

North Tyneside

Joint strategic needs assessment

Learning disability

September 2024



North
Tyneside
Council

1. Introduction

Learning disabilities (LD) are defined by three core criteria (1):

- Lower intellectual ability (usually an IQ of less than 70)
- Significant impairment of social or adaptive functioning
- Onset in childhood

Examples of LD include Down's syndrome and cerebral palsy. Living with a LD can significantly impact an individual's physical, mental and social wellbeing. Individuals with LD typically require some form of long-term support in one or more aspects of their life. They represent one of the most vulnerable groups in society and are typically subject to many health inequalities, social exclusion and stigmatisation.

It is important to highlight that LD are often confused with learning difficulties. Learning difficulties, instead, refer to specific challenges that affect a person's ability to learn in a particular area such as dyslexia (reading) or dyspraxia (physical co-ordination) (2). A key distinction is that people with learning difficulties are generally able to function well in other areas of life and live independently. Confusingly, a person with a learning disability can also have one or more learning difficulties (2).

2. Key issues

- People with LD face a wide range of inequalities and poor health outcomes.
- Women with LD have worse outcomes than men with LD.

- North Tyneside has a higher-than-average prevalence of people living with LD.
- There are insufficient employment opportunities for people with LD, limiting their ability to be financially independent members of society.
- The proportion of people with LD living in stable/suitable accommodation is relatively high in North Tyneside.
- Unpaid carers for those with LD, in particular, face long-term challenges and this can negatively impact their health if not supported appropriately.

3. High level priorities

Improve the recording of LD on GP registers

One of the biggest barriers stopping people with LD from accessing good quality healthcare is not being correctly identified as having a LD.

Estimates suggest that only 25% of adults with LD are recorded on their GP LD register (3). Failure to be properly identified can lead to a) reasonable adjustments not being made e.g. easy-read information, which can result in people not accessing services such as cancer screening, and b) can result in people with LD not being invited to attend annual health checks. Both of these knock-on effects contribute to the health inequalities experienced by the LD community.

Annual audits could be carried out, at a practice level, to identify individuals with LD who are not on the GP LD register.

Annual health checks

There should be a drive to increase the percentage of people with LD who attend for their annual health check. Part of that includes ensuring people are correctly registered and therefore receive invitations. However, even then, recent data suggests that only 60% of those registered attended for an annual health check. Ensuring people with LD attend their annual health checks will ultimately mean better detection of preventable/treatable diseases and ensure appropriate referrals are made to support individuals. This is much needed as people with LD are three times more likely to die from a preventable cause compared to the average person (4). Such action would hopefully reduce the health gap between those with LD and the general population.

An initial target could be considered, ensuring at least 75% of people with LD receive an annual health check each year, in line with the target set out in the NHS Long Term Plan (3).

Employment opportunities

Paid work for those with LD, as indeed anyone, can provide a sense of purpose, important social opportunities, and financial reward. Despite a majority of people with LD wanting to work, only a quarter are in some form of employment, the majority of which are working fewer than 16 hours a week (5,6). The employment figures are even lower for those requiring long term support and have fallen significantly over the last 5 years in North

Tyneside. Improving both the number of people with LD in employment and the hours of those already in employment, would likely improve individuals' overall health and wellbeing. There is also evidence to suggest it could be a cost-effective approach for local authorities via reducing the costs of day care provision (7).

Unpaid carer support

From a local commissioning perspective, it is important to ensure there is adequate support for unpaid carers. There are very high rates of burnout and carer distress when it comes to looking after an individual/s with LD. Carer burnout can negatively impact their own health and wellbeing to a point where they can't cope anymore, meaning the responsibility and costs of care are transferred to local health and social care providers. In such instances, there is a net cost-benefit to ensuring unpaid carers receive adequate support.

4. Who is at risk

There are around 1.3 million people in England living with a LD (8), which equates to a prevalence of around 0.6% (9). The main risk factors for LD are those which affect the development of the brain either before birth, during birth or in early childhood. This tends to be the result of non-modifiable risk factors e.g. random chromosomal abnormalities, unforeseen birthing complications, or rare childhood illnesses such as meningitis (10). LD are typically persistent throughout the life-course and hence there are no notable age-specific variations in prevalence (11).

Inequalities

- **Health:** People with LD have an increased prevalence of health issues linked to premature mortality e.g. diabetes, obesity, severe mental illness etc. As a result, there is a significant life expectancy gap of ~20 years between individuals with LD and the general population (12).
- **Ethnicity:** There is a higher prevalence of LD amongst South Asian communities relative to the general population (13).
- **Deprivation:** In the most deprived areas, one in every 165 people have a diagnosed LD, compared with one in every 272 people in the least deprived areas (14).
- **Gender:** On average, men with LD can expect to live 3 years longer than women with LD (12). This is likely explained by the increased prevalence of co-morbidities amongst women with LD compared to men with LD (12).

5. Level of need

Prevalence

- The prevalence of people with LD living in North Tyneside is 0.8%, slightly higher than the national average of 0.6%.

Accommodation

- The percentage of adults in North Tyneside with a LD who live in

stable and suitable accommodation is 94.3%, compared with the national average of 80.5%.

Annual health checks

- In 2022/23, the percentage of individuals (aged 14yrs or older) on GP LD registers in North Tyneside who had a GP health check in the last year was 60.1%, compared with the national average of 52.3%.

Long term support

- North Tyneside has a higher prevalence of adults with LD receiving long term support from the local authority compared to England as a whole (4.64 per 1,000 compared to 3.46 per 1,000).

Employment

- In 2022/23 around 3% of working age adults in North Tyneside with LD, who receive long-term support from the local authority, were in paid employment. This is the lowest percentage recorded in the last 5 years and is part of a downward trend (Figure 1).

Inequalities

- There is insufficient data at a local level to allow for analysis of inequalities such as gender and ethnicity.

6. Unmet needs

Registering individuals with LD

Data from the Quality Outcomes Framework (2019/20) showed that only 308,000 of the 1.2 million people with a LD in England were on the LD register (15). Being on the register makes it easier to access specific LD services and support. It also entitles people to annual health checks which are key to tackling some of the health inequalities facing people with LD.

Employment

Around 25% of working age adults (aged 18 to 64) with LD have a paid job, compared with the general population average of 76% of working age adults (aged 16 to 64) in employment (6). Estimates suggest the majority of those with LD in employment (68.3%) are working less than 16 hours per week (5).

Cancer screening

National data has shown that people with LD are markedly less likely to receive cancer screenings than people without LD (16):

- **Cervical cancer:** In 2018 only 31% of eligible women with LD had received cervical smear tests, in contrast to 73.2% of women without LD.
- **Breast cancer:** In 2017/18, 52.5% of women with LD had been screened for breast cancer, compared to 68% of women without LD.
- **Colorectal cancer:** In 2019, of those eligible for a colorectal cancer screening, 77.8% of people with LD were screened, compared to 83.7% of those without.

Unpaid carers

The care needs of people with LD can be life-long, highly complex and at times very challenging. This can have adverse financial and health impacts on unpaid carers. For instance, just over half of unpaid carers looking after someone with LD have a household income below or around the poverty line, and score far lower than the national average on wellbeing measures, including loneliness and burnout (17). Insufficient support for unpaid carers has the potential to reduce the quality of care they can provide to individuals, or worse still, the possibility they are unable to continue providing care in the long-term.

Physical inactivity

People with learning disabilities are at increased risk of being overweight or obese compared to the general population (18,19), in particular women with LD (20). Estimates suggest around 37.5% of people with a learning disability are obese (16). High rates of obesity significantly contribute to the reduced life expectancy of the LD population (19). Data from the 2022/23 Sport England Active Lives Adult Survey, showed disabled adults are almost twice as likely as non-disabled adults to be physically inactive (43 per cent vs 23 per cent) (21). The relatively high levels of physical inactivity, amongst those with disabilities, is an important unmet need given the negative health consequences related to physical inactivity.

7. Projected need and demand

The main risk factors for the development of LD are typically random and non-modifiable e.g. chromosomal abnormalities. There is no broad expectation that these risk factors will become more prevalent in the future, which likely explains why the projected trends in adult LD are relatively stable, and in line with general population increases (Figure 1)(11). It is therefore reasonable to conclude there will be no significant increase in the prevalence of LD across North Tyneside in the future.

	2023	2025	2030	2035	2040
People aged 18-24 predicted to have a learning disability	124,330	126,462	140,571	143,478	135,170
People aged 25-34 predicted to have a learning disability	188,271	185,268	176,230	182,124	196,488
People aged 35-44 predicted to have a learning disability	185,771	187,829	190,404	186,060	177,726
People aged 45-54 predicted to have a learning disability	169,440	168,200	171,405	180,771	183,770
People aged 55-64 predicted to have a learning disability	167,529	170,918	167,199	158,842	161,813
Total population aged 18-64 predicted to have a learning disability	835,341	838,678	845,807	851,275	854,967

Figures may not sum due to rounding
Crown copyright 2020

Figure 1- Adult learning disability baseline projections for England (Data source PANSI).

8. Community assets and services

There are a range of services available to support adults with LD in North

Tyneside:

- **Local authority or NHS services**
 - Northumbria healthcare LD service
 - North Tyneside council LD adult social care team
 - Active North Tyneside disability friendly exercise programs

- **Charity/voluntary organisations**
 - LD North East- North Tyneside based charity group
 - Hft Newcastle- a national LD charity
 - Living well NT- social care support service
 - North Tyneside united response- LD charity
 - North Tyneside disability forum
 - North Tyneside LD partnership board

9. Evidence for interventions

The 2021 NICE report '*People with a Learning Disability*' identified five priority areas for people with LD (22):

- Annual health checks.
- Reasonable adjustments and accessible communication.
- Supporting people to live independently in the community.
- Integrated local commissioning of health and social care services.
- Health and social care workforce development.

Annual health checks

A systematic review of studies regarding health checks for people with LD found clear evidence that they typically lead to the detection of unmet, unrecognised and potentially treatable health conditions (23). Targeted health checks are an important measure to help to tackle the unmet health needs and inequalities experienced by many individuals with LD, and may help to bridge the gap in life expectancy compared with the general population (24).

Reasonable adjustments

The Confidential Inquiry into premature deaths of people with LD (CIPOLD), highlighted the lack of reasonable adjustments provided to people with LD as a contributory factor in a number of avoidable deaths (25).

Supported employment

An interim cost-benefit report on supported employment in Kent found that the scheme was able to save the local authority money compared with paying for LD day care, as well as providing financial income and a sense of purpose for individuals with LD (7).

Commissioning of care placements

A review looking into the commissioning of care placements for individuals with LD found that many are being supported in out-of-area placements. Not only are these placements often far removed from the personal support networks of individuals, but they are also generally more expensive compared with providing local care placements. The use of expensive out-of-area placements limits investment in local services and therefore has the potential to lead to a long term reliance on out-of-area placements (26). This is not only bad for the individual but also the local authority provider.

10. Views of population

The Mencap 'Hear My Voice Campaign' collated the insights and views of people living with LD to develop a set of proposals outlining positive changes that could be made to support those with LD in the following areas (27):

Healthcare

- Everyone with a LD should be offered a hospital passport so doctors and nursing staff understand their needs when they go to hospital.
- We ask that all doctors and nurses have training on the reasonable adjustments they need to make to give quality care to people with LD and their families.

Education

- Young people with LD's should be supported to gain the right skills to prepare them for adulthood and have access to learning opportunities throughout their lives.

Housing

- There is often limited housing choice and not enough support to live independently. People want to be part of the community and not in a LD housing cluster.

Employment

- A survey of 1,625 working age adults with LD found that 62% wanted to work, but many reported barriers to employment, including:
 - I find it hard to fill in application forms (28.5%).
 - I have applied for jobs, but I haven't got one (25.9%).

- I don't know how to get a job (23.4%).
- I am worried about losing my benefits (21.2%).

11. Key contacts

- Key contact: Dr Tom Seasman
- Job title: ST1 Public Health Specialty Registrar
- Email address: TSEA7269@northtyneside.gov.uk
- Telephone number: 0191 643 3764

12. References

1. NICE. Learning disabilities: What is it? [Internet]. 2023 [cited 2024 Sep 11]. Available from: <https://cks.nice.org.uk/topics/learning-disabilities/background-information/definition/>
2. Public Health England. Learning disability - applying All Our Health [Internet]. 2023 [cited 2024 Sep 11]. Available from: <https://www.gov.uk/government/publications/learning-disability-applying-all-our-health/learning-disabilities-applying-all-our-health#what-a-learning-disability-is>
3. NICE. The learning disability health check programme [Internet]. 2024 [cited 2024 Sep 19]. Available from: <https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-use-of-nice-guidance/impact-of-our-guidance/niceimpact-children-and-young-peoples-healthcare/ch3-learning-disability-health-check-programme>
4. University of Bristol. The Learning Disabilities Mortality Review (LeDeR) Programme. 2017.
5. Public Health England. People with learning disabilities in England [Internet]. Chapter 2: paid employment. 2020 [cited 2024 Sep 16]. Available from: <https://www.gov.uk/government/publications/people-with-learning-disabilities-in-england/chapter-2-employment>
6. Mencap. Support for people with learning disabilities to find work [Internet]. Having a job matters. 2022 [cited 2024 Sep 16]. Available from: <https://www.mencap.org.uk/advice-and-support/employment>
7. Social Value UK. Reports Database: A Financial Cost:Benefit Analysis of Kent Supported Employment [Internet]. 2010 [cited 2024 Sep 16]. Available from: <https://socialvalueuk.org/reports/financial-costbenefit-analysis-kent-supported-employment/>
8. Mencap. How common is learning disability? [Internet]. 2020 [cited 2024 Sep 16]. Available from: <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability>
9. Department of Health & Social Care. Fingertips Public Health Profiles- Learning Disability Profiles [Internet]. 2024 [cited 2024 Sep 18]. Available from: <https://fingertips.phe.org.uk/profile/learning-disabilities>
10. NICE. Learning disabilities: What are the risk factors? [Internet]. 2023 [cited 2024 Sep 11]. Available from: <https://cks.nice.org.uk/topics/learning-disabilities/background-information/risk-factors/>

11. PANSI. LD- Baseline estimates [Internet]. [cited 2024 Sep 11]. Available from: <https://www.pansi.org.uk/index.php?pageNo=388&arealD=8640&loc=8640>
 12. University of Bristol. The Learning Disabilities Mortality Review (LeDeR) Programme. 2023.
 13. Heer K, Rose J, Larkin M. Understanding the experiences and needs of South Asian families caring for a child with learning disabilities in the United Kingdom: an experiential–contextual framework. *Disabil Soc.* 2012 Dec;27(7):949–63.
 14. UK Parliament. Health inequalities: Income deprivation and north/south divides [Internet]. 2019 [cited 2024 Sep 16]. Available from: <https://commonslibrary.parliament.uk/health-inequalities-income-deprivation-and-north-south-divides/#:~:text=For%20example%3A%20in%20the%20most%20deprived%20areas%2C%20one,65%25%20more%20likely%20to%20have%20a%20learning%20disability.>
 15. NHS England. Quality and Outcomes Framework, 2019-20 [Internet]. 2020 [cited 2024 Sep 19]. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2019-20#resources>
 16. Mencap. Health inequalities [Internet]. 2019 [cited 2024 Sep 19]. Available from: <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/health-inequalities>
 17. Fraser of Allander Institute. Learning disabilities and the value of unpaid care. 2021.
 18. Public Health England. Obesity and weight management for people with learning disabilities: guidance [Internet]. 2020 [cited 2024 Sep 18]. Available from: <https://www.gov.uk/government/publications/obesity-weight-management-and-people-with-learning-disabilities/obesity-and-weight-management-for-people-with-learning-disabilities-guidance>
 19. Harris L, Melville C, Murray H, Hankey C. The effects of multi-component weight management interventions on weight loss in adults with intellectual disabilities and obesity: A systematic review and meta-analysis of randomised controlled trials. *Res Dev Disabil.* 2018 Jan;72:42–55.
 20. Ranjan S, Nasser JA, Fisher K. Prevalence and potential factors associated with overweight and obesity status in adults with intellectual developmental disorders. *J Appl Res Intellect Disabil.* 2018 Jan;31(S1):29–38.
 21. Sport England. Disabled people [Internet]. 2023 [cited 2024 Sep 18]. Available from: <https://www.sportengland.org/research-and-data/research/disabled-people>
 22. NICE. NICE impact people with a learning disability [Internet]. 2021 [cited 2024 Sep 16]. Available from: <https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-use-of-nice-guidance/impact-of-our-guidance/nice-impact-people-with-a-learning-disability>
 23. Robertson J, Roberts H, Emerson E, Turner S, Greig R. The impact of health checks for people with intellectual disabilities: a systematic review of evidence: Impact of health checks. *J Intellect Disabil Res.* 2011 Nov;55(11):1009–19.
 24. Public Health England. Annual health checks and people with learning disabilities [Internet]. 2016 [cited 2024 Sep 16]. Available from: <https://www.gov.uk/government/publications/annual-health-checks-and-people-with-learning-disabilities/annual-health-checks-and-people-with-learning-disabilities>
 25. Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet.* 2014 Mar;383(9920):889–95.
 26. Emerson E, Robertson J, Whelton B. Commissioning Person-Centred, Cost-Effective, Local Support for People with Learning Disabilities. *Tizard Learn Disabil Rev.* 2009 May 13;14(2):49–51.
 27. Mencap. Hear my voice [Internet]. 15 [cited 2024 Sep 12]. Available from: <https://www.mencap.org.uk/get-involved/campaign-mencap/hear-my-voice>
-