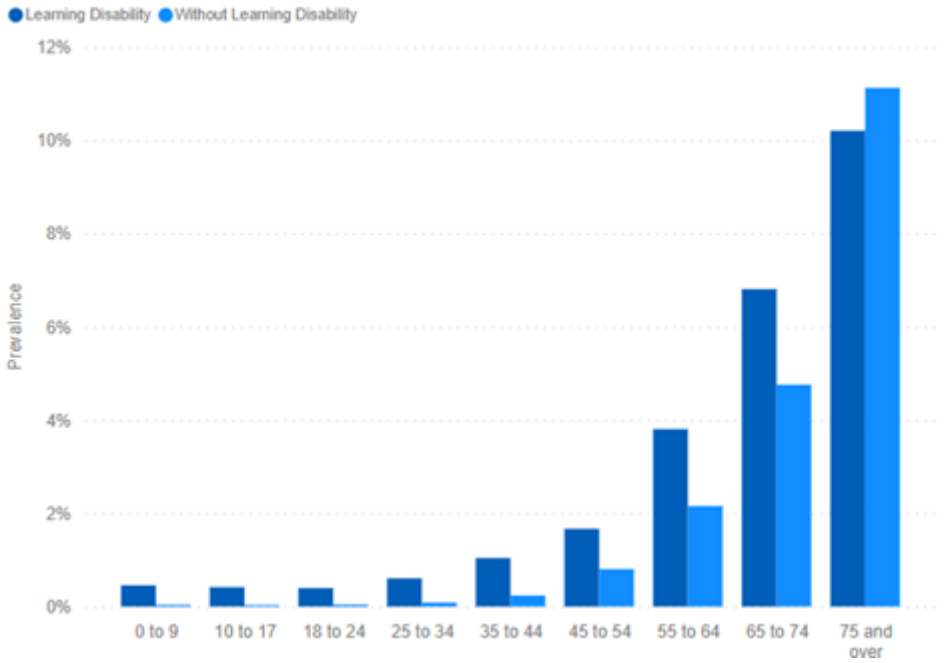


Figure 30: Percentage of patients with and without learning disability, with a diagnosis of Stroke or TIA, by age band (NHSE national data 2022/23)

Risk factors

Risk factors for CVD are also common in people with learning disabilities.
Congenital or genetic

- CVDs are associated with some genetic causes of learning disabilities. For example, almost half of all people with Downs syndrome are affected by congenital heart defects, which is a leading primary or underlying cause of death.
- However, people with Downs syndrome seem to have reduced rates of atherosclerosis, arterial hypertension and coronary artery disease.

Behavioural risk factors

- People with learning disabilities are more likely to experience risk factors for CVD than the wider population, including poorer diets, higher rates of obesity, higher rates of diabetes and lower levels of physical activity, all of which are strongly driven by socioeconomic determinants, as referenced in other sections.
- Whilst people with learning disabilities known to specialist services (likely to be those with more complex needs) may be less likely to smoke and drink alcohol than the general population, there is little data around those who receive little or no support, and those living without a recorded diagnosis.
- The effects of the above behavioural risk factors may present in individuals as raised blood pressure, raised blood glucose, raised blood lipids, as well as excess weight, all of which are direct risk factors for CVD.
- People with learning disabilities may have reduced awareness and understanding of the risk factors associated with CVD, and reduced access to healthier lifestyle options which help reduce these risk factors. People with learning disabilities may also experience barriers to screening, diagnosis and treatment which can impact on outcomes.

Ref: Learning Disability Profiles - OHID (phe.org.uk)

The Annual Health Check (ref AHC chapter) which is offered to people registered as having a learning disability each year, is intended to help screen for indicators of the above health conditions and risk factors, via bloods and lifestyle related conversations, and to support early intervention. This is therefore an important preventative healthcare service; support should be made to encourage and facilitate access including considering reasonable adjustments.

This service is distinct from the NHS Health Checks, which are offered to anyone aged 40-74 without an existing long term condition, every 5 years.
Each Annual Health Check should result in an action plan; interventions or referral pathways offered should be appropriate and accessible to meet each person's needs, and well linked so that any flagged reasonable adjustments is communicated across appropriately.
Additional resources:

- Guidance and standards in cardiovascular health and care for health and care professionals: LeDeR - Guidance
    - Useful data and research on cardiovascular health for health and care professionals -LeDeR - Data/Research
    - Cardiovascular disease prevention - Cardiovascular disease prevention: applying All Our Health - GOV.UK (www.gov.uk)

Diabetes (Type 2)

Diabetes is a condition which causes a person's blood sugar levels to become too high. There are two main types of diabetes; type 1 is a lifelong condition where the body's immune system attacks and destroys the cells that produce insulin, type 2 diabetes is a condition where the body does not produce enough insulin, or the body's cells do not react to insulin properly. Type 2 diabetes is far more common than type 1. In the UK, over 90% of all adults with diabetes have type 2. This section refers to diabetes type 2.
People with a learning disability are more likely to live with diabetes than the wider population. Primary care data from Leeds suggests a prevalence of diabetes in this population of around 8.5% in 2021/22, which appears to be gradually increasing each year (from 7.7% in 2017-18). This is compared to a prevalence of around 5% of the wider population of Leeds.

Prevalence

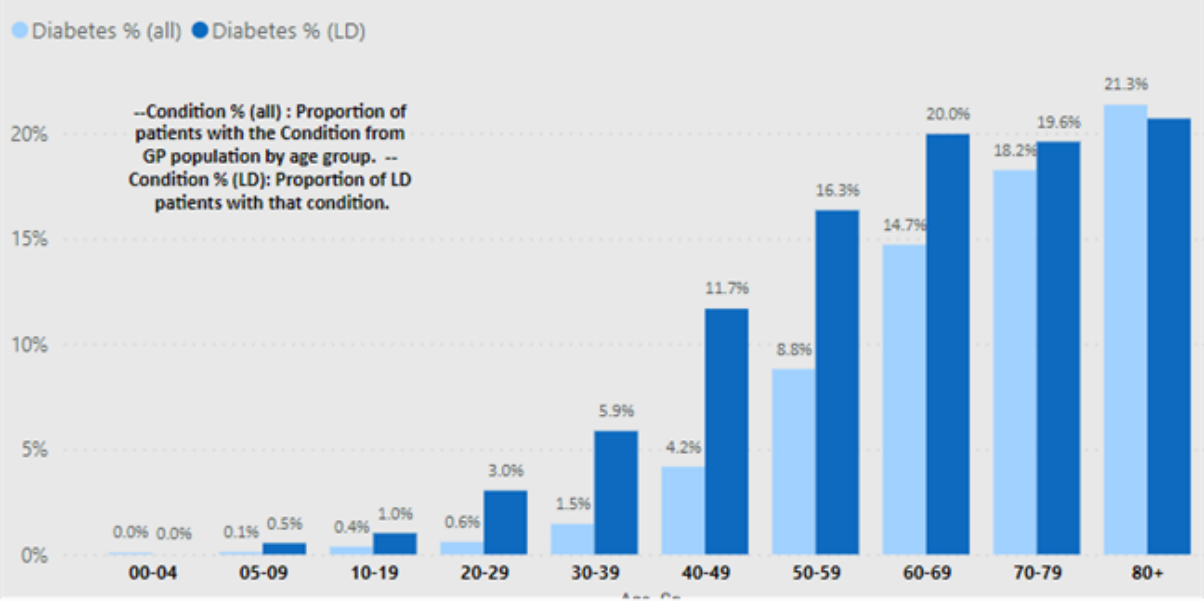


Figure 31: Diabetes prevalence for people with and without learning disabilities, by age group – Leeds Primary care data 2021/22

Figure 31 shows the pattern of slightly higher prevalence and earlier presentation of diabetes in people with learning disability compared to those without. However the more frequent screening offered to people with learning disabilities, eg via annual health checks, may lead to better rates of diagnosis, compared to a potential underdiagnosis in the wider population. Data for the older age bands should be interpreted with caution due to reduced life expectancy impacting patient numbers.

Risk Factors

People with a learning disability have a higher risk of developing diabetes than the wider adult population, and at an earlier age, so support to reduce this risk is important.

- Congenital risk linked with certain syndromes, such as Downs syndrome and Prader-Willi syndrome.
- People with learning disabilities are more likely to be exposed to behavioural risk factors for developing type 2 diabetes. For example, they may have reduced awareness of, or less ability to independently make healthy food choices, including reliance on other people and limited access to more active lifestyles and other behaviour that supports healthy weight management (this is explored in the healthy lifestyles section)
- Living with overweight or obesity. Some Psychotropic medications commonly prescribed to people with a learning disability can lead to weight gain.
- Barriers to accessing screening, diagnosis and healthcare that is often experienced by this population could also mean that an elevated risk of developing diabetes is not identified or acted on as early as it could.
- Support and interventions aimed at preventing diabetes may not be accessible or appropriate for this population, who experience significant barriers when accessing healthcare services.

The "*Leeds Diabetes Strategy Working together to deliver the best outcomes for people at risk of or living with diabetes"*, outlines the intentions to improve health outcomes, acknowledging that prevalence is higher for this group.

Impact

The cost of managing diabetes and its complications for the individual and the health services is high and growing, which highlights the importance of preventative measures, early intervention support and treatment.

People with learning disabilities also have higher rates of hospital admissions resulting from outpatient-treatable diabetes-related conditions.

Introduction - Managing with Learning Disability and Diabetes: OK-Diabetes – a case-finding study and feasibility randomised controlled trial - NCBI Bookshelf (nih.gov)

If not well managed, diabetes can be life threatening and can have life-changing consequences; it is major cause of blindness, kidney failure, heart attacks, stroke and lower limb amputation. It also has links with certain forms of cancer and reduced survival rates.

Diabetes can be hard to manage, particularly for those with obesity and poor dietary habits, certain prescription medications that increase risk, cognitive issues and generally poor self-management skills- which exacerbate the difficulty for people with learning disabilities. Risk factors for harm cause by diabetes are worse if the condition is poorly managed.

The Leeds Programme (Community Diabetes Service) provides care and support around managing diabetes and can provide reasonable adjustments for those with a

learning disability and has piloted a specialist programme to support this group specifically, including easy read resources.
Other support could include increased use of wearable technology to support easier, effective monitoring and delivery of insulin.
Improving care for people with diabetes and a learning disability | Diabetes UK

Prevention

Screening can identify patients who are considered to be at high risk of developing diabetes. With lifestyle changes, it can be possible to prevent diabetes from developing in the “at-risk” patient.

The NHS Diabetes Prevention Programme (NDPP) gives participants personalised support to help them achieve a healthy weight, improve their diet, and become more physically active, which can prevent the development of diabetes.

In Leeds, 44,000 people, or around 5% of the city’s population aged over 16 are living with type 2 diabetes. A further 35,500 people (aged 16 years and over) are known to be at high risk of developing type 2 diabetes and are therefore a target group for this programme.

Population	Population size	At high risk of developing diabetes, aged over 16		Living with diabetes type 2	
		Number	% of total population	Number	% of total population
Leeds	~850,000	~35,500	~4%	~44,000	~5%
People with diagnosed Learning disability	4,687	**431**	9.2%	**384**	8.2%

Figure 32: Data on diabetes type 2 and high risk of diabetes. Sources: Leeds Primary care records 2023, and NDPP (2022/23 Q2 data)

Figure 32 demonstrates the higher prevalence and risk of diabetes in this population. However, the numbers of people with learning disabilities referred to the NDPP do not appear to reflect the projected need. In West Yorkshire out of 19,144 referrals made to the NDPP, only 144 were for people with Learning disabilities which suggests that service access is low for this population.
Little information is held about completion of intervention, impact of intervention and longer-term outcomes for this group, as such it is hard to ascertain how effective this programme is for this population.

Epilepsy

Epilepsy is a common condition that affects the brain and causes seizures. Epilepsy can be lifelong, and start at any age, but usually starts either in childhood or in people over 60.
Epilepsy is more common in people with a learning disability than in the general population.

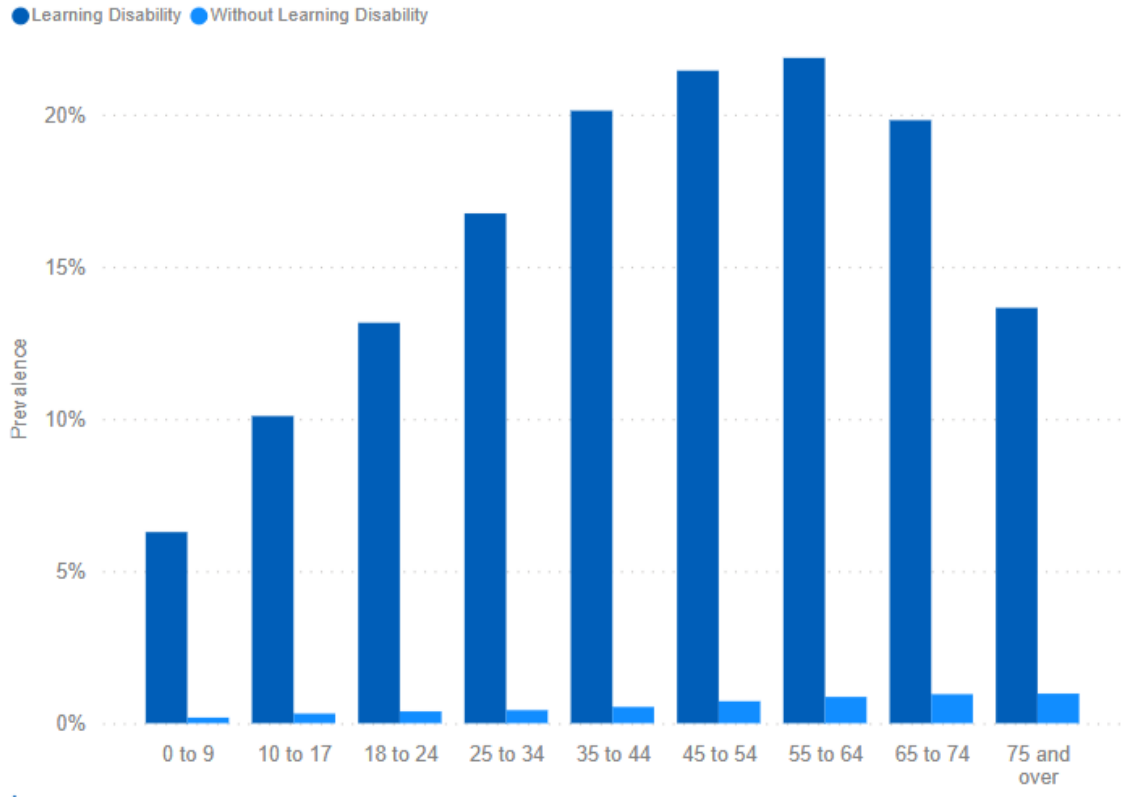


Figure 339– Percentage of patients with an active diagnosis of epilepsy and are currently on drug treatment for epilepsy, by age band (NHSE National Data 21/22)

Figure 33 shows the significantly higher prevalence of epilepsy in people with learning disabilities, being up to twenty times higher than for the general population, with the difference apparent from an early age.

Seizures in this population are commonly multiple and resistant to drug treatment (*Amiet et al 2008, Branford et al 1998, Matthews et al 2008)*. This is especially true in severe and profound learning disability. Uncontrolled epilepsy can have serious negative consequences on both quality of life and mortality (*Kerr et al 2001).* Epilepsy is the long term condition most strongly associated with dying at an earlier age according to the 2022 LeDeR review. The condition adversely affects people's health, safety and well-being and carries a significant increased risk of sudden unexpected death in epilepsy (SUDEP).

Supporting people with poorly controlled epilepsy therefore requires high levels of competence and confidence in staff in community settings.

Resources around care and management of this condition:

- NICE recommendations: NG217 Visual summary (nice.org.uk)
- Good Psychiatric Practice: CR203: Management of epilepsy in adults with intellectual Disability - college-report-cr203.pdf (rcpsych.ac.uk)
- rightcare-epilepsy-toolkit-v2.pdf (england.nhs.uk) for recommendations
- Supporting people with a learning disability who have epilepsy (youtube.com)
- Epilepsy | Intellectual Disability and Health

Respiratory Problems

Respiratory disease is any condition that affects the lungs and causes difficulty in breathing. The most common long term respiratory conditions are Chronic Obstructive Pulmonary Disease (COPD) and asthma. Respiratory disease affects one in five people and is the third biggest cause of death in England after cancer and cardiovascular disease. (NHS England » Respiratory disease). Respiratory disease is one of the biggest causes of death for people with a learning disability in England (listed as the 4th most common immediate cause of death for people with learning disabilities in the LeDeR 2023 review), but many of these deaths are avoidable (NHS England » RightCare learning disability and aspiration pneumonia scenario).

Approximately 50% of people with learning disabilities have had some form of breathing problems, compared to 15% of the general population. *(E. Emerson, S. Baines, L. Allerton and V. Welch, "Health Inequalities and People with Learning Disabilities in the UK: 2011," IHAL, 2011.)* emerson_baines_health_inequalities.pdf (complexneeds.org.uk)

Prevalence and mortality

Higher rates of asthma, chronic obstructive pulmonary disease (COPD), upper respiratory tract infections and poorer measured lung function have been reported for people with learning disabilities.

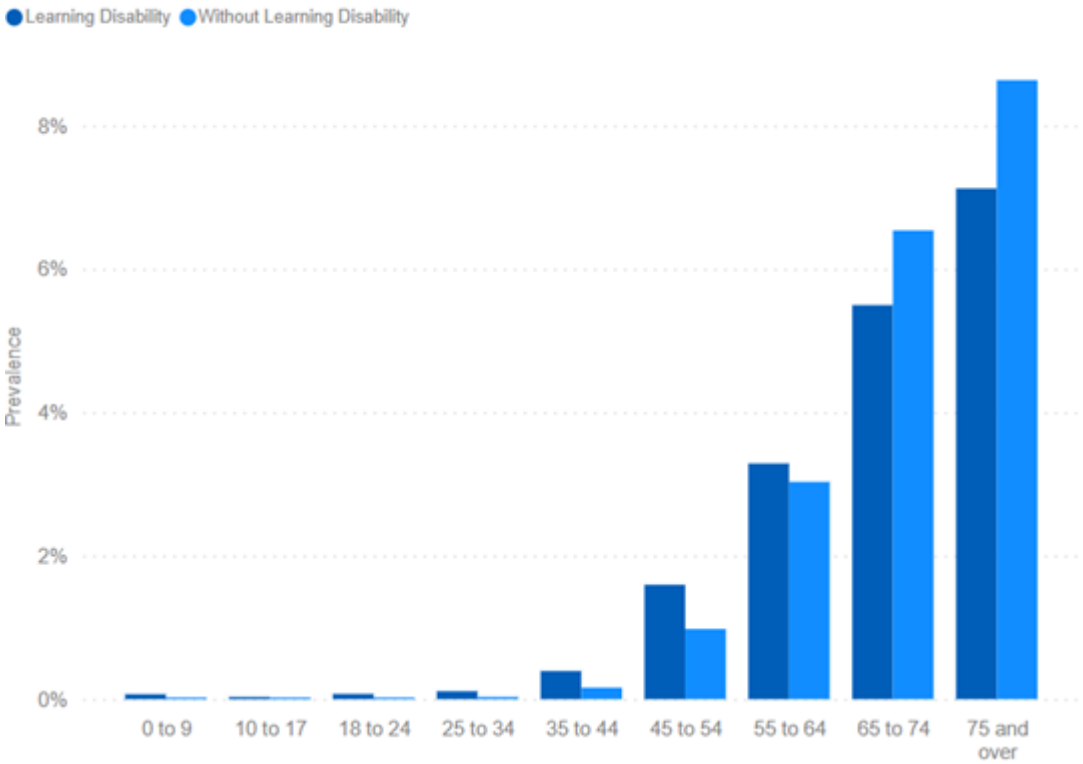


Figure 34: Percentage of patients with a diagnosis of COPD: NHSE Health and care of people with learning disabilities – national data 21/22

Figure 34 demonstrates the higher prevalence (under 65) and earlier presentation of COPD in people with learning disabilities. As with other datasets, note that additional screening is available for people with learning disabilities, and conversely

underdiagnosis is a factor in the wider population for COPD. Caution should be taken in interpreting the results for older age bands due to shorter life expectancy and smaller patient numbers.

Figure 35: Percentage of patients with an active diagnosis of asthma: – NHSE Health and care of people with learning disabilities – national data 21/22
Figure 35 demonstrates the higher prevalence (under 75) and earlier presentation of asthma in people with learning disabilities.

Risk Factors

Many people supported by learning disability services will have compromised or vulnerable respiratory status.
Incidence and mortality rates from respiratory disease are higher in disadvantaged groups and areas of social deprivation. Generally, more deprived communities have a higher incidence of risk factors including rates of smoking, exposure to higher levels of air pollution, poor housing conditions and exposure to occupational hazards.

Children with learning disabilities are significantly more likely than their peers to live in more deprived areas of the city thereby exposing them disproportionately more to these risk factors. *Emerson E and others. Risk of exposure to air pollution among British children with and without intellectual disabilities. Journal of Intellectual Disability Research, 2019. 63(2): p. 161-167*

The Healthy Leeds Plan Dashboard gives data around unplanned hospital admissions and bed usage. This helps to understand the impact of different health conditions on unplanned care. For people with learning disabilities and/or autism (the populations are combined for this dataset) the most common issue for unplanned admission is around accidents, the second most common reason is respiratory issues. [Healthy-Leeds-Plan-Document-070923.pdf (healthandcareleeds.org)]

Cancer

Globally, it is estimated that over 18 million people are diagnosed with cancer each year. The burden of this disease increases every year with increases in life expectancy, and while survival rates for some cancers improve with medical advances, increasing numbers of people are now living with cancer.

38% of cancers cases in the UK are considered preventable, with the largest preventable cause being smoking (15%) and the second largest being obesity (6%) (*Cancer Research UK, 2023)*
The incidence and pattern of cancer amongst people with learning disabilities is changing partly due to increased life expectancy, as the incidence of cancer rises dramatically with age.

Prevalence

Figure 36 below shows that cancer prevalence is higher and that this difference appears at a lower age, in this population.

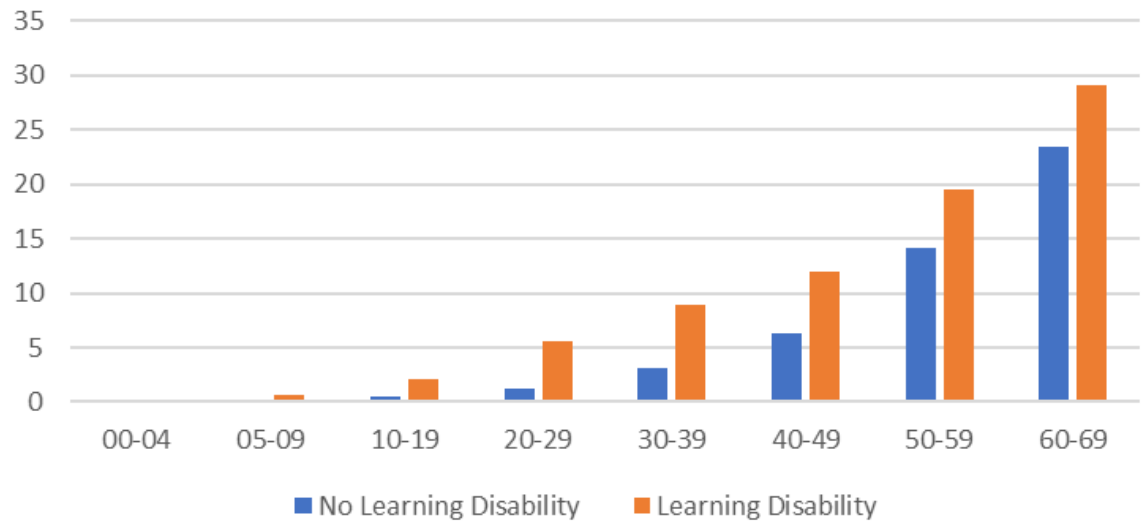


Figure 36 Prevalence (percentage) of cancer diagnosis by age: Leeds Primary care data 2023

Risk Factors

One of the main risk factors for developing cancer is age, and as life expectancy for people with learning disabilities gradually increases, rates of diagnosis are projected to increase.
Preventable risk factors for specific cancers vary, but it is known that people with learning disabilities are more likely to experience some of the risk factors for certain types of cancers than the wider population.

People with learning disabilities are less likely than the wider population to have access to healthier lifestyles, with higher prevalence of overweight and obesity, lower rates of physical activity and often poorer access to a healthy balanced diet. People with mild learning disabilities may be more likely to smoke although the evidence around this is unclear as all forms of learning disability are grouped together for smoking data.

Another risk factor is lower socio-economic status; people with learning disabilities are more likely to live in the more deprived parts of the city, living on lower incomes, and often with increased exposure to unclean air.

They are also less likely to benefit from awareness and insight around these risk factors for cancer and may have a reduced ability to independently make lifestyle choices or take steps that reduce these risks.

Barriers to early and effective diagnosis

People with learning disabilities may have less awareness of early symptoms of cancer due to inaccessibility of most mainstream health promotion materials and health education.
Communication and cognitive issues may create barriers to identifying and clearly communicating specific symptoms or pain to others, on whom they might be reliant to determine if/ how to communicate this on to health professionals.

People with learning disabilities are less likely to attend routine screening, this can be for various reasons including lack of awareness, inaccessibility of screening invitation communication, difficulties with transport and access, services not meeting needs, sensory issues and fear and anxiety around invasive screening.

Low screening rates lead to later presentation and identification of cancer than in the wider population, and hence poorer outcomes.

Differences in presentation

Due to some of the barriers identified, people with learning disabilities are more likely to have their cancer diagnosed later than people without learning disabilities.

- Cancer is often diagnosed at a later stage for people with a learning disability than for the general population, and these late diagnoses are unfortunately often made during emergency presentation at hospital.
- Late presentation unfortunately leads to poorer outcomes for patients.
- Only 3% of people with learning disabilities who died of cancer, had the cancer identified through screening.
- Late or emergency presentation can make it harder to determine where the cancer originated. This can make it harder to accurately understand the prevalence of some types of cancers for this population, particularly those with less obvious early symptoms.

An English population-based study using linked data from three sources (BMJ 2022) concluded:

> *In decedents with intellectual disabilities, symptoms suggestive of cancer had tended to be identified most frequently as an emergency and at a late stage. There is a need for greater awareness of symptoms of cancer in this population, a lower threshold for referral by General Practitioners (GPs), accelerated access to diagnosis and treatment and consideration paid to lowering the age for colorectal screening.*

People with learning disabilities experience a different cancer profile when compared to the general population. Studies that specify types of cancer deaths indicate that most underlying causes of cancer deaths for people with learning disabilities are from diseases of the digestive organs. This differs from the pattern of cancers found in the general population, in whom lung, breast and prostate cancer predominate.

Down Syndrome has associations with some cancers. Bonell (2010) found that children and adults with Down syndrome experienced more of some cancers such as leukaemia and lymphomas compared with to the non-disabled population, and from an earlier age. Other cancers such as testicular, pancreatic, ovarian, uterine, skin, retinoblastoma and malignant tumours of the brain are also more prevalent in people with Down syndrome (Satge et al., 2006; Sullivan et al., 2007). Men with learning disabilities, particularly Down syndrome, are more likely to develop testicular cancer than other men.

National evidence highlights the higher prevalence of cancer of the oesophagus, stomach, and gallbladder, with lower prevalence rates of cancers commonly found in the general population (Heslop et al., 2013).

People with learning disabilities have been found to experience Helicobacter pylori gastric infection at twice the rate of the general population. Helicobacter pylori is a class 1 carcinogen linked to stomach cancer, gastric ulcer, and lymphoma particularly among people with learning disabilities. Some digestive system cancers may be influenced by poorer gastrointestinal health, which is more common in people with learning disabilities.

Screening

National cancer screening programmes are targeted at eligible parts of the population and aimed at detecting breast, cervical and bowel cancers. There is a

need to ensure that all people with learning disabilities have equal access to national cancer screening programmes and the necessary support and reasonable adjustments to mitigate the various barriers they may face in accessing screening.

Figure 38 demonstrates the difference in screening uptake for this population.

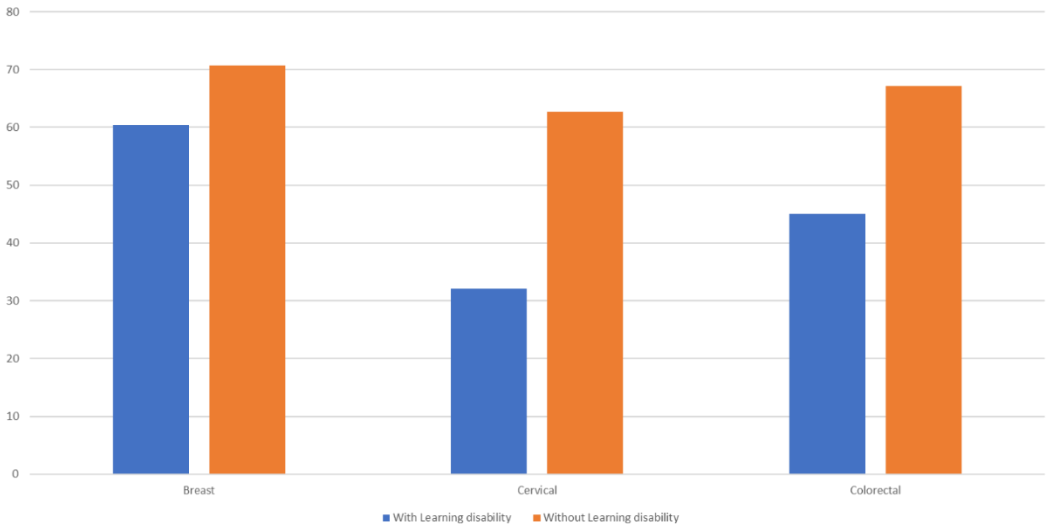


Figure 38: Screening rates breast, cervical and colorectal, as a percentage of those eligible – Leeds primary care data 21/22 (NHSE)

Leeds City Council Public Health commission the Leeds Health Awareness Service to take a community approach to raising awareness around cancer and long-term condition risk factors, awareness of signs and symptoms and the importance of screening. They focus specifically on breast, bowel, lung, cervical and prostate cancer and target their work in areas of highest deprivation and with specific groups where cancer outcomes are poorer which includes people with learning disabilities.

Breast cancer

Nationally Breast Screening uptake for 2020/21 was 47.2% in people with learning disability compared to 69.1% in the general population. Figures in Leeds were higher - 60.4% compared to 70.7%. This may be due to considerable efforts to improve access to screening in Leeds, for example the ongoing work undertaken by Leeds Health Awareness.

Evidence from England suggests that death rates from breast cancer in women with learning disabilities do not differ from those in the general population and is thus as significant a health issue as for other women. For women with learning disabilities however, knowledge of breast cancer including associated risks, preventative factors and signs and symptoms may be extremely limited. Women with learning disabilities may not easily communicate their symptoms and may be at risk of delayed diagnosis.

Barriers to accessing mammography include literacy problems, consent issues and physical health conditions (Willis et al., 2008). Practical barriers such as transport and timing of appointments, and barriers attributed to healthcare professionals, including staff attitude and lack of awareness and access to resources and training, have also been identified (Tuffrey-Wijne et al., 2005; McIlfatrick et al., 2011). Therefore, screening approaches and services need to be individualised to the needs of people with learning disabilities to ensure equality of access.

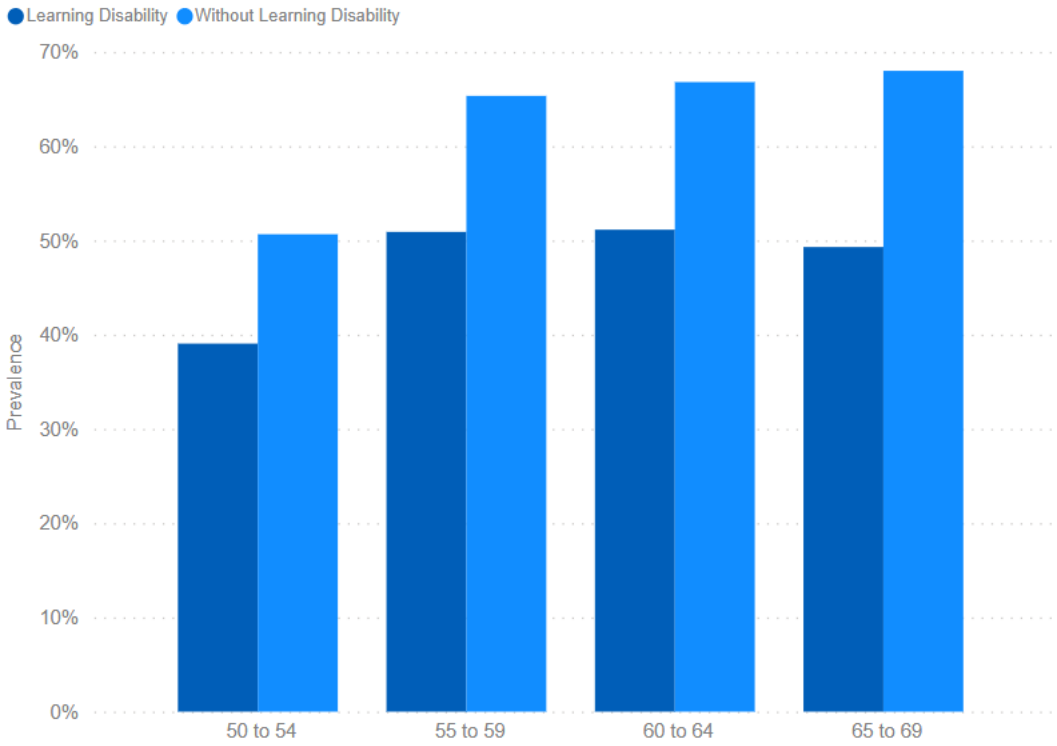


Figure 39: Breast Screening rates: percentage of patients who are female, aged 50-69 and received breast cancer screening in the 5 years previous- NHSE Health and care of people with Learning disability: National data 2023)

Screening rates illustrated in figure 39 are even lower for people who have autism as well as learning disabilities.

Cervical cancer

It is hard to determine the true prevalence of cervical cancer in this population. As patients with learning disabilities are more likely to present and be diagnosed quite late with cervical cancer, at a stage where secondary cancers may have developed, it is sometimes harder to determine where the primary cancer occurred.

One of the most significant risk factors for cervical cancer is the presence of the HPV virus, detected via screening. A common presumption by carers or family members that a person with a cervix and a learning disability is not sexually active (this is also explored in the section on sexual health). This may not always be the case, and withdrawing them from the screening cycle, could lead to missed opportunities for screening.

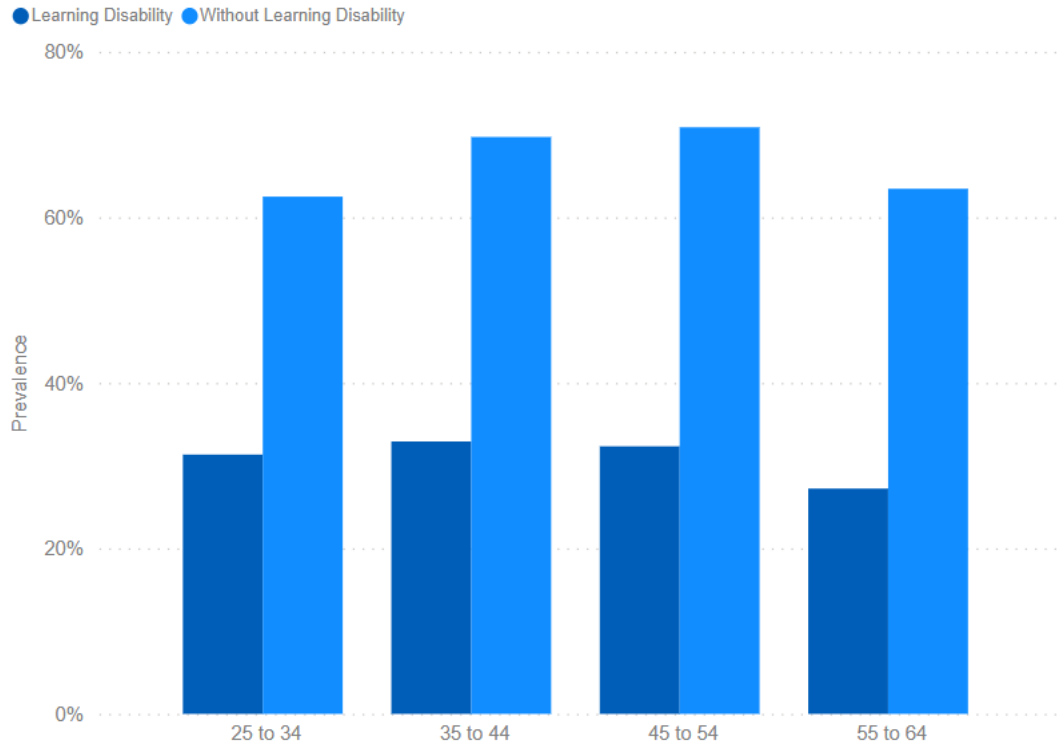


Figure 40: Percentage of patients eligible for cervical screening (female, aged 25-64 with no hysterectomy), having had a cervical smear test in the last 3.5 years, by age band- NHSE, 2023 (National Data)

Uptake for 2019/20 reports that 31.2% of women aged 25 to 64 with learning disabilities had a cervical smear in the prior 5 years compared to 73.2% of women without learning disabilities (England data). For Leeds this figure is slightly higher at 32.9% (2019/20). (Source NHS Digital)

Cervical Screening and Learning Disability patients – Rachel Bethell, Cancer Wise Leeds Programme June 2021

It is recognised nationally that there is low uptake of cervical screening by women with learning disabilities.

> '*The low uptake of cervical screening by women with learning disabilities does not appear to be primarily due to these women being excluded from invitation for screening. Women with Learning disabilities have been found to be significantly less likely to respond to invitations for screening than other women. Other barriers to the uptake of cervical screening by women with learning disabilities include practical issues such as not being registered with a GP or not receiving an invitation letter due to out of date contact details, lack of accessible information regarding cervical screening, fear and anxiety around having the test performed, concerns around the capacity of women with learning disabilities to consent to the test, lack of understanding of the purpose of the test, and patient refusal' (source: Public Health; Health Inequalities)*

Colorectal or Bowel Cancer

26% of people with learning disabilities who died of cancer, died of bowel cancer. People with a learning disability have been shown to have a higher risk of developing bowel cancer than the general population, and the 2022 LeDeR report found that bowel cancer accounted for a higher percentage of cancer deaths among this population group.
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.

Figure 41 shows screening rates for bowel cancer, with is a discrepancy which increases with age. The rates are even lower for people who have autism as well as learning disabilities.

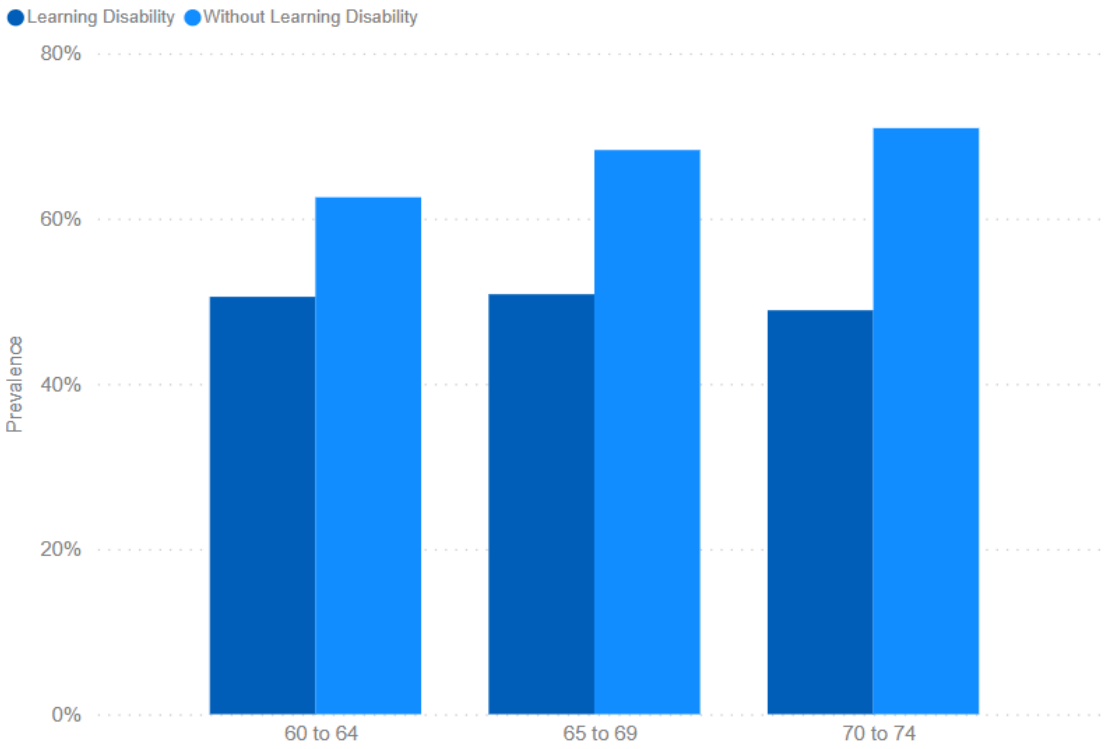


Figure 41: Percentage of patients eligible for colorectal screening (aged 60-74) who have undergone screening in the last 2.5 years, by age – NHSE - Health and care of people with LD, National data 2023)

Other Cancers

There is little other data available around screening and outcomes for other cancers for this population that would help to understand inequalities and help to inform targeted work to improve outcomes – further data would be welcomed.

Work to address these inequalities in Leeds is co-ordinated by the Cancer and Learning disabilities task group. This group contributes towards the strategic outcomes of the Leeds Cancer Population Board.
They have identified 3 initial focus areas (bowel, breast and cervical) and initiatives have included:

- Working with the Gateshead bowel screening hub to ensure that codes or flags for learning disability from primary care records, are added to the bowel screening records, meaning that practices are alerted when a kit is sent out and can send out easy read instruction letters.
- Training to workforce e.g., social prescribers to improve knowledge and confidence around screening processes.
- Co-ordinating with the ongoing work by Leeds Health Awareness Service, who have delivered sessions to groups of people with learning disabilities to raise awareness of signs, symptoms and screening, in an accessible way within a familiar group environment.
- Work is underway to develop both breast screening and cervical screening packs to support uptake of screening among people with a learning disability, and support improvements in the screening pathways.
- Improving awareness of reasonable adjustments and flexibility with appointments
- Letters have been reviewed and improvements made for accessibility – for example the two week wait letter which advises patients about next steps after screening.
- The “You Can Ask” campaign aims to encourage patients to request reasonable adjustments to support their care, including at screening appointments.

Conclusions

- There is a need for general health promotion to people with learning disabilities to support healthy lifestyles, which reduce the risk factors for cancers.
- There is also a need for appropriate health promotion around understanding the signs and symptoms of cancer and around screening processes, to help encourage uptake.
- It is important that the circle of support around those with learning disabilities are also involved, to help support positive conversations, facilitate communication about concerns and help remove barriers to screening.
- Improvements to accessibility of screening, including:
    - Accessible, easy to understand communication.
    - Joining up of services so that flags for reasonable adjustments are carried from primary care records to screening services.
    - Prevention of blanket exceptions
    - Any other provision of reasonable adjustments as appropriate such as longer appointment times, desensitisation, and a flexible approach to each individual’s needs.

Digestive Health: Constipation

Prevalence of constipation

People with learning disabilities are more likely to suffer from chronic constipation than people without learning disabilities. NHSE GP data in England from 2020/2021 records that around 13% of people with learning disabilities had been diagnosed with chronic constipation. Figure 42 suggests prevalence steadily increasingly with age, from around 10% in childhood to 32% of those over 75.

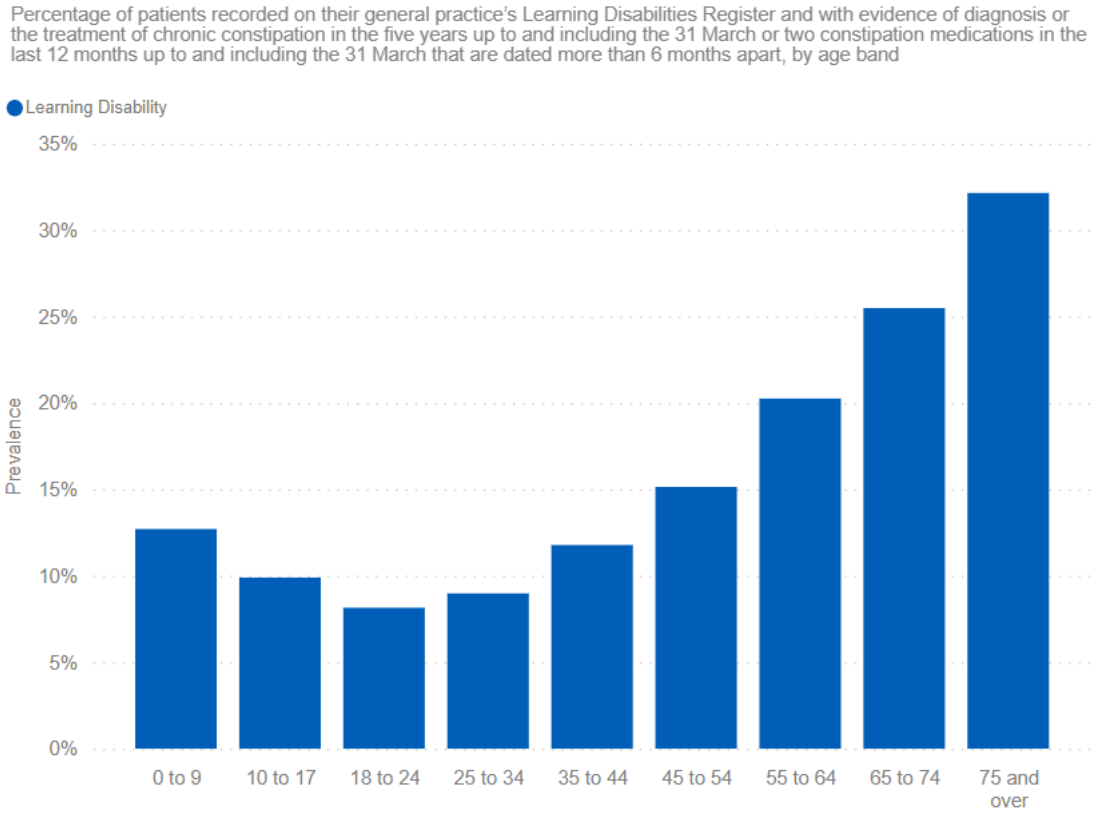


Figure 42: Percentage of patients with learning disabilities with diagnosis or treatment of chronic constipation: NHSE experimental data: 2020/21

The LeDeR Action Learning Report 2021/22 suggests a higher figure of 20–50% of people with a learning disability are affected by constipation, compared to 10% of the wider population. Action-From-Learning-Report-2021-22.pdf (leder.nhs.uk)
The Leder report also lists Constipation as one of the 10 most frequently reported long-term health conditions among people with a learning disability who died in 2020 (55%).
Over a third (38%) of those whose deaths were reviewed in the 2020 annual report were usually prescribed laxatives. (NHS England » University of Bristol LeDeR annual report 2020: Action from learning report)

Causes and risk factors

People with learning disabilities are more likely to be exposed to the factors that cause constipation, these include;

- Primary causes, due to lifestyle: inadequate diet and fluid intake, reduced mobility and lack of exercise
- Secondary, caused by or linked to physiological conditions such as cerebral palsy *(Robertson J, Baines S, Emerson E and Hatton C. (2017a) Prevalence of constipation in people with intellectual disability: a systematic review. Journal of Intellectual & Developmental Disability),* hypothyroidism, depression and diabetes, all of which have higher rates in this population (primary care data)
- Latrogenic: side effects of antipsychotic, antidepressant and anticonvulsant medication
- Environmental risk factors potentially related to having a learning disability, such as inappropriate toileting facilities or a lack of privacy or time to use them, disruption in routine or changes to their care or environment, and difficulty in communicating need can all negatively affect bowel habits.

People with learning disabilities are also more likely to be prescribed laxatives, although long term reliance on laxatives is not generally recommended. Constipation can lead to serious illness and death, and it is also a common cause of avoidable, non- emergency hospital admission *(Hospital Admissions That Should Not Happen Admissions for Ambulatory Care Sensitive Conditions for People with Learning Disabilities in England (IHAL)*

LYPFT have developed and deliver a new bowel care pathway, involving specialist observation and assessment, and working with a MDT to improve consistency of care This will help primary care who may have limited time to talk with patients.

Support for carers around bowel health, signs and symptoms:
Where appropriate, people with learning disabilities and carers should be made aware of the causes and risks of constipation, the elevated risk for this population and issues with communication and presentation.

https://fingertips.phe.org.uk/documents/Health_inequalities_constipation.pdf
LeDeR - Action from learning report 2021-22
Learning from Lives and Deaths - people with a learning disability and autistic people (LeDeR) - King's College London (kcl.ac.uk)
Constipation_RA_report_final_easy_read.pdf (publishing.service.gov.uk)
Constipation: making reasonable adjustments - GOV.UK (www.gov.uk)
IHAL-2013-02_Hospital_admissions_that_should_not_happen_ii.pdf (ndti.org.uk)

Oral and Dental Health

"I worry about my son's dental health – he won't let anyone look in his mouth at all and he hasn't been to a dentist for a long time"

Parent carer of a non-verbal man with learning and physical disabilities

"[the person I support] didn't respond to letters from their dentist about routine checkups as they can't read- so they were discharged"

Support worker

Prevalence:

There is little local data around the prevalence of poor oral health in this population. National study from Public Health England indicated that approximately one in 3 adults with learning disabilities have unhealthy teeth and gums, that people with learning disabilities were less likely to brush their teeth twice a day (63%) than a group without learning disabilities (75%), and had fewer remaining teeth on average for all age groups.
Public Health England Adults_with_learning_disabilities_dental_summary.pdf (publishing.service.gov.uk)

A recent UK survey involving 387 adults with learning disabilities reported that participants with learning disabilities had higher rates of untreated decay, a greater number of extractions and were less likely to have posterior functional contacts than adults in the general population.
Davies G. Oral health among adults with learning disabilities in England 2010/11, in Better Dental Services for People with Learning Disabilities. 2012: Birmingham

Risk factors and causes of poor dental/ oral health

- Difficulty in maintaining proper oral hygiene due to motor or cognitive impairments.
- Limited access to accessible, appropriate dental treatment (including availability of NHS dentists)
- Dependence on carers (in or outside of a care setting) for oral care which may vary in quality.
- Refusal to co-operate with brushing (due to behavioural or sensory issues, fear or distress)
- Poorer diet
- Personal and social circumstances
- Higher prevalence of dental anxiety and fear leading to avoidance of dental visits
- Limited communication skills with which to express pain or discomfort.
- Limited awareness of the importance of oral health
- gastroesophageal reflux
- Use of medications that can have side effects on oral health e.g. by reducing salivation.
- Being a non-oral feeder ('peg' fed)

Impact

Poor oral health can cause pain, discomfort and distress that can be difficult to communicate. Difficulties in expressing pain can lead to issues with behaviour if unaddressed.
It also has an impact on general health, with links to major chronic diseases such as cardiovascular disease, diabetes, respiratory disease and stroke.

In people with learning disabilities and dysphagia, oral microbial status is associated with pneumonia, and it has been suggested that the oral cavity of people with learning disabilities may serve as a reservoir for bacteria that may be aspirated into the lungs, which may cause aspiration pneumonia.
Problems chewing due to pain or missing teeth can lead to nutritional deficiencies and obesity.
Poor oral health can also affect an individual's psychological health, ability to socialise, feelings of social wellbeing, growth, appearance, speech, eating and enjoyment of life
Wilson N and others. Oral health status and reported oral health problems in people with intellectual disability: A literature review. Journal of Intellectual & Developmental Disability, 2018: p. 1-13

In Leeds a community dental service offers treatment to those for whom mainstream services might not be suitable, by practitioners trained and experienced in working with this group, and able to make reasonable adjustments to make the service as accessible as possible. However there may be people for whom even this service does not meet their needs, who are not registered with a dentist or do not attend check-ups or treatment.
Scarcity of NHS dental services in Leeds means that affordable treatment is unlikely to be available to many people on lower incomes, and little is known about oral health for people in the city who have an undiagnosed/ unrecorded learning disability.

Conclusions

- It is recommended that all children, young people and adults with learning disabilities should visit the dentist twice a year.
- Community dental services can help improve access.
- Support staff and carers working with people with learning disabilities should be offered training on the importance of oral health and how to help someone clean their teeth, and how to manage reluctance to brush teeth, as well as trained be alert to changes in behaviour such as loss of appetite, mood, sleeplessness, irritability or self-harm, and should find out if mouth or tooth pain is a possible cause of these changes.
- NICE recommendations for the oral healthcare of adults in care homes: Overview | Oral health for adults in care homes | Guidance | NICE

Sexual Health

The topic of sexual health for the purposes of this HNA includes:

- Screening and treatment for STIs, and HIV
- Access to advice and choice around contraception
- Education around healthy relationships, sexuality/ sexual identity, sex and consent (including exploitation and sexual abuse)

There is little research focus in the field of sexual healthcare for people with a learning disability despite this population being sexually active and at risk of sexual exploitation. This group can be more likely to have negative experiences within

healthcare which can be compounded by societal stigma, lack of understanding and infantilisation.
Although some people with a learning disability may be deemed not able to consent to having sex or a relationship, this is the minority.

1. *"..Young people with mild to moderate learning disabilities were as likely to have had sexual intercourse by the age of 19/20 as their peers from the general population. However, young people with mild to moderate learning disabilities were more likely to practice unsafe sex compared to young people from the general population. Young women with mild to moderate learning disabilities were more likely to have been pregnant or be a mother"* *Baines S, Emerson E, Robertson J, and Hatton C. (2018) Sexual activity and sexual health among young adults with and without mild/moderate intellectual disability. BMC Public Health, 18(1)*

The right to a sex life is enshrined in legislation but people with learning disabilities can sometimes face barriers due to concerns around consent, vulnerability and the possibility of exploitation.

Very little data is available around the sexual health of people with learning disabilities however there are known barriers around accessing information, support and healthcare which will lead to health inequalities:

Barriers to accessing services and other issues:

- Carers, support workers, or health practitioners incorrectly assuming that the person is not sexually active. This is due to societal stigma or infantilising attitudes.
- The Annual Health Check should provide an opportunity for the practitioner to discuss sexual health and activity with a patient. While the presence of a carer can help support them to communicate or feel comfortable, it could also mean the opposite when questions about sexual health are asked, potentially leading to declines or skipped questions.
- Inaccessibility of services – not understanding people's needs due to failure to identify, record, or put in place reasonable adjustments.
- Potential lack of awareness amongst practitioners around how to communicate effectively with people with learning disabilities
- Patient fear and anxiety around procedures, tests and outcomes. Some people with learning disabilities have anxiety around unfamiliar or intimate procedures. Poor experiences during procedures (often as a result of poor communication) can reinforce fear.

From a Listening exercise between Lucy Simpson and Because We Matter (Women's Health Matters)

The women spoke of the difficulty of getting an appointment such as being on the phone for a long time and having to ring at a specific time being a barrier. The women discussed the location of the services and stated the need to have services closer to where they live. Many people with learning disabilities have limited independence therefore accessing services which

they cannot walk to, is a barrier. The women felt rushed during appointments when they needed a bit more time to articulate their needs. When asked what other barriers people may feel they stated they may feel embarrassed, shame, and nervous about seeking support around sexual health.

Barriers in education and information

- Lack of access to education around relationships and sex- education provided in schools might have been missed, or a long time ago, or not provided in a way that was accessible to the person, leading to incomplete or inaccurate knowledge around the biological, emotional and legal issues that surround these topics - this can lead to unhealthy relationships, exploitation or even sexual assault or rape.
- Lack of awareness around sexual health, contraception, signs and symptoms of infection and the importance of regular screening.
- Over-contraception – women have been reported to have been prescribed long term contraception without their consent or informed choice, to prevent risk of pregnancy in case they are sexually active. *Ledger S and others. Contraceptive decision-making and women with learning disabilities. Sexualities, 2016. 19(5-6): p. 698-724*

Insight from a Listening exercise between Lucy Simpson (LCC Public Health) and Because We Matter (Women's Health Matters)

The group had mixed knowledge around sexual health. There was a general understanding of what contraception is and they knew of the contraceptive pill and the depo injection, and they knew that these were taken to prevent unwanted pregnancy. However, there was limited knowledge of other contraception and what the side effects were to all contraception as they all stated that this has never been discussed with them. Additionally, they did not know that they could go back to the healthcare provider to change their contraception if they wanted too. They therefore presumed they just had to put up with the side effects. The group knew what condoms were and some have been shown how to use one, however while they knew of their use for preventing unwanted pregnancy, no one knew what an STI was, and again stated that they have never been told. However, in addition to this some felt that they could not speak to their doctor because they would not understand their needs.

There was in depth discussion on their experiences with healthcare professionals. The women stated that in addition to not giving full information, there were many assumptions being made about themselves such as assuming they do not have sex. They felt that healthcare workers make presumptions about them due to their learning disability, such as "it worked for this person with a learning disability, therefore it will work for you", therefore taking away treating that person as an individual. The women felt that the healthcare workers did not trust them to trust their own bodies and often they did not feel listened too.

Barriers to forming relationships

- Support workers and family members could be a support or a barrier in terms of helping people develop relationships. Some may feel there is a lack of guidance as to what is an appropriate level of intervention to support a relationship, how to discuss things sensitively, and where safeguarding becomes an issue. What constitutes proper consent to a sexual relationship for people with learning disabilities is very difficult to determine – there are no well-established methods for making this judgment.
- Some may lack confidence in supporting sexual relationships or navigating boundaries for someone they care for. It might feel embarrassing or uncomfortable discussing with a family member, carer or support worker.
- Potential assumption or expectation by carers or family that a person is heterosexual, or reluctance to accept that they are not; stigma still exists around LGBTQ+ issues can lead to double/ intersectional discrimination.
- Practical barriers to forming relationships – some people may experience a lack of opportunities to socialise freely and support to engage in a loving and sexual relationship with others, or experience restrictions from housing providers.

Sexual health service data in Leeds

Sexual Health services and access to contraception in Leeds are either offered via primary care or via the Integrated Sexual Health Service. The ISHS offers more specialist support, more choice and more confidentiality; clients of sexual health and HIV treatment services do not need to register for them using their NHS number and, if they are still concerned about their privacy, can register using an alias. Healthcare records at these services are not shared with other services within the respective NHS Trust, GPs, or the NHS Summary Care Record, unless explicit consent is given.

The ISHS does not systematically record whether someone has a learning disability. If it is recorded by GPs, SHS clinicians can potentially see this data, and may also record it as part of the local patient record. However, this is not coded in a way that allows the Business Intelligence team to extract the data for analysis.
It is therefore not possible to determine accurately to what extent people with learning disabilities are accessing this service.

It is also hard to determine accurately what the impact of these health inequalities is on people with learning disabilities – data is similarly hard to locate around STI prevalence and unplanned pregnancies.

National Data/ indicators around sexual exploitation and abuse

- People with learning disabilities are known to be vulnerable to sexual exploitation and abuse.
- Disabled children are almost three times more likely to experience sexual violence than non-disabled children *Residential schools investigation report (2022) Independent Inquiry into Child Sexual Abuse, Crown copyright : https://www.iicsa.org.uk/document/residential-schools-investigation-report-march-2022.html*
- Young people with learning disabilities are more vulnerable both to being sexually abused and to displaying inappropriate or problematic sexual

behaviour ((*McNeish & Scott (2023) Key messages from research on children and young people who display harmful sexual behaviour. Centre of Expertise on CSA.)*

- A recent study on a sexual assault support service in Manchester found that people with learning disabilities were disproportionately highly represented in those seeking help *(The disproportionately high prevalence of learning disabilities amongst adults attending Saint Marys Sexual Assault Referral Centre - Majeed-Ariss - 2020 - Journal of Applied Research in Intellectual Disabilities - Wiley Online Library*
- Abuse tends to be undisclosed; the scale of the problem is not known with estimated prevalence ranging from 8% to 95%.
- Victims are usually women (73% vs 27%)
- Abused children 5 times as likely to be learning disabled.
- Perpetrators were usually male service users (53%), staff (20%), or family members (8%)
- A significant proportion of perpetrators of abuse against people with learning disabilities are thought to be known men with learning disabilities, who perhaps lack appropriate ways of expressing their own sexuality, which may increase their motivation to offend *(BILD. Underprotected, Overprotected (2015) & Peckham NG. The vulnerability and sexual abuse of people with learning disabilities. British Journal of Learning Disabilities. 2007 June)*

Current work in Leeds

- Sexual Health education for young people with learning disabilities and SEND is a statutory requirement, there is a range of resources available to support this. In Leeds, support is provided to schools around PHSE / PH, as well as to foster carers.
- A sexual health outreach team can offer services including contraception and cervical screening at home or another appropriate place for communities who are more at risk of health inequalities. This could include people with learning disabilities
- There is a range of Easy Read resources available, around sexual health, sexuality and healthy relationships
- Several third sector organisations in Leeds offer programmes that explore topics such as sexual health and healthy relationships in a safe and supportive environment, as well as groups for socialising, for example the People Matters “My Body My choice” project
- Desensitisation can be arranged by the health facilitation team to help prepare people for healthcare procedures that they might feel anxious about.

Conclusions

- As with all health and care services, sexual health services should be accessible – this includes ensuring that reasonable adjustment requirements which are flagged on a patient record are visible to clinicians in sexual health services, and that these reasonable adjustments can be made to improve access for the patient. For example, extended or repeat appointments may be useful, or different methods of contact.

- Sexual health services should endeavour to promote, communicate and provide their services in a way that is accessible to people with a learning disability, using Easy Read resources where appropriate.
- Consideration around how to improve data collection via monitoring of attendance at commissioned services, and outcomes, to better understand if this population uses these services- bearing in mind the confidentiality and sensitive nature of these services.
- Training for practitioners who come into contact with this group, around how to talk about sexual health with people with learning disabilities, including communicating with carers or family.
- Good quality and appropriate relationship and sex education in school and day centre settings is essential. It should be accessible to meet the needs of the audience, and should cover healthy relationships, consent, sexuality and gender, sexual rights, appropriate and inappropriate behaviours, contraception, STI testing and treatment, cervical screening, abortion, domestic and sexual violence services.
- Support for carers around coping with the developing sexuality of someone in their care is useful to help support this, and should include:
    - Educating and informing around puberty, sexuality, healthy relationships, contraception
    - Sensitively and positively enabling, facilitating and creating safe boundaries to support the sexuality of the people in their care.
    - Supporting access to sexual health services

Other information and references:
https://fingertips.phe.org.uk/documents/Health_inequalities_contraception.pdf

https://fingertips.phe.org.uk/documents/Health%20Inequalities_Sexual%20health.pdf

Learning Disability Sex and Relationships Research | Mencap

Sexual health and people with learning difficulties factsheet.pdf (hscni.net)
https://libkey.io/libraries/2593/10.1136/sextrans-2016-052718.240 ;

Mental Health

Summary / Definition

Mental health refers to a person's psychological, emotional and social wellbeing. It encompasses how individuals think, feel and act, and influences how they handle stress, relate to others and make choices. Highly influenced by external factors, its also a highly subjective concept and can mean different things to different people, depending on their own perceptions around their wellbeing.

Poor mental health can lead to challenges including impaired relationships, physical health issues, decreased productivity, substance abuse, and in severe cases, suicidal thoughts or actions. It can affect all aspects of a persons' life, diminishing their quality of life and overall functioning.

NICE estimates that at any given time, 28% of adults with a learning disability will be experiencing a mental health problem, compared to around 17% of the general population (source: Adult psychiatric morbidity survey 2014)

Despite a higher prevalence of mental health problems in people with a learning disability, access to effective treatments appears to be poor. People with a learning disability are less likely to be referred for talking therapies and more likely to be prescribed psychotropic medicines than the wider population. Further to this, a significant number of adults with a learning disability are prescribed antipsychotic medicines even though they do not have a diagnosis of the conditions the medicines are prescribed for.
Preventing people with a learning disability from dying too young (nuffieldtrust.org.uk)

Prevalence

Compared with the general population, people living with a learning disability are at an increased risk of mental ill-health. While estimates of prevalence vary (two systematic reviews (Whitaker & Read, 2006, and Buckles et al., 2013) reported prevalence rates of poor mental health in this population from 3.9% to 46.3% or from 13.9% to 75.2% respectively) they all agree that the rate of mental health problems is higher; NICE (2016) suggests a prevalence of around double that of the general population.

For the purposes of this health needs assessment, and in line with the way that much of the data is collected, mental health diagnoses are divided into *Common Mental Health Problems* (including depression, anxiety, and phobias- some datasets may refer to this as *common mental health illnesses*); and *Severe Mental Illnesses* or *SMI*, (including schizophrenia, Bipolar Disorder and psychosis). All of these conditions can potentially be complex and enduring, and may have a debilitating impact on someone's life and wellbeing.

Prevalence of Common Mental Health Problems

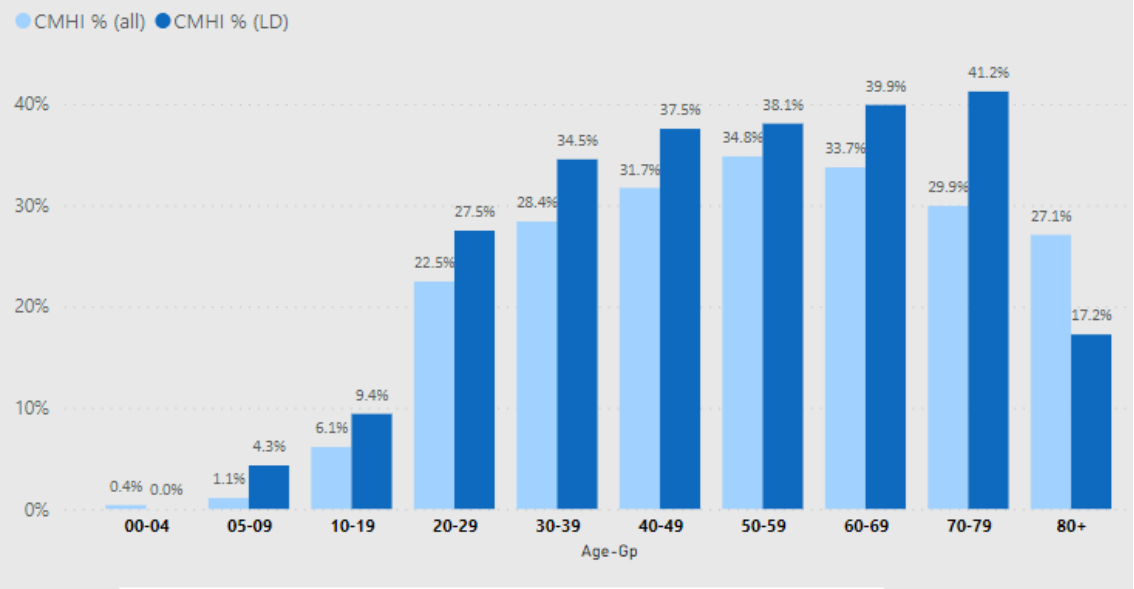


Figure 43: Prevalence of Common Mental Health Problems amongst learning-disabled and non learning-disabled patients (Leeds Primary Care records, 20/21)

Figure 43 demonstrates that people with learning disabilities are slightly more likely to have a recorded diagnosis of a common mental health problem than the general population, and this difference starts from a young age. Data for the over 70 age brackets should be interpreted with caution due to smaller population numbers, due to lower life expectancy.

For children and young people, the prevalence rate of a diagnosable psychiatric disorder is 36% in children and adolescents with learning disabilities, compared with 8% of those who did not have a learning disability. These young people were also 33 times more likely to be on the autistic spectrum and were much more likely than others to have emotional and conduct disorders. Learning disability statistics: mental health problems | Foundation for People with Learning Disabilities

Prevalence of SMI (Severe Mental Illness)

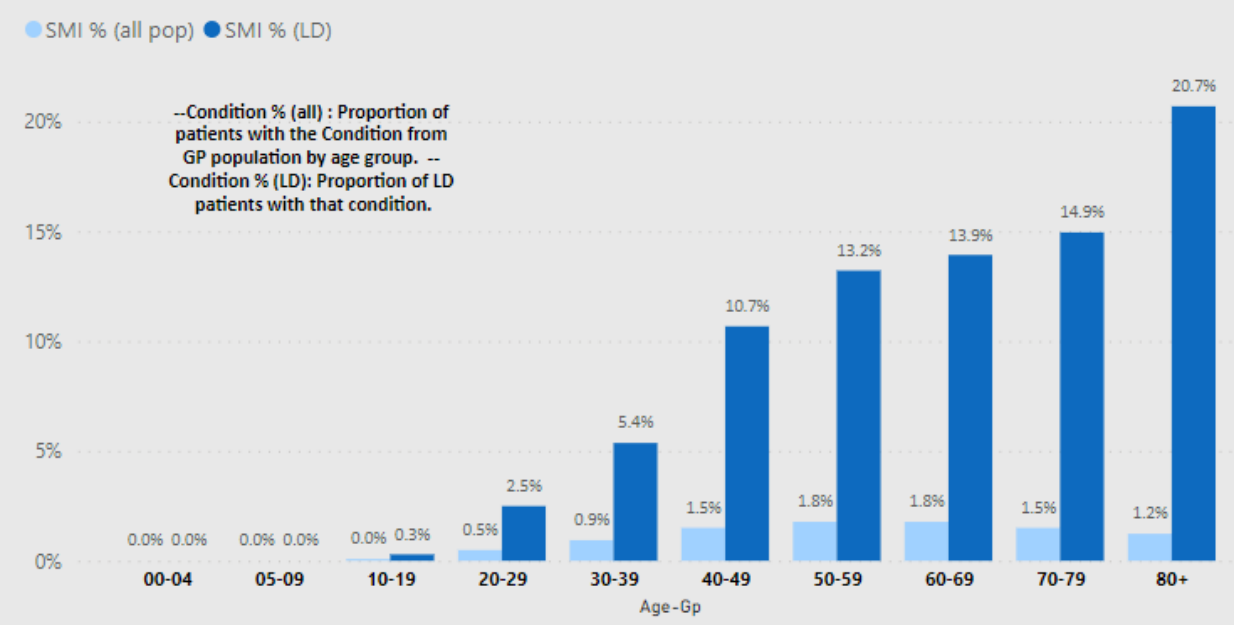


Figure 44: Prevalence of Severe Mental Illness amongst learning disabled and non learning disabled patients (Leeds Primary Care records, 20/21)

Figure 44 demonstrates that people with learning disabilities are significantly more likely to have a diagnosis of SMI than those without; prevalence is around 7 or 8 times higher for this group – the discrepancy starts from a young age and increases with age. Data for the over 70 age brackets should be interpreted with caution due to smaller population numbers.

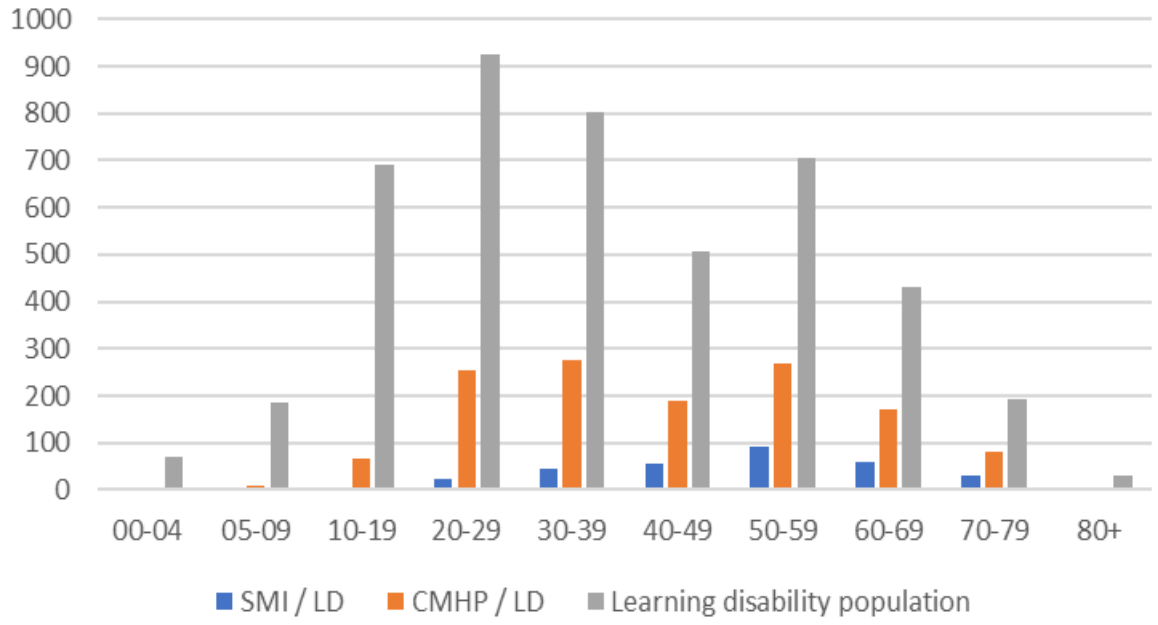


Figure 45: Numbers of patients with learning disability by age band, and of those, numbers with SMI and CMHP (Leeds Primary Care data, 20/21)

Figure 46 shows the significant number of people with a learning disability that live with common mental health problems or SMI; this demonstrates that prevalence of these mental health problems appears to increase with age. Date for age groups above 70 years should be interpreted with caution due to smaller patient numbers.

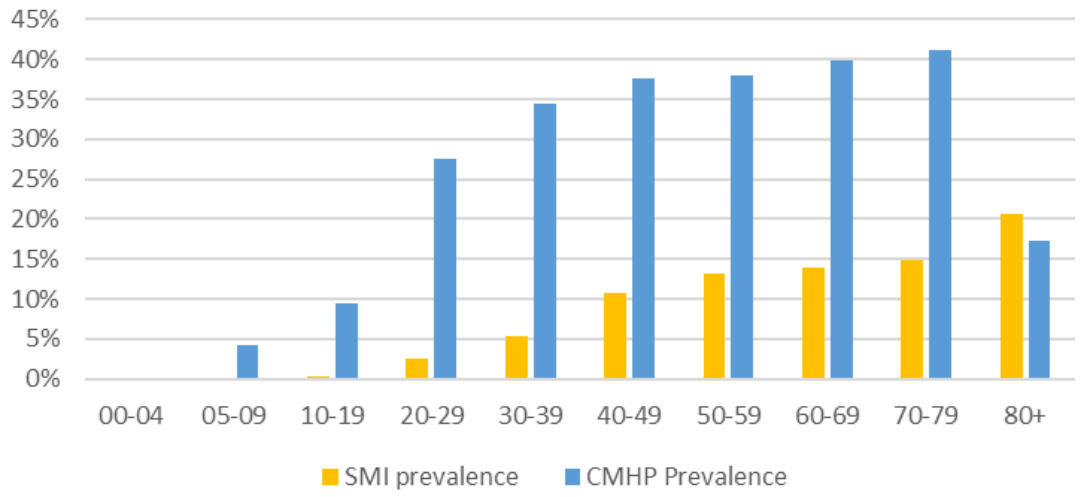


Figure 46: Prevalence of SMI and CMHP amongst people with learning disabilities, by age (Leeds Primary Care Data, 2020/21)

Prevalence rates for schizophrenia in people with learning disabilities are approximately three times greater than for the general population (3% vs 1%) (Source: Doody et al., 1998)

Risk Factors

Risk factors for poor mental health for people with learning disabilities are similar to those for the wider population, however there are a number of these factors that people with a learning disability are particularly more likely to be exposed to:

- Genetic predisposition
- Barriers of access to mental health services and resources, and poorly co-ordinated transitions between services
- Co-existing physical health conditions or sensory impairments (strongly linked to mental health problems).
- Socioeconomic factors:
    - Higher levels of deprivation and poverty
    - Inappropriate housing environments
    - Increased exposure to adverse life events
    - Low expectations by mainstream society alongside reduced opportunities.

- Dependence on family carers
- Lower levels of employment
- Smaller social networks, social exclusion and loneliness.
- Time or cost-restricted support, limiting access to leisure or other activities
- Higher rates of abuse, neglect and discrimination throughout lives, particularly in the early years

https://www.learningdisabilities.org.uk/learning-disabilities/help-information/learning-disability-statistics-/187699

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.mencap.org.uk/learning-disability-explained/ research-and-statistics/health/mental-health.

Insight from focus groups as well as parents and carers told us how people with learning disabilities often want to get out more, to connect with others, take part in activities, to be able to learn and participate in society; all of which are well evidenced as protective factors for well-being and mental health – however the barriers to all of these activities are significant for this population.

"He really doesn't have a life.. I want him to live an enriched life"
(Parent carer of a men with learning disabilities, 2023)

" He is very isolated.. it's hard to get him to places, and support feels sporadic.."
(Carer for someone with learning disabilities, 2023)

" I am bored. I want to do something every day. I want to get out and meet people and get a girlfriend"
(Man with learning disabilities in a focus group, 2024)

Efforts to improve the mental health of this population would benefit from being focussed further "upstream", i.e. on prevention; mitigating the negative impact of these wider and social determinants and improving opportunities for people to experience the positive, protective factors for good mental health, rather than on the treatment of mental health conditions as they appear, which appears to be more challenging (and medicalised) for this population.

Issues with understanding the mental health profile of this population - Identification and diagnosis

Issues around identifying and correctly diagnosing mental health problems among people with a learning disability can be a barrier to providing the care and support they need.

A fundamental and well-recognised challenge in identifying mental health problems in people with learning disabilities, is '*diagnostic overshadowing'*, whereby mental health problems and their presentations can be mistaken as being part of the individual's learning disability behaviour profile, and disregarded, thereby leaving them undiagnosed and unaddressed.

This may be partly a result of mental health diagnosis assessments having been designed to meet the needs of the general population, and not people with learning disabilities. Poor mental health within the learning disability population can also present differently than the general population, for example presenting as withdrawn behaviour, or behaviour that challenges- including aggression, destruction or self-injury.

People with a learning disability may find it harder to recognise or communicate any difficulties they are experiencing due to reduced cognitive ability, awareness of mental health symptom or poor health literacy. They may also be reluctant to communicate problems around their mental health because of stigma.

They may also need to rely on a carer being able to recognise and act on a mental health problem effectively, which in turn may lead to other barriers.
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.

To address known challenges in identification of mental health problems in this population, the NICE guidelines suggest training programmes for parents or carers of children with a learning disability to help prevent or treat mental health problems. Further to this, training such as the Oliver McGowen training around learning disabilities and autism can also help facilitate better communication, and identification and addressing of concerns, however this provides only a very basic foundation in understanding the issue.

Access to Appropriate Treatments and Therapies

Community learning disability teams can provide specialist support with mental health problems to those registered as having a learning disability.
However some mainstream therapies that are offered in response to mental health problems, may not always be suitable for those with learning disabilities.

Despite the higher prevalence of common mental health problems among people with a learning disability, it is unclear how effectively they are able to access mental health support in Leeds via mainstream referral routes (for example primary care) as referral data is unavailable.

Insight from people and organisations supporting people with learning disabilities, suggests a prevailing feeling that most mainstream mental health services are not

appropriate for their needs. For someone with a learning disability needing support with their mental health, there are more hurdles in getting to the most appropriate support than for others.

Data provided by NHS Digital showing the NHS Mental Health Service Data Set (MHSDS) is helpful in giving a scale of hospital admission for mental health for people with learning disabilities and for regional comparisons of admission rates, however this information does not offer clear indication of local demand in Leeds. When reviewing this data, for instance around duration of hospital stay, it is difficult to make conclusions without additional information around for example, diagnoses.

Talking Therapies

NHS Talking Therapies (previously known as 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, the most common being cognitive-behavioural therapy (CBT).

While there is evidence of IAPT being successful for some people with a learning disability, they generally have poorer recovery rates compared with the general population.

- Research with therapists suggests that those working within IAPT services do not receive sufficient training or support on how to adapt the therapies for people with a learning disability.

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

- Nationally, 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, which was lower than those without a learning disability.

- People with a learning disability are less likely to be referred to IAPT services than the general population. This may be because a mental health problem may not be correctly diagnosed, they may not be aware of the IAPT service, they may struggle with self-referrals or the appointment booking process, or a clinician may choose not to make a referral to the service at all.

(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)

Talking therapies are also not a viable option for those who have limited speech or are non-verbal. People with a learning disability may benefit from other approaches to improve their mental health, such art and music therapy. There is some evidence around the benefits that creative therapies can 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. *(nacwellbeing)*

More insight around the most effective support for people with learning disabilities may be beneficial, particularly whether specialist services rather than mainstream services are best placed to deliver these, as has been the findings in other health topics such as weight management.

Antidepressants and Antipsychotics

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, even though they do not have the health conditions that the medicines are generally prescribed for.
These medicines are commonly prescribed to people whose behaviour is seen as challenging. These medicines can cause concerning side effects such as chronic kidney disease and weight gain, which can cause further health complications.

The STOMP (Stopping the Over-Medication of People with a Learning Disability, Autism or Both) project was launched in 2016, aiming to encourage structured medication reviews, to improve involvement of patients and their carers in decisions about medications, and increase awareness of non-drug therapies and other ways of supporting people.

The NHS Long Term Plan included the expansion of the STOMP programme as one of its actions, however the data below in figures 48-51 still demonstrates the high level of medication prescribed to people with learning disabilities.

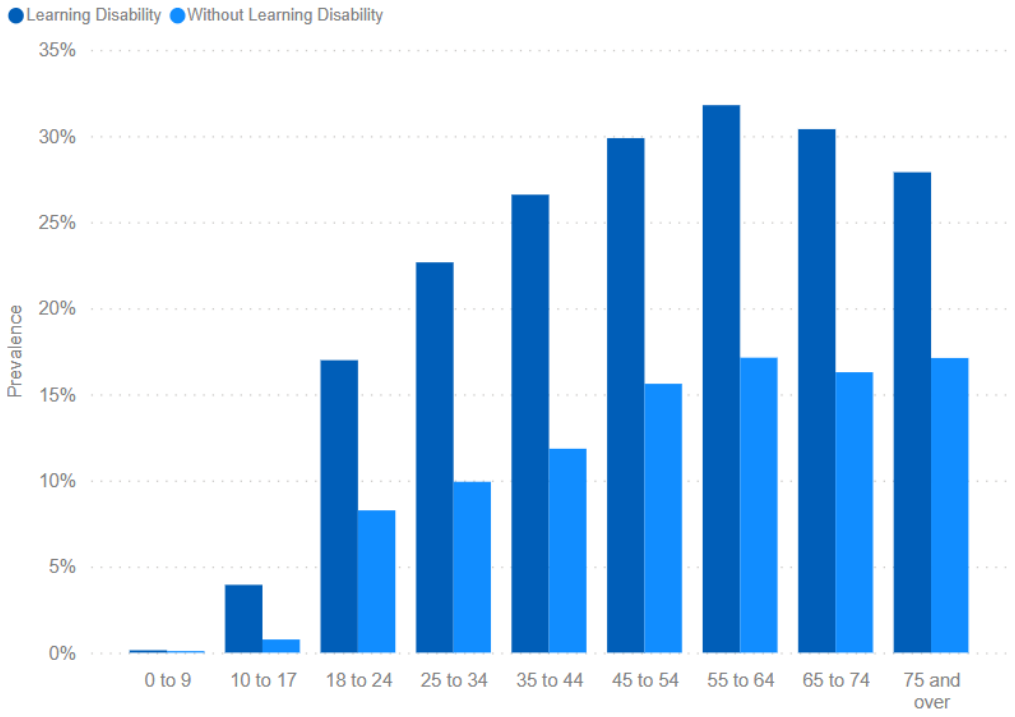


Figure 48 – percentage of patients with and without learning disabilities currently treated with antidepressants, by age band (Health and Care of people with learning disabilities, experimental data - National Data, 2022)

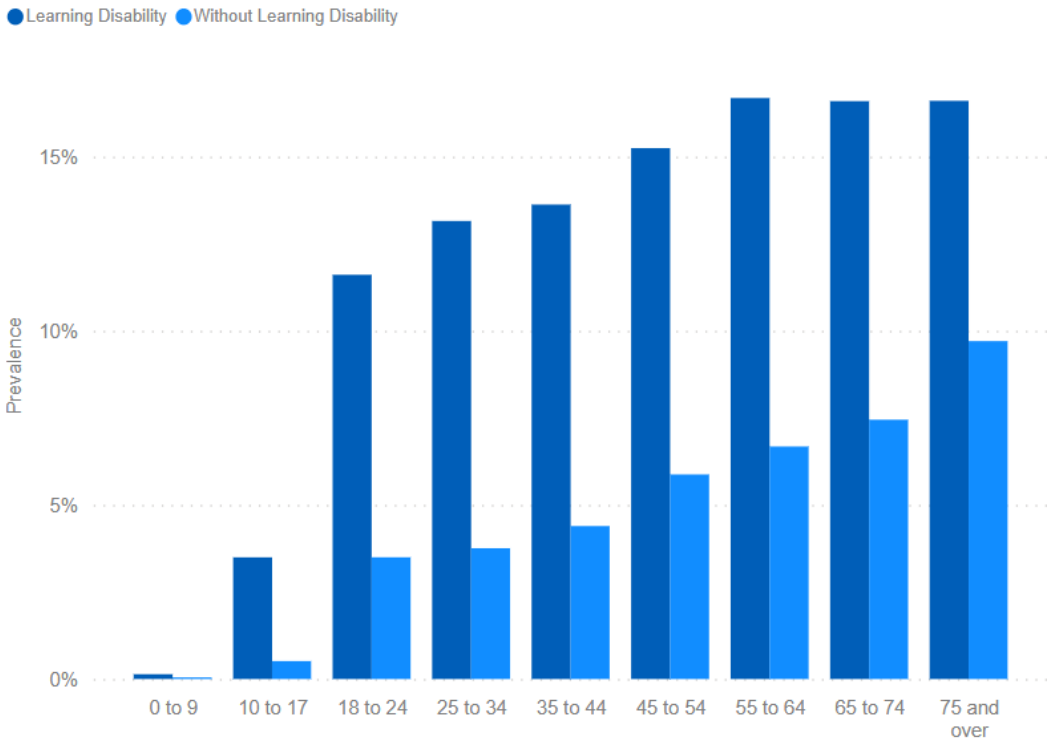


Figure 49 – percentage of patients with and without a learning disability, who do not have an active depression diagnosis, but who are prescribed antidepressants

(Health and Care of people with learning disabilities, experimental data - National Data, 2022)

Figure 48 and 49 demonstrate the higher use of psychotropic medication to treat people with learning disabilities than the wider population. This may suggest that medication is more frequently used than other treatments such as talking therapies.

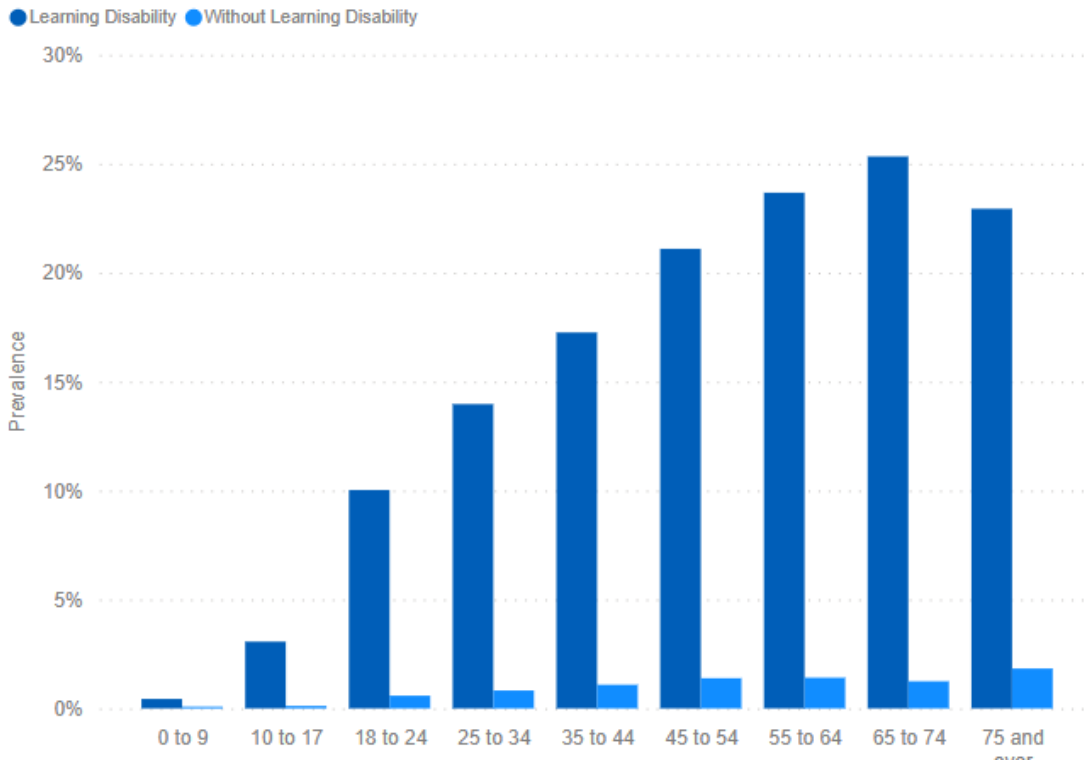


Figure 50 – percentage of patients with and without a learning disability who are prescribed antipsychotics (Health and Care of people with learning disabilities, experimental data - National Data, 2022)

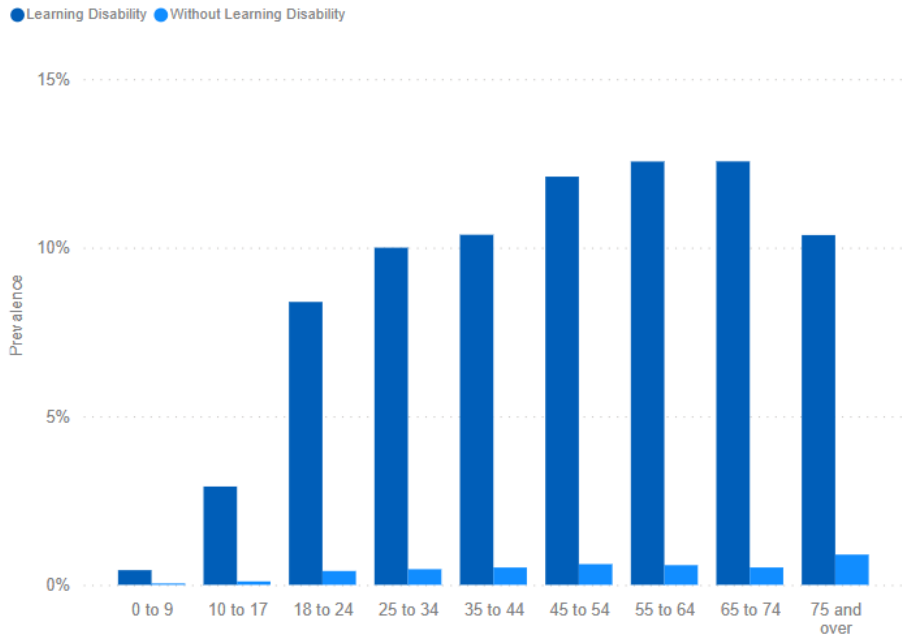


Figure 51 – percentage of patients with and without a learning disability who do not have a diagnosis of psychosis, but are prescribed antipsychotics (Health and Care of people with learning disabilities, experimental data - National Data, 2022)

Figures 50 and 51 indicate the higher rate of prescription of antipsychotic medications to people with learning disabilities, even in the absence of symptoms for which these medications are usually prescribed. These medications are often prescribed long term to people with learning disabilities who also have autism, for managing behaviour that challenges.

References:

Emerson E, Baines S. (2010) Health Inequalities & People with Learning Disabilities in the UK: 2010.

Preventing people with a learning disability from dying too young (nuffieldtrust.org.uk)

Neurodiversity and Autism

Autism and other forms of neurodivergence (for example, dyslexia, dyspraxia, ADHD), are common amongst people with learning disabilities, but are not themselves learning disabilities. Autism is 35 times more common amongst people with learning disability than in the wider population. Not all people with learning disabilities will have autism and vice versa, however there is significant overlap – around a third of people with autism may also have a learning disability.

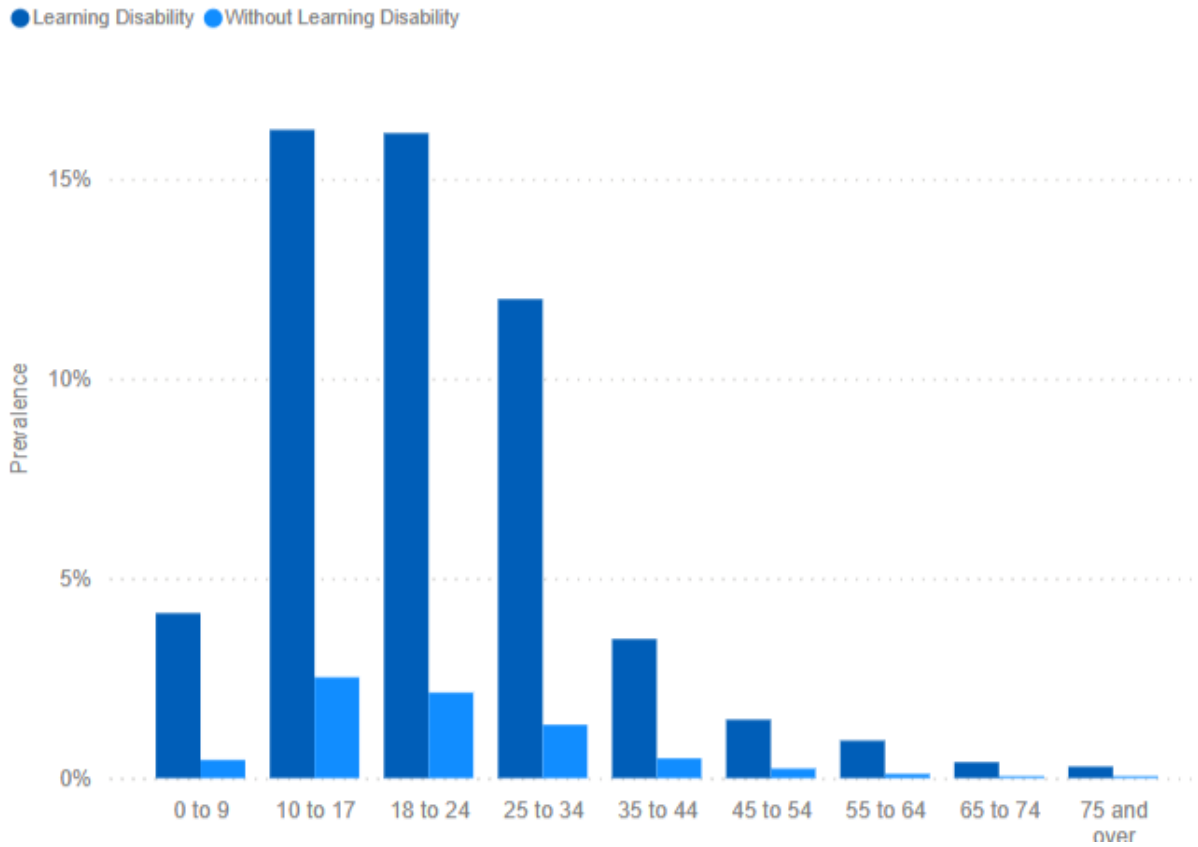


Figure 52: Percentage of patients with ADHD – with learning disability and without. NHSE Experimental data (national) - 2022/23

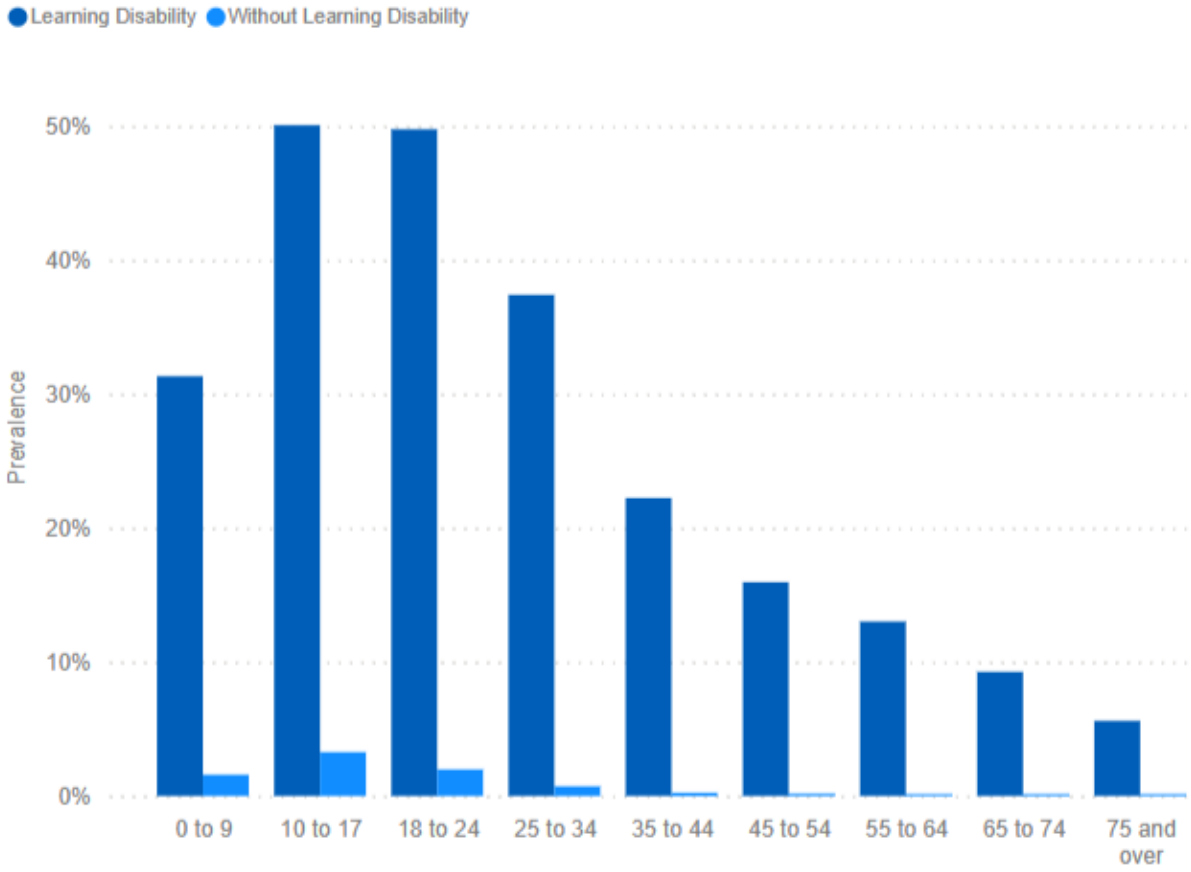


Figure 52: Percentage of patients with autism– with learning disability and without. NHSE Experimental data (national) - 2022/23

Figures 51 and 52 which provide national data, demonstrate the significantly higher rates of diagnosed autism and ADHD in people with learning disabilities than in the wider population. Due to suspected high levels of underdiagnosis of both autism and ADHD, these figures should be interpreted with caution.

Neurodivergent and autistic people are more likely to suffer from poorer mental health and also less likely to use mainstream services than neurotypical people. People who have learning disabilities and are also neurodivergent are therefore at risk of additional health inequalities.

While there is significant overlap between people with learning disabilities and neurodivergence the spectrum of experiences is wide, health inequalities differ and needs are very different. Further work to understand the differing health experiences and needs of this group would be useful.

A substantial amount of data available on learning disabilities also includes autism - for example the LeDeR review now includes deaths of people with autism. The health segmentation model also combines the two populations together for data purposes. While it is helpful to understand the health inequalities faced by both groups, wherever possible, its preferable to have the data separated out so that the differences in health inequalities for these two often overlooked groups can be understood.

References to consider:
Building Healthier, Happier Longer lives – Autistica Briefing Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf
Premature mortality in autism spectrum disorder - PubMed (nih.gov)
Mortality in Persons With Autism Spectrum Disorder or Attention-Deficit/Hyperactivity Disorder - PMC (nih.gov)
Overview | Autism spectrum disorder in adults: diagnosis and management | Guidance | NICE

Dementia

Summary
People with Learning disabilities are at higher risk of developing dementia at a lower age (see Figure 1), particularly those with Downs Syndrome, and particularly the Alzheimer's sub-type.

Prevalence
Estimates of the prevalence of dementia in people with learning disabilities vary, in part because of challenges with recognition, assessment and diagnosis.

- Age-related dementia of all types is more common, and appears at earlier ages in people with learning disabilities than in the rest of the population (about 13% in the 60 to 65 year old age group compared with 1% in the general population)
- Across all over-60 age groups the prevalence was estimated at 2 to 3 times greater in people with learning disabilities
- People with Down's syndrome are at particular risk of early onset Alzheimer's disease- this is thought to be a genetic disposition. Around 90% of patients currently using Leeds' specialist service for dementia and learning disabilities, have Downs Syndrome.

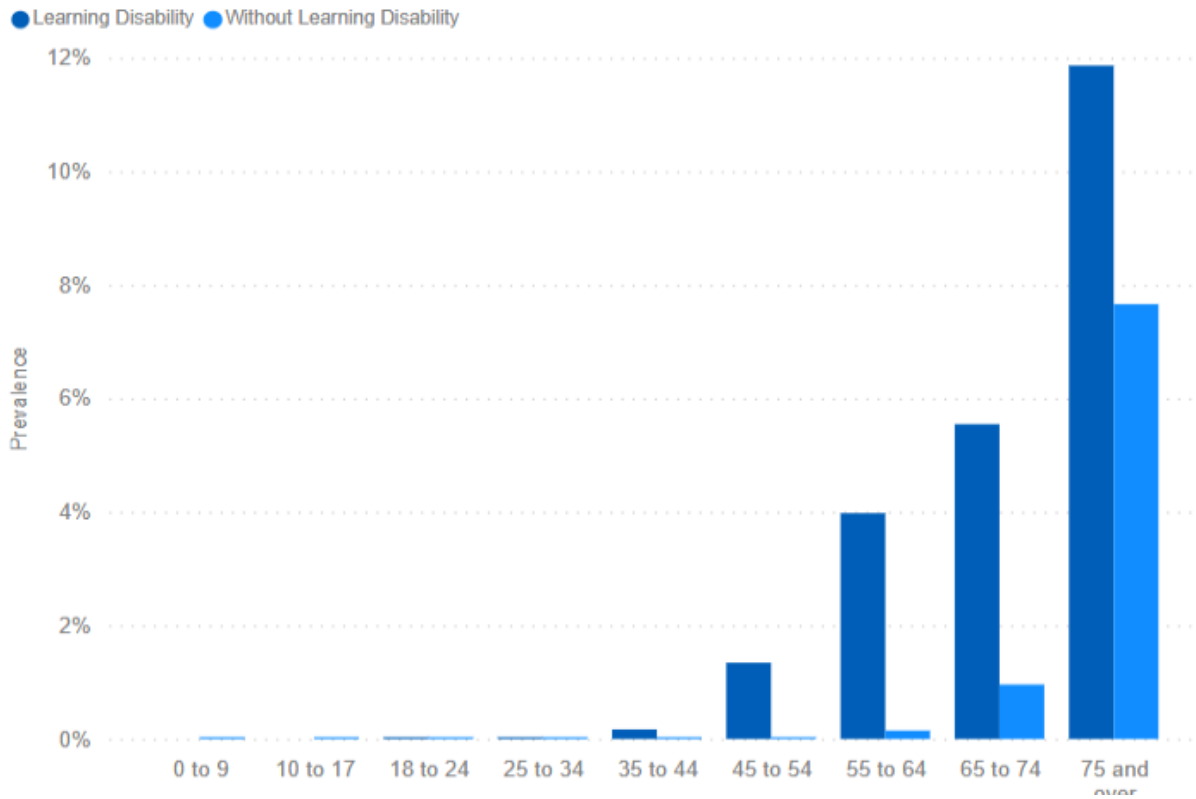


Figure 53: Percentage of patients with a diagnosis of dementia as of 31st March, by age band:

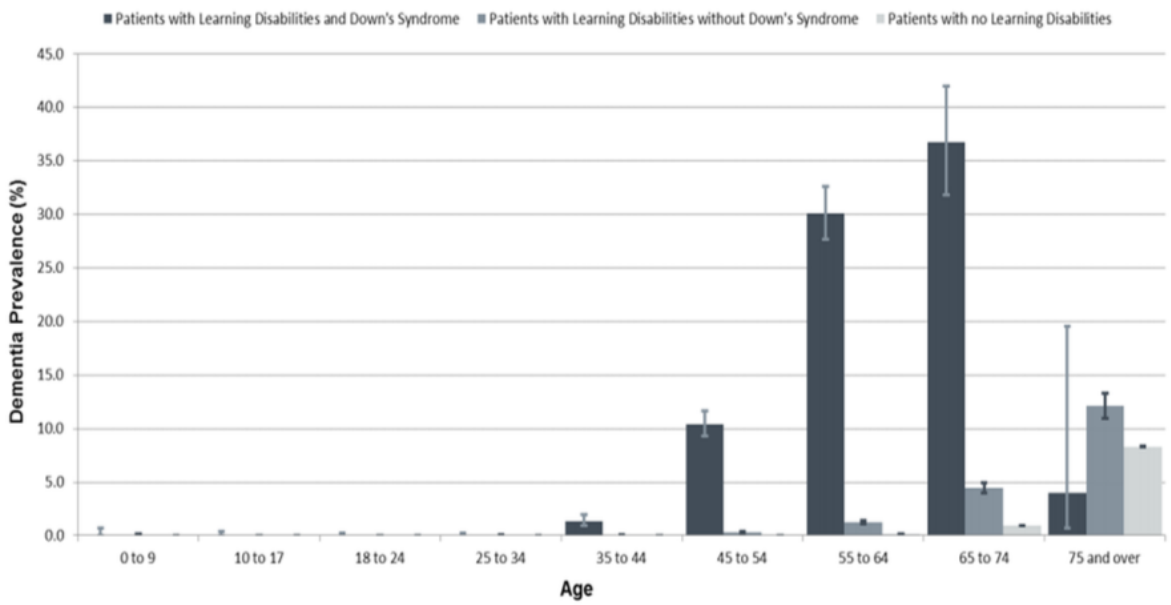


Figure 54: Patients with learning disability, Downs Syndrome and Dementia: [Dementia and people with learning disabilities: making reasonable adjustments - guidance - GOV.UK (www.gov.uk)]

Screening and diagnosis

Communication barriers and atypical presentations (e.g., personality change, behaviour that challenges or development of epilepsy) can make recognition more difficult, and early signs of dementia may missed or masked, or simply be dismissed as behaviour that challenges. This can be difficult for individuals who do not have insight or understanding of what dementia means, as well as for their carers.

Dementia is diagnosed differently in this population due to atypical presentations. Cognitive and functional baseline assessments may be undertaken and repeated 6 months later to identify any decline in function. Neuroimaging does not give a clear or consistent indication of deterioration due to differences in the appearance of the brain in some patients. Also, some patients may be unwilling to undertake a scan.

Diagnosis in Leeds is undertaken by a specialist team within Learning Disabilities in LYPFT– patients would need a recorded learning disability to be referred to this rather than a mainstream dementia service.

Proactive, regular screening for people with Downs Syndrome from age 30 is undertaken in some areas, but there is a lack of evidence as to the effectiveness of this against the considerable resource implications. Currently patients are offered screening reactively, i.e., if symptoms or concerns arise.

Preventative measures

(formerly)Public Health England (PHE) estimates suggest that 30% of the current incidence of dementia in the general population would be preventable by addressing risk factors such as diabetes, high blood pressure, obesity, physical inactivity, depression and smoking; people with learning disabilities have a higher exposure to many of these risk factors.

Other risk factors for dementia, likely to also disproportionately affect those with learning disabilities include:

- Lower levels of childhood education,
- reduced social engagement,
- poor management of hearing loss,

Livingston G and others. Dementia prevention, intervention, and care. The Lancet, 2017. 390(10113): p. 2673-2734

There is a known association between hearing loss and cognitive decline, and development of dementia. Both hearing loss and dementia can have similar presentations – including behaviour change and reduced functioning. It is therefore important that people with learning disabilities, particularly Downs Syndrome, have their hearing (and sight) checked regularly.
Receiving support earlier with hearing or other sensory loss may help reduce the risk of associated cognitive decline.

Conclusions

- Leeds offers a specialist service in this area with assessments and diagnosis tailored to the different presentation of the disease.

- While there is a significant genetic element to the pattern of developing dementia in this population, the risk may be to some degree reduced by living healthier lifestyles. Therefore it is recommended to continue to promote and support access to healthy lifestyles for those with learning disabilities.
- Promote awareness of the risk factors for, and presentation of dementia for this population, particularly those with Downs' Syndrome, to the circle of support involved in people's care. This will support earlier diagnosis.
- People with learning disabilities, particularly Downs Syndrome, should be offered regular hearing and sight tests, so that appropriate management of sensory loss prevents this compounding cognitive decline.
- All treatments or interventions should be bespoke and adapted to the individual's needs as per NICE guidelines

Re:

Livingston G and others. Dementia prevention, intervention, and care. The Lancet, 2017. 390(10113):

Co-morbidity and complexity

NICE (National Institute for Health and Care Excellence) guidelines define multimorbidity as the presence of two or more long-term health conditions. Information about multimorbidity was available for the deaths of 1,095 people with learning disabilities who died in 2021 nationally, with initial review data.

Figure 55 provides this data; in 2021, the average number of long-term health conditions per person, for people with learning disabilities, was 2.45. Only 10% of people were reported to have no long-term health conditions at death, but around 70% of people had 2 or more long term health conditions. This leads to complexity of care, which increases with age.

Long-term health conditions (cont)	4 to 17	18 to 64	65+	Total No.
Dementia	*	123	107	230
Kidney problems	*	79	113	194
Diabetes	*	77	87	164
Respiratory conditions	*	81	71	152
Hypertension	*	50	86	136
Osteoporosis	*	30	35	65
Cancer	*	25	38	63
Degenerative conditions	*	28	18	46
DVT	*	25	13	38
Number of long-term health conditions (of deaths with initial review data)**				
0	*	66 (11%)	37 (8%)	104 (10%)
1	*	133 (22%)	86 (18%)	223 (20%)
2	*	153 (26%)	114 (23%)	271 (25%)
3	*	125 (21%)	107 (22%)	234 (21%)
4		70 (12%)	80 (16%)	150 (14%)
5 or more	*	50 (8%)	62 (13%)	112 (10%)
Total	11	597	486	1,094

Figure 55: Type, and number of long-term conditions present at death, by age - LeDeR 2021, national data (equivalent data is not provided within the more recent report)

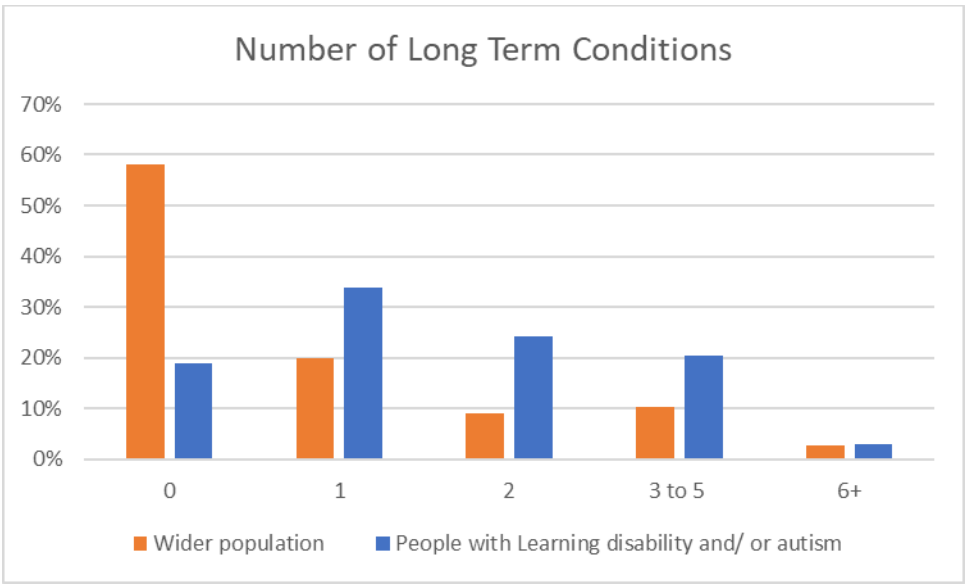


Figure 56: Long-term health conditions/ population summary by long term condition subsegment (Healthy Leeds Population data 2024)

Figure 56 demonstrates how much more likely people with learning disabilities or autism are to live with more than one long term health condition compared to the wider population.
Note that this data includes people with autism rather than just learning disability, whereas figure 55 data does not include autism.

Figure 57: Number of long-term conditions diagnosed amongst people with learning disabilities and/ or autism (Healthy Leeds Population data 2024)

Autism and learning disabilities are combined together in this population subsegment model. Gaining access to data at a more granular level would be valuable to understand the particular health inequalities faced by each distinct population.
There is a strong overlap with learning disabilities and autism/ neurodivergence as well as mental health conditions, as well as the physical health conditions listed above.

Recommendations

The following recommendations are intended to support work to reduce the inequalities discussed above. These recommendations have been co-produced,

taking into account conclusions from this health needs assessment and reflections from people with lived experience.

1. Improvements to identification

If you use data to drive services, be aware that many people will not be represented in this data.

Data in this HNA and elsewhere indicates a significant under-recording of learning disabilities on GP registers, as well as areas of within this population where there may be a particularly significant identification deficit. These gaps should be used to drive **targeted campaigns to promote and encourage people to seek diagnosis and be identified on the LD register**. This work should particularly focus on the under-representation of people from culturally diverse communities on the LD register, as well as across the life-course.

Targeted campaigns should consider;

- addressing the stigma of learning disabilities (or lack of trust in health services generally) in different communities
- promoting the benefits of a diagnosis being recorded.
- promotion within education settings (mainstream and specialist provision as well as at transition).
- co-production and delivery in partnership with trusted voices, organisations or community leaders

This will improve health outcomes; those who may otherwise be living with unmet needs and facing significant disadvantages in life should be offered additional support (e.g. priority for vaccines, AHCs, invitation to seek reasonable adjustments to care etc)

This will improve the coverage of the population in data held by health services – more would be known about the health inequalities experienced by these subgroups and help health services to understand and adapt to differing needs.

This also contributes to other studies and reviews such as LeDeR.

2. Annual Health Checks

While Leeds has successfully improved uptake of the annual health check, there is opportunity for gaining better insight into their quality and effectiveness.

Work programmes to **improve the effectiveness of the annual health check programme** should include;

- Better granular data collection around attendance demographics. This will help to inform if there are particular parts of the population less likely to attend and drive targeted promotional work to increase uptake.
- Improve understanding of reasonable adjustments and communication needs in the invitation process.
- Auditing to determine quality of checks and drive improvements including patient feedback and understanding.
- Better data collection around the AHC beyond just attendance- for example completeness, outcomes, action plans, referrals out, patient experiences etc- this will help to provide insight into quality, gaps and areas of improvement.
- Ensuring there are appropriate and suitable (and up to date) referral options for any areas that are flagged as concerns, or follow-up calls where appropriate.

Impact – this should drive measurable improvements in the effectiveness and impact of the intervention for those having their checks.

3. Accessibility and Reasonable Adjustments

Work programmes to **ensure services are accessible and reasonable adjustments are used** should include;

- Good care co-ordination so that communication or accessibility needs are known and required reasonable adjustments are identified and acted on appropriately and consistently.
- Consistency in services about what constitutes “reasonable”, and that accessibility isn’t just physical.
- Awareness raising around the right to seek reasonable adjustments, and what they might look like- including the promotion of campaigns such as “You Can Ask”
- Appropriate use of the reasonable adjustments digital flag across health records – including efforts to integrate / migrate flags across different healthcare systems. Where systems do not include this, an alternate method of recording requirements should be used.
- Improving awareness and consideration of the practical barriers that might affect this population, such as transport - including location of services, appointment times, needing to change appointments to fit around support worker’s availability etc.

4. Supporting Access to Healthy lifestyles

Wider system healthy living opportunities and services should **help support people with learning disabilities to have access to healthy lifestyles,** and should;

- Improve the accessibility of mainstream services and provide bespoke services to support those with more complex needs.
- Providing a range of advice, resources and activities available to help support healthy lifestyles. Practitioners who undertake interventions such as Annual Health Checks should be aware of opportunities and be confident in promoting and referring or signposting.
- All commissioned services should include monitoring to determine their effectiveness and accessibility to marginalised groups; better data collection around this will help to understand the reach and impact of support available.

5. Health Education and Health Promotion

The promotion of healthy lifestyles for this population needs a different approach to the wider population and is crucial for the reduction of risk factors for other health conditions.

Healthy lifestyles programmes should:

- Approach health promotion with a holistic, positive and social understanding of health rather than medicalised.
- Be delivered by a trusted organisation with expertise in learning disabilities
- Include the circle of support; taking collective responsibility for supporting healthy lifestyles – empowering families, organisations and individuals to explore shared aims and understandings around health.
- Be co-produced and use accessible messaging
- Training health champions to spread positive health messages in their communities, or ongoing peer support groups to support long term behaviour change
- Be offered widely to help improve awareness, i.e. as a preventative measure rather than in response to someone developing a health condition

These programmes are also an invaluable opportunity to bring in other health messages e.g. around cancer screening or vaccinations.

Health promotion programmes and the organisations that deliver them, ideally would be funded in a way that supports sustainability in a sector already facing severe financial challenges. This would help to ensure projects which address health inequalities can be delivered sustainably in the longer term.

6. Workforce Training

Support should be provided to the health and social care workforce by providing quality training around learning disabilities with the aim of:

- Raising awareness of the profile of inequalities associated with learning disabilities and barriers to accessing care.
- Improving communication between patients and health and social care professionals
- Reduction of diagnostic overshadowing
- Improving confidence of workforce to navigate issues around best interest, capacity and consent - appropriately, compassionately and within a legal framework.

Useful training could include:

- Oliver McGowen Learning Disabilities and Autism training (OMMT)
- Practice-based learning disabilities training delivered by the Health Facilitation Team
- Training around working under the Mental Capacity Act
- Advanced Clinical Practice training that incorporates specific modules around learning disabilities and autism
- Restore 2 Mini
- Learning-Disability-Framework-Oct-2019.pdf (skillsforhealth.org.uk)

Improving the number of advanced roles in this area, as well as improving the general level of awareness of learning disabilities amongst the wider health and social care workforce, will help to drive improvements in the sector.

7. Anticipating and Planning for Population Changes

Commissioners of services should be aware of the projected changes in the population profile – including an increase in recorded population, increase in life expectancy and increased length of time living with complex health needs of people with learning disability, when designing and future planning for services such as healthcare, education, social care, housing etc.

The increasing complexity of care needs in an aging population will necessitate the better integration of medically trained staff into supported housing.

8. Addressing the Wider Determinants of health

The conditions in which people grow up, work, live and age have a huge impact on their health, and these conditions are often worse for people with learning disabilities. Any work that addresses the social or wider determinants of health for this population would be beneficial to help address health inequalities - work programmes should consider:

- Improving access to meaningful, sustainable education and employment

- Understanding the practical and logistical barriers faced by people with learning disabilities when designing and delivering any services or offers that support better health – including considering the location of services, and how people travel, and timings of services, as well as keeping any costs down as far as possible.
- Ensuring support is available ad promoted for anyone struggling or on a low income, including families and carers, around cost of living etc.
- Improving the provision of appropriate, affordable accommodation in areas of choice
- Working to reduce stigma and improve positivity and understanding of learning disabilities.

9. Health Protection

A whole-system approach in some areas of health protection such as seasonal vaccinations has been demonstrated to be effective – this should be replicated for wider health protection priorities, rather than to tackle different areas separately.

Continuation or expansion of the Restore2 Mini training around Sepsis awareness should be explored.

10. Data Collection

The segmentation model of the population boards combines data on learning disabilities with data on autism. Improved separation of data on autism from learning disabilities will improve understanding of these two overlapping but distinct areas. A separate HNA around autism and neurodiversity would help provide further clarity and understanding.

Better and more consistent collection of data from all commissioned services around learning disabilities will help improve understanding of health inequalities generally.

If General Practice systems collected and provided data consistently this would also help improve insight in this area; currently coverage is incomplete in some areas due to the differences in the systems used.

Thank You

Thanks to everyone whose support, advice and insight has helped to inform and bring together this piece of work, particularly those who shared their own experiences, as well as:

> Sam Browning, Julie Royle-Evatt, Victoria Treddenick, Dominique Burley, Alison Conyers, Amy Hirst, Carolyn Dewhurst, Lisa Smith, Rosie Armitage, Audrey Okyere-Fosu, Sally Townsend and everyone else who has contributed

And the following organisations including their members:

> People In Action, Advonet, Hamara, Pyramid of Arts, People Matters, Women's Health Matters, Aspire, Healthwatch, Forum Central, the People's Parliament, Carer's Leeds, Connect in the North, the Health Facilitation Team at LYPFT