# Learning Disabilities in Birmingham
# JSNA Deep Dive Report (2024)

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# Foreword

**Councillor Mariam Khan** - *Cabinet Member for Health and Social Care, and Chair of the Birmingham Health and Wellbeing Board, Birmingham City Council.*

*I am delighted to introduce this learning disabilities deep dive joint strategic needs assessment for children and adults in Birmingham. I am sure it will be a tremendous asset to support commissioners and those involved in working with people with a learning disability and their families within our local communities, to improve and transform our services and support in the future.*

*This deep dive is an in-depth review of the evidence surrounding the health and wider determinants of the health of our citizens with learning disabilities in Birmingham. We know that people with learning disabilities currently face a lower life expectancy, higher rates of physical and mental health conditions and poorer access to health and social care support. The recent COVID-19 pandemic highlighted these inequalities, with people with learning disabilities being among the groups classed as vulnerable.*

*Tackling these inequalities will require collaboration, compassion and care. Our ambition is to create a city where all are empowered and have equal opportunities to live healthy, safe, and fulfilled lives. To achieve this, we all have a responsibility to understand and respond to these unjust differences in health status that people with learning disabilities face.*

*Our hope is that this report sheds light on the health inequalities associated with learning disabilities, and ways of reducing and overcoming these. The evidence collated in this deep dive will support commissioners, researchers, professionals and members of the public in understanding the inequalities that people with learning disabilities and their carers face on a daily basis.*

*This deep dive highlights some of the fantastic work Birmingham is doing to support people who need help. Services such as day centres, advocacy services and the neighbourhood network scheme are providing vital support for them, many of whom have complex needs. Nevertheless, gaps in support remain for many. Perhaps most importantly, this deep dive provides a space to hear the voices of service users, parents and professionals who have shared their experiences and to whom we are very grateful. It is my hope that the recommendations and actions coming from this research have a direct and positive impact on the lives of those living with learning disabilities in Birmingham and their families.*

*Finally, I am hugely grateful to the members of our communities who live with, or support those with, learning disabilities who gave their time, experience and insights to inform the research and to bring to life our collective commitment to make a significant difference to the lives of our citizens and their families.*

**Professor Graeme Betts CBE** – Director of Adult Social Care, Birmingham City Council.

**Sue Harrison** – Director of Children and Families, Birmingham City Council.

**Dr Justin Varney** - Director of Public Health, Birmingham City Council.

*We are pleased to present this deep dive report for citizens in Birmingham. We believe this will be a valuable source of information, data and research evidence which will guide and shape learning disability support in Birmingham over the coming years.*

*In Birmingham we are committed to looking at our health and social care services and wider provision to understand how together we can support people with a learning disability and their families to maintain their independence, stay safe and lead fulfilling lives.*

*This deep dive explores the data and evidence around the health and wellbeing of citizens living with learning disabilities in Birmingham. It highlights the significant and avoidable health inequalities, including reduced life expectancy, difficulties accessing healthcare and support, and the social stigma experienced by people living with learning disabilities. And, based on evidence and the views of people living with learning disabilities, their carers and professionals who work in this area, makes recommendations for action. In this way, the deep dive provides the health and social care system with a comprehensive and up to date assessment of need which can help improve people's lives in Birmingham, reduce significant inequalities and provide focus. We are delighted that this assessment has, through close partnership working, informed the Framework for Change, Re-Imagining a Better Life 2023-2033 and we look forward to it further influencing decisions.*

*We all have a responsibility to care for those most vulnerable in society, and this deep dive opens the conversation about how we are currently doing this for our citizens and where we can create positive actions for change. Across our city, we want to develop communities and organisations who can openly talk about improvements that can be made to develop a more accessible and less disabling city, whilst raising awareness of these health and wellbeing issues and working to achieve the best outcomes for our citizens who live with learning disabilities.*

*We would like to thank those who shared their lived experiences, the extensive range of stakeholders who have supported the research throughout and the individuals and organisations who have agreed to take forward the recommendations which will make a real difference to the citizens of Birmingham. We would also like to extend our thanks to the research team for their hard work in shaping this deep dive.*

*We are committed to bringing evidence-based change to the city of Birmingham and working towards the aims of the Birmingham Joint Health and Wellbeing Strategy (2022-30).*

# Contents

# Executive Summary

> ***"Society isn't set up for people with a learning disability - things like transport, reading letters and so on."***
>
> Birmingham health professional.

This deep dive report into the health and wellbeing of citizens living with learning disabilities in Birmingham is part of a series of enhanced Joint Strategic Needs Assessment (JSNA) deep dive reviews, aimed at reducing health inequalities. We have examined multi-agency data and evidence relating to learning disabilities to inform the Birmingham Health and Wellbeing Board of this group's life course needs. In January 2023, there were 10,389 patients (of all ages) with learning disabilities, registered to Birmingham GP practices.[1] In the West Midlands, life expectancy of citizens living with learning disabilities is 59 years (see section 2.3).

This research has been undertaken within the context of existing strategies and guidelines. The Birmingham Joint Health and Wellbeing Strategy (2022-30) aims to create a city where every citizen, whoever they are, wherever they live and at every stage of life, can make choices that empower them to be healthy and happy. The Strategy also recognises that significant health inequalities affect citizens living with learning disabilities and it is committed to 'closing the gap'. The Learning Disability and Autism Strategy (2019) and the LeDeR 3 Year Strategic Plan in Birmingham and Solihull (2021-24) commit to addressing these health inequalities and working to improve health and social care services. Citizens living with learning disabilities should face no disadvantage compared to other citizens within the city. *The No Child Left Behind Strategy (2019-23)* extends these principles to education, training and transition pathways to adulthood.

In this deep dive report's Opportunities for Action section, we have set out recommendations for how local partners can work towards improving health and wellbeing and reducing inequalities for people living with learning disabilities in Birmingham. The recommendations are based around our five key findings:

- There is demand for strengthening the 'whole system approach' for coordinating and supporting the health and wellbeing of citizens with learning disabilities.
- There is currently insufficient data to gain a full understanding of the size and needs of the local learning disabilities population.
- There are opportunities in frontline healthcare to improve identification and assessment of citizens with learning disabilities.
- There is demand for improved learning disability services, through person-centred and consistent care across the city.
- There is a need for more research to support the evidence base around health inequalities for citizens with learning disabilities.

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[1] Source: Business Intelligence BSOL ICB January 2023. Accessed Jan 2023.

# 1 Introduction

## 1.1 Deep Dive

The deep dive reports are in-depth needs assessments, which are intended to provide a focused and thorough exploration of a specific topic area or population of need, to inform strategy, commissioning and practice.

This deep dive is part of the Joint Strategic Needs Assessment (JSNA) Deep Dive Programme, which is overseen by Birmingham's Health and Wellbeing Board. The findings are presented through a series of publications and this report (the Deep Dive Report) is accompanied by an easy read version, infographic summary and evidence base report.

## 1.2 Why Focus on Learning Disabilities?

Citizens living with learning disabilities experience significant health and wellbeing inequalities throughout their lives. It is recognised that many citizens living with a learning disability will experience poorer health and die at a younger age than the general population. The Birmingham Health and Wellbeing Board aimed to reduce these inequalities by commissioning this learning disabilities deep dive, to provide an evidence base for the commissioning of care and support services. The report has also been used to inform the *Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change (2022-32).*

## 1.3 Scope

This deep dive report focuses on the health and wellbeing of Birmingham citizens living with learning disabilities, through a life course approach. The aim is to establish an evidence base to support strategy development and commissioning processes in Birmingham, including identifying the level of need in the population, and the gaps and barriers in service provision. The specific objectives were to:

- Use epidemiological approaches and a broad range of quantitative and qualitative data to comprehensively and comparatively assess the needs of citizens living with learning disabilities in Birmingham, across the life course.
- Review service provision in Birmingham (e.g., health, social care, community and accommodation) to identify gaps and areas of unmet need and inequalities.
- Make recommendations to address the needs of Birmingham.

This deep dive report has concentrated on the experience of individuals with learning disabilities. In addition, the valuable views and experiences of carers, who are often parents, has been included through focus group research with carers.

## 1.4 Terminology and Definitions

It is recognised that there are different preferences with regards to the language used around learning disabilities.

### 1.4.1 Learning Disabilities

The White Paper *Valuing People* (2001) defined learning disability as the presence of a significant difficulty understanding new or complex information ('impaired intelligence') with a reduced ability to cope independently ('impaired social functioning'), which started in childhood with a lasting effect on development.[2]

A child can be born with a learning disability, if the mother has an accident or illness while she is pregnant, or due to the genetic makeup of the unborn child. Furthermore, a child can be born with a learning disability if he or she does not receive enough oxygen during childbirth, has trauma to the head, or is born too early. After birth, a learning disability can also be caused by early childhood illnesses, accidents and seizures.[3] Genetic causes of learning disabilities include Down syndrome, where the child has an extra chromosome,[4] and Fragile X syndrome, which is a genetic condition and the most common inherited learning disability cause.[5]

The term learning disability does not include all those who have a learning difficulty.[6] The presence of a low IQ (below 70) is not in itself sufficient to decide if someone might need additional health and social care support. Therefore, an assessment of social functioning and communication skills should also be considered when determining need.

In 2022, the ICD-11 was released with new definitions for 'disorders of intellectual development'. This update recognised that these disorders are diverse in their causes and are characterised by significantly below average intellectual functioning and adaptive behaviour. It also recognised that different domains of intellectual functioning (e.g., perceptual reasoning, processing speed and verbal comprehension) are affected to different extents in different individuals. Adaptive behaviour includes conceptual, social and practical skills. The previous categorisation of severity by IQ in ICD-10 (Mild (IQ between 50-69), Moderate (IQ between 35-49), Severe (IQ between 20-34) and Profound (IQ less than 20) was removed. Instead, severity is determined by both the level of intellectual ability and adaptive behaviour of the individual, and these are compared with the average in the general population.[7]

For individuals with mild disorder of intellectual development, there may be difficulties in the comprehension of complex language concepts and academic skills, and most will be able to achieve relatively independent living and employment. Individuals with moderate disorder of intellectual development may have difficulties in carrying out some basic skills and most people will need consistent support to achieve independent living and employment. For those with severe or profound disorder of intellectual development, individuals may have limited language skills and capacity for developing academic skills is restricted to basic concrete skills. These individuals may need daily support in a supervised environment.[8]

Many countries use the term 'intellectual disability' rather than 'learning disability', but these terms have the same meaning and are interchangeable.[9] Health conditions which are associated with learning disabilities include autism, cerebral palsy, dementia, Down syndrome, epilepsy, Fragile X syndrome, Williams syndrome and mental health problems.[10]

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[2] Department of Health. Valuing People: A New Strategy for Learning Disability for the 21st Century. (2001). Accessed Nov 2021.

[3] Mencap. What is a learning disability? Accessed Feb 2023.

[4] Mencap. Down's syndrome. Accessed Feb 2023.

[5] Mencap. Fragile X syndrome. Accessed Feb 2023.

[6] Department of Health. Valuing People: A New Strategy for Learning Disability for the 21st Century. (2001). Accessed Nov 2021.

[7] ICD-11. 6A00. Disorders of Intellectual Development. Accessed Sep 2022.

[8] ICD-11. 6A00. Disorders of Intellectual Development. Accessed Sep 2022.

[9] Emerson, E. et al. A Working Definition of Learning Disabilities. Accessed Dec 2022.

[10] Mencap. Learning Disability and Conditions. Accessed Feb 2022.

### 1.4.2 Learning Disability and Learning Difficulty: Understanding the Difference

This report focuses on ‘learning disabilities’, not learning difficulties. The terms 'learning disability’ and ‘learning difficulty’ can often be confused by the general public but are not interchangeable. Learning disability affects general intellect, whereas a learning difficulty does not (Figure 1).

**Figure 1: Understanding the Difference between Learning Difficulties and Learning Disabilities.**

*Source: Produced Internally.*

However, both can be experienced to a mild, moderate or severe degree. A learning disability is a reduced intellectual ability and affects someone for their whole life. Someone with a learning disability may have difficulty with everyday activities such as household tasks, socialising or managing money. A learning difficulty can cause difficulty learning in a traditional classroom setting, and examples include dyslexia, attention deficit hyperactivity disorder (ADHD) and dyspraxia.[11-12]

The SEND Code of Practice (2015)[13] outlines the different SEND codes used within education contexts. Broad areas of need include:

- Communication and interaction. This includes children with speech, language and communication needs and children with autism.
- Social, emotional and mental health difficulties.
- Sensory and/or physical needs.
- Cognition and learning. This includes children with specific (SpLD), moderate (MLD), severe (SLD) and profound and multiple learning difficulties (PMLD). Children with MLD and SLD are likely to need support in all areas of the curriculum and may have additional needs around mobility or communication. Children with PMLD may have complex learning difficulties in addition to other physical disabilities or sensory impairments.[14-15]

Any child with specific, moderate, severe, or profound and multiple learning difficulties, may (or may not) also have a learning disability. This occurs where the criteria for a disability is

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[11] Mencap. Learning difficulties. Accessed Feb 2022.

[12] Mencap. What is a learning disability? Accessed Feb 2022.

[13] Department for Education and Department for Health. (2015). Special educational needs and disability code of practice: 0 to 25 years. Accessed Dec 2022.

[14] BILD. (2011) Factsheet: Learning Disabilities. Accessed Feb 2022.

[15] Bristol University. Learning Disabilities: A Working Definition. Accessed Dec 2022.

met, in accordance with the Equality Act (Figure 2).[16] For more information on the Equality Act, please see section 1.4.4.

While the terms ‘learning disability’ and ‘learning difficulty’ may be used interchangeably in some contexts, this deep dive report will be distinguishing between these terms, and the scope of this report is the health and wellbeing of citizens with learning disabilities only.

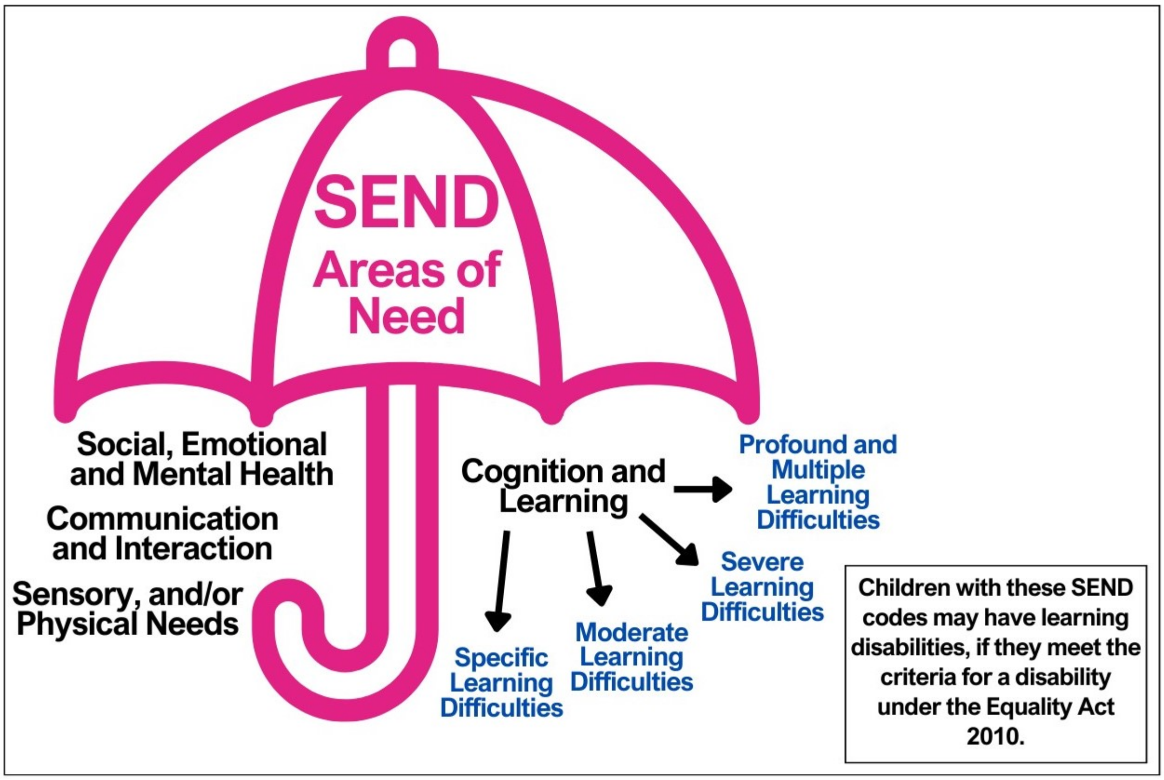

**Figure 2: SEND Areas of Need.**

*Source: Produced Internally.*

### 1.4.3 Learning Difficulties

A learning difficulty is a type of special educational need (SEN), which affects areas of learning such as reading, writing and spelling. Learning difficulties are categorised by severity:

- Specific learning difficulty – A difficulty such as learning to read or write.
- Moderate learning difficulty – Achievement is below what is expected, despite interventions.
- Severe learning difficulty – Significant intellectual or cognitive impairments.
- Profound and multiple learning difficulty – Multiple learning difficulties including severe and often complex learning needs, in addition to other needs, such as physical disabilities or sensory impairment.[17]

Learning difficulty examples include:

- Dyspraxia – A developmental co-ordination disorder.
- Dyslexia – A learning difficulty that can cause problems with reading, writing and spelling.

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[16] Information reviewed with the Children and Families Directorate, Birmingham City Council.

[17] NHS. NHS Data Model and Dictionary. Accessed Feb 2022.

- Attention deficit hyperactivity disorder (ADHD) – A condition that affects behaviour.
- Dyscalculia – A learning difficulty to understand, perform and learn maths and things based around numbers.
- Dysgraphia – A learning difficulty that affects the ability to write.

Learning difficulties are not within the scope of this deep dive report.

### 1.4.4 The Equality Act (2010)

A person is classified as having a disability under the Equality Act (2010) if they have a physical or mental impairment which has substantial and long-term (above 12 months) negative impact on the person's ability to do daily activities.[18]

### 1.4.5 Challenging Behaviour

'Challenging behaviour' is a broad term describing any behaviour that is challenging to others, such as parents, health professionals or carers. It includes behaviour which causes harm to the individual or others around them, and behaviours which prevent the individual from achieving things in daily life. Challenging behaviour may be a way of expressing frustration or pain where the individual has difficulty communicating. Challenging behaviour is not a learning disability, but many people with a learning disability may demonstrate behaviour that challenges services.[19]

### 1.4.6 Diagnostic Overshadowing

Diagnostic overshadowing occurs when a healthcare professional assumes that signs or symptoms that a person may be displaying are due to the person's learning disability or condition, without exploring other factors, such as biological determinants.[20] It has been observed that symptoms of physical ill health can often be mistakenly attributed to either mental or behavioural problems or as being inherent in the person's learning disabilities, potentially leaving other co-existing conditions undiagnosed.[21]

### 1.4.7 Reasonable Adjustments

The Equality Act 2010 requires public sector organisations to make changes in their provision and approach to make their services accessible to all. These changes are known as 'reasonable adjustments'.[22] Examples include providing Easy Read appointment letters, providing longer appointments and making sure there is wheelchair accessibility.[23]

## 1.5 The National Picture

### 1.5.1 Prevalence

An estimated 1.1 million children, young people and adults in England have a learning disability (Figure 3).

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[18] Gov.UK. Definition of disability under the Equality Act 2010. Accessed Dec 2023.
[19] Mencap. Challenging Behaviour. Accessed Feb 2022.
[20] Neurotrauma Law Nexus. Neuroglossary. Accessed Jun 2022.
[21] Emerson & Baines. (2010). Improving Health and Lives: Learning Disability Observatory. Accessed 8 Jun 2022.
[22] GOV.UK. (2018). Reasonable Adjustments for People with a Learning Disability. Accessed Oct 2022.
[23] NHS England. Reasonable Adjustments. Accessed Oct 2022.

**Figure 3: Number of People with a Learning Disability in England.**

*Source: QOF 2020-21.*[24]

It has been estimated that only 23% of the estimated 1.1 million people with a learning disability are however on their GP's learning disability register.[25] Part of this discrepancy is due to the GP register only accounting for patients aged 14 years and above, and that GP registers only account for the citizens where their learning disability is diagnosed and known to their GP. QOF data available from 2021-22 accounts for all ages, rather than just those aged 14+. In 2020-21, there were 338,195 patients registered as having learning disabilities on GP registers, as part of the Quality Outcomes Framework (QOF) in England (0.55%). As this figure does not include those who have not been diagnosed, or those who are not known to their primary healthcare services, it does not represent true prevalence.

Table 1 provides a comparison between Birmingham and the national picture for England. This shows that there is a higher percentage of citizens (all ages) on the learning disability QOF register in Birmingham and Solihull Integrated Care Board (ICB) than England.

**Table 1: Number (and Percentage) of Patients Included on the QOF Learning Disability Register (Birmingham and Solihull ICB and England) (2021-22).**

| Population | Number on QOF Register | % |
|---|---|---|
| **Birmingham and Solihull ICB** | 10,835 | 0.69% |
| **England** | 338,195 | 0.55% |

*Source: QOF, NHS Digital.*[26]

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[24] NHS England and NHS Improvement. (2020). QOF Quality Improvement domain 2020-21 – Supporting people with learning disabilities. Accessed Feb 2022.

[25] Public Health England. (2016). Learning Disabilities Observatory People with learning disabilities in England 2015: Main report. Accessed Jan 2022.

[26] NHS Digital. Quality and Outcomes Framework (QOF). Accessed Dec 2022.

Across England, there were 142,485 people accessing long-term care supported by local authorities with the primary reason of learning disabilities support. This is 42.1% of those registered on QOF, and 13% of the estimated 1.1 million people with learning disabilities in England. The majority of people accessing care for learning disabilities are aged 16-64 125,795 (88%) and there are 19,745 (15.5%)[27] people aged 16-64 who are in residential care primarily due to learning disabilities.[28]

Information on learning disabilities in children can be obtained from data on special educational needs (SEN). In January 2023, the number of pupils with SEN increased to 1,183,384 in England, which was 14% of pupils.[29] Within the umbrella term 'special educational needs', certain SEN codes encompass children with learning disabilities. The proportion of children known to schools who have been assigned the SEN code moderate learning difficulties (2.6%), was higher than those with severe learning difficulties (0.40%) and profound and multiple learning difficulties (0.13%). To read more about the differences in terms used to refer to learning disabilities within education, please see section 1.4.2.

In 2022-23, 1,093,234 (12.9%) of pupils had SEN support and 360,342 (4.2%) of pupils had an *Education, Health and Care Plan* (EHCP). The most common type of need for children with SEN support was speech, language and communication needs, whereas the most common type of need for children with an EHCP was autism.[30]

#### 1.5.1.1 Prevalence of Down Syndrome, Edward's Syndrome and Patau's Syndrome

Babies usually inherit two copies of each chromosome. Where a baby has three copies of a chromosome, it is termed 'trisomy' and the imbalance in genetic material leads to physical differences and developmental difficulties.[31] Down syndrome (Trisomy 21), Edward's syndrome (Trisomy 18) and Patau's syndrome (Trisomy 13) are the three most commonly identified genetic conditions linked to learning disabilities. In England (2018-20), the percentage of babies diagnosed antenatally was 63.3% for Down syndrome, 77.2% for Edwards' syndrome and 65.4% for Patau's syndrome.[32] Across Birmingham, Sandwell and Solihull (2018-20), these antenatal diagnosis rates were lower than the national average; 47.2% of babies with Down syndrome (n=84), 75.9% of babies with Edward's syndrome (n=44) and 61.1% of babies with Patau's syndrome (n=11).[33]

In 2018-20, the national birth prevalence in England for Down syndrome was 1 in 377 births, for Edward's syndrome this was 1 in 1,352 births and for Patau's syndrome this was 1 in 3,707 births. Across Birmingham, Sandwell and Solihull (2018-20), there were more births diagnosed with each condition in comparison to the national figures; Down syndrome (1 in 367 births), Edward's syndrome (1 in 1,145 births) and Patau's syndrome (1 in 3,163 births).

The majority of people who are born with Edward's syndrome and Patau's syndrome do not survive into adulthood.

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[27] NHS England. Adult Social Care Activity and Finance Report, England, [2022-23]. Accessed Nov 2023.

[28] Public Health England. (2020). Deaths of people identified as having learning disabilities with COVID-19 in England in the spring of 2020. Accessed Nov 2021.

[29] Department for Education. (2019). Special educational needs in England: January 2019. Accessed Nov 2021.

[30] GOV.UK. (2021). Special Educational Needs in England. Accessed Mar 2022.

[31] Public Health England. (2018). National Congenital Anomaly and Rare Disease Registration Service. Congenital anomaly statistics. Accessed Dec 2021.

[32] NHS Digital Timing of confirmation of Down's syndrome, Edwards' syndrome and Patau's syndrome. Accessed Aug 2023.

[33] Provided by the National Congenital Anomaly and Rare Diseases Registration Services. Accessed Jan 2024.

### 1.5.2 Projections

National projections for adults living with a learning disability or Down syndrome can be seen in Table 2. This data suggests that there will be a national increase in the number of individuals living with a learning disability (from 1,778,395 in 2020 to 1,959,438 by 2040) and Down syndrome (from 21,661 in 2020 to 22,292 in 2040).

**Table 2: Projections for Adults living with a Learning Disability or Down Syndrome (2020-40).**

| Type of Disability | 2020 | 2025 | 2030 | 2035 | 2040 |
|---|---|---|---|---|---|
| **Learning Disability** | 1,318,401 | 1,351,529 | 1,391,883 | 1,427,237 | 1,448,961 |
| **Down Syndrome** | 21,661 | 21,902 | 22,068 | 22,189 | 22,292 |
| **Total** | **1,778,395** | **1,825,129** | **1,880,479** | **1,928,850** | **1,959,438** |

*Source: PANSI and POPPI.*[34]

### 1.5.3 Life Expectancy and Mortality

National data from 2019-20, shows that males with a learning disability have a life expectancy of 55.7 years, which is 23 years lower than the males in the general population (78.7 years). Furthermore, females with a learning disability have a life expectancy of 55.6 years, which is 27 years lower than females in the general population (82.6 years).[35] LeDeR's 2022 Annual Report highlighted that between 2018 and 2022, the median length of life among those who lived to at least 18 years, was 62.9 years.[36]

> ***"Society isn't set up for people with a learning disability - things like transport, reading letters and so on."***
>
> Birmingham health professional.

## 1.6 National Strategies and Guidance

Significant health and wellbeing policy developments relating to citizens living with learning disabilities are summarised in this chapter, by report type. Some of the strategies and guidance documents relate to specific stages of the life course, whilst others are aimed at all stages of the life course and only policies from 2001 onwards are included.

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[34] PANSI. Projecting Adult Needs and Service Information. POPPI. Projecting Older People Population Information. Accessed Aug 2021.

[35] NICE. Learning Disability Impact Report. Accessed Oct 2022.

[36] King's College London. (2023). LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People. Accessed Dec 2023.

### 1.6.1 Government Strategies

Key Government strategies include ***Valuing People (2001)***[37] and ***Valuing People Now: A New Three-Year Strategy for People with Learning Disabilities (2009).***[38] These recognised that people with a learning disability are amongst the most vulnerable and socially excluded in society. The ***National Disability Strategy (2021)*** set out a vision of transforming disabled people's everyday lives. It recognised the enduring barriers disabled people face every day across all domains of life.[39]

### 1.6.2 Milestone Reports

***Death by Indifference (2007)*** published by Mencap*,* described the stories of six people with learning disabilities who were deemed to have died unnecessarily. This report outlined serious concerns about the treatment and institutional discrimination against people with learning disabilities. Factors contributing to this included the 'low priority' status of patients with learning disabilities, the lack of understanding among staff, the lack of involvement of families and carers, the lack of legal understanding of consent and capacity, incorrect estimates of quality of life, and an ineffective NHS complaints system.[40] Following this, ***Six Lives – The Provision of Public Services to People with Learning Disabilities (2009)***, summarised investigations of complaints about the six cases outlined in the Mencap report. Several areas of concern were highlighted by these investigations, including communication, failure to follow routine procedures and advocacy.[41]

***Healthcare for All, Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities (2008)*** followed the publication of *Death by Indifference*. This report produced ten key recommendations and concluded that individuals with learning disabilities have higher levels of unmet need and also receive less effective treatment.[42]

***Transforming Care: A National Response to Winterbourne View Hospital (2012)*** was an in-depth review published by the Department for Health*,* which was set up in response to the 2011 Panorama programme that focused on Winterbourne View.[43] The programme revealed criminal abuse of patients by staff, leading to the closure of Winterbourne View. A serious case review was launched by the local Safeguarding Board and there was a police investigation which resulted in eleven criminal convictions. The Quality Care Commission carried out inspections of all other homes and hospitals operated by the same company, as well as undertaking a broader inspection of learning disability services nationally.[44]

The report set out a programme of action to transform services and work towards safeguarding people with learning disabilities and/or autism, so that they no longer receive inappropriate care in hospitals and are cared for in line with published best practice. One of the actions in

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[37] Department of Health. (2001). Valuing People: A New Strategy for Learning Disability for the 21st Century. Accessed Nov 2021.

[38] Department for Health. (2009). Valuing People Now: A New Three-Year Strategy for people with learning disabilities. Accessed Nov 2021.

[39] HM Government. National Disability Strategy 2021. Accessed Dec 2021.

[40] Mencap. (2007). Death by indifference. Accessed Nov 2021.

[41] Department of Health. (2010). Six Lives: The Provision of Public Services to People with Learning Difficulties. Second Report, Session 2008-2009. Accessed Nov 2021.

[42] Michael Jonathan. (2008). Healthcare for all: report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities. Accessed Nov 2021.

[43] Department for Health Review. (2012). Transforming care: A national response to Winterbourne View Hospital. Accessed Nov 2021.

[44] Department of Health. Winterbourne View. Summary of Government Response. Accessed Dec 2022.

this report was the reviewing of all current hospital placements, with the view to moving all of those inappropriately in hospital to community-based support no later than June 2014.

Subsequent reports, ***Winterbourne View – Time for Change (2014)***[45] and ***Winterbourne View – Time is Running Out (2015)*** highlighted progress and challenges with growing community care and reducing the number of inappropriate hospital placements.[46] ***No Voice Unheard, No Right Ignored (2015)*** was a consultation for people with learning disabilities, autism and mental health conditions, presented due to the lack of progress on transforming care.[47]

The ***Confidential Inquiry into Premature Deaths of People with Learning Disabilities (2013)*** (CIPOLD) investigated the avoidable and premature deaths of 247 people with learning disabilities through retrospective reviews over a two-year period. The most common underlying causes of death were heart and circulatory disorder (22%) and cancer (20%). 42% of deaths were assessed as being premature, with common reasons for this being delays or problems with diagnosis or treatment and in providing appropriate care in response to changing needs. This report showed that the quality and effectiveness of both health and social care was insufficient for patients with learning disabilities. Among the issues identified was the fragmented nature of care, with poor communication between services and poor adherence to the Mental Capacity Act. CIPOLD recognised three associated factors that enhance the vulnerability of people with learning disabilities within care pathways: a lack of reasonable adjustments, a lack of coordination of care, and a lack of effective advocacy.[48]

***Valuing Every Voice, Respecting Every Right (2014)*** was published in response to the House of Lords Select Committee Report on the Mental Capacity Act 2005. This report set out plans to improve awareness and understanding of the Act.[49]

***Building the Right Support (2015)*** set out a national plan to develop community services and to close inpatient facilities for people with a learning disability and/or autism whose behaviour challenges, including those with a mental health condition.[50]

***Independent Review of Deaths of People with a Learning disability or Mental Health Problem in Contact with Southern Health NHS Foundation Trust (2015)*** was a report carried out due to the preventable death of Connor Sparrowhawk in 2013, which subsequently led to a number of investigations into Southern Health NHS Foundation Trust.[51] ***Learning, Candour and Accountability (2016)*** was a review of the way NHS trusts review and investigate the deaths of patients in England, carried out in response to low numbers of investigations or reviews of deaths at Southern Health NHS Foundation Trust. It made recommendations for improvements needed by the NHS about reviews and learning from reviews.[52]

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[45] NHS. (2014). Winterbourne View: Time for Change. Accessed Nov 2021.

[46] ACEVO. Winterbourne View – Time Is Running Out (2015). Accessed Dec 2021.

[47] Department of Health. (2015). Government response to No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions. Accessed Nov 2022.

[48] University of Bristol. (2013). Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Accessed Dec 2022.

[49] HM Government. (2014). Valuing every voice, respecting every right: Making the case for the Mental Capacity Act. Accessed Nov 2022.

[50] NHS England. (2015). Building the Right Support. Accessed Jan 2022.

[51] Mazars. (2015). Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015. Accessed Dec 2022.

[52] Quality Care Commission (CQC). (2016). Learning, candour and accountability. Accessed Nov 2021.

***Right to be Heard (2019)*** was the Government's response to a consultation on learning disability and autism training for health and care staff. The need for improved training around learning disabilities and autism was identified through the LeDeR programme and further reinforced by the case of Oliver McGowan, whose mother petitioned for training to be mandatory for all health and care staff, following Oliver's death.[53]

***Good Practice Guidance on Working with Parents with a Learning Disability (2021)*** was produced by the Working Together with Parents Network.[54] This set out how child and adult services can support parents with a learning disability. Features of good practice included:

- Accessible information and communication.
- Clear and co-ordinated referral and assessment processes and procedures, eligibility criteria and care pathways.
- Support designed around identified needs based on assessment.
- Long-term support if needed.
- Access to independent advocacy.

The ***Learning Disabilities Mortality Review (LeDeR)*** improvement programme, established in 2015, aims to improve care, reduce inequalities and prevent early deaths for people with learning disabilities and/or autism. LeDeR review the deaths (of those notified to them) of people with a learning disability and look at key episodes of health and social care that person has received. These reviews look for areas for improvement and examples of good practice in someone's care.[55] Currently, local integrated care systems are responsible for carrying out the LeDeR review.[56] In 2022, LeDeR expanded the scope of their mortality review to also include people with autism.

The data gathered by LeDeR has shed light on the large inequalities for some groups, such as the experiences of people from minority ethnic groups compared to white British, and the unequal impact of the COVID-19 pandemic on death rates for those with a learning disability. The data has also highlighted key factors associated with a greater likelihood of dying aged 18-49 years, including having severe or profound learning disabilities and being subject to mental health or criminal justice restrictions in the five years prior to death. These findings give avenue for further research and areas of focus for the future.[57]

The *LeDeR Annual Report* (2020) stated that a total of 9,110 deaths were reported to the LeDeR programme between 2018-20, of whom 622 were children. Recommendations from this report included that LeDeR reviews be undertaken through a lens of greater racial awareness and that local authorities ensure JSNAs collect and publish data on the needs of people with learning disabilities, with particular attention to data relating to specific ethnic groups.[58] Reporting the death of a person with a learning disability can be completed through the LeDeR reporting portal, which can be accessed via this link.[59]

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[53] Department of Health and Social Care. (2019). 'Right to be heard': The Government's response to the consultation on learning disability and autism training for health and care staff. Accessed Nov 2022.

[54] Working Together with Parents Network. (2021). Good practice guidance on working with parents with a learning disability. Accessed Sep 2022.

[55] NHS. About LeDeR. Accessed Feb 2022.

[56] NHS. About LeDeR, Role and Responsibilities. Accessed Jul 2022.

[57] University of Bristol. Findings from LeDeR review 2015-2020. Accessed Jul 2022.

[58] LeDeR Programme. Annual Report. (2020). Accessed Feb 2022.

[59] NHS. Report the death of someone with a learning disability or an autistic person. Accessed Jul 2023.

> ***“School could and should do more to improve awareness about disability in a child friendly way, so peers have a better understanding of daughter’s condition.”***
>
> Birmingham parent.

The *Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan, Right Support, Right Place, Right Time* was published in 2024.[60] The new national SEND and alternative provision plan aims to fulfil children’s potential, build parental trust and provide financial sustainability in the system.

This report acknowledged the experiences of some, describing it as a ‘vicious cycle of late intervention, low confidence and inefficient resource allocation’. Aspects of this plan to improve the system include new National Standards will be published to support this new system and these will support early intervention and provide clarity on support that families can access. Standardised EHCPs will support a process which is less complex and less bureaucratic and the creation of a ladder of intervention will support accountability at a local level. Local SEND and alternative provision partnerships, creating a network of professionals to collaboratively work together locally will support co-production and transparency in decision-making and communication. To support positive relationships at a local level, a refresh of the co-production model will set out best practice for working with families and prevent escalation of issues.

To support successful transitions including preparation for adulthood and employment, new guidance will be published, and further investments to increase the capacity of Supported Internships Programmes. Additionally, the Adjustments Passport pilot will continue to be supported and there will be new National Standards for Personal, Social and Employability Skills Qualifications. Careers Leaders will support education providers to identify career guidance needs of pupils with the support of the Careers and Enterprise Company to deliver careers education programmes.

The key themes of ***The Independent Review of Children’s Social Care (2022)*** were:

- A revolution in Family Help.
- A just and decisive child protection system.
- Unlocking the potential of family networks.
- Fixing the broken care market and giving children a voice.
- Five ‘missions’ for care experienced people.
- Realising the potential of the workforce.
- A system that is relentlessly focused on children and families.
- Implementation.

During 2020-21, 10% of assessments into children in need reported that a learning disability of the child contributed to them being in need. This Independent Review notes that parents of

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[60] HM Government. (2023). Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan. Accessed Jun 2024.

children with learning disabilities have consistently reported difficulty in accessing support and experienced frustration in navigating services. Improving children's social care for these children is essential because they are more likely to be re-referred to children's social care, compared to other children. This theme is further explored throughout this deep dive report (see section 5 Lived Experience).

The review proposed a new category; 'Family Help', to replace 'targeted early help' and 'child in need' work in order to reduce the number of times families are passed between services and provide more meaningful support. The recommendations for Family Help aim to ensure that there is reduced stigma associated with asking for help, and increased support provided for families, with fewer handovers between services. The review also raised the importance of improving the experience of transitioning to adult services and encourages the Government to ensure that local authorities plan and record in advance how children will make this transition.[61]

### 1.6.3 Relevant Acts

The ***Mental Health Act (1983)*** gives legal power to detain someone, known as 'sectioning', under the Act for the purpose of assessment and treatment of a mental health disorder, where the person may be at risk of harm to themselves or others.[62]

The ***Human Rights Act (1988)*** sets out human rights accorded to all people, and includes rights such as right to life, right to liberty and security and protection.[63]

The ***Equality Act (2010)*** established that disabled people have important rights of access to everyday services. Service providers are now obliged to make reasonable adjustments to premises or to the way they provide services.[64]

The ***Care Act (2014)*** introduced into law the duty to carry out care and support planning and personal budgets, which provide the individual with greater control over their choices and wishes. This act also set out the legal right of carers to assessment and support. A new adult safeguarding framework was outlined which set out how local authorities and other relevant professionals should protect adults from abuse and neglect.[65]

The ***Children and Families Act (2014)*** replaced statements of educational needs with a single combined Education, Health and Care Plan. This covers children and young people up to 25 years of age and relates to education, social care and health needs.[66]

The ***Reforming the Mental Health Act White Paper (2021)*** set out proposed changes to the 1983 *Mental Health Act*. Many of the proposed changes originate from the 2018 independent review of the Mental Health Act and aim to reduce use of the Act in relation to people with learning disabilities, autism, and people from ethnic minority backgrounds.[67]

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[61] MacAlister. (2022). Independent Review of Children's Social Care. Accessed Jun 2022.
[62] Mind. Sectioning. Accessed Jan 2023.
[63] Equality and Human Rights Commission. The Human Rights Act. Accessed Jan 2022.
[64] Gov.UK. Equality Act 2010: Guidance. Accessed Nov 2021.
[65] Department of Health and Social Care. (2016). Care Act Factsheets. Accessed Jan 2022.
[66] Information, Advice and Support Programme. Factsheet: An Introduction to Part 3 of the Children and Families Act 2014. Accessed Nov 2022.
[67] Local Government Association. Reforming the Mental Health Act white paper 2021. Accessed Apr 2022.

The ***Down Syndrome Act (2022)*** requires the Secretary of State to provide guidance to relevant authorities as to how to meet the needs of people living with Down syndrome. Guidance will be presented to parliament before being published.[68]

### 1.6.4 NHS

The ***NHS Learning Disability Improvement Standards (2018)*** were developed based on evidence that people with learning disabilities encounter difficulties when accessing NHS services which can lead to poorer treatment experiences, when compared to the general population. The standards provide a benchmark, against which NHS Trusts can measure performance. Categories include respecting and promoting rights, inclusion and engagement, workforce, and specialist learning disabilities services.[69]

In 2019, the ***Learning Disability Standards Benchmarking Report*** was published, which gathered baseline information from providers on their compliance with the standards. Over 90% of acute, mental health and learning disability trusts took part. [70] This report showed that 83% of acute hospital staff said they record and share information about the reasonable adjustments people need, and 80% of specialist learning disability services and 45% of acute hospital trusts provided accessible appointment letters.[71]

In the ***NHS Long Term Plan (2019),*** improving the care quality and outcomes for people with learning disabilities and autism was one of the NHS's priority areas. Key commitments in the Long Term Plan for people with learning disabilities included further work to reduce preventable deaths, and an improved understanding of their needs. Actions to deliver this included further training for staff and ensuring that reasonable adjustments are being made. The Long Term Plan also set out commitments to reduce numbers in inpatient care and move more care to the community.[72]

***Delivering High Quality End of Life Care for People who have a Learning Disability (2017)*** was a guide written by the Palliative Care for People with Learning Disabilities Network and NHS England for delivering end of life care to people with learning disabilities. The guide outlined six ambitions for delivering a high-quality palliative care framework:

- Ambition 1: Treating people as individuals, supporting people with learning disabilities to be involved in conversations about death and dying as well as families and carers.
- Ambition 2: Ensuring fair access to care.
- Ambition 3: A focus on comfort and wellbeing.
- Ambition 4: Care is coordinated.
- Ambition 5: All staff should be prepared to care and to do this they need to be supported professionally and emotionally.
- Ambition 6: Each community should be prepared to help.[73]

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[68] UK Parliament. Down Syndrome Act 2022. Accessed Jun 2022.
[69] NHS. (2018). The Learning Disability Improvement Standards for NHS Trusts. Accessed Mar 2022.
[70] NHS. The Learning Disability Improvement Standards for NHS trusts. Accessed Jan 2022.
[71] NHS. Performance against the learning disability improvement standards Findings from the benchmarking exercise July 2019. Accessed Jan 2022.
[72] NHS. (2019). The NHS Long Term Plan. Accessed Mar 2022.
[73] PCPLDD Network and NHS England. (2017). Delivering high quality end of life care for people who have a learning disability. Accessed Mar 2022.

### 1.6.5 National Institute for Health and Care Excellence (NICE)

NICE guidelines are evidence-based recommendations for health and care in England.[74] Over the years, NICE have published four guidelines for working with people with learning disabilities:

- Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (NG11, 2015).
- Mental health problems in people with learning disabilities: prevention, assessment and management (NG54, 2016).
- Learning disabilities and behaviour that challenges: service design and delivery (NG93, 2018).
- Care and support of people growing older with learning disabilities (NG96, 2018).[75]

Recording a learning disability on health records is an important step to ensuring that people obtain the care and support they need. NICE guidelines recommend that health and social care commissioners identify the number of adults with learning disabilities in their area, to identify where gaps in provision may exist, and to organise and plan services. NICE suggest and encourage GPs to develop and maintain registers of people with a learning disability as one way to achieve this.[76]

NICE have published two guidelines on complex needs:

- Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education (NG213 2022).[77]
- Social work with adults experiencing complex needs (NG216, 2022).[78]

The NICE guideline entitled '*Disabled Children and Young People up to 25 with Severe Complex Needs: Integrated Service Delivery and Organisation Across Health, Social Care and Education' was* published in 2022 includes a diverse and comprehensive list of recommendations, some of which have been summarised below due to their relevance to this deep dive.

- Provide travel training for children and young people with severe complex needs, in order to increase independence and participation.
- Improve support around exploring possible employment options in the SEND local offer, because this is not currently easy to understand for families and the assistance provided is variable.
- Education, health and social care services should organise an interagency team with all the relevant practitioners working with a child or young person. Interagency teams will facilitate coordinated support across education, health and social care.
- There was a recommendation to make the process around EHCPs easier to understand. There is recognition that there is a lack of transparency around how decisions are made and how families can appeal decisions.

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[74] NICE. NICE guidelines. Accessed Feb 2022.

[75] NICE. People with Learning Disabilities. Accessed Feb 2022.

[76] NICE Impact. (2021). People with a learning disability. Accessed Jan 2022.

[77] NICE. (2022). Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education. Accessed Nov 2023.

[78] NICE. (2022). Social work with adults experiencing complex needs. Accessed Nov 2023.

- More training is required to support professionals in understanding the different roles and responsibilities of other practitioners and services. This will help professionals disseminate clear information.
- A training need was highlighted for education providers to better serve children and young people with severe complex needs in mainstream education. Professionals may need further training to understand the social, emotional and mental health needs of disabled children with severe complex needs.
- Integrated care systems will need to work collaboratively with local authorities. Joint working can currently be seen in some, but not all areas of the sector. To support this, a joint commissioning framework needs to be developed across education, health and social care. It is hoped that this way of working will improve health through earlier identification and support, but will require education, health and social care services to provide more joined-up processes. Dynamic support registers, developed and maintained by clinical commissioning groups will support this recommendation. They can be a valuable source of information about the child or young person.[79]

NICE conducted an evidence review of barriers and facilitators of joined up care for disabled children and young people with severe complex needs. Among key themes identified were:

- Steps to overcome language and cultural barriers are required.
- There is stigma and fear associated with social services involvement.
- A lack of funding can be a barrier to getting the right resources.
- Rigid criteria for services lead to gaps in support.
- Work around transition is not adequate.
- Information sharing should support a more streamlined process, and service providers should work closely with parents and keep them informed.
- EHCPs take too long to obtain and there is a lack of transparency throughout the process.
- Staff lack understanding and skills to meet the needs of children and young people and staff are overloaded with onerous paperwork.[80]

The NICE Impact report ***People with a Learning Disability (2021)*** reviewed key themes covered in their guidance, focusing on key areas identified by partners. Stakeholders across the social and health care system identified five priority areas for people with learning disabilities:

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

To address these priority areas, NICE will support NHS England and NHS Improvements in their work to develop a Health Improvement Framework, deliver reasonable adjustments in

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[79] NICE Guideline [NG213]. (2022). Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education. Accessed Jul 2022.

[80] NICE Guideline [NG213]. (2022). Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across education, health and social care [K] Evidence review of barriers and facilitators of joined-up care. Accessed Jun 2022.

healthcare (including reasonable adjustments digital flag), and implement recommendations from the *Lives and Deaths of People with a Learning Disability Review*.[81]

### 1.6.6 Core20PLUS5 Model

The Core20PLUS5 is a national NHS England approach to reducing health inequalities at national and local levels.[82] The Core20PLUS5 approach has several elements and is comprised of:

- 'Core 20' – the most deprived 20% of the national population, defined by the Index of Multiple Deprivation.
- 'PLUS' – PLUS population groups are groups which have been identified to be affected by health inequalities for each local area. Examples may include ethnic minority communities, people with multiple long-term conditions, or people with learning disabilities.
- '5' – there are five national clinical areas of focus which require improvement. These differ for adults and for children. For adults, these are maternity, severe mental illness, chronic respiratory disease, early cancer diagnosis, and hypertension. For children, these are asthma, diabetes, epilepsy, oral health and mental health.

## 1.7 Birmingham Strategies and Guidance

Key Birmingham strategies, reports and guidance documents are outlined here. Some of the strategies and guidance documents below relate to specific stages of the life course, and others are aimed at all stages of the life course.

### 1.7.1 Our Future City Plan (2021)

In Birmingham's 'Our Future City Plan', published in 2021, aspirations for central Birmingham 2040 are set out. These are based on the principles of being a Green City, a Liveable City, and Equitable City and a Distinctive City. This plan highlights six 'city themes' which together could deliver the vision for 2040. One action under the theme 'City of Centres' is to identify a network of 15-minute neighbourhood areas. These are localised areas, where amenities and services are available with green spaces and schools. Another of the actions under this theme is the creation of diverse affordable homes, enabling a range of housing types to be available to meet all needs.[83] For citizens of Birmingham with learning disabilities, these two actions could provide improved housing, access to local services and community engagement, and could reduce issues around transport.

### 1.7.2 Birmingham Joint Health and Wellbeing Strategy (2022-30)

The Health and Wellbeing Strategy is Birmingham's high-level plan for reducing health inequalities and improving health and wellbeing across the city. This strategy recognises the significant gaps experienced by people living with learning disabilities and set the aim of a 25% increase in the number of annual health checks for people with learning disabilities by 2027.[84]

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[81] NICE Impact. (2021). People with a learning disability. Accessed Jan 2022.

[82] NHS England. Core20PLUS5 (adults) – an approach to reducing healthcare inequalities. Accessed Dec 2022.

[83] Birmingham City Council. Our Future City Plan 2021. Accessed Nov 2022.

[84] Birmingham City Council. Creating a Bolder, Healthier City (2022 to 2030), Accessed Nov 2022.

### 1.7.3 Birmingham's Levelling Up Strategy (2021)

Birmingham's Levelling Up Strategy (2021) is the city's contribution to the Government's goal of levelling up the country. The early intervention and prevention approach was identified as a key anchor of the Levelling Up Strategy. It aims to work at an early stage, preventing crises from happening and addressing the inequalities people face. The initiative is seeking to expand the neighbourhood networks and prevention first approaches to include more services, including housing, and to target a wider population, including adults with learning disabilities. Other actions of this programme include investment in community hubs, to connect citizens with resources and investment in digital inclusion.[85]

### 1.7.4 A Bolder and Healthy Future for People of Birmingham and Solihull (2023-33)

Outlined within this strategy is Birmingham and Solihull Integrated Care Board's commitment to improving the health and wellbeing of residents and their carers who have a learning disability. This includes improved access to services, assistance with issues (e.g., obesity) and improved communication around where to access support information for carers. The strategy highlights that a specific learning disability strategy will be developed, involving both local authorities and their partners.[86]

> ***"I go out to the shops with carer, it is nice, and I don't have any problems."***
>
> Birmingham citizen living with learning disabilities.

### 1.7.5 Birmingham SEND Strategy (2023-28)

This Strategy was co-produced with stakeholders and identifies eight priority areas:[87]

1. Early identification of need with timely assessments across Education, Health and Care.
2. A collaborative, graduated approach where support can be given without a diagnosis or EHCP, delivered consistently across the city.
3. Smooth transitions across Education, Health and Care at every stage of life, in particular the transition to adulthood.
4. A review of provision in education across Birmingham to provide an offer aligned with national and regional best practice.
5. Locality-based provision, right support, right place, right time.
6. Communication and engagement between children, young people, families, Education, Health and Care services and schools.
7. A skilled SEND Partnership team delivering impact and positive outcomes for all children and young people with additional needs.
8. Improved data collection and analysis to inform SEND priorities.

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[85] Birmingham City Council. Birmingham's Levelling Up Strategy. Accessed Nov 2022.
[86] Birmingham and Solihull Integrated Care System. Our Priorities. Accessed Aug 2023.
[87] Local Offer Birmingham. SEND and Inclusion Strategies Overview. Accessed Sep 2023.

### 1.7.6 Birmingham SEND Services

In 2018, Ofsted and the Care Quality Commission (CQC) carried out an inspection of Birmingham, which concluded that a *Written Statement of Action* was necessary due to significant areas of weakness, including issues in parental engagement, co-production, quality of education, health and care plans.[88] In 2021, Ofsted and the CQC carried out a revisit of Birmingham, which determined that only one of the thirteen areas of significant weakness (which was in the area of joint commissioning) had made sufficient progress.[89]

The ***Improving Special Educational Needs and Disability (SEND) Services in Birmingham*** report was published in February 2022 and provided an up-to-date assessment of the services and leadership, with recommendations for reform. The report highlighted the lack of continuity in leadership of SEND services contributing to difficulties with the service over the past decade. Other issues in the SEND system included staffing and the IT system, which was noted to be inadequate and will be replaced. 2,000 EHCPs had not been resourced, i.e., not being provided for at the time of this review, 20-week timescales for EHCPs were not being met in most new cases, and annual reviews were infrequent. The backlog of cases led to queries and complaints which had not been well coordinated. Staff recruitment should help return average caseloads to acceptable levels. Inadequacies regarding the health and NHS aspects of SEND services have also been noted, such as the long delays associated with the provision of therapies in the city. A lack of co-production with children and families has also been reported, as well as some parents reporting feeling tired and distrustful of the system. Despite this, the Birmingham Parents and Carers Forum has been seen as a good example of where the system is working well to engage parents.[90]

***SEND Improvement Updates*** were outlined in the June 2022 newsletter. Progress included the development of a co-produced refreshed SEND strategy and a new EHCP template and documentation. Improvements on several outcomes have been reported between 2021 and 2022, including more EHCPs being processed within the 20-week timescale, and fewer young people with EHCPs not in education, employment or training (NEET). These are outlined below (Figure 4).[91]

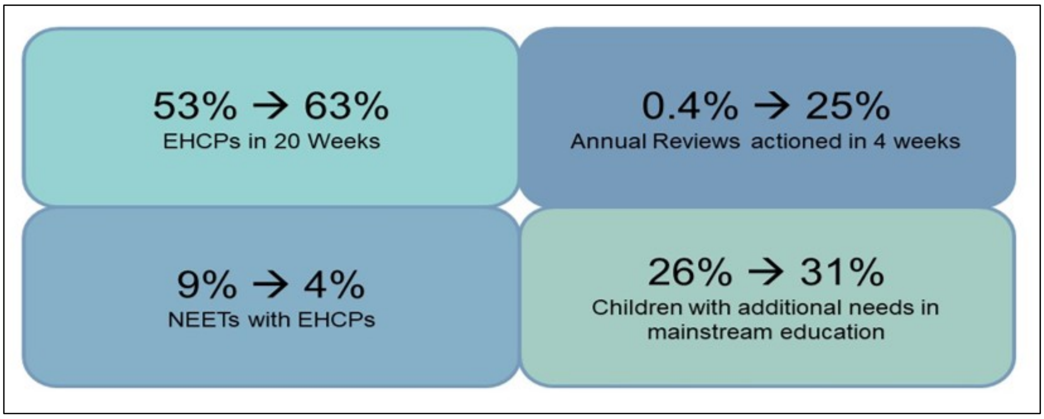

**Figure 4: Birmingham SEND Improvement Updates (2021-22).**

*Source: Birmingham City Council SEND Improvement Update.*

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[88] CQC and Ofsted. (2018). Joint local area SEND inspection in Birmingham. Accessed Dec 2021.
[89] CQC and Ofsted. (2021). Joint local area SEND revisit in Birmingham. Accessed Dec 2021.
[90] Coughlan. (2022). Improving Special Educational Needs and Disability (SEND) Services in Birmingham. Accessed Jun 2022.
[91] Birmingham Local Offer. SEND Improvement Update – June 2022. Accessed Nov 2023.

### 1.7.7 Birmingham and Solihull LeDeR Programme (2021-24)

Birmingham and Solihull CCG have set out a 3-year plan for the local LeDeR Programme which set out actions to act on the learning from reviews. It noted that at the time of publication, 150 adult LeDeR reviews had been carried out across Birmingham and Solihull. Twenty areas for improvement were identified in this plan:[92]

1. Carry out place inspections to ensure local services are ‘Learning Disability Friendly’.
2. Promote a ‘Rights Based Approach’ in Birmingham.
3. Improve application of the Mental Capacity Act across partner organisations.
4. Make better use of Annual Health Checks.
5. Improve the systems for the management of, and response to, instances where ‘Did not Attend’ or were not brought to health care appointments.
6. Actively support and encourage Advance Care Planning.
7. Improve the recognition and management of pain.
8. Improve the understanding and awareness of additional health needs in community service providers.
9. Ensure consistent access to End of Life care.
10. Ensure RESPECT and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms are always completed comprehensively.
11. Work to improve the continuity of care when transitioning between primary and secondary services.
12. Maximise partnership with family and paid carers when persons with a learning disability are admitted to secondary care.
13. Meet the health needs of citizens from black and ethnic minority backgrounds with a learning disability.
14. Develop a ‘virtual’ offer to persons with a learning disability.
15. Review the role of health facilitation and acute liaison services, these are roles to support patients with learning disabilities in healthcare settings.
16. Develop and embed increased knowledge and understanding of best practice in primary care networks.
17. Promote system learning.
18. Scope and review the range and availability of specialist community learning disability resources.
19. Define and establish a working local model of care coordination.
20. Meet the dementia care needs of citizens with a learning disability.

From April 2021 to March 2022, there were 75 notifications of deaths of citizens with a learning disability to Birmingham and Solihull’s LeDeR programme.[93] These are called ‘notifications’ because some of the deaths are in the process of being reviewed and processed. Not all deaths are reported to LeDeR, therefore these do not represent all deaths of citizens with a learning disability in Birmingham and Solihull for this time period. Constituencies with the largest number of notifications include Erdington (n=14), Selly Oak (n=12) Yardley (n=11), Meriden (n=7) and Hall Green (n=6).

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[92] Birmingham and Solihull ICB. The LeDeR Programme. Accessed Jan 2023.
[93] Data supplied by BSoL LeDeR programme.

### 1.7.8 Children and Young People's Mental Health and Emotional Wellbeing Local Transformation Plan (2021-22)

The *Children and Young People's Mental Health and Emotional Wellbeing Local Transformation Plan* (2021-22) is aligned with the Learning Disability and Autism Operational Plan (2021-24) and the SEND plan response to Written Statement of Action.[94] Learning Disability and Autism Partnerships in the Midlands created a co-produced 3 year plan to support citizens with learning disabilities to access care and support, and to reduce inequalities. The objectives of this plan included:

- Reducing inpatient admissions through utilisation of the Dynamic Support Register (this is a system to identify those at risk of a mental health inpatient admission),[95] the Learning Disabilities Mortality Review, the Care, Education and Treatment Review process and increased capacity of community provision.
- Reducing the length of stay for inpatient admissions through the implementation of the discharge hub, discharge protocol and increased risk management across inpatient providers.
- Reducing the breakdown of care and support packages within the community through provider forums, and tailored training for community care providers.
- Through this increased offer, increase the positive experience of care and support the reduction of health inequalities.

> ***"Not having information readily available to you to help educate you as a parent. It makes you feel really guilty not having all the information and not knowing where to go to make sure your child has the best support possible".***
>
> Birmingham parent.

### 1.7.9 Learning Disability and Autism Strategy (2019)

Outlined within this strategy is the University Hospitals Birmingham (UHB) Trust's commitment to improving care and treatment of people with learning disabilities and/or autism, when accessing care within the Trust. The aims of this strategy were to:

- Set out how patients with learning disabilities and/or autism would be supported.
- Set out the governance and audit requirements around patients with learning disabilities and/or autism.
- Ensure staff are competent and confident in understanding the needs of patients with learning disabilities and/or autism.
- Put Birmingham services in line with National Standards.[96]

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[94] NHS England and NHS Improvement. Children and Young People's Mental Health and Emotional Wellbeing Local Transformation Plan 2021/22 Birmingham. Accessed Dec 2022.

[95] NHS England. Dynamic support registers and Care (Education) and Treatment Review code of practice. Accessed Nov 2023.

[96] University Hospitals Birmingham. (2019). Learning Disability and Autism Strategy. Accessed Nov 2023.

# 2 The Birmingham Picture

## 2.1 Prevalence

In January 2023, the total number of patients (of all ages) with learning disabilities, registered to Birmingham GP practices was 10,389.[97] This data was provided by Birmingham and Solihull ICB. An additional source is the NHS Digital Quality Outcomes Framework (QOF), which provides an annual prevalence for patients (all ages) from data for learning disabilities (including Down syndrome) from GP practice records. This data source shows that there are 9,594 Birmingham citizens (0.7%) on the QOF register who are cared for regularly by our GPs, compared to a national prevalence of 0.5% (2021-22).

Birmingham has one of the highest recorded prevalence for learning disabilities among the Core Cities, alongside Sheffield, Newcastle, and Manchester (Table 3). However, QOF data does not encompass all learning disability patients, but just those who have received a diagnosis where the GP recognises that they need to be clinically cared for.[98]

**Table 3: Learning Disabilities QOF Prevalence Comparison in Core Cities (2021-22).**

| Core City | QOF Prevalence for LD |
|---|---|
| **Birmingham** | 0.7% |
| **Bristol** | 0.5% |
| **Leeds** | 0.5% |
| **Liverpool** | 0.6% |
| **Manchester** | 0.7% |
| **Newcastle** | 0.7% |
| **Nottingham** | 0.5% |
| **Sheffield** | 0.8% |
| **England** | **0.5%** |

*Source: Locally calculated prevalence data based on QOF (2021-22).*

QOF registers are based on GP practice registers. They have recently been published at a local authority level and ward calculations have been produced internally, which show that learning disabilities prevalence in Birmingham varies around the city. Our highest prevalence is in Kings Norton North ward (1.3%) and our lowest is in Edgbaston ward (0.3%). However, the differences in prevalence are generally small, with many wards having similar prevalence. Kings Norton was the location of Monyhull Hospital, which was an institution that housed citizens living with learning disabilities, until it closed during the 1990s.[99] Therefore, this may be a contributing factor for the higher prevalence of citizens living with learning disabilities in the Kings Norton area.

In the QOF guidance (2021-22), learning disability registers will be enhanced to include people with learning disabilities of all ages. One of the benefits of this is that complete GP registers will allow practices to be aware of the children and young people with learning disabilities who may need reasonable adjustments.[100]

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[97] Source: Business Intelligence BSOL ICB January 2023. Accessed Nov 2023.
[98] NHS Digital. (2021). Quality and Outcomes Framework, 2020-21. Accessed Oct 2021.
[99] BBC News. (2011). Domesday Reloaded: Mental asylums to care in the community. Accessed Nov 2023.
[100] BMA and NHS. Quality and Outcomes Framework Guidance for 2021-22. Accessed Mar 2022.

Figure 5 provides an estimate of QOF prevalence for learning disabilities, by ward. This is shown for QOF data 2020-21 (representing citizens aged 14+) as later data, which encompasses all ages, was not available by ward at the time of writing.

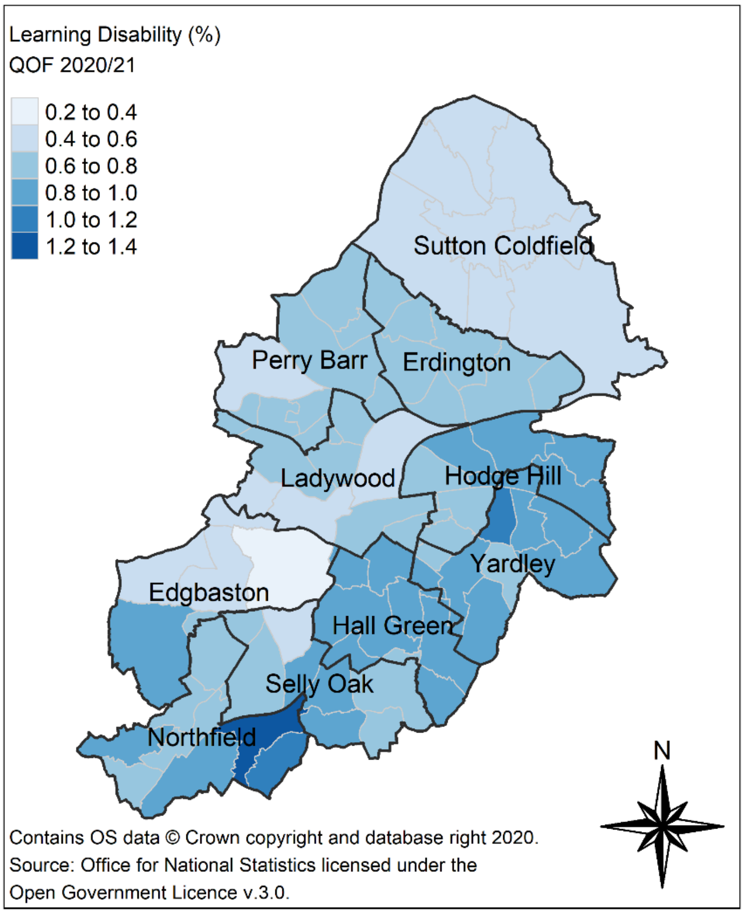

**Figure 5: Learning Disabilities QOF Prevalence by Ward (2020-21).**

*Source: Locally calculated prevalence data based on QOF (2020-21).*

### 2.1.1 Characteristics of Birmingham Citizens with Learning Disabilities

The majority of people registered as having learning disabilities on the GP register (January 2023) in Birmingham are male (64% male, 36% female) and under 35 years of age. Table 4 and Figure 6 provide an age summary of these patients.

**Table 4: Age Group Summary of Birmingham's Learning Disability Patients.**

| Age Group | Number of LD Patients | % |
|---|---|---|
| Under 20 | 2,556 | 25% |
| 20 to 34 | 3,549 | 34% |
| 35 to 49 | 1,943 | 19% |
| 50 to 64 | 1,623 | 16% |
| 65 to 79 | 615 | 6% |
| 80+ | 104 | 1% |

*Source: Business Intelligence BSOL ICB (Jan 2023).*

The largest percentage of patients (34%) are between 20 to 34 years of age, with a further 25% under the age of 20. The low percentages in the over 65s age groups are indicative of the low life expectancy that citizens living with learning disabilities experience.[101]

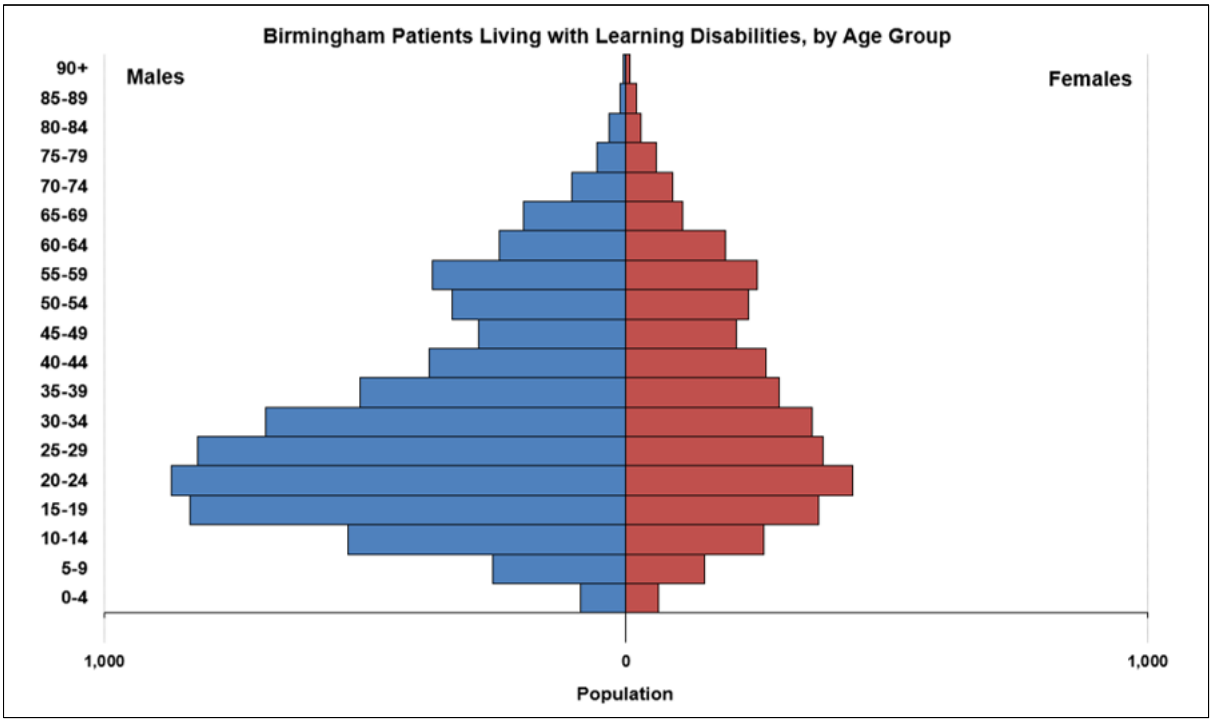

**Figure 6: Population Pyramid Displaying Age Range of Birmingham Patients Living with Learning Disabilities (January 2023).**

*Source: Business Intelligence BSOL ICB (Jan 2023).*

Table 5 provides an ethnicity summary of patients flagged with learning disabilities. The majority of patients (47%) are from a white background, whilst patients from an Asian background form the second largest cohort (24%). The 2021 Census recorded that 49% of our population are from a white background.[102] Therefore, the percentage of learning disability patients from a white background in this table is reflective of this. Unfortunately, 13% (1,390) of learning disability patients were recorded as having no known ethnicity.

**Table 5: Ethnicity Breakdown of Birmingham's Learning Disability Patients.**

| Ethnicity | Number of LD Patients | % of Patients with LD | % Total Population (2021 Census) |
|---|---|---|---|
| **White** | 4,920 | 47% | 49% |
| **Asian** | 2,529 | 24% | 31% |
| **Black** | 812 | 8% | 11% |
| **Mixed** | 297 | 3% | 5% |
| **Any Other ethnic group** | 441 | 4% | 5% |
| **Not known** | 1,390 | 13% | 0% |

*Source: Business Intelligence BSOL ICB Jan 2023,* [103] *and 2021 Census.*

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[101] Information supplied by Business Intelligence BSOL ICB. January 2023. Accessed Jan 2023.
[102] ONS. 2021 Census. Accessed Jan 2023.
[103] Information supplied by Business Intelligence BSOL ICB. January 2023. Accessed Jan 2023.

## 2.2 Projections

*PANSI* and *POPPI* provide projection figures for Birmingham residents (aged 18+) with various vulnerabilities, including learning disabilities.[104,105] Projections cover 2025 to 2040 and are for varying degrees of learning disabilities, ranging from moderate to severe, with Down syndrome recorded separately.[106] These data forecast an increase in prevalence, meaning that the demand on Birmingham's health and care services for people with learning disabilities will increase over the coming decades (Table 6 and Figure 7). The projections are based on 2021 Census.

**Table 6: Projections of Learning Disability Group Populations in Birmingham (2020-40).**

| **Type of Learning Disability** | **2023** | **2025** | **2030** | **2035** | **2040** |
|---|---|---|---|---|---|
| Mild learning disability | 20,967 | 21,188 | 21,831 | 22,446 | 22,780 |
| Moderate to severe learning disability | 4,488 | 4,537 | 4,676 | 4,794 | 4,844 |
| Severe learning disability | 1,106 | 1,117 | 1,149 | 1,172 | 1,176 |
| Down syndrome | 847 | 865 | 918 | 965 | 994 |
| **Total Projections Learning Disabilities** | **27,408** | **27,707** | **28,574** | **29,377** | **29,794** |
| **Birmingham Population projection** | **874,000** | **883,100** | **909,000** | **933,500** | **948,000** |
| **Cumulative Percentage Increase since 2023** | **0** | **1.1%** | **4.2%** | **7.0%** | **8.4%** |

*Source: PANSI and POPPI projections (2023).*

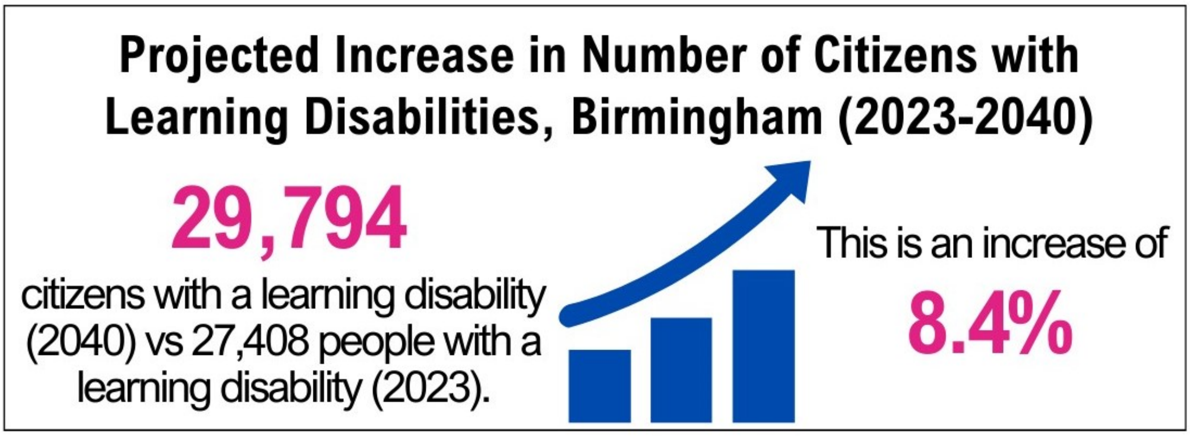

**Figure 7: Projections of Citizens with Learning Disabilities (2023-40).**

*Source: PANSI and POPPI projections (2023).*

## 2.3 Life Expectancy and Mortality

Local mortality data shows that between 2016-20, there were only five cases where the death certificate included learning disability as a cause of death. Whilst many others with learning disabilities would have died, learning disability has rarely been entered on the death certificate as a cause of death. In contrast, Down syndrome is recorded more regularly on death certificates. Between 2016-20, there were a total of 40 deaths in Birmingham where Down syndrome was recorded as a secondary cause of death on Part 1 of the certificate. Ages range

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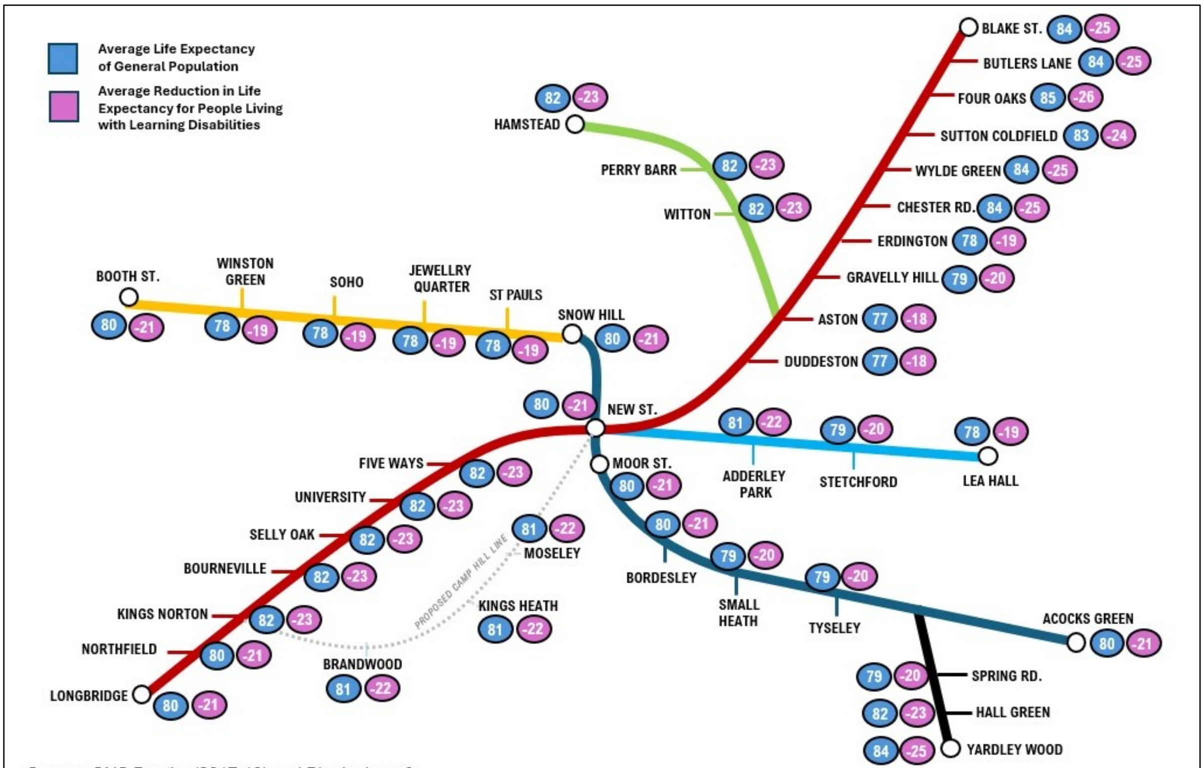
[104] PANSI. Projecting Adult Needs and Service Information. Accessed Aug 2023.
[105] POPPI. Projecting Older People Population Information. Accessed Aug 2023.
[106] Information confirmed by email from PANSI. Accessed Sep 2021.

from infants to 80+ years, indicating that people with Down syndrome have had increased life expectancies over time, but often with health complications.[107]

National life expectancy data has been calculated using gender breakdowns, whereas the local West Midlands data has been calculated per person. Although we are able to identify a picture of lower local life expectancy than the general population, we are unable to correlate national and regional data. There is no local authority life expectancy for learning disabilities, therefore the research team have utilised the regional West Midlands life expectancy of citizens living with learning disabilities (59 years) as a substitute.[108] This suggests a higher local life expectancy, compared to the national average. Further research is needed to understand the causes behind these geographical differences in life expectancy. The life expectancy gap between those with or without learning disabilities can vary considerably, particularly in a city like Birmingham. Figure 8 illustrates these differences. Numbers in blue bubbles represent the life expectancy of the general population in the ward, and numbers in purple bubbles represent the difference in life expectancy years for citizens living with learning disabilities.



Source: ONS Deaths (2017-19) and Birmingham & Solihull LeDer Annual Report (2020-21)
© Birmingham Public Health 2024

**Figure 8: Life Expectancy Gap for Citizens with Learning Disabilities Compared to General Population, by Railway Stations.**

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[107] Esbensen. (2010). Health conditions associated with aging and end of life of adults with Down syndrome. Accessed Nov 2023.
[108] Supplied locally by LeDeR locality commissioning November 2021. Accessed Nov 2023.

# 3 Health and Wellbeing Inequalities

## 3.1 Health Inequalities

Health inequalities are avoidable and unfair differences in health status between groups of people.[109] People with learning disabilities face many health inequalities, with differences in health status often beginning at an early age and life expectancy much lower than the general population.[110] National data from 2019-20, shows that life expectancy for males with a learning disability is 55.7 years, and 55.6 years for females.[111] LeDeR's latest annual report noted that at the time of death, 46% of people with a learning disability had endured between seven and ten long-term health conditions (Figure 9). Furthermore, LeDeR reports have shown that people with a learning disability are 3 to 4 times more likely to die from an avoidable medical cause, compared to the general population.[112]

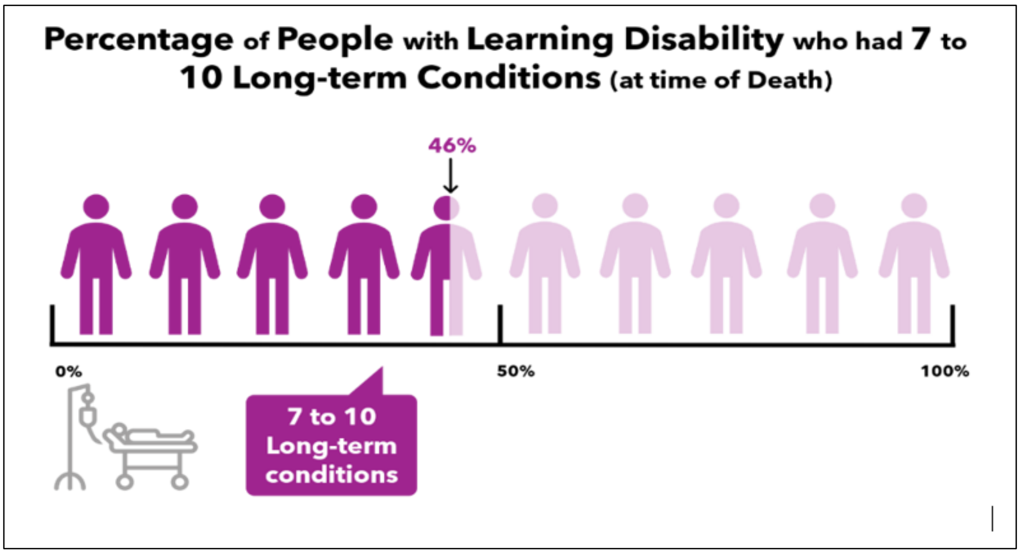

**Figure 9: Percentage of People with a Learning Disability who had 7 to 10 Long-Term Conditions at Time of Death.**

*Source:* LeDeR *Annual Report.*[113]

The five most common causes of death for people with a learning disability in 2022 (whose death was reported to the LeDeR programme) were due to the circulatory system (16.7%), cancers (14.6%), respiratory system (14.5%), nervous system (13.6%) and congenital malformations and chromosomal abnormalities (13.3%).[114]

Deaths are regarded as 'avoidable' in cases where the person dies before the age of 75 years and where steps could have been reasonably taken, that may have changed the outcome. LeDeR's 2022 Annual Report highlighted that in England, 42% of people with learning disabilities had died from avoidable causes, which was almost double the figure for avoidable deaths in the general population (22%). Deaths of citizens with learning disabilities were more likely to be seen as avoidable for those aged 25-64 years, compared to adults who were

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[109] Public Health England. (2018). Health Profile for England: 2018: Inequalities in Health. Accessed Feb 2022.
[110] Emerson & Baines. Health inequalities and people with learning disabilities in the UK. Accessed Feb 2022.
[111] NICE. Learning Disability Impact Report Accessed Oct 2022.
[112] NICE Impact. (2021). People with a learning disability. Accessed Jan 2022.
[113] LeDeR Programme. Annual Report 2020. Accessed Jan 2022.
[114] King's College London. (2023). LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People. Accessed Dec 2023.

younger than 25 years or older than 65 years. Men with a learning disability were 22% more likely to die from an avoidable death than women with a learning disability. The conditions which accounted for the highest proportion of avoidable deaths included cardiovascular conditions (26.4%), respiratory conditions (23.8%, excluding COVID-19) and cancers (15.7%).[115]

### 3.1.1 Comorbidities

#### 3.1.1.1 Neurological Conditions

Local data from the *Health and Care of People with Learning Disabilities dataset (2019-20)* showed that citizens with learning disabilities are significantly more likely to have autism (35.6%) than the general population (0.8%).[116]

Table 7 provides a summary of learning disabilities patients in Birmingham by area, who also have either Down syndrome or autism recorded on their patient record. While these conditions are recorded separately, some patients may have both conditions (data unavailable). In total, 9% of Birmingham's learning disabilities patients have Down syndrome and 37% have autism.

The North and West of Birmingham have the highest percentage of patients with learning disabilities and Down syndrome (11%). However, the South has the highest percentage of patients with learning disabilities and autism (43%).

**Table 7: Learning Disability Patients with Down Syndrome or Autism, by Area.**

| Birmingham Area | Patients with LD | Patients with LD and Down Syndrome | Percentage with LD and Down Syndrome | Patients with LD and Autism | Percentage with LD and Autism |
|---|---|---|---|---|---|
| **North** | 1,941 | 215 | 11% | 623 | 32% |
| **East** | 2,429 | 222 | 9% | 903 | 37% |
| **Central** | 2,277 | 165 | 7% | 937 | 41% |
| **South** | 2,110 | 196 | 9% | 897 | 43% |
| **West** | 1,632 | 178 | 11% | 486 | 30% |
| **Birmingham** | **10,389** | **976** | **9%** | **3,846** | **37%** |

*Source: Business Intelligence BSOL ICB Jan 2023.*[117]

19% of citizens of Birmingham with learning disabilities had epilepsy, 12.1% had ADHD and 1% had dementia (Table 8).

**Table 8: Long-Term Health Conditions among Learning Disability Patients.**

| Long-term Conditions | Epilepsy | ADHD | Dementia |
|---|---|---|---|
| **Birmingham LD Patients** | 2,000 | 1,257 | 90 |
| **% of LD Patients** | 19% | 12.1% | 1% |

*Source: Business Intelligence BSOL ICB (Jan 2023).*

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[115] King's College London. (2023). LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People. Accessed Dec 2023.

[116] NHS Digital. (2021). Health and Care of People with Learning Disabilities. Accessed Sep 2021.

[117] Information supplied by Business Intelligence BSOL ICB. January 2023. Accessed Jan 2023.

### 3.1.1.2 Cardiovascular Disease

Research from a population study in Denmark showed that people with learning disabilities had higher rates of cardiovascular disease than the general population.[118] Table 9 provides a summary of the most prevalent cardiovascular illnesses that affect patients living with learning disabilities in Birmingham. This shows that among these conditions, hypertension is the most prevalent for patients with learning disabilities (9.6%).

**Table 9: Cardiovascular Diseases among Learning Disability Patients.**

| Cardiovascular Disease | Hypertension | CHD | Stroke | TIA | Myocardial Infarction | Heart Failure |
|---|---|---|---|---|---|---|
| **Birmingham LD Patients** | 1,002 | 115 | 127 | 45 | 53 | 99 |
| **% of LD Patients** | 9.6% | 1.1% | 1.2% | 0.4% | 0.5% | 0.9% |

*Source: Business Intelligence BSOL ICB (Jan 2023). (TIA = transient ischaemic attack, CHD = chronic heart disease).*

### 3.1.1.3 Respiratory Disease

Nearly 1 in 5 patients with learning disabilities on GP registers have a diagnosis of asthma (19%), and 1% have COPD (Table 10).

**Table 10: Respiratory Disease Prevalence among Learning Disability Patients.**

| Respiratory Disease | Asthma | COPD |
|---|---|---|
| **Birmingham LD Patients** | 1,966 | 104 |
| **% of LD Patients** | 19% | 1% |

*Source: Business Intelligence BSOL ICB (Jan 2023).*

### 3.1.1.4 Diabetes

Nearly 1 in 10 patients with learning disabilities on GP registers have a diagnosis of diabetes (9%). (Table 11).

**Table 11: Diabetes Prevalence among Learning Disability Patients.**

| Long-Term Condition | Diabetes |
|---|---|
| **Birmingham LD Patients** | 967 |
| **% of LD Patients** | 9% |

*Source: Business Intelligence BSOL ICB (Jan 2023).*

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[118] Wang et al. (2023). Association of intellectual disability with overall and type-specific cardiovascular diseases: a population-based cohort study in Denmark. Accessed Nov 2023.

#### 3.1.1.5 Mental Health

> ***"People with learning disabilities who suffer with their mental health can need a lot of emotional support, which if not provided, can make [people with learning disabilities] more challenging to manage."***
>
> Birmingham health professional.

Rates of mental health problems are particularly high among people living with learning disabilities. Challenging behaviours (e.g., aggression, destruction and self-injury) are also common among individuals with learning disabilities. It has been estimated that in the UK, 40% of adults, and 36% of children and young people with learning disabilities experience mental health problems. When excluding problem behaviours, these figures are reduced to 28% and 24% respectively. These rates of mental health problems are significantly higher than those estimated in the general population,[119] where 1 in 6 adults (16.6%) experience symptoms of common mental health problems.[120]

Data from GP records across 56% of patients in England indicate that the prevalence of severe mental illness is 7.5% for people with learning disabilities compared to 0.9% for those without. However, depression is more comparable between learning disability and general populations (14.6% vs 13.6%, respectively).[121] People with severe mental illness often experience a poor quality of life, with negative feelings (e.g., distress, lack of control, low self-esteem and confidence, isolation, hopelessness and demoralisation) characterising the problem.[122]

Despite the high prevalence of mental health problems in people with learning disabilities, they continue to be under-recognised,[123] and subsequently remain largely untreated.[124] Diagnostic overshadowing may exacerbate the problem, leading to a lack of suitable care and prolonged distress for the person with learning disabilities.[124] The prevalence of mental health problems and challenging behaviour may be influenced by the underlying cause of the person's learning disabilities.[125] However, social and environmental risk factors (e.g., poverty, victimisation, lack of meaningful employment and social exclusion) are also influential. Exposure to these significantly increases the risk of developing mental health problems and challenging behaviour among people living with learning disabilities.

In England, 16.9% of the population aged 16+ are reported to have a common mental health disorder (2017), 12.7% of adults are reported to have depression (2021-22), and 0.95% are

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[119] NICE. (2016). Mental health problems in people with learning disabilities: prevention, assessment and management. Accessed Dec 2022.
[120] Mental Health Foundation. (2016). Fundamental Facts About Mental Health 2016. Accessed Dec 2022.
[121] NHS digital. Health and care of people with learning disabilities. Accessed Dec 2021.
[122] Connell et al. (2012). Quality of life of people with mental health problems: a synthesis of qualitative research. Accessed Dec 2021.
[123] Hassiotis and Turk. (2012). Mental Health Needs in Adolescents with Intellectual Disabilities: Cross-Sectional Survey of a Service Sample. Accessed Dec 2021.
[124] NICE Guideline. Mental health problems in people with learning disabilities: prevention, assessment and management. (2016). Accessed Dec 2021.
[125] Situ et al. (2015). Behavioural phenotypes of autism spectrum disorder patients and their parents. Accessed Dec 2021.

estimated to have a severe mental illness (all ages, 2011-22).[126] Mental health conditions are common for people with learning disabilities, and in particular the prevalence of severe mental illness is more frequently recorded for citizens with learning disabilities than the general population in Birmingham. Data received from Birmingham and Solihull ICB (2023) shows the prevalence of three mental health conditions for patients with learning disabilities who are registered with Birmingham GPs. Depression has the highest prevalence (16%) and nearly 1 in 10 patients are recorded with a severe mental health problem (9%). However, it should be noted that the data received only included three mental health conditions (as shown), and the figures may include patients who have previously had a mental health condition 'flag' coded against their records, but who no longer experience the condition (Table 12).[127]

**Table 12: Mental Health Conditions of Patients with Learning Disabilities.**

| **Condition** | **Severe Mental Health** | **Anxiety** | **Depression** |
|---|---|---|---|
| **Learning Disability Patients** | 893 | 418 | 1,642 |
| **Percentage of Patients** | 9% | 4% | 16% |

*Source: Business Intelligence BSOL ICB (Jan 2023).*[128]

There are also inequalities in medication prescriptions among citizens with learning disabilities. Citizens living with a learning disability have been shown to be more likely to have a prescription of antipsychotics (15.8%) and benzodiazepines (6.8%) than those without a learning disability (1.1% and 1.8% respectively).[129]

### 3.1.1.6 Self-harm and Suicide

Suicide risk among individuals living with learning disabilities is an under-recognised issue. Recent research evidences the strong link between learning disabilities and suicide attempts. The lifetime prevalence of suicide attempts is significantly greater in individuals with learning disabilities (11.1%) than without (2.7%).[130] However, the seriousness of suicidal behaviour does not always relate to the level of intention to die. This is of greater concern among people with learning disabilities who may be less able to link cause and effect, and may exhibit impulsive behaviours.[131,132] The high prevalence of mental health problems in this community and the social difficulties they face (e.g., bullying) contribute to the increased risk.

Unlike in the general population where men have a 3 times greater risk of suicide than women, the odds of attempting suicide are 1.7 times greater in women with learning disabilities than men with learning disabilities.[130] Research has also shown that a higher proportion of female adolescents with learning disabilities report suicidal attempts (9%) compared to their male counterparts (4%).[133] In addition to gender, exposure to chronic parental domestic violence has been shown to increase suicide risk, doubling the odds of suicide attempts. Adults with

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[126] Office for Health Improvement and Disparities. Mental Health Profile. Accessed Nov 2023.

[127] *Locally calculated by Business Intelligence BSol ICB (January 2023).*

[128] Information supplied by Business Intelligence BSOL ICB. January 2023. Accessed Jan 2023.

[129] NHS Digital. (2021). Health and Care of People with Learning Disabilities. Accessed Sep 2021.

[130] Fuller-Thomson et al. (2018). Suicide Attempts Among Individuals with Specific Learning Disorders: An Underrecognized Issue. Accessed Dec 2021.

[131] Bender et al. (1999). Stress, Depression, and Suicide among Students with Learning Disabilities: Assessing the Risk. Accessed Dec 2021.

[132] BOND Consortium. Children and young people with learning difficulties – understanding their mental health. Accessed Dec 2021.

[133] Svetaz and Blum. (2000). Adolescents with learning disabilities: risk and protective factors associated with emotional well-being: findings from the National Longitudinal Study of Adolescent Health. Accessed Dec 2021.

learning disabilities who had been sexually abused in childhood also had twice the odds of having ever attempted suicide and those with a history of major depression had seven times the risk;[130] both are well-recognised risk factors in the general population. Certain subgroups of individuals with learning disabilities may also be predisposed to higher rates of suicide. Those with nonverbal learning disabilities are more likely to suffer with depression and have an increased risk of suicide.[131] These findings emphasise the need to prioritise early detection and provide timely and effective interventions for individuals with learning disabilities to reduce suicide attempts and associated adverse outcomes.

#### 3.1.1.7 Cancer

Heslop et al. (2022) investigated cancer in adults with learning disabilities in England, whose deaths had been reported to the LeDeR programme between 2017 and 2019. During this period, there were 771 adults known to have died with cancer, who had linked data from the national cancer registry. The most frequently recorded cancer type for males was cancer of the digestive organs, whilst cancer of the breast was most frequently recorded for females. Of the 771 individuals, information about the route to diagnosis was available for 462 adults. Among these, 35% received a cancer diagnosis through an emergency referral or attendance, 27% through a non-urgent GP referral and 25% through an urgent referral. Those diagnosed through an emergency route were more likely to be male, younger, and living in their own home or the family home rather than a residential setting. 66% of cancer diagnoses were at stage 3 or 4. Overall, 19% were identified as having a type of cancer which was a preventable cause of death.[134]

LeDeR's 2022 Annual Report showed the most common causes of cancer deaths for people with a learning disability were digestive system (35.9%), respiratory and intrathoracic organs (11.1%), unspecified or secondary (9.1%), breast (7.4%), and lymphoid, haematopoietic and related tissue (7.4%).[135]

In 2022, bowel cancer accounted for 15.8% of cancer deaths among people with a learning disability, which was higher than the general population (10%) between 2017-19. Furthermore, 58% of cancer deaths in the general population aged 75+ were from bowel cancer, which was a similar proportion to people with a learning disability aged 60+. This data supports the need for lowering the age of screening for bowel cancer for people living with learning disabilities. Screening for bowel cancer is offered to every person aged 60+ years and the screening age is lowering to 50+ years by 2025.[136]

Data provided by Birmingham and Solihull ICB in January 2023 showed that 228 patients with learning disabilities registered with a Birmingham GP also had cancer. This represented 2% of total learning disability citizens in Birmingham at that time.[137] For further information on cancer and cancer screenings, please see section 4.4.

### 3.1.2 Over Medication

STOMP (*stopping the over medication of people with a learning disability, autism, or both, with psychotropic medicines)* is a multi-organisation national project. Psychotropic medicines

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[134] Heslop et al. (2022). Cancer in deceased adults with intellectual disabilities: English population-based study using linked data from three sources. Accessed Jan 2023.
[135] King's College London. (2023). LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People. Accessed Dec 2023.
[136] King's College London. (2023). LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People. Accessed Dec 2023
[137] Information supplied by Business Intelligence BSOL ICB January 2023. Accessed Jan 2023.

include medicines which treat depression, psychosis, anxiety, sleep problems and epilepsy. These are also sometimes prescribed to individuals who display ‘challenging behaviour’, and people with a learning disability are among those more likely to be given these medicines than the general population. These medicines can help individuals stay well and safe. However, in 2015, *Public Health England* produced a report showing the widespread prescribing of psychotropic medicines (antipsychotics, antidepressants and hypnotics) in absence of a relevant diagnosis recorded for people with a learning disability, estimating this to be affecting between 30,000 and 35,000 adults with a learning disability in England.[138] For example, someone may be prescribed antidepressants in absence of a diagnosis of depression. These medicines can cause problems such as weight gain, feeling tired, and physical health problems when taken for too long, at a dose that is too high, or for the wrong reason.[139]

Figure 10 shows a comparison of those treated with antipsychotics, those treated with benzodiazepines, those without an active depression diagnosis who were treated with antidepressants, and those without an active epilepsy diagnosis who were treated with epilepsy drugs. A significantly higher percentage of those with a learning disability were being treated with these medications, compared to those in the general practice population. Among citizens with a learning disability, the prescription of antipsychotics (15.8%) and benzodiazepines (6.8%) were significantly higher than the general population (1.1% and 1.8% respectively). Among citizens with a learning disability who did not have a diagnosis of depression, 9.6% were prescribed antidepressants, compared to 4% of the general population (who did not have a diagnosis of depression). Among citizens with a learning disability who did not have a diagnosis of epilepsy, 5.6% were prescribed epilepsy drugs compared to 2.3% of the general population who did not have epilepsy.

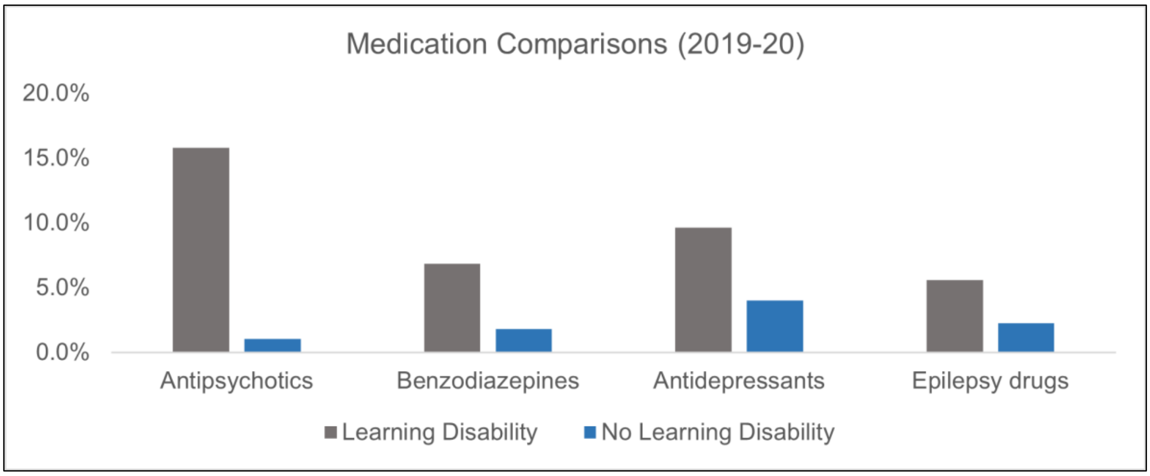

**Figure 10: Medication Comparisons in Birmingham: Antipsychotics, Benzodiazepines, Antidepressants (in Absence of a Diagnosis of Depression) and Epilepsy Drugs (in Absence of a Diagnosis of Epilepsy).**

*Source: Health and Care of People with Learning Disabilities (2019-20).*[140]

Birmingham Community Healthcare Foundation Trust have developed Multicultural STOMP, which is the first initiative of its kind in the UK, supporting the availability of the national STOMP

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[138] Public Health England. (2015). Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England. Accessed Jan 2022.

[139] NHS. Stopping Over Medication of People with a Learning Disability, Autism or Both). Accessed Dec 2021.

[140] NHS Digital. (2021). Health and Care of People with Learning Disabilities. Accessed Sep 2021.

programme to individuals from an ethnic minority background.[141] The website contains leaflets about STOMP and STAMP and leaflets are translated into eight community languages; Punjabi, Romanian, Urdu, Somali, Bengali, Gujarati, Hindi and Polish. These aim to raise awareness for all communities around Birmingham.[142]

### 3.1.3 Ambulatory Care Conditions

Ambulatory Care Sensitive Conditions are conditions which can be effectively managed through primary care and should not result in a hospital admission. Research into hospital admissions of people with learning disabilities found that across a four-year period, emergency hospital admissions for ambulatory care conditions were estimated to be five times more common among people with learning disabilities (and associated conditions) than the general population. Furthermore, people living with learning disabilities were 25% more likely to be admitted as an emergency admission and 70% more likely to be admitted as an emergency admission with an ambulatory care sensitive condition. 'Convulsions and epilepsy' were the most frequent cause of emergency admissions for ambulatory care sensitive conditions among people with learning disabilities, accounting for 40%. Some ambulatory care sensitive conditions are more common among people with learning disabilities (e.g., epilepsy), and others may carry particular difficulties with their management (e.g., diabetes). However, the data points to weaknesses in primary care for people with learning disabilities. This research suggested that local areas should review admissions in their areas to assess the extent to which this is a problem for their citizens with learning disabilities. They also suggest that where an emergency admission occurs, GPs and community learning disability services should be notified, and this should prompt a review of the person's Health Action Plan.[143]

### 3.1.4 Long-term Impact of the COVID-19 Pandemic

> ***"[COVID-19] affected service users in lots of different ways."***
>
> Birmingham health professional.

It is well established that people living with learning disabilities face significant health inequalities. The COVID-19 pandemic has widened the inequalities gap, causing many to be further marginalised, isolated from their communities, and facing greater barriers in accessing healthcare services. People with learning disabilities were noted to be vulnerable to COVID-19, due to high rates of death from respiratory infections compared to the general population, and higher rates of COVID-19 risk factor (e.g., diabetes and obesity).[144]

In February 2022, Mencap conducted a survey of 580 family members and carers of people with a learning disability, to explore the long-term impact of the COVID-19 pandemic on social

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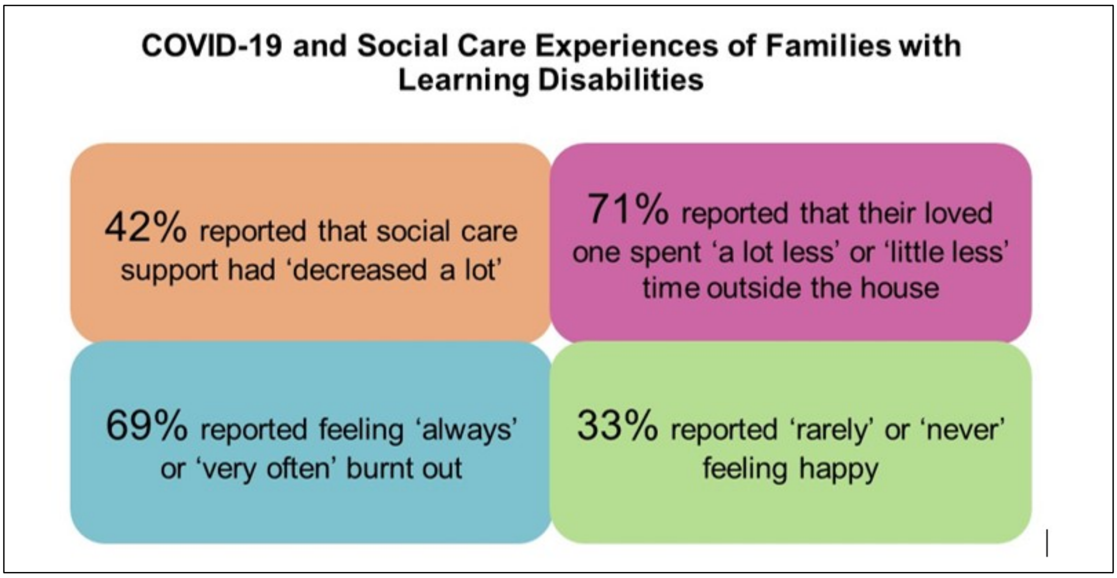
[141] Birmingham Community Healthcare Foundation Trust. Multicultural STOMP (MC-STOMP). Accessed Nov 2022.
[142] Birmingham Community Healthcare Foundation Trust. Useful Resources. Accessed Nov 2022.
[143] Glover and Evison. (2013). Hospital Admissions That Should Not Happen. Accessed Feb 2022.
[144] Public Health England. Deaths of people identified as having learning disabilities with COVID-19 in England in the spring of 2020. Accessed Dec 2021.

care and experiences of families with learning disabilities.[145] Figure 11 highlights some of the key findings from this survey.



**COVID-19 and Social Care Experiences of Families with Learning Disabilities**

42% reported that social care support had 'decreased a lot'

71% reported that their loved one spent 'a lot less' or 'little less' time outside the house

69% reported feeling 'always' or 'very often' burnt out

33% reported 'rarely' or 'never' feeling happy

**Figure 11: Responses to Survey on COVID-19 Pandemic and Social Care Experiences of Families with Learning Disabilities.**

*Source: Mencap Left Behind and Locked Down (2022).*

## 3.2 Wider Determinants of Health

> ***"I think the key factors people with learning disabilities face are public ignorance and public lack of education and understanding."***
>
> Birmingham health professional.

Citizens living with a learning disability are significantly affected by inequalities in wider determinants of health. This includes being more likely to live in poverty and deprivation, social isolation, prejudice, difficulties accessing transport, education and employment opportunities, and inequalities associated with accommodation, the criminal justice system and accessing healthcare. The following section outlines the inequalities in the wider determinants of health and their impact on people living with learning disabilities. This section often relies on national data. However, local data has been included, where available.

### 3.2.1 Poverty and Social Isolation

Research from the UK looked at exposure to income poverty over time for households with and without disabled children. This showed that 59% of children living with learning disabilities

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[145] Mencap. (2022). Let Behind and Locked Down – New Figures from Mencap Highlight how Social Care has been 'Ravaged by the Pandemic'. Accessed Jul 2022.

were exposed to income poverty at multiple time points, compared with 47% of children in the general population.[146]

Social isolation is a common feeling amongst people with learning disabilities. A survey by Home Farm Trust with over 1,000 people with a learning disability highlighted the impact of social isolation. 36% of people reported feeling lonely nearly always, or all of the time; 37% reported hardly ever or never going out to socialise; and 56% reported that they felt lonelier, due to having less care and support during the pandemic.[147]

### 3.2.2 Prejudice

In 2018*,* Scope carried out research into the prejudice that disabled people face in their lives and to understand the public's attitude towards disability. Results showed that more disabled people felt there was 'a lot' of prejudice towards those with disabilities, compared to non-disabled people. Reasons put forward for this gap included non-disabled people being potentially unaware of prejudice faced by people with disabilities, or their own unconscious prejudicial attitudes towards disabled people.[148]

### 3.2.3 Physical Activity

Low physical activity is the 4th highest behavioural cause of disease and disability in England.[149] Engaging in physical activity is a protective factor for health with benefits to both mental and physical health and wellbeing.[150,151] Recent evidence has shown that adults and adolescents with learning disabilities are less physically active than those without. Only 9% of adults with a learning disability achieve the minimum recommended levels of physical activity, whilst sport and exercise participation rates are consistently lower for adolescents and young people with mild to moderate learning disability, compared to their peers without learning disabilities.[152,153]

### 3.2.4 Transport

> ***"The key inequality I see is accessibility via transport."***
>
> Birmingham health professional.

The *National Disability Strategy* (2021) recognises that everyday journeys are still not accessible for many people with disabilities, especially spontaneous journeys. This strategy

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[146] Public Health England. (2015). The determinants of health inequities experienced by children with learning disabilities. Accessed Dec 2022.

[147] Hft. Lockdown on Loneliness. Accessed Dec 2022.

[148] Scope. (2018). The Disability Perception Gap. Policy Report. Accessed Dec 2021.

[149] Steel et al. (2018). Changes in health in the countries of the UK and 150 English Local Authority areas 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. Accessed Dec 2021.

[150] Warburton and Bredin. (2017). Health benefits of physical activity. A systematic Review of Current Systematic Reviews. Accessed Dec 2021.

[151] Lukács et al. (2018). Physical activity and physical fitness as protective factors of adolescent health. Accessed Dec 2021.

[152] Robertson et al. (2018). Self-reported participation in sport/exercise among adolescents and young adults with and without mild to moderate intellectual disability. Accessed Dec 2021.

[153] Dairo et al. (2016). Physical activity levels in adults with intellectual disabilities: A systematic review. Accessed Dec 2021.

set out steps to improve this through tackling persistent accessibility issues across all forms of transport and improving staff training and the attitudes and behaviours of others, with the view to increasing passenger confidence.[154]

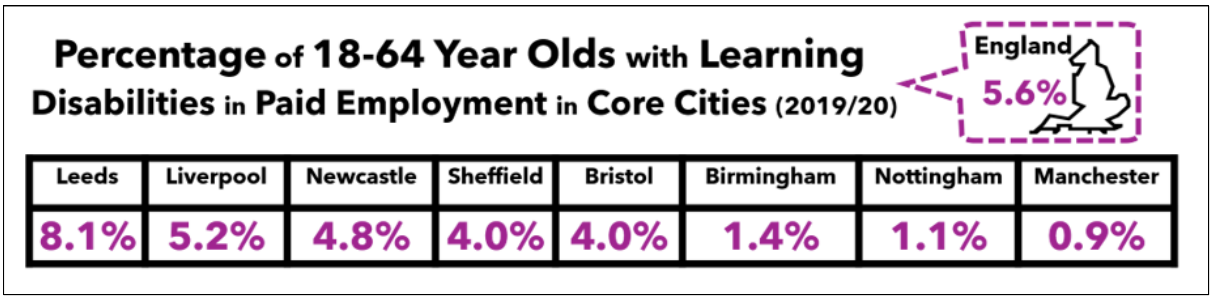
### 3.2.5 Education

Nationally, students with special educational needs (SEN) including learning disabilities, experience significant inequalities during their education:

- In 2018-19, 25% of students with SEN received a good level of development in early years, compared to 77% without.
- At Key Stage 2, 22% of pupils with SEN achieved the expected levels in reading, writing and mathematics, compared to 74% without SEN. For students with SEN who were looked after, this percentage was 17%.
- In 2019-20, the average attainment 8 score was 36.4 for students with SEN, 15.2 for students with an EHCP, and 53.7 for students with no SEN. For students with SEN who were looked after, this average score was 14.8.[155]

### 3.2.6 Employment

Local authorities in the UK report low levels of employment among individuals of working age with learning disabilities. In 2019-20, England's national employment rate for 18–64-year-olds with learning disabilities (who were supported by social care and in paid employment) was 5.6%. This was higher than all the Core Cities, with the exception of Leeds (8.1%). Birmingham had the third lowest employment rate, at 1.4%, which was only higher than Nottingham (1.1%) and Manchester (0.9%) (Figure 12).[156]



**Percentage of 18-64 Year Olds with Learning Disabilities in Paid Employment in Core Cities (2019/20)**

England 5.6%

| Leeds | Liverpool | Newcastle | Sheffield | Bristol | Birmingham | Nottingham | Manchester |
|---|---|---|---|---|---|---|---|
| 8.1% | 5.2% | 4.8% | 4.0% | 4.0% | 1.4% | 1.1% | 0.9% |

**Figure 12: Number of People with a Learning Disability of Working Age and Supported by Social Care in Paid Employment (2019-20).**

*Source: Learning Disabilities Profiles.*

Published in 2019, Cheetham et al. carried out research in the Northeast of England to understand the impact of Universal Credit on claimants and staff. This research involved interviews and focus groups with 33 Universal Credit claimants with complex needs, disabilities and health conditions, and 37 staff who were supporting these claimants. The claim process was described by claimants as 'complicated, difficult, demeaning, impersonal and punitive'. The digital-only nature of the system was difficult to navigate, and it was difficult to seek support from a member of staff, with long helpline wait times reported. Many claimants

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[154] HM Government. National Disability Strategy. Accessed Dec 2021.

[155] Department for Education. (2021). Special educational needs and disability: an analysis and summary of data sources. Accessed Jan 2022.

[156] Public Health England. Proportion of Supported Working Age Adults with Learning Disability in Paid Employment. Accessed Aug 2021.

had poor digital literacy and lack of digital access, leading to stress when trying to complete a claim. System errors resulted in payment delays, and these were not quick to be fixed.

Staff noted the negative impact of Universal Credit on claimants. They also reported a negative impact on their stress and workload as they required spending a significant amount of time supporting vulnerable claimants with their claims. Staff felt the system would not support the needs of those with complex needs, with one staff member saying *"… if you wanted to devise a system that discriminated against people with learning disabilities, this would be it … it absolutely particularly discriminates against people with mental health problems and people with learning disabilities*."[157]

In 2017-18, the majority of those in work (68.3%) were working less than 16 hours per week.[158] *Mencap* undertook a survey with 1,625 people with learning disabilities about their experiences working and seeking employment. This survey found that 62% of working age adults with learning disabilities 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%).[159]

> ***"I can fill in forms to a certain extent, but as soon as they get too wordy, I really struggle. It's affected my confidence with applying for jobs."***
>
> Birmingham citizen living with learning disabilities.

In Accordance with the Equality Act, employers must make reasonable adjustments to make sure workers with disabilities are not disadvantaged when doing their jobs. Reasonable adjustments include changing the recruitment process, making physical changes in the workplace, changing equipment or where someone works, and offering training opportunities.[160]

### 3.2.7 Housing

People with learning disabilities known to local authorities live in the following types of accommodation: living with family and friends (38%), a registered care home (22%), supported accommodation (16%), local authority accommodation or housing association (12%), living in privately rented accommodation (3%), and other (9%) (Figure 13).

The Housing Report by Mencap*,* highlighted that 86% of parents and carers would like those who they support with learning disabilities to live independent lives. Unfortunately, lack of places, funding and accessing of appropriate reviews mean that many remain with their

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[157] Cheetham et al. (2019). Impact of Universal Credit in Northeast England: a qualitative study of claimants and support staff. Accessed Nov 2022.

[158] Public Health England. (2020). Chapter 2: paid employment. Accessed Dec 2021.

[159] Mencap. Inaccessible application forms are a barrier for nearly a third of people with a learning disability who want to work, according to a new survey from Mencap. Accessed Oct 2022.

[160] Gov.UK. Reasonable adjustments for workers with disabilities or health conditions. Accessed Jan 2022.

parents. This takes away their independence, causes them to be reliant on others, reduces their confidence to live independently and adds stress to their carers.[161]

Poor housing is a key driver of health inequalities and influences health throughout the life course. Research has shown that inadequate housing conditions are linked to poor physical and mental health.[162]

The Learning Disability and Autism Housing Network[163] (a coalition of twelve housing associations) launched its Charter at the 2021 National Housing Federation's National Housing Summit. The Learning Disability and Autism Housing Network calls for action to address the barriers for new, sustainable quality housing for people with learning disabilities and/or autism. The rationale is that overwhelming evidence shows that strategically planned sustainable quality supported housing for people with learning disabilities and/or autism provides long-term positive benefits for them and delivers value for money for social care and health commissioners.

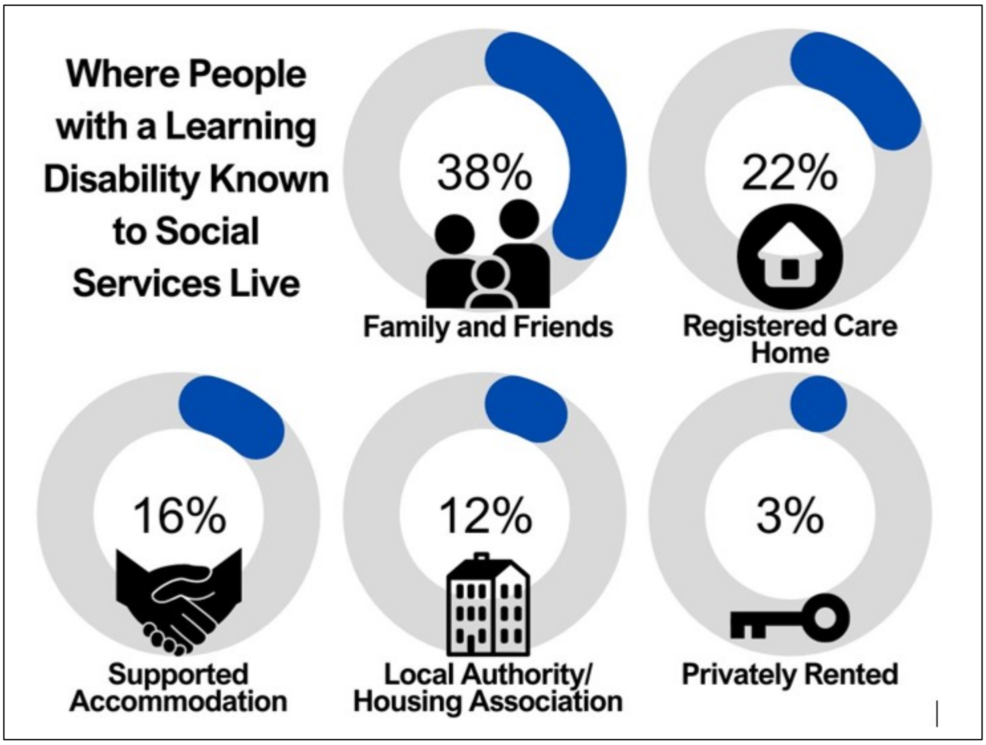

**Figure 13: Where People with a Learning Disability Known to Social Services Live.**

*Source: Mencap Housing Report v7.*

Citizens living with disabilities may encounter additional challenges (e.g., unemployment or financial difficulty) which may increase the risk of experiencing homelessness. People with disabilities may also face barriers which make it difficult to remove themselves from a situation of homelessness, such as difficulty finding suitable housing and difficulty accessing a diagnosis. In England and Wales, local authorities should provide housing to people at risk of homelessness with a priority need. This can include vulnerable people, due to a disability which needs to be evidenced by applicants.[164]

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[161] Mencap. Housing for People with a Learning Disability. Accessed Dec 2021.
[162] Bonnefoy. (2007). Inadequate housing and health. Accessed Jan 2022.
[163] Advance. Learning Disability and Autism Housing Network Launch Charter. Accessed Jan 2022.
[164] Stone and Wertans. (2023). Homelessness and disability in the UK. Accessed May 2024.

Between October and December 2023 in England, households assessed as being at risk of homelessness are owed a prevention duty while those assessed as homeless are owed a relief duty. Among households owed a homelessness duty, the most common support need were mental health problems (26.2%) followed by physical ill-health and disability (19.2%).[165]

In Wales, data collected by local authorities in 2018-19 recorded the reasons that households qualified for priority need. 11% of households had physical disability, and 21% had a mental illness or learning disability/difficulty. In England, there has been an increase in the households with a support need category of 'learning disabilities' who are owed a homeless duty. In 2018-19, this was 11,030 households (4%) and in 2021-22 this rose to 15,060 households (5%). This is higher than the prevalence in the general population, suggesting there may be an increased risk for citizens with learning disabilities.[166]

### 3.2.8 Living Well in the Local Area

There is a 'liveable neighbourhoods' pilot in Birmingham's Bordesley Green area which aims to strengthen local economies and provide walkable environments for people to live and work in. These include green spaces, schools and appropriate housing. Perceived benefits of this pilot will include reduced traffic and pollution, improved physical and mental health, improved accessibility to healthcare, and a stronger sense of community.

**Leeds City Council's Whole System Approach**

Since 2012, Leeds City Council have been developing a collaborative whole system approach to reduce inequalities that citizens with learning disabilities endure, and to improve care and support. These include examples of good practice, which are summarised below.

Leeds Learning Disability Partnership Board's ***Being Me Strategy (2018-21)*** outlines three areas for priority: being well, being safe, and being connected (including social, travel and employment). This strategy outlines key achievements, including Independent Travel Training where 41 adults with learning disabilities were trained to travel independently between 2016 and 2017.[167]

***Through the Maze*** is an Easy Read website providing information about services in Leeds for citizens with learning disabilities, their family carers and professionals. It is a comprehensive resource for citizens to access, presented in an Easy Read format.[168]

***Being Employed*** is an Easy Read website, collating paid and voluntary work opportunities for citizens with learning disabilities.[169]

***Forum Central*** is the collective voice of Leeds' third sector providing a network of learning disability organisations. Membership includes over a hundred third sector organisations, who work to improve services and opportunities for people with learning disabilities. The work is focused on the 'Being Me' Strategy and is divided into themed task groups. Forum Central lead on the Employment Task Group, which takes a city-wide partnership approach, including experts by experience, third sector representatives (e.g., Lighthouse

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[165] Department for Levelling Up, Housing and Communities. (2024). Statutory homelessness in England: October to December 2023. Accessed May 2024.

[166] Stone and Wertans. (2023). Homelessness and disability in the UK. Accessed May 2024.

[167] Leeds Learning Disability Partnership Board Strategy. Being Me. Accessed October 2022.

[168] Through the Maze. Accessed Oct 2022.

[169] Being Employed Leeds. Accessed Nov 2022.

Forward Trust) and employers. This group co-ordinate activities across the city to engage more citizens with learning disabilities into employment.[170]

### 3.2.9 Adverse Weather

People living with learning disabilities are vulnerable to the impact of both hot and cold adverse weather.[171] Illness and mortality due to cold weather exposure can occur directly (e.g., through hypothermia), or through illnesses caused by the cold weather, such as chest infections or falls.[172]

LeDeR's Annual Report (2022) highlighted that deaths among people with learning disabilities can also increase during hot weather. England experienced a heatwave during July 2022 which led to a 67% excess in deaths among people with learning disabilities (who had been reported to LeDeR), compared to 10% in the general population. The LeDeR report subsequently advised ensuring that care plans for people with a learning disability include mitigations and advice for dealing with hot and cold weather. For example, plans should include ensuring adequate hydration, adequate access to temperature controls (such as air conditioning or fans), and during the colder winter months, how to enable access to adequate heating and insulation. The report also recommended that the advice should be conveyed to patients in accessible ways.[173] In 2014, Public Health England created an Easy Read version of the Heatwave Plan for England, which includes advice on how to stay cool in the heat.[174]

The Adverse Weather and Health Plan aims to reduce deaths and morbidity from adverse weather.[175] Weather warnings occur in England when there is a possibility that the weather impacts on health and wellbeing.[176] The Weather-Health Alerting System is delivered by the UK Health Security Agency and the Met Office and provides the health and social care sector and the voluntary and community sector with both Cold-Health and Heat-Health Alerts. These are delivered via email to anyone who has registered to receive them. However, people with learning disabilities are not currently included in the guidance's list of vulnerable demographics.[177]

### 3.2.10 Long-Term Inpatients

In October 2021, there were 3,490 people with learning disabilities and/or autistic spectrum disorders (LDA) in hospital within England, representing those with 'a bed' designated for mental illness treatment or care, who have been diagnosed or are understood to have a learning disability and/or autistic spectrum disorder.[178] In this sample, a third of inpatients (32%) with a planned discharge date experienced an overdue discharge, with common

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[170] Forum Central. About the Learning Disability Network. Accessed Oct 2022.
[171] King's College London. (2022). LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People. Accessed Dec 2023
[172] UK Health Security Agency. (2023). Cold-Health Alert action card for health and social care providers. Accessed Dec 2023.
[173] King's College London. (2022). LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People. Accessed Dec 2023
[174] Public Health England. (2014). Heatwave Plan for England. Accessed Dec 2023.
[175] UK Health Security Agency. (2023). Adverse Weather and Health Plan. Accessed Dec 2023.
[176] UK Health Security Agency. (2023). Supporting vulnerable people before and during hot weather: social care managers, staff, and carers. Accessed Dec 2023.
[177] UK Health Security Agency. (2023). Weather-Health Alerting System. Accessed Dec 2023.
[178] NHS Digital. (2021). Learning Disability Services Monthly Statistics, AT: October 2021, MHSDS: August 2021 Final. Accessed Nov 2021.

reasons including awaiting care home placements or support accommodation availability. Over half of the 3,490 inpatients had been admitted for over a year.[179]

The *NHS Long Term Plan* sets out the target that by 2023-24, inpatient provision will have been halved (compared to 2015) and that there will be no more than 30 adults with a learning disability and/or autism per million in an inpatient unit. For children and young people, this target is 12 to 15 per million.[180]

### 3.2.11 Domestic Abuse

Domestic abuse is relatively well understood in the general population. However, domestic abuse against people with learning disabilities is less so. Forms of domestic abuse vary and can include physical, sexual, psychological, emotional, and financial harm. Approximately 20% of people with a disability related to learning, understanding or concentrating report experiencing domestic abuse in the last year, compared to approximately 5% of non-disabled people.[181] It has also been reported that people with learning difficulties may experience more intensive coercive control from perpetrators.[182]

Information on domestic abuse services is not always accessible or understandable for people with learning disabilities. Research conducted at the *Tizard Centre* at the *University of Kent* has shown that 2 in 3 women with mild learning disabilities who had experienced domestic violence had poor knowledge of available services. Of the women who had reported domestic violence, the majority felt unsupported and experienced problems in seeking help, especially those who had children.[183]

As of 2015, only 13% of refuges could provide temporary personal care assistants.[184] Furthermore, Beverley Lewis House in London, run by the L&Q housing group, is the only specialist refuge in the UK for women with learning disabilities and/or autism.[185] Due to a lack of understanding around women's specialist support needs, and the lack of awareness about these tailored schemes, victims often end up in psychiatric facilities, hotels or back with their abusers.[186] The manager of Beverley Lewis House said: "*There are lots of special services for domestic abuse and lots for people with learning difficulties, but there is a big deficit in that those who work with people with learning difficulties don't always understand the needs of domestic abuse victims and vice versa. There's definitely a massive gap and we're the only service bridging that gap*".

### 3.2.12 Substance Misuse

Recent data received from the drug and alcohol treatment provider in Birmingham, Change Grow Live (CGL), show that there are currently 47 clients with learning disabilities of varying ages utilising treatment services. CGL commented that there may be other clients with learning disabilities, but that this demographic is not always recorded.[187]

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[179] NHS Digital. (2022). Learning Disability Services Monthly Statistics, AT: December 2021, MHSDS: October 2021 Final. Accessed Feb 2022.
[180] NHS. (2019). NHS Long Term Plan. Learning Disability and Autism. Accessed Feb 2022.
[181] ONS. (2022). Disability and Crime. Accessed Nov 2023.
[182] Safe Lives. (2017). Disabled Survivors Too: Disabled people and domestic abuse. Accessed Nov 2023.
[183] McCarthy et al. (2016). 'I Know it was Every Week, but I Can't be Sure if it was Every Day: Domestic Violence and Women with Learning Disabilities. Accessed Jan 2022.
[184] Public Health England. (2015). Disability and Domestic Abuse. Accessed Oct 2022.
[185] Youde. (2018). Inside the only refuge specifically for women with learning disabilities. Accessed Sep 2021.
[186] L&Q Housing. (2020). The UK's only refuge for women with learning disabilities and the people who live and work there. Accessed Sep 2021.
[187] Information supplied directly by Change Grow Live. (2021).

There are many barriers to treatment for people with learning disabilities. One identified issue is that staff in substance misuse services are not equipped for working with people with learning disabilities. Similarly, staff in learning disability services are not equipped with the knowledge to assess and treat people with substance misuse problems. There is a lack of integration between these services, meaning that people with learning disabilities may fall through gaps in provision.[188]

### 3.2.13 Criminal Justice System

The Office for National Statistics (ONS) published data on disability and crime in 2019, which showed that disabled adults (23.1%) were more likely to have experienced crime than non-disabled adults (20.7%). Approximately 20% of people with a disability related to learning, understanding or concentrating, reported experiencing domestic abuse in the last year, compared to approximately 5% of non-disabled people.[189] Children with disabilities were more likely to have experienced being the victim of crime (21%), compared with non-disabled children (10%).[190]

People with learning disabilities may be more vulnerable to mate crime because many can find it challenging to make friends and a desire for friends can be exploited. While a disability hate crime may be motivated by prejudice against a victim's disability, a mate crime begins with a counterfeit friendship and can involve more subtle forms of criminality. When coupled with increased independent living and reduced support from services, this can leave people vulnerable and isolated. Mate crime may be considered an 'invisible crime' as it can appear consensual and occur in private, making it harder to detect.[191]

An evidence review of neurodiversity in the criminal justice system estimated that around half of those entering prison could be living with some form of neurodiversity. However, there is a lack of reliable data and variance in approaches to screening. A survey of police, prison and probation staff revealed low levels of awareness and understanding of neurodiversity, which points to a need for further staff training. It was also recognised that there is a need to grow provision of offending behaviour programmes tailored for these offenders, because current provision is not available in every area and can be subject to long waiting lists.[192]

Prison healthcare services are expected to have learning disability care pathways which allow for screening, assessment and referrals and should work with other prison services to support these individuals. It is recommended that prison health care services appoint a learning disability and autism healthcare champion, and that prisons employ a learning disability nurse or practitioner. Duties of a champion include helping to make healthcare services accessible for people with a learning disability including the use of accessible communication, keeping a register of people with a learning disability and promoting adapted offending behaviour programmes to offender managers.[193]

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[188] Public Health England. (2017). Substance misuse and people with learning disabilities: making reasonable adjustments to services. Accessed Dec 2022.

[189] ONS. (2022). Disability and Crime. Accessed Nov 2023.

[190] ONS. (2019). Disability and Crime, UK: 2019. Accessed Mar 2022.

[191] Landman. "A counterfeit friendship": mate crime and people with learning disabilities. Accessed Mar 2022.

[192] Criminal Justice Joint Inspection. (2021). Neurodiversity in the Criminal Justice System. A review of evidence. Accessed Dec 2021.

[193] NHS. (2021). Meeting the healthcare needs of adults with a learning disability and autistic adults in prison. Accessed Mar 2022.

## 3.3 Groups with Specific Needs

While this report has covered the health and wellbeing needs of people living with learning disabilities, it is recognised that different subgroups will experience unique needs and challenges that require consideration.

### 3.3.1 Transition

Citizens living with learning disabilities experience transition in many different forms and may experience difficulties associated with this and require additional support. The transition from primary to secondary school has been acknowledged as a stressful experience for many children. For children with SEN, there is an increased risk of poor adjustment due to additional challenges faced. Children with SEN may also have lower self-esteem or lack social skills which lead to differences in how emotion is expressed. These differences can be negatively perceived by peers, impacting on relationships.[194]

> ***"There's no transition from childhood to adulthood. As soon as my child became an adult, she was made invisible."***
>
> Birmingham parent.

Transitioning between child and adult services can be challenging for young people with a learning disability and their families. Children with a health, education and social care plan will receive support up to the age of 25 years.[195] This may be a time when young people experience a change in professionals and services, as well as considering future options with regards to education, training or employment. These changes should be planned in advance and should not leave any gaps in provision, with children's services continuing until adult services are able to take over, where eligible.[196]

### 3.3.2 Parents and Carers of Children and Adults with Learning Disabilities

> ***"Further education beyond the age of 25 - More awareness from the council that a lot of people with a learning disability maintain a really young mental age throughout their lives and need consistent education to ensure their minds are still active."***
>
> Birmingham parent.

Learning disabilities can be diagnosed either during pregnancy or during the first formative

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[194] Hughes et al. (2013). Secondary school transition for children with special educational needs: a literature review. Accessed Nov 2022.

[195] NHS. Getting Support: Learning Disabilities. Accessed Nov 2022.

[196] Mencap. Transition into adulthood. Accessed Feb 2022.

years of a child's life,[197] and most parents will be affected by this both emotionally and physically for the remainder of their lives. It is important to recognise the true impact that this places on a parent's life and its implications. Surveys by Bath and Chester universities into parental experiences have highlighted the challenges of dealing with a lack of social care continuity for both the child and the parent. Both the parents and the child with the disability feel that providing continuity in social care would reduce stress and trauma. From a financial aspect, these reports also highlighted confusion over how care budgets can be used.[198]

> ***"I feel the inequalities my child faces would be far worse if his parents weren't around to fight for him."***
>
> Birmingham parent.

> ***"Would need to know daughter is safe, know someone is fighting her corner, know she's being listened to, and knowing she'll always have somewhere to call home."***
>
> Birmingham parent.

A study of 21 older carers of adults with learning disabilities and/or autism in England noted their difficulty with the continuing responsibilities and duties to care while in their 70s and 80s, with little respite available. Whilst recognising the pressures on the health and social care system, these carers reported challenges with social service provision, including lack of continuity of social worker input, negative attitudes towards carers and variable levels of expertise of professionals. These carers lived in fear for the future, due to doubt over who would take over the care of their loved one, when they would no longer be able to do this themselves.[199]

### 3.3.3 Maternity Care for Citizens with Learning Disabilities

> ***"My experiences of maternity were terrible with the first child. I was only 17, and with my disability to add, they treated me like a child. They expected me to listen, and do things, and they didn't want to help. They wouldn't answer any of my questions."***
>
> Birmingham citizen living with learning disabilities.

A UK maternity study looking at the experiences of women with disabilities included survey results from 120 women living with learning disabilities. Women with learning disabilities were less likely to have partners at the time of the survey, compared with non-disabled women (68%

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[197] Public Health England. NCARDRS Congenital anomaly statistics report 2018. Accessed Jan 2022.

[198] Gant and Bates. (2019). 'Cautiously optimistic': Older parent-carers of adults with intellectual disabilities – Responses to the Care Act 2014. Accessed Jan 2022.

[199] Forrester-Jones. (2019). People with learning disabilities and/or autism and their carers getting older. Accessed Feb 2022.

vs 87%). While most women in this study were of similar ages, women with learning disabilities were more likely to be under 20 years (7% vs 2%). Other findings of this study included:

- Women with a learning disability were less likely to see a health professional by 12 weeks gestation (85% vs 95%).
- Fewer women with learning disabilities were always spoken to in a way they could understand (66% vs 84%).
- Fewer women with learning disabilities were involved in care decisions (63% vs 74%).
- Fewer women with learning disabilities were always given support after making contact with a midwife (58% vs 73%).

Despite having negative views about their antenatal care, these women with learning disabilities rated their antenatal care as good or better (93%). Postnatally, fewer women with a learning disability initiated or continued breastfeeding.[200]

In 2017, a maternity care pathway for women with learning disabilities was set up in Leeds, to specifically support women with a learning disability, difficulty, hidden disability or autism. The pathway works to support these women to engage with additional services, to support early identification of their disabilities, difficulties and conditions, and places an emphasis on reasonable adjustments, prevention and early support.[201]

In South Birmingham, CASBA Advocacy run a Pregnancy to Parenthood programme, supporting women with learning disabilities who are pregnant or new mothers. Support is offered through attendance at appointments, help filling out forms and understanding information, signposting to relevant services, supporting parents to prepare for their baby's arrival, and linking parents to other citizens with learning disabilities who are parents.[202]

### 3.3.4 Parents with Learning Disabilities

Approximately 7% of adults in the UK living with a learning disability are parents. Many of these individuals have mild to borderline impairments, which may mean that they are not always identified.[203] Evidence from national research has suggested that parents with learning disabilities are over-represented in child welfare cases.[204] In 2021-22, there were 14,185 assessments undertaken by social workers at Birmingham Children's Trust to determine whether a child was in need of support services, protection or care. 608 were recorded with a risk factor of learning disability (child) (4.3%), 202 of learning disability (parent) (1.4%) and 152 of learning disability (person, referring to anyone in the household who is not the parent or child with learning disabilities e.g., a sibling) (1.1%).[205]

Parents with learning disabilities often face difficult circumstances (e.g., poverty, social isolation and mental health difficulties), which may impact on parenting ability. Social support has been shown to improve effective parenting. When parents with learning disabilities enter the child protection system, there is evidence that parents can endure multiple disadvantages, such as difficulty instructing a solicitor, problems understanding the processes and being

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[200] Redshaw et al. (2013). Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. Accessed Jan 2022.

[201] Leeds Maternity Care Pathway for Women with Learning Disabilities. (2016). Accessed Sep 2022.

[202] CASBA Advocacy. Pregnancy to Parenthood. Accessed Dec 2023.

[203]. CHANGE and PEN. Hidden Voices of Maternity. Accessed Dec 2021.

[204] Booth et al. (2005). The prevalence and outcomes of care proceedings involving parents with learning difficulties in the family courts. Accessed Jan 2022.

[205] Birmingham City Council. Children and Young People JSNA (2024).

judged more stringently than other parents. Advocates may be an important source of support and help for parents throughout this process.[206]

### 3.3.5 Citizens from a Minority Ethnic Background

Born in Bradford is a longitudinal birth research cohort study involving 12,400 families who were enrolled during pregnancy between 2007-11. The research aims to explore the impact of health inequalities through data collection and access to health records.[207] One facet of this research has been the impact of consanguineous marriages (marriages between blood relatives) on genetic conditions in children. These marriages are common in some areas of the world (e.g., Pakistan, the Middle East),[208], and their impact in the UK has grown due to migration. The risk of congenital anomalies, leading to childhood disability, (sometimes called birth defects), is doubled among children born to parents who are in consanguineous marriages (6%). This is because when people from a small gene pool who are more likely to carry certain disease-linked genes have children, this in turn increases the risk of those genetic conditions among their children. Among white British mothers, the risk of having a child with congenital anomalies is elevated when they are aged 34 and above.[209]

Congenital anomalies are a leading cause of death and disability among infants in the UK. An analysis of the Born in Bradford cohort data has shown that children from Pakistani backgrounds have the highest rates of infant deaths and that congenital anomalies are the most common cause of death among children under 12 years from a Pakistani background. Consanguineous marriages were associated with a doubled risk of congenital anomaly and a third of anomalies in children from Pakistani backgrounds was attributed to consanguinity. The Born in Bradford research also showed that having an education to degree level was a protective factor, associated with a reduced risk by half of having a baby with congenital anomalies, for mothers from both white and Pakistani backgrounds.[210] Data collected from the Born in Bradford study between 2007-11 and again from 2016-20 showed a reduction in consanguineous marriages from 60% to 43% among British Pakistani couples.[211]

Table 13 provides data on individuals with learning disabilities who died between 2018-20 and whose deaths were notified to the LeDeR Programme, by age group and ethnic group.[212]

**Table 13: Deaths Notified to the LeDeR Programme 2018-20, by Ethnicity and Age.**

| Ethnicity | 4-17 years | 18-24 years | 25-49 years | 50-64 years | 65+ years |
|---|---|---|---|---|---|
| White British | 4% | 3% | 15% | 36% | 42% |
| Asian / Asian British | 31% | 12% | 32% | 17% | 7% |
| Black / African / Caribbean / Black British | 22% | 11% | 27% | 35% | 5% |
| Mixed / Multiple ethnicities | 32% | * | 24% | 31% | * |

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[206] Atkin and Krose. (2021). Exploring the experiences of independent advocates and parents with intellectual disabilities, following their involvement in child protection proceedings. Accessed Sep 2022.

[207] Born in Bradford. Born in Bradford Family Cohort. Accessed Dec 2023.

[208] Olubunmi et al. (2019). A review of the reproductive consequences of consanguinity. Accessed Dec 2023.

[209] Born in Bradford. Brilliant Bradford. Accessed Dec 2023.

[210] Sheridan. (2013). Risk factors for congenital anomaly in a multiethnic birth cohort: an analysis of the Born in Bradford study. Accessed Dec 2023.

[211] Born in Bradford. Evidence Briefing, Genes and Health: Inheritance and Risk. Accessed Dec 2023.

[212] NHS. University of Bristol LeDeR annual report 2020. Accessed Nov 2021.

| | | | | | |
|---|---|---|---|---|---|
| Other ethnic groups | 19% | 6% | 14% | 25% | 36% |

*Source: LeDeR Annual Report (2020).*

LeDeR mortality data from 2018-20 shows that individuals from a white ethnic background were much more likely to die in the 65 years+ category, compared to other ethnic groups. The report suggests that the greater proportion of deaths for those of white ethnicity (92%) compared to the English census data of 2011 (85.4%) is likely to represent an under-reporting of deaths from minority ethnic backgrounds.

The LeDeR mortality analysis also showed that the proportion of treatable medical causes of death was higher in both adults and children from Black/African/Caribbean/Black British ethnic groups, and mixed/multiple ethnicities in 2018-20 (44% and 43% respectively) than people from other ethnic groups. Furthermore, the report showed that the proportion of deaths where there were problematic aspects of care were higher in all ethnic groups than white British.[213]

The 2022 LeDeR Report shows further evidence of inequalities between citizens from different ethnic backgrounds. Using data from 2022, this report found that people with a learning disability from an ethnic minority background were more likely to die at a younger age than those with a white ethnicity. Black, black British, Caribbean or African people with a learning disability had a 190% increased risk of dying earlier than people with a white ethnic background, this was 168% for those with 'other' ethnicity recorded, 150% for Asian or Asian British people, and 81% for those with a mixed ethnicity.[214]

LeDeR has set out commitments to gaining an understanding of the needs of citizens from black and ethnic minority backgrounds. Every LeDeR steering group has been required to name a local lead to address the needs of people from minority ethnic communities. This work includes ensuring that reviewers understand the challenges faced by people from minority ethnic communities, such as accessing services, establishing links with local organisations working with minority ethnic communities, and increasing the notification of deaths from individuals with learning disabilities from minority ethnic communities.[215] The 3-year LeDeR strategy in Birmingham and Solihull has also included a commitment to gaining a better understanding of the needs of citizens from black and ethnic minority backgrounds with a learning disability.[216]

The 'healthy migrant effect' is a term which describes the trend of migrants having better overall health in comparison to the general population of the host country. This is in part due to the fact that people who choose to migrate are on average younger and in better health than those who do not migrate. In 2019, research showed that 27% of migrants reported long-lasting health problems, compared to 42% of UK-born people. The number of migrants reporting a long-lasting health problem rises with time spent in the host country, with 6% reporting a limiting health problem among those who had migrated within the previous two years compared to 11% for those who had migrated between 11 and 15 years prior. [217] Further research is needed to understand whether the healthy migrant effect may have an impact on the number of people from ethnic minorities in the UK with learning disabilities. This could be

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[213] NHS. University of Bristol LeDeR annual report 2020. Accessed Nov 2021.

[214] King's College London. (2023). LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People. Accessed Dec 2023.

[215] NHS. Learning disability mortality review (LeDeR): Action from learning report 2020-21. Accessed Feb 2022.

[216] Birmingham and Solihull ICB. The LeDeR Programme. Accessed Jan 2023.

[217] The Migration Observatory. (2020). The Health of Migrants in the UK. Accessed Dec 2023.

one possible explanation for lower numbers of deaths of people with learning disabilities to LeDeR, along with other possible explanations such as underreporting among some ethnic minority communities. These require further exploration and research.

### 3.3.6 Citizens Identifying as LGBTQ+

*Dinwoodie et al.* (2020) explored the experiences of five LGBT people with a learning disability and reported that they endured unique difficulties. Participants reported their sexuality to be often problematised by others, despite accepting it personally. Participants also reported a desire to access services which are sensitive to their sexuality and learning disability needs.[218]

Locally, we do not have data about the number of people living with learning disabilities who identify as LGBT. In 2011, Out and About in Birmingham estimated that 10% of their respondents had a disability of some description. Unfortunately, the survey did not distinguish between the types of disability involved.[219] Choice Support is an organisation working to support people with learning disabilities, autism and mental health needs, based on their choice and not defining people by their support needs. Their services operate in many areas throughout England, but this is not currently extended to Birmingham.[220] Further research is required to access local statistics and to understand the way in which sexuality for people living with learning disabilities is addressed in Birmingham.

### 3.3.7 End of Life

People living with learning disabilities should be encouraged and supported to talk about their wishes should they become seriously ill, or if they reach the end of their life. These conversations can be facilitated by reasonable adjustments and their wishes should be recorded in an Advance Care Plan. This may include a *Do Not Attempt Cardiopulmonary Resuscitation* (DNACPR) decision. The NHS clearly state that a DNACPR decision should not be on a person's record simply because of having a learning disability.[221] While the significant majority of LeDeR reviewers note DNACPRs have been completed correctly, a small proportion are noted to be inaccurately or inappropriately completed. The *2020 LeDeR Annual Report* reported that in 2020, a small proportion (6%) of DNACPR decisions had not been correctly completed and followed. Reasons for this included:

- A lack of evidence of proper decision-making (25 cases).
- Problems with the document (e.g., missing sections) (16 cases).
- The rationale for the decision being based on an inappropriate medical condition or impairment, or circumstance of the individual (e.g., 'learning disabilities', 'Down syndrome' or 'care home resident') (14 cases).[222]

In 2020, GP practices were asked to review DNACPR decisions for their patients with learning disabilities, to ensure these decisions were determined appropriately and remain appropriate.[223] However, at the time of writing, there was no local data available on this.

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[218] Dinwoodie et al. (2016). 'Them two things are what collide together': understanding the sexual identity experiences of lesbian, gay, bisexual and trans people labelled with intellectual disability. Accessed Jan 2022.

[219] Birmingham LGBT. (2011). Out and About. Accessed Dec 2021.

[220] Choice Support. Find support near you. Accessed Dec 2023.

[221] NHS. Action from learning: What happens with reviews once they are completed? Accessed Feb 2022.

[222] University of Bristol. (2021). LeDeR Annual Report 2020. Accessed Feb 2022.

[223] NHS. Learning disability mortality review (LeDeR): Action from learning report 2020-21. Accessed Feb 2022.

# 4 Services

As part of this Learning Disability Deep Dive, the research team carried out a service-mapping exercise for Birmingham. The research team attempted to include as many services as possible for this exercise (and additional services can be found listed in the evidence base document). However, the research team also recognise that it was not feasible to include every service in the final report, often due to lack of available information.

> ***"Feel like you don't want to tell others about what support is available in fear that resources will be overstretched, and you'll lose out on the support."***
>
> Birmingham parent.

> ***"I'm constantly having to fight for support my son needs."***
>
> Birmingham parent.

> ***"I was very lucky- had a lot of support and help with transition."***
>
> Birmingham parent.

## 4.1 Primary Care Services

- Routine health care services are run by several NHS providers, including Birmingham Community Healthcare NHS Foundation Trust who run the *Learning Disability Service* for adults aged 19+, providing day services, short stays, residential care, and community healthcare services.[224]
- Health Checks are carried out by Birmingham GPs.
- Birmingham Community Healthcare NHS Trust run a *Special Care Dentistry* for adults aged 16+, who have a severe disability, or a medical or mental health condition.[225]

### 4.1.1 Annual Health Checks for People with Learning Disabilities

NICE guidelines recommend that people with a learning disability should be offered an annual health check.[226] Health checks can help recognise co-morbid conditions as early as possible and work to maintain good health.[227] Nationally, there was an increase in annual health checks for citizens with learning disabilities carried out between 2018-19 (59.3%) and 2020-21 (75.2%).[228]

The research team believe this increase may in part be due to an increase in virtual consultations during this time. However, there is currently no data available on this topic.

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[224] Birmingham Community Healthcare NHS. Birmingham LD Service for Adults. Accessed Nov 2021.
[225] Birmingham Community Healthcare NHS. Special Care Dentistry for professionals. Accessed Nov 2021.
[226] NICE Impact. (2021). People with a learning disability. Accessed Jan 2022.
[227] LeDeR Programme. Annual Report 2020. Accessed Jan 2022.
[228] NHS Digital. Health and Care of People with Learning Disabilities. Accessed Jan 2023.

Mencap noted the potential for issues to be exacerbated by virtual consultations, because this may lead to more communication difficulties, and because diagnostic overshadowing may occur. Furthermore, learning disability nurses have highlighted that limited contact with healthcare professionals may lead to symptoms being missed, a decline in mental health, and delayed diagnoses.[229]

Published in 2017, Public Health England set out a quality checking process for annual health checks for people with learning disabilities, which can support practices and primary care staff to improve the quality and uptake of their checks.[230]

### 4.1.2 Barriers to Accessing Healthcare

> ***"Things need to be made more accessible. There needs to be more learning disability health facilitators, but there's not enough."***
>
> Birmingham parent.

> ***"… the doctor gave me time, listened to me and my dad."***
>
> Birmingham citizen living with learning disabilities.

The *Confidential Inquiry into Premature Deaths of People with Learning Disabilities* (CIPOLD) identified that problems in the care pathways of people with learning disabilities most frequently occur at the point of investigating, diagnosing or treating illness, and not in identifying that a person is unwell. CIPOLD recognised three associated factors that enhance the vulnerability of people with learning disabilities within care pathways; a lack of reasonable adjustments, effective advocacy, and coordination of their care.[231] Reasonable adjustments are a legal requirement under the *Equality Act* (2010) and meet people's needs through taking account of sensory concerns, offering longer appointment times or Easy Read appointment letters.[232]

A review of research exploring professional carers' experiences of caring for individuals with both learning disabilities and dementia was published in 2017.[233] The literature highlighted poor staff knowledge of dementia, particularly in recognising the early signs of dementia and the benefits and importance of training.

Since 2016, there has been a legal requirement for all organisations providing NHS care and/or publicly funded adult social care to follow the *Accessible Information Standard*.[234] The Standard directs organisations to ask people about their communication needs and flag the

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[229] Mencap. My Health, My Life: Barriers to healthcare for people with a learning disability during the pandemic. Accessed Jun 2022.

[230] Public Health England. (2017). Quality Checking Health Checks for People with Learning Disabilities. Accessed Apr 2022.

[231] Heslop et al. (2013). Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Assessed Dec 2022.

[232] NICE Impact. (2021). People with a learning disability. Accessed Jan 2022.

[233] Cleary et al. (2017). Professional carers' experiences of caring for individuals with intellectual disability and dementia: A review of the literature. Accessed Jan 2023.

[234] NHS. Accessible Information Standard. Accessed Jan 2022.

person’s file (and communication needs) and how these can be met. This information should be shared across NHS providers where appropriate, and steps should be taken to meet these communication needs.

Therefore, it is important that professionals within the NHS and social care have a full understanding of how to care and provide for individuals with learning disabilities,[235] and are able to identify where an issue with a patient is to do with their learning disability, rather than another disease. This has been highlighted many times in the press over the years and none more so than the case of Oliver McGowan, whose case highlighted the need for further training among clinical staff. *Right to Be Heard* was published in November 2019, following a review of Oliver’s case and the findings of LeDeR, after a campaign by his parents to recognise that all professionals need appropriate training to recognise the difference.

The Oliver McGowan Mandatory Training on Learning Disability and Autism Programme has been included in the Health and Social Care Act (2022) and is mandatory for staff working in CQC registered services.[236] The Government response to the consultation on proposals for introducing mandatory learning disability training for health and social care (published in 2019) reported overwhelming support. Furthermore, the consultation proposed training to be focused on understanding learning disability, the legislative context and making reasonable adjustments – all of which was supported by 5,155 respondents, including Birmingham City Council.[237] It is planned that throughout Birmingham and Solihull, 800 staff will have received Tier 1 training by March 2023, and that 20 experts by experience will have been recruited and trained to help facilitate this training. Tier 2 training is planned to be rolled out in 2023-24.[238]

The system-wide rollout of the Oliver McGowan training by BSOL will affect over 100,000 staff in the health and care system, the majority of whom will require Tier 2 level training. It is aimed that Oliver McGowan training will become the main training programme for learning disabilities and autism in BSOL by 2026. A phased approach is being undertaken to achieve this:

- University partners will embed the Oliver McGowan Programme in relevant undergraduate curricula (minimum Tier 1), supporting new entrants to the workforce.
- Each organisation will include the Oliver McGowan Programme as a compulsory element of induction packs for all new staff. The tier required for each staff member will be decided by the employer.
- The current workforce receive a ‘refresh’ on their learning disabilities and autism training every three years. From April 2023, this ‘refresh’ is replaced by the Oliver McGowan Programme.
- Organisations are working to prioritise staff groups to receive the Oliver McGowan training. The e-learning package is already available to all staff.[239]

Hospital passports are another way that access to healthcare can be improved for citizens living with learning disabilities. A hospital passport provides important information, such as personal details, the type of medication being used and any pre-existing health conditions.

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[235] Department of Health and Social Care. (2019). ‘Right to be heard’: The Government’s response to the consultation on learning disability and autism training for health and care staff. Accessed Aug 2021.

[236] NHS Health Education England. The Oliver McGowan Mandatory Training on Learning Disability and Autism. Accessed Sep 2023.

[237] Department of Health and Social Care. Learning disability and autism training for health and care staff. Accessed Sep 2023.

[238] Oliver McGowan Mandatory Training in Learning Disability & Autism. Monthly newsletter for stakeholders in Birmingham and Solihull - Oct 2022. Accessed Nov 2022.

[239] Information supplied internally by NHSE. (2023).

The passport also includes information about how a person communicates and helps staff to understand the needs of an individual and any reasonable adjustments needed.[240] In 2017, a review was published which oversaw how hospital passports were being used in the UK. The reviewers noted a considerable variation between documents, with notable differences in format, length and terminology used. The authors noted a need to increase the standardisation of hospital passports.[241]

**Reasonable Adjustment Flags Pilot (Gloucestershire and Devon)**

A pilot scheme during 2019-20 introduced *Reasonable Adjustment Flags* in Gloucestershire and Devon. These flags allowed healthcare professionals (including doctors and nurses) to know when a patient has a disability or other impairment and if they have any specific needs requiring reasonable adjustments. Feedback from this pilot was positive, with staff saying they could 'get it right' more easily for patients.[242] It is hoped that capability will be made available for wider use across health and care in the future.[243] However, the extent to which these have been taken up in Birmingham is unclear.

### 4.1.3 GP Accreditation

In some areas, innovative work is being developed to improve access to primary healthcare for people living with a learning disability. The Southern Health NHS Foundation Trust have developed a *Learning Disability Friendly Award Scheme* for GP practices. This example of a work programme is described in more detail in the grey box below. The authors of this report understand that no such work is currently being carried out in Birmingham.

**Learning Disability Friendly Award Scheme**

Southern Health NHS Foundation Trust have developed a *Learning Disability Friendly Award* scheme which provides awards to GPs in that area.[244] To date, 42 practices have achieved this award. These GP practices work with health facilitators (learning disability nurses) to establish a learning disability champion within their surgery, offer annual health checks, make reasonable adjustments and be person centered. Examples include:

- Learning disability champions: the champion works to improve learning disability awareness with all the practice staff and is part of a Champion Network.
- Reasonable adjustments: identify and flag patient reasonable adjustments on the system.
- Annual health checks: ensure the learning disability register is up to date, ensure at least 75% of learning disability patients receive an annual health check and that those which identify a health need result in a Health Check Action Plan.
- Be person centered: actively follow up patients who do not attend appointments, encourage patients to complete a personalised care plan (e.g., hospital passport).
- Communication: add communication alert on system, ensure implementation of the alert across all practice staff.

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[240] Mencap. Health Guides. Accessed Jun 2022.

[241] Northway et al. (2017). Hospital passports, patient safety and person-centred care: A review of documents currently used for people with intellectual disabilities in the UK. Accessed Jun 2022.

[242] NHS Digital. (2020). Patient record flag can positively affect care of people with learning disabilities. Accessed Dec 2021.

[243] NHS Digital. Reasonable Adjustment Flag. Accessed Dec 2021.

[244] NHS Southern Health NHS Foundation Trust. Learning Disability Friendly GP Award. Accessed Jan 2022.

### 4.1.4 Veterans Friendly Framework

The Veteran Friendly Framework (VFF) supports armed forces veterans and their families living in social care settings in England. This research team has consulted with the Framework organisers about the potential for this framework to be adapted to benefit citizens living with learning disabilities. By mutual agreement, it was decided that the Framework could be included in this report as an example of good practice, in the hope that it can be considered in the future as a possible extension of the Learning Disabilities GP Friendly Accreditation Scheme, which could form a Learning Disabilities Friendly Framework, supporting citizens living with learning disabilities in secondary and tertiary care.

**Veteran Friendly Framework**

The Veteran Friendly Framework is a programme led by the Military Care Home Providers: The Royal British Legion and Royal Star and Garter. The initiative aims to equip care and nursing homes in England with the knowledge and tools required to support residents who have served in the Armed Forces and their spouses. There are eight standards that need to be evidenced for a care or nursing home to achieve VFF Accreditation:

**Standard 1:** Signing of the Armed Forces Covenant. This Covenant is a promise from the nation that those who serve or have served in the Armed Forces, and their families, are treated fairly.[245] By signing up to the Covenant, a care or nursing home agrees to provide specialist support to all veterans and spouses in their care.

**Standard 2:** Care or nursing home to nominate Armed Forces Communities Champions to support and deliver the Framework. One or more members of staff at the care or nursing home need to be identified to help support the programme.

**Standard 3:** Care or nursing home to ensure Armed Forces Community status is included in veteran's care plans. All staff caring for a resident should be aware of their service in the Armed Forces.

**Standard 4:** Care or nursing home to share a person's Armed Forces Community status with clinical services. This should ensure they receive the appropriate care as Veteran Friendly GP Practices and Hospitals will have information about the individual before they arrive for an appointment or admission.

**Standard 5:** Staff at the care or nursing home to receive training. Veterans Awareness training should be part of induction training for all staff.

**Standard 6:** Care or nursing home to establish links to local services for the Armed Forces Community. This standard will help to create a network of Armed Forces support for care or nursing homes (e.g., Breakfast Clubs, Dementia Cafes, or links with Veteran charities).[246]

**Standard 7:** Care or nursing home to support the Armed Forces Community as an employer. This involves signing up to the Employee Recognition Scheme (ERS) Award programme, which offers employment support for service leavers.

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[245] GOV.UK. Armed Forces Covenant: guidance and support. Accessed Dec 2023.

[246] NHS. Mental health support for veterans, service leavers and reservists. Accessed Dec 2023.

**Standard 8:** Care or nursing home to raise awareness of the Armed Forces Community. This is an opportunity for the care or nursing home to showcase all their hard work and evidence their care for the Armed Forces community.[247,248]

## 4.2 Secondary Care Services

### 4.2.1 General Inpatient Admissions

Birmingham inpatient data shows a steady increase in local hospital admissions for people with learning disabilities (for all ages) during the last five years, rising from approximately 5,000 in 2016-17 to just over 6,000 inpatients during 2019-20. The under 19 years age group consistently accounts for approximately half of hospital admissions (Figure 14).

**Figure 14: Inpatient Admissions for People with Learning Disabilities.**

*Source: Local calculations based on inpatient data from NHS Digital.*

### 4.2.2 Learning Disability and Mental Health Admissions

*Assuring Transformation* and the *Mental Health Services Dataset* are two datasets reporting on learning disability and mental health inpatients for people with learning disabilities. The purpose of the *Assuring Transformation* data collection is to ensure that public awareness of the NHS commitments in the Winterbourne View Concordat are transparent and robust. Specifically, these datasets report on the following:

- Inpatients with 'a bed' for the treatment or care of people with a learning disability.
- Those with 'a bed' designated for mental illness treatment or care, who have been diagnosed or are understood to have a learning disability and/or autistic spectrum disorder.[249]

In October 2021, there were 3,490 people with learning disabilities and/or autistic spectrum disorders (LDA) in hospital within England. 67% were male, 31% were female, and 2% had an unknown gender. The largest number of patients were of white ethnicity (75%), followed by black (7%), Asian (5%), unknown (8%), mixed (3%) and other (2%).

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[247] VFF. Supporting guidance, hints & tips for completion of the VFF application. Accessed Dec 2023.

[248] VFF. Framework process flow chart. Accessed Dec 2023.

[249] NHS Digital. Learning Disability Services Monthly Statistics, AT: October 2021, MHSDS: August 2021 Final. Accessed Nov 2021.

The Mental Health Services dataset recorded that only 620 patients (18%) of the total 3,490 inpatients in England had received a planned discharge date. Therefore, 82% of inpatients had not received a planned discharge date at all (Figure 15).

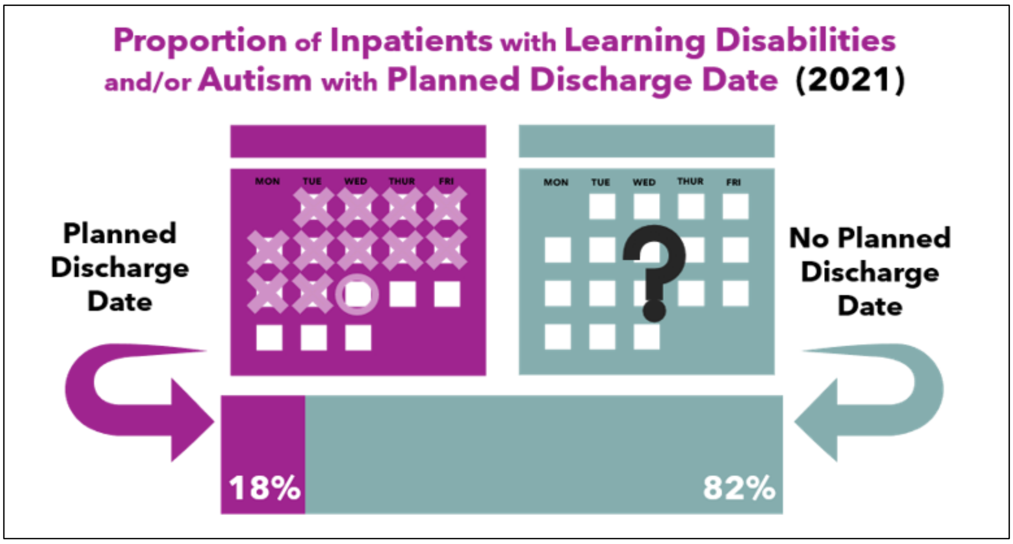

**Figure 15: Inpatients with Learning Disabilities and/or Autism with and without a Planned Discharge Date.**

*Source: Mental Health Services Dataset.*[250]

Table 14 shows that of the 3,490 inpatients in England who were recorded at the end of October 2021, the majority (89%) were admitted for more than a month, and over half (53%) were admitted for more than a year.

**Table 14: Length of Stay of Inpatients with Learning Disabilities and/or Autism (England, October 2021).**

| Length of Stay | Inpatient Hospital Episodes | Inpatient Hospital Episodes (%) |
|---|---|---|
| **0-3 days** | 80 | 2% |
| **4-7 days** | 55 | 2% |
| **1-2 weeks** | 110 | 3% |
| **2-4 weeks** | 160 | 5% |
| **1-3 months** | 460 | 13% |
| **3-6 months** | 375 | 11% |
| **6-12 months** | 425 | 12% |
| **1-2 years** | 480 | 14% |
| **2-5 years** | 795 | 23% |
| **5-10 years** | 340 | 10% |
| **10+ years** | 205 | 6% |
| **All patients** | **3,490** | **100%** |

*Source: Mental Health Services Dataset.*[251]

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[250] NHS Digital. (2022). Learning Disability Services Monthly Statistics, AT: December 2021, MHSDS: October 2021 Final. Accessed Feb 2022.

[251] NHS Digital. (2022) Learning Disability Services Monthly Statistics, AT: December 2021, MHSDS: October 2021 Final. Accessed Feb 2022.

In September 2020, the Birmingham rate of adult inpatients with a learning disability, who were receiving specialist mental or behavioural health care in a hospital, was 53 adult inpatients per million adults. This was considerably higher than the national average, which was 42 adult inpatients per million.[252]

### 4.2.3 Mental Health Services

- Children's mental health services are provided by Birmingham Women's and Children's NHS Foundation Trust*,* who coordinate child and adolescent mental health services (CAMHS*)* provision across Birmingham. They provide community provision through Forward Thinking Birmingham, and inpatients provision through Parkview Clinic.[253,254]
- The Birmingham Women's and Children's NHS Foundation Trust provides a *Learning Disability Liaison Nurse* at Birmingham Women's Hospital.[255]
- Reach Out is the West Midlands Provider Collaborative for low and medium adult secure mental health services, commissioned by NHS England from October 2021, and led by Birmingham and Solihull Mental Health NHS Foundation Trust.[256]

### 4.2.4 Forensic Services

Forensic services provide support for citizens with learning disabilities who are living in the community, and have come into contact, or are at risk of coming into contact, with the criminal justice system.[257]

- Youth First is a community mental health service for children and young people, provided by Birmingham and Solihull Mental Health NHS Foundation Trust.[258]
- Birmingham Community Healthcare NHS Foundation Trust provide a *Community Forensic Learning Disability Team* for adults with moderate to severe learning disabilities with forensic needs.[259]
- The *Criminal Justice Liaison and Diversion Team* at Birmingham and Solihull Mental Health Foundation Trust are a specialist team working in police custody suites, Birmingham Magistrates Court and the community.[260]

## 4.3 Social Care Services

### 4.3.1 Children's Social Care

Birmingham Children's Trust provide the *Children with Disabilities Service,* which provides support for families caring for a child aged 0-18 years, with complex or critical needs. This service is provided for children with a disability and all disabled children come under the category of 'children in need'. Children termed 'children in need' can access Disabled

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[252] NHS. (2020). Learning disability and autism – adult inpatient rates by TCP Accessed Nov 2021.
[253] Birmingham Women's and Children's Trust. Forward Thinking Birmingham. Accessed Nov 2021.
[254] Birmingham Women's and Children's Trust. Health in Mind. Accessed Nov 2021.
[255] Birmingham Women's and Children's Hospital. Learning Disabilities. Accessed Nov 2021.
[256] Birmingham and Solihull Mental Health Trust. Reach Out Provider Collaborative. Accessed Feb 2022.
[257] Directors of Adult Social Care Services (2015). Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. Accessed Dec 2023.
[258] Birmingham and Solihull CCG. Birmingham Children and Young People's Mental Health and Wellbeing Refresh Local Transformation Plan 2020-21 Accessed Nov 2021.
[259] Birmingham Community Healthcare Trust. Birmingham Learning Disability Service for Adults. Accessed Jan 2022.
[260] Birmingham and Solihull Mental Health NHS Foundation Trust. Criminal Justice Liaison and Diversion Team. Accessed Feb 2022.

Children's Social Care, through a social worker assessment. Children can access home support, direct payments, short break fostering provision, children's residential home placements, and preparation for adulthood support through these assessments.[261] Disabled children requiring extra support from multiple agencies may be referred to a Family Support or Early Help team. Higher levels of social need may require statutory specialist services and these children will receive a family assessment by a social worker.[262] Information and available data on SEND services can be seen in section 1.7.6.

### 4.3.2 Transition from Children to Adult Services

Birmingham City Council's *Preparation for Adulthood* programme provides an early intervention for young people aged between 14 and 30 years, helping to identify support services for these individuals to support them during their transition to adulthood.[263]

Birmingham City Council's *Adult Transitions Team* supports those aged 18-25 years with a range of disabilities and/or complex health needs with transition planning from child to adult services.[264]

### 4.3.3 Social Care Funding

> ***"As a family, we focus on what our son can do. We dread completing these PIP forms every 3 years, with the automatic assumption that his disability is going to change. The form is degrading and mentally draining, having to think about all the things that he's unable to do. The questions are extremely unclear."***
>
> Birmingham parent.

> ***"More help from people who know how to fill in the form."***
>
> Birmingham parent.

Some individuals with long term and complex health needs qualify for free social care, which is arranged and funded by the NHS, known as *NHS Continuing Healthcare*.[265]

Personal health budgets are financial supports from local councils where a person is eligible. This is assessed through a needs assessment and a financial assessment. The amount will be decided when the council makes a *care and support plan* with the person.[266]

For those eligible, benefits available to support children and young people with SEN and their families include:

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[261] Birmingham Children's Trust. One Minute Guide to Social Care. Accessed Dec 2022.
[262] Birmingham Children's Trust. Our thresholds explained. Accessed Dec 2022.
[263] Birmingham City Council. Post 16 and Preparation for Adulthood. Accessed Aug 2021.
[264] Birmingham City Council. Progression into Adult Services / Community Activities. Accessed Nov 2021.
[265] NHS. NHS Continuing Healthcare. Accessed Nov 2021.
[266] NHS. When the Council Might Pay for your Care. Accessed Nov 2021.

- Disability Living Allowance for Children (benefit for children under 16 to support costs caused by long term ill-health or disability).
- Personal Independence Payment (benefit for young people 16+ to support with costs associated with the disability or condition).
- Employment and Support Allowance (for those unable to work due to an illness or disability).
- Carers Allowance (financial support for carers caring for someone with substantial caring needs).
- Disability Student Allowance (allowance in addition to student finance to support with costs associated to mental health, long term illness or disability).[267]

### 4.3.4 Services Funded by Adult Social Care

In January 2023, there were 10,389 patients of all ages with learning disabilities registered to GP practices in Birmingham.[268] Data from August 2023, showed that there were 2,076 adults with learning disabilities funded by Adult Social Care in Birmingham. These data sources are not comparable, due to referring to different populations, and having different data sources and dates.

Table 15 shows the range of long-term services that Adult Social Care fund for citizens living with learning disabilities. The table highlights that Adult Social Care currently fund 2,076 individuals, which include 500 citizens who commission their own services with direct payments, 485 citizens in day care centres, 439 citizens in residential care homes, 317 citizens who are funded for supported living, 231 citizens receiving home care, 51 being supported by shared lives, 48 citizens supported with nursing needs, and 8 citizens supported with extra care.

**Table 15: Service Funded by Adult Social Care (August 2023).**

| Service | Long-Term Learning Disability Support |
|---|---|
| **Direct Payments** | 500 |
| **Day Care** | 485 |
| **Residential** | 439 |
| **Supported Living** | 317 |
| **Home Care** | 231 |
| **Shared Lives** | 51 |
| **Nursing** | 45 |
| **Extra Care** | 8 |

*Source: Birmingham City Councill Intelligence & Analysis team.*

Among citizens living with learning disabilities who are funded by Adult Social Care, there are more male citizens (57.1%) than female citizens (42.9%).

Table 16 provides a summary of citizens with learning disabilities who are funded by Adult Social Care, by ethnic group. Citizens from a white background (63.0%) are the largest ethnic group supported, followed by citizens from an Asian background (20.6%). When comparing the proportion from different ethnicity groups who are funded by Adult Social Care and those

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[267] Local Offer Birmingham. Benefits. Accessed Dec 2022.

[268] Source: Business Intelligence BSOL ICB Jan 2023. Accessed Nov 2023.

recorded in the 2021 census, it seems that people from a white ethnicity are overrepresented among those funded by Adult Social Care, while those from an Asian background are underrepresented. The reasons for this difference are not known.

**Table 16: Citizens with Learning Disabilities Funded by Adult Social Care, by Ethnic Group (August 2023).**

| Ethnicity | Number of Patients Living with LD | % of Patients Living with LD | % of Total Population (2021 Census) |
|---|---|---|---|
| **White** | 1,119 | 63.0% | 49% |
| **Asian** | 365 | 20.6% | 31% |
| **Black** | 199 | 11.2% | 11% |
| **Mixed** | 44 | 2.5% | 5% |
| **Any other ethnicity** | 31 | 1.7% | 5% |
| **Not known** | 18 | 1.0% | 0% |

*Source: Birmingham City Councill Intelligence & Analysis team.*

**Future Research**

In July 2022, the ***Association for Real Change England Learning Disability Research Unit*** was launched which is a strategic research programme aiming to provide improved data for the autism and learning disability adult social care sector. This programme recognises the lack of available data in this area and will allow insights into the size, value and structure of the sector which will provide a knowledge base to inform planning and policy.[269]

### 4.3.5 Transport

> ***"Since my dad does not drive at night,***
> ***I can't find anyone to pick me up."***
>
> Birmingham citizen living with learning disabilities.

Birmingham's *Home to School Transport Service* is for students who are vulnerable or have special educational needs. This service supports over 4,000 pupils around the city, aged 5-18 years.

In 2022-23, Birmingham City Council launched the Independent Travel Training Programme. This is a free scheme to develop young people's confidence and skills for safe and independent travel. In July 2023, Birmingham City Council's cabinet approved the provision of the Independent Travel Training Programme across Children's services, and the provision of travel support to programmes promoting travel independence to clients of Adult Social Care services.[270]

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[269] ARC England. ARC England Learning Disability Research Unit. Accessed Sep 2022.
[270] Birmingham City Council. Children and Young Person's Travel Service. Accessed Nov 2022.

## 4.4 Screening Services

National and local data show a low uptake of cancer screenings among citizens living with learning disabilities. Citizens living with learning disabilities are less likely to access cancer screenings than the general population. Further information about the inequalities relating to cancer among citizens with learning disabilities can be seen in section 3.1.1.7.

### 4.4.1 Breast Cancer Screening

Figure 16 contains Birmingham and Solihull ICS (2021-22) breast screening data for women aged 50-59, who received breast screening within the preceding five-year period.[271] These figures show that women with a learning disability were significantly less likely to receive breast cancer screening (38.8%) than women without a learning disability (53.7%). However, these percentages are lower than England, where 47.2% of women with a learning disability received breast cancer screening (vs 61.9% of women without a learning disability).

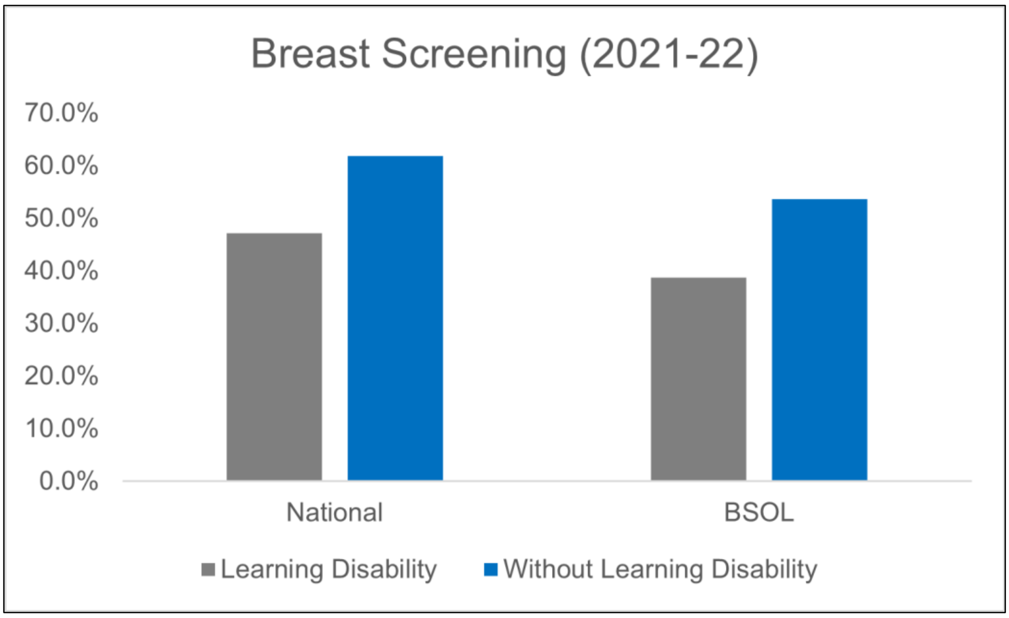

**Figure 16: Breast Cancer Screening of Women Aged 50-69 with and without a Learning Disability (2021-22).**

*Source: Health and Care of People with Learning Disabilities.*

### 4.4.2 Cervical Cancer Screening

Figure 17 shows that for those who were eligible for cervical cancer screening nationally, there were a significantly lower percentage of women with a learning disability receiving adequate cervical cancer screening (31%), compared to women without a learning disability (66.6%). These figures reflect a similar pattern to the local ICS data, where women with a learning disability were significantly less likely to receive adequate cervical cancer screening (31.3%), compared to women without a learning disability (61.7%).[272]

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[271] NHS Digital. (2022). Health and Care of People with Learning Disabilities Experimental Statistics 2021 to 2022. Accessed Aug 2023.

[272] NHS Digital (2022). Health and Care of People with Learning Disabilities, Experimental Statistics 2021 to 2022. Accessed Aug 2023.

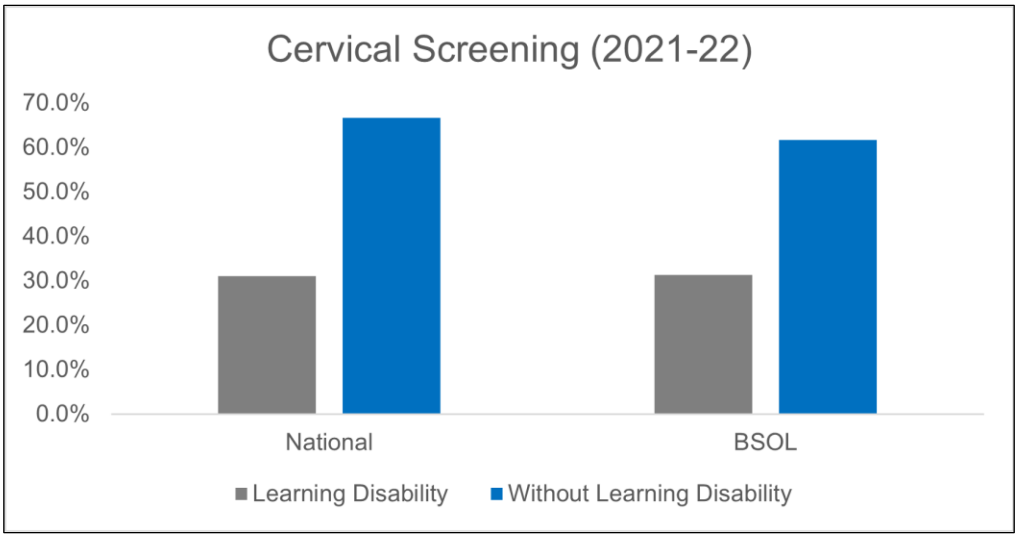

**Figure 17: Cervical Cancer Screening of Women Aged 25-64 with and without a Learning Disability (2021-22).**

*Source: Health and Care of People with Learning Disabilities.*

### 4.4.3 Colorectal Cancer Screening

Figure 18 shows that nationally there was a lower percentage of people with a learning disability receiving adequate colorectal cancer screening (50.3%), compared to people without a learning disability (66.8%). These figures reflect a similar pattern to the local ICS data, where citizens with a learning disability were significantly less likely to receive adequate colorectal screening (45.3%), compared to citizens without a learning disability (60.2%).[273]

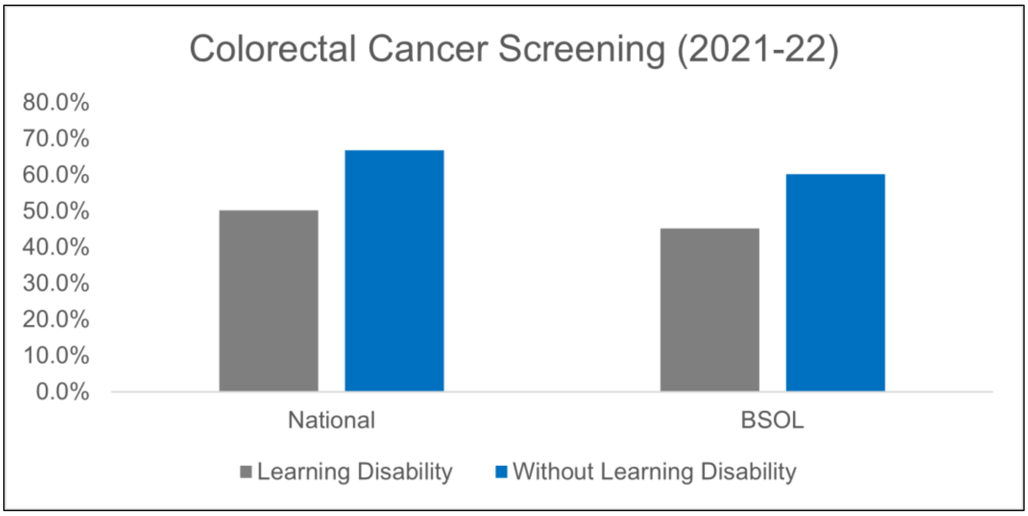

**Figure 18: Colorectal Cancer Screening of People with and without a Learning Disability (2021-22).**

*Source: Health and Care of People with Learning Disabilities.*

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[273] NHS Digital. (2022). Health and Care of People with Learning Disabilities, Experimental Statistics 2021 to 2022. Accessed Aug 2023.

## 4.5 Community Service

### 4.5.1 Sexual Health Services

Umbrella is a free, accessible and confidential sexual health service in Birmingham and Solihull. It provides contraception, STI testing and treatment for all people without the need for a prior GP appointment. These services are delivered by University Hospitals Birmingham NHS Foundation Trust, in partnership with other organisations.[274]

### 4.5.2 Substance Misuse Services

Change Grow Live provide adult drug and alcohol services across the city. Their services include information and advice, peer and group support, and alcohol and drug treatment options. Change Grow Live run the *Park House Inpatient Treatment Service* in Birmingham, which provides detoxification and stabilisation programmes to meet client's needs.[275]

## 4.6 Accommodation and Housing

### 4.6.1 Respite and Short Breaks

Birmingham Children's Trust provide a *Short Breaks* service to give parents and carers of disabled children the opportunity and support to have a break from their caring responsibilities, while the child is cared for in another setting.[276] Providers of adult short break services include Priory's Learning Disability service,[277] Real Life Options,[278] Respite Breaks,[279] Birmingham Community Healthcare NHS Foundation Trust[280] and Mencap.[281]

### 4.6.2 Housing

In July 2022, a new Vulnerable Adults Pathway was commissioned by Birmingham City Council. This will initially run for five years until June 2027, with the possibility of a further two year extension. This has involved the commissioning of multiple providers. The commissioning for adults with learning disabilities includes long-term and emergency planning, in addition to lead worker services, whose role will be to provide longer-term and personalised support. This includes the development of support plans to equip individuals to overcome challenges they face. Midland Mencap and Longhurst Group have been commissioned to provide lead worker services. Trident Reach, Green Square Accord and Birmingham Rathbone have been commissioned to provide the accommodation services.[282]

Local authorities publish accommodation data for adults with learning disabilities who are living independently within supported settled accommodation. Table 17 compares Birmingham with national data for England.[283]

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[274] Umbrella. About Us. Accessed Nov 2022.
[275] Change Grow Live. Park House Inpatient Treatment Service – Birmingham. Accessed Apr 2022.
[276] Birmingham Children's Trust. Short Breaks Statement 2020-21. Accessed Dec 2021.
[277] Priory Adult Care. Learning Disability Services and Support. Accessed Aug 2021.
[278] Real Life Options. Supporting You. Accessed Aug 2021.
[279] Respite Breaks Respite Breaks. Accessed Aug 2021.
[280] BCHC. Birmingham Learning Disability Service for Adults. Accessed Nov 2021.
[281] Midland Mencap. Residential Respite Services - Birmingham Multi-Care. Accessed Nov 2021.
[282] Information emailed directly from Adult Social Care. Accessed Sep 2022.
[283] Public Health England. Learning Disability Profiles. Accessed Mar 2022.

**Table 17: Percentage of People with Learning Disabilities (Aged 18-64) in Supported Settled Accommodation (2019-20).**

| Area | % |
|---|---|
| **Birmingham** | 69.0 |
| **England** | 77.3 |

*Source: Learning Disability Profiles.*

Providers of adult care residential and supported living services for citizens with learning disabilities include Priory,[284] Real Life Options,[285] Trident Reach,[286] Mencap,[287] Green Square Accord[288] and Birmingham Rathbone.[289]

Birmingham City Council currently commissions beds in 127 care/nursing homes across the city, who are able to care for people living with learning disabilities. These have a maximum capacity of 1,333 beds available for those with learning disabilities. Currently, 586 individuals with learning disabilities are resident in these commissioned beds.[290]

## 4.7 Education

> ***"My son loved school, but his first 2 years of secondary school were difficult until he got diagnosed."***
>
> Birmingham parent.

Most children with special educational needs and disabilities (SEND) will be able to have their needs met within mainstream settings without additional support. However, for some, an Education, Health and Care Plan (EHCP) will be needed which sets out the child or young person's education, health and social care needs.[291] In 2020, there were more children with learning difficulties known to schools in Birmingham (60.5 per 1,000) than England (34.4 per 1,000).[292]

Table 18 provides a summary of the number of people aged 25 and under, who currently have an EHCP assessment by Birmingham City Council (n=2,546). Overall, 11,186 assessments have been completed and 2,546 (23%) of these are for children and young people with moderate learning difficulties, severe learning difficulties or profound and multiple learning difficulties. It should be noted that the data refers to a child's primary need. Therefore, this may be an underestimate, where children with moderate, severe, or profound and multiple learning difficulties have these needs secondary to their primary reason for an EHCP. 63% of

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[284] Priory Adult Care. Autism Support and Care. Accessed Aug 2021.
[285] Real Life Options. Supporting You. Accessed Aug 2021.
[286] Trident Reach. Learning Disabilities Services. Accessed Aug 2021.
[287] Midland Mencap. Supported Living Services. Accessed Aug 2021.
[288] Green Square Accord. Learning Disability. Accessed Sep 2022.
[289] Rathbone Rathbone Birmingham Accessed Dec 2023.
[290] Birmingham City Council Adult Social Care. Local Calculations.
[291] Birmingham City Council. Education, Health and Social Care Plan. Accessed Apr 2022.
[292] Office for Health Improvement & Disparities. Children with learning difficulties known to schools. Accessed Dec 2023.

children and young people with moderate, severe, or profound and multiple learning difficulties were male.

**Table 18: Number of ECHPs by SEN Learning Difficulty Codes and Age Group (Dec 2022).**

| Quinary Ages | Moderate Learning Difficulty | Profound and Multiple Learning Difficulty | Severe Learning Difficulty | Total |
|---|---|---|---|---|
| **1 to 4** | 20 | 28 | 13 | 61 |
| **5 to 9** | 190 | 95 | 131 | 416 |
| **10 to 14** | 477 | 99 | 208 | 784 |
| **15 to 19** | 528 | 86 | 203 | 817 |
| **20 to 25** | 309 | 43 | 116 | 468 |
| **Grand Total** | 1,524 | 351 | 671 | 2,546 |
| **Percentage** | **60%** | **14%** | **26%** | **100%** |

*Source: SEN Assessment & Review (SENAR) team Birmingham City Council.*[293]

Birmingham City Council lists 27 special schools in the directory of schools within Birmingham,[294] and a further 42 schools with resource bases for children with SEN.[295]

Providers of education services for citizens living with learning disabilities aged 16+ include Care First,[296] Community Prospects,[297] Queen Alexandra College,[298] Argent College,[299] Heart of Birmingham Vocational College,[300] Hive College[301] and Sense College.[302]

### 4.7.1 Birmingham SEND Local Offer

> ***"When you think about having kids, you don't think about disabilities they may have. As parent/carers, I feel we're thrown into the deep end as soon as we have a diagnosis for our child, with no information on what life could be like going forward, or information and support that's available going forward. If more 'trusted' information was provided at the point of diagnosis, it would help massively with identifying next steps."***
>
> Birmingham parent.

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[293] Information provided directly by SENAR. December 2022.
[294] Birmingham City Council. Special. Accessed Aug 2021.
[295] Birmingham City Council. Schools With Resource Bases for SEN. Accessed Aug 2021.
[296] CareFirst. Accessed Aug 2021.
[297] Community Prospects. Accessed Aug 2021.
[298] Queen Alexandra College. Accessed Dec 2021.
[299] Ruskin Mill. Argent College. Accessed Jan 2022.
[300] Heart of Birmingham Vocational College. Who Are We? Accessed Jan 2022.
[301] Hive College. Accessed Jan 2022.
[302] Sense. Sense College. Accessed Sep 2022.

#### 4.7.1.1 Early Years

All early education providers are required to make reasonable adjustments to ensure their inclusivity. Children requiring extra support can gain this with a 'graduated approach', whereby the support provided matches the child's level of need.[303] The three graduated stages of intervention include: 1) additional support from schools, 2) additional support from schools together with advice or involvement from external agencies, and 3) an Education Health Care Needs Assessment to establish if an EHCP is required.[304]

*The Early Years Inclusion Service* support children and families and early education settings to provide support for these settings to be inclusive for the needs of early years children with SEND.[305]

#### 4.7.1.2 Specialist SEND Support

Access to Education consists of four specialist services, comprising of the *Communication and Autism Team, the Sensory Support and Physical Difficulties Support Service*, and the *Pupil and School Support Service*.[306] *The Pupil and School Support Service* are a team of teachers who work with children and young people with cognition, learning and language difficulties.[307]

Table 19 shows the number of pupils with an EHCP or a funded SEND Support Provision Plan who have received support from *the Pupil and Support Service*. This shows that the majority of support is given to pupils in primary school, accounting for 70% (n=1329) of pupils.[308]

**Table 19: Pupils with Funding or EHCP Supported by Pupil & School Support.**

| School Type | Summer 1 (2022) | Summer 2 (2022) | Autumn 1 (2022) | Autumn 2 (2022) |
|---|---|---|---|---|
| **Early Years** | 27 | 74 | 17 | 58 |
| **Primary** | 211 | 486 | 302 | 330 |
| **Secondary** | 55 | 138 | 91 | 108 |
| **Post 16** | * | * | * | * |

*Source: Birmingham City Council Pupil & School Support (2023). (Note that the symbol '*' denotes a value of 5 or below).*

#### 4.7.1.3 Health and Wellbeing Services

Birmingham Community Healthcare NHS Foundation Trust has a special school nurse provision, whereby these school nurses provide assessments and care plans for each new starter in special schools.[309]

Birmingham Community Healthcare Trust's *SEND Therapy Team* are a team of occupational therapists and speech and language therapists.[310] They work with mainstream schools,

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[303] Local Offer Birmingham. Choosing a Setting for a Baby or Young Child with Special Educational Needs or Disability (SEND). Accessed Dec 2022.
[304] Local Offer Birmingham. SEND Support and Information. Accessed Dec 2023.
[305] Local Offer Birmingham. Early Years Inclusion Support (EYIS). Accessed Dec 2022.
[306] Access to Education. Accessed Dec 2022.
[307] Local Offer Birmingham. Pupil and School Support. Accessed Dec 2022.
[308] Directly supplied by SEND Birmingham. January 2023.
[309] Birmingham Community Healthcare NHS Foundation Trust. Special School Nursing. Accessed Aug 2021.
[310] Local Offer Birmingham. Health and Wellbeing. Accessed Dec 2022.

resource bases, nurseries and child minders and bridge the gap between health and education support for children.

The Children's Trust provide the *Children with Disabilities Service,* which provides support for families caring for a child aged 0-18 years, with complex or critical needs.[311]

### 4.7.1.4 SEND Parent and Carer Surveys

In May 2022, Birmingham SEND services carried out a survey with parents and carers.[312] There were 788 responses and 76% of respondents reported looking after children aged 5 to 16. Some of the key responses to questions asked in this survey are summarised below. However, not all of the 788 respondents are represented in each of the questions.

- 32% of parents/carers felt that SEND services were 'Good' or 'Very Good', 28% felt SEND services were 'OK', and 40% felt they were 'Very Poor' or 'Poor'. Some parents/carers reported positive experiences of their child's support at school. However, some reported issues with a lack of communication, delays, and a lack of services to support their child.
- When asked whether SEND services had improved in the previous year, 45% felt they were 'The Same', 28% reported services 'Had Got Worse', 19% responded 'Improved' and 8% 'Improved Significantly'. Compared to other services, parents and carers were more likely to say that education services had improved.
- Excluding 'Don't Know' responses, 16% felt they had an opportunity to influence changes in SEND services either 'A Little' or 'A Lot', 76% responded 'Not Very Much' or 'Not At All', and 8% responded 'I Hadn't Wanted To Do This'.

## 4.8 Employment

> ***"I can't work because it causes me too much stress, and I have back problems."***
>
> Birmingham citizen living with learning disabilities.

A range of services offer support with employment needs for citizens with learning disabilities locally and nationally.

- Mencap has a *Careers Education, Information, Advice and Guidance service* (CEIAG) which supports individuals in developing a career. This includes helping people search for jobs, preparing for interviews, and help with applying to university.[313]
- Remploy is a national organisation supporting individuals with disabilities to access employment opportunities.[314]
- Disability Resource Centre provide employment, training and volunteering opportunities and have a local branch in Yardley.[315] Disability Resource Centre run

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[311] Birmingham Children's Trust. One Minute Guide to Social Care. Accessed Dec 2022.
[312] Birmingham City Council. Birmingham SEND Parent and Carer Survey May 2022. Accessed Sep 2022.
[313] Mencap. Careers, Education, Information, Advice and Guidance (CEIAG). Accessed Aug 2021.
[314] Remploy. About Us. Accessed Aug 2021.
[315] Disability Resource Centre. Accessed Aug 2021.

*Opportunities for Life* courses which aim to tackle barriers that disabled people face in accessing employment and training opportunities.[316]
- Better Pathways is a mental health charity which supports citizens with poor mental health and those with learning difficulties and disabilities with employment support.[317]
- Birmingham Rathbone[318] and Trident Reach provide employment support through the *PURE project,* which helps individuals aged 29+ with multiple and complex barriers to enter the labour market.
- Birmingham Careers Service provides careers information, advice and guidance to young people aged 16-19 years, who are not in education, employment or training. For those with a learning disability, support can be provided until they reach the age of 25. This service is part of Birmingham City Council*,* who work alongside other local services.[319]

**Supported Employment**

Birmingham Women's and Children's NHS Foundation Trust was the first Trust in the West Midlands to launch a new programme in partnership with Calthorpe Academy. It offers those aged 14 to 25 with moderate to severe learning disabilities supported employment opportunities in a department for one day a week for a year, which is paid work. In 2022, six young people were on the scheme, and it is hoped the programme will expand next year. The young people are supported by Calthorpe job coaches, as well as receiving support from the *Aspire Team* at the Trust. Calthorpe Academy is a full-time day provision providing key employability and support living skills for students with moderate to severe learning disability and autism spectrum disorder needs. As of this point in time, this opportunity is only available to students at Calthorpe Academy*,* but this is hoped to be expanded to other students in Birmingham in the future.[320]

## 4.9 Voluntary and Community Support

Neighbourhood Network Schemes are a city-wide initiative, funded by *Birmingham City Council* to ensure citizens aged 50+ and those aged 18-49 years with long-term conditions and disabilities can access community-based support.[321] Each Birmingham constituency works with the local community, voluntary and faith organisations to identify community activities and services, which are collated on the Connect to Support website.[322]

In 2018, a Community Catalysts Community Micro-Enterprise project was set up in Birmingham in partnership with Birmingham City Council, focused on developing a range of micro-enterprises, offering opportunities for adults living with learning disabilities. These allow flexible support, enabling people to pursue their interests in an accessible way. This work has been focused in Hodge Hill, Erdington and Hall Green.[323]

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[316] Disability Resource Centre. Employment Training and Volunteering Opportunities. Accessed Sep 2022.
[317] Better Pathways. What We Do. Accessed Sep 2022.
[318] Birmingham Rathbone. Accessed Aug 2021.
[319] Birmingham Careers Service. About Us. Accessed Jan 2022.
[320] Birmingham Women's and Children's Trust. Employment for People with a Learning Disability. Accessed Feb 2022.
[321] Disability Resource Centre. Yardley Neighbourhood Network Scheme (NNS). Accessed Aug 2021.
[322] Connect to Support. Accessed Oct 2022.
[323] Community Catalysts. Birmingham: The Story So Far. (2019). Accessed Dec 2023.

> ***"I feel like waiting lists go on forever. I essentially feel forgotten about."***
>
> Birmingham parent.

> ***"It would be useful to have a good resource centre in each constituency of Birmingham, where people can go for help, advice and support face to face, rather than online, which further excludes people with a learning disability."***

Across Birmingham and Solihull ICB, there is an active development of Small Supports, which are local organisations supporting citizens with a learning disability, autism or both, within their own home with a bespoke support team. There is a focus on the organisation being small in scale and with a person-centred focus. The ICB has the ambition to increase the choice of providers in this type of care and promote others to set up and run their own small organisations.[324]

> ***"I used to attend [a club] which was designed for adults with a learning disability. I felt like as a group, we were treated like babies, not adults with a learning disability, so I stopped going. I'd love to see age-appropriate exercise classes for people with disabilities."***
>
> Birmingham citizen living with learning disabilities.

> ***"There are many with dietary needs, hoisting needs, and other disabilities that only get sorted at the centre."***
>
> Birmingham health professional

Birmingham day centre services are provided by Birmingham City Council, the NHS and a range of third sector and private providers. Birmingham City Council provides nine internal day centres, four of which include gardening projects. Seven of these centres are accessed primarily by citizens with a learning and/or physical disability, and one supports citizens who are growing old with a learning disability. Two centres cater for citizens with physical disabilities. There are also twenty-seven external day service providers in Birmingham and neighbouring authorities, offering both building-based day centre services and outdoor activities, across 35+ sites. These services support citizens where the primary care need is learning disability and/or autism.[325]

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[324] BSOL CCG. Small Supports. Accessed Aug 2021.

[325] Information Supplied by Adult Social Care. December 2022.

### 2021 Weight Management Pilot

In 2021, Birmingham City Council Public Health used a government grant to pilot new adult weight management programmes for people with a learning disability, sensory and mobility impairment. Lifestyle company Beezee Bodies were commissioned to develop a bespoke 12-week programme that included one-to-one support and advice around diet, exercise, and mental and physical health. The programme was co-created with people with learning disabilities, sensory and mobility impairment, as well as carers and healthcare professionals, and was delivered in both home and community settings.

149 of the 167 adults recruited to the programme completed it and 88% of all participants lost weight. There was a 44% increase in average mental wellbeing score from before and after the programme and all participants increased the number of days they did physical activity – going from 0.2 days at the beginning of the programme to an average of 3 days per week at the end.[326]

## 4.10 Services for Carers and Families

> ***"I see [my mother] about once a month when my carer books it for me. He books it and drives me there and supports me. The dementia has taken hold of her and its upsetting for me to see her. I'm quite worried about her. I would like to go at weekends to see her, that would be better. My carer books it, I don't know why I can't go more often."***
>
> Birmingham citizen living with learning disabilities.

> ***"My experience of seeking social support was vile! I feel completely answerable to Birmingham City Council, which is quite frankly degrading, and I feel like they work against me rather than with me, which is ironic given that's what they're designed to do."***
>
> Birmingham parent.

There are approximately 2,000 carers with learning disabilities in Birmingham. CASBA Advocacy provide a unique service, supporting carers in Birmingham who have learning disabilities.[327] CASBA work in partnership with the Alzheimer's Society and Mencap and are exploring a national rollout of further work based on this pilot.[328-329]

Forward Carers is a West Midlands based carer and family support organisation.[330] Their local Birmingham Carers Hub provides a range of services, including a *Young Adult Carer Service*,

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[326] Birmingham and Solihull Integrated Care System. A Bolder Healthier Future for the People of Birmingham and Solihull: Strategy for Health and Care 2023-3033. Accessed Aug 2023.

[327] CASBA. Supporting carers with learning disabilities. Accessed Feb 2024.

[328] Information provided directly from CASBA advocacy. Accessed Feb 2024.

[329] Alzheimer's Society. Supporting Dad after his dementia diagnosis as a person with a learning disability. Accessed Feb 2024.

[330] Birmingham Carers Hub. Accessed Aug 2021.

delivered by YMCA Sutton Coldfield and the *Carers Emergency Response Service,* providing emergency care. Birmingham Carers Hub also undertakes carer assessments on behalf of Birmingham City Council, and in 2019 provided over 1,000 of these across their locations. Other services include training for carers, parent carer support, and carer support groups.[331]

The Birmingham Parent Carer Forum is run by parents of children on the SEND register. It provides links with Social Care, Health and Education for parents, helping to support parents to negotiate the system and obtain support and help where needed. The forum is available to anyone with a disability on the register, including those living with a learning disability.[332]

## 4.11 Advocacy Services

*The Birmingham Advocacy Hub* is a partnership between POhWER, Advocacy Matters, East Birmingham Collective and deafPLUS. This Hub delivers a range of advocacy services, including Care Act Advocacy, Community Advocacy, NHS Complaints Advocacy, Independent Mental Health Advocacy and Peer Advocacy.[333]

CASBA Advocacy is an independent advocacy service for people with learning disabilities in South Birmingham. CASBA provide self and peer advocacy groups, one-to-one advocacy, training, and workshops.[334] They also provide *Pregnancy to Parenthood* which works to reverse the trend to remove children of parents who have learning disabilities into statutory care, by ensuring that parents have access to the right information and help, to support their ability to parent.

## 4.12 Services Supporting Parents with Learning Disabilities

CanDo Doulas supports parents with complex needs throughout pregnancy to birth and post birth in the West Midlands. CanDo work with qualified doulas to deliver practical and emotional support to parents during this time who are faced with challenging circumstances, including finances, housing issues, domestic violence and vulnerable adults.[335]

Dudley Lodge is a family assessment centre providing safeguarding services in Coventry and Birmingham. They provide family assessments, place of safety placements and protective behaviour programmes for children. For parents with learning difficulties, a Parent Assessment Manual (PAMS) assessment is offered. This helps to identify specific areas of parenting which require support, that is delivered with visual aids, addressing issues in small steps and breaking down tasks.[336]

Working Together with Parents Network support professionals who work with parents who have learning difficulties or disabilities, in addition to their children. The network is UK-wide and allows professionals to share good practice across four regional groups in England.[337]

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[331] Forward Carers. Impact Review 2019. Accessed Aug 2021.
[332] Birmingham Parent Carer Forum. What is Birmingham parent carer forum. Accessed Dec 2021.
[333] POhWER. Birmingham Advocacy Hub. Accessed Nov 2021.
[334] Information supplied directly from CASBA. Accessed Sep 2022.
[335] CanDo Doulas CIC. About Us. Accessed Sep 2022.
[336] Dudley Lodge. Parenting Services. Accessed Sep 2022.
[337] University of Bristol. Working Together with Parents Network. Accessed Sep 2022.

# 5 Lived Experience

Birmingham City Council commissioned lived experience research for this deep dive because it is important to involve the local population, whose needs are being assessed.

Targeted lived experience research was carried out with three groups of citizens living with learning disabilities, two groups of carers and two groups of healthcare professionals:

- **Citizens with Learning Disabilities and Autism** - This targeted focus group was organised by staff at the Hockley Day Centre. Eleven citizens with learning disabilities and autism participated in the focus group. Six of the participants were male and five were female, and all are regular visitors to the Hockley Day Centre.
- **Black and Ethnic Minority Citizens with Learning Disabilities** - This targeted focus group was organised by staff at the Hockley Day Centre. Twelve citizens with learning disabilities from black and ethnic minorities groups participated in the focus group. Four of the participants were male and eight were female, and all are regular visitors to the Hockley Day Centre.
- **Day Centre Staff** - A structured questionnaire was circulated by email to staff throughout Birmingham City Council's day service centres. The purpose of the questionnaire was to gain an insight into how professionals view the day service and where they believe gaps exist and improvements could be made. There were twenty-five staff respondents from a range of job roles, including managers, drivers and care assistants.
- **Parents of Children who have Learning Disabilities** - This targeted research group was organised by Midland Mencap. Five citizens who are parents of children with learning disabilities participated in structured interviews. One of the participants was male and four were female.
- **Parents of Adult-Children who have Learning Disabilities** - This targeted research group was organised by Midland Mencap. Five citizens who are parents of adult-children with learning disabilities participated in structured interviews, all of whom were female. Also, seven parents participated in a focus group where there was one male and six females.
- **Parents who have Learning Disabilities** - This targeted research was organised by Midland Mencap. Five women participated in this research, two through individual interviews and three through a focus group.
- **Healthcare Professionals who work with Parents who have Learning Disabilities** - This targeted research was organised by Midland Mencap. Four professionals who work alongside parents with learning disabilities participated in the focus group and an additional professional was interviewed separately, using a structured questionnaire. This included four females and one male.

The research team recognise that not all views were able to be represented below, and we therefore recommended future work be undertaken to continue to hear the voices of diverse groups with unique needs, including citizens with learning disabilities who are LGBTQ+, citizens who have experienced transition (e.g., educational transitions, transitions between hospital and community settings, and transition from child to adult services) and citizens with both learning disabilities and sensory impairment which the research team were unable to commission for this report.

## 5.1 Summary of Lived Experience of Citizens Living with Learning Disabilities

### 5.1.1 Health and Wellbeing

Many of the citizens who took part in the focus groups and interviews experienced comorbidities with other conditions. Examples include anxiety, diabetes and epilepsy. Some parents noted that their own health conditions can make caring more difficult.

Experiences of accessing primary care were mixed. Some citizens reported experiencing reasonable adjustments, which made a big difference. *"The doctor gave me time, listened to me and my dad."* Another citizen said, *"My surgery has put a note on my file to only be seen by the same nurse I feel comfortable with each time."* Differences were seen between professionals: *"Our regular GP makes an effort to talk to my daughter, whereas others don't make that effort."*

Conversely, some participants reported a lack of reasonable adjustments or communication adaptations by some professionals. *"They talk to me, and I end up having to say, 'she's there' and 'she's old enough to understand herself' which really frustrates me."* One citizen identified that talking on the phone was a barrier to accessing appointments: *"I find I get really anxious trying to talk over the phone. I prefer seeing people face to face, but most appointments have been over the phone which puts me off going."* Some parents felt GPs had become better over time at making reasonable adjustments. Suggestions to improve access to healthcare included shorter waiting times and more access to information.

Two citizens with learning disabilities discussed their experiences of maternity care, with both suggesting varying experiences between their births and a need for more information and support throughout their pregnancies and births. *"My experiences of maternity were terrible with the first child - I was only 17, and with my disability to add, they treated me like a child. They expected me to listen, and do things, and they didn't want to help. They wouldn't answer any of my questions."* Another participant said *"Everything was ok with the first 2 children, but my third one caused lots of problems. Felt like they ignored me a lot of the time, and any information they gave me was difficult to understand."*

Citizens reported that children and adults with learning disabilities are restricted in their ability to participate in groups, clubs and activities. Many felt that learning disabilities is an *"invisible"* condition, which contributes to the lack of general public understanding.

### 5.1.2 Education and Employment

The citizens reported mixed experiences of education. Some citizens described negative experiences of school, particularly prior to receiving a diagnosis. Citizens described children with learning disabilities being labelled as *"naughty"* or *"difficult"* at school. In particular, some parents noted difficulties with schools during periods where their child did not have a diagnosis. *"Yes, my son loved school, but his first 2 years of secondary school were difficult until he got diagnosed."* Another parent said, *"since my son had his diagnosis last year, the school have been a whole lot more helpful. I really pushed to get my son's diagnosis to get him the support he needs and is entitled to."* This demonstrates how the transition from not being diagnosed to having a diagnosis can open up support and help from education services. This may also point to a gap in service provision for children without a formal diagnosis.

Parents noted a need for more transparency and choice around school support. Some have experienced long waiting lists and only received support when fought for. However, experiences of schools were positive for some.

Some parents of adult children reported wanting more educational opportunities for citizens who have transitioned beyond 25 years. *"Further education beyond the age of 25 [and] more awareness from the council that a lot of people with a learning disability maintain a really young mental age throughout their lives and need consistent education to ensure their minds are still active."*

Most citizens were not in employment or voluntary roles, but adult education opportunities were viewed as desirable. However, the process of gaining employment or voluntary roles was regarded as difficult. Two parents reported that their adult-children had volunteer roles at college or with local charities. One parent noted that it was *"difficult getting him into work"*, referring to their adult-child. Another parent noted that her child had enjoyed their apprenticeship, but that the workplace needed more awareness of how to support them in their job. Some citizens felt they could not work; *"I had a short-term role in childcare but was told I wasn't good enough for the role because of my [health condition]."* Others were unable to work, due to health or care reasons.

There were many suggestions about how to improve support in accessing employment, including support in accessing computers, and job application forms being provided in Easy Read. *"I tried when I was younger and couldn't fill in the form."* Another participant said *"I can fill in forms to a certain extent, but as soon as they get too wordy, I really struggle. It's affected my confidence with applying for jobs."* Some participants also noted the importance of employers being disability aware.

### 5.1.3 Services

Parents' experiences of seeking social care support for their children with learning disabilities were generally negative. Examples included information being difficult to access and the application process being lengthy and complex. Parents felt it was difficult to get support and that the information was not easy to access. Some described it as *"jumping through hoops",* feeling *"fobbed off"* and *"not being listened to."* Applying for funding was seen as very difficult and described as *"fractured- very stop/start."* Parents noted difficulty filling in the forms, particularly where their English was not good.

One parent described struggling for support. *"I'm constantly having to fight for support my son needs."* Another parent noted the need for more information; *"far more readily available information of all the help and support that's available that my son is eligible for, instead of having to constantly dig and fight for what's needed."* Parents felt having a shorter and easier process of organising and applying for funding for their child would be helpful.

Furthermore, waiting lists for services were described as too long. *"I feel like waiting lists go on forever. I essentially feel forgotten about."* When a place becomes available, parents can feel that they do not want to share this information with others out of fear of the service becoming overstretched. *"Feel like you don't want to tell others about what support is available in fear that resources will be overstretched, and you'll lose out on the support."*

Some parents reported good experiences of transition from children's to adults' social services, and felt supported in this. One parent who had a positive experience of transition, described it as *"lucky."* *"I was very lucky - had a lot of support and help with transition."* For others, transition from child to adult services was described as a particularly difficult time for families. Transition from child to adulthood felt like being *“thrown off a cliff.” “There’s no transition from childhood to adulthood. As soon as my child became an adult, she was made invisible.”*

Citizens recognised that when support is received, it is welcomed and enjoyed, but the criteria for some services can be a barrier to entry. Some parents felt that the activities their child could attend were limited. *“Very restricted to only being able to take part in activities that are specifically designed for people with special educational needs.”* Another participant said*, “I’d love to see age-appropriate exercise classes for people with disabilities.”* Citizens attending day centres reported wanting to attend clubs or local groups, but not doing so at present. Conversely, some citizens reported positive experiences of being out in the community*. “I go out to the shops with carer, it is nice, and I don’t have any problems.”*

Citizens identified a need for more services for adults with learning disabilities. Many citizens with learning disabilities did not have clubs or local groups to attend outside of their day centre. Also, most did not have friends to socialise with outside of other clients at the day centre. Transport was viewed as a barrier to going out for social events. One citizen reported being reliant on a parent for transport which limited their opportunities to go out on evenings; “*since my dad does not drive at night, I can’t find anyone to pick me up.”*

Citizens reported that more information about available support and services is desired, particularly for families with English language difficulties. Resource centres in the local area could support families in finding information and support. Applying for financial support was viewed as a complicated and disheartening process but could be improved with help in filling out forms.

### 5.1.4 Home and Family

Many citizens with learning disabilities received support with daily tasks, either from support workers or family members. Most citizens did not use public transport when going out, but instead relied on family members with cars. One citizen reported being reliant on a carer to visit their mother who had dementia. *“I see her about once a month when my carer books it for me. He books it and drives me there and supports me. The dementia has taken hold of her and its upsetting for me to see her. I’m quite worried about her. I would like to go at weekends to see her, that would be better. My carer books it, I don’t know why I can’t go more often.”*

Parents who were carers received mixed levels of support from services and family/friends, and parents generally felt they did not receive enough support as carers. Parents reported challenges in *“looking after themselves”* and *“never knowing what the day is going to bring behaviour wise.”* Others felt that a difficulty of being a carer was getting the right support for their child. Parents with learning disabilities also reported needing more support, particularly with childcare.

Some citizens that live in supported living reported positive experiences, due to being able to make independent choices.

Some parents had no plan in place for when they would no longer be able to care for their adult child with learning disabilities. Parents felt there was a lack of support and clarity around planning for the future. *“Would need to know daughter is safe, know someone is fighting her corner, know she’s being listened to, and knowing she’ll always have somewhere to call home.”*

### 5.1.5 Impact of COVID-19

There were mixed experiences of lockdown for families. Some citizens reported the difficulty of being separated from wider family and feeling *“frustrated because routine had changed.”* However, others reported that the lockdowns enabled more family time. One parent commented *“I survived well.”* Citizens also noted that some services had returned to *“normal”*, but others hadn’t.

## 5.2 Summary of Lived Experience of Professionals

### 5.2.1 Inequalities

Professionals noted the lack of accessible information for people with learning disabilities. *“Social barriers - society isn’t set up for people with a learning disability- things like transport, reading letters and so on.”*

Professionals also noted the need for more support during the transition period to adult services. The transition period from childhood to adulthood was described as *“like a cliff edge.”* Professionals noted that if you don’t have a good support system (e.g., parents who can fight for what’s needed), those people will be forgotten about.

Inequalities experienced by people with learning disabilities that staff identified, included public attitudes resulting in social exclusion, discrimination by society and a lack of accessible transport. *“I think the key factors people with learning disabilities face are public ignorance and public lack of education and understanding.”* Another professional noted; *“the key inequality I see is accessibility via transport.”*

Some respondents noted that people with learning disabilities are not visible to the general public, leading to exclusion from everyday life. *“People with disabilities should have key visible roles and should have an input on the decisions that affect them.”*

### 5.2.2 Education and Employment

Staff identified a gap between day services and employment, with not enough opportunities for people to develop employment skills. *“There is a big gap in transition from day services to employment. Citizens should have the opportunity to learn skills for the job they wish to apply for, and staff who know them well should be allowed to support them.”* Respondents said that teaching employable skills at the centre or allowing staff from the centre to support people with learning disabilities would boost their confidence and trust.

They noted that opportunities for education and placements had reduced over time and that more employment opportunities for people with learning disabilities are needed. Furthermore, education should focus on practical skills over academic skills, and employers need more awareness about making reasonable adjustments.

### 5.2.3 Staff Experiences

Staff identified difficulties with staff capacity and service budgets. *“Lack of resources is probably the biggest gap; we are expected to provide a first class service with hardly any resources.”* Staff perceived a lack of adequate staff capacity within their services and while training was perceived as adequate, there were barriers to further training, including a need to have enough staff at any one time and a lack of computers available.

However, most staff felt they were supported in their roles. *"I do get support and feel I have a good staff group around me. Dealing with bereavements, early onset dementia, and challenging behaviour can sometimes take their toll, so emotional support is very important."*

### 5.2.4 Service Provision

Staff reported that service provision is hindered by a lack of resources and investment, and by staff turnover, whilst there is also a lack of coordination between services. *"A person with a learning disability has to repeat their story over and over because the crossover between different services isn't good enough."* Face to face contact, information in multiple languages and joined up working, were all suggestions to improve service provision.

Professionals noted that there should be more support for parents and carers. *"More support for parents and carers to enable them to do a better job at supporting the child or adult with learning disabilities."*

More opportunities for social activities are needed for people to feel included, in particular for people with mild learning disabilities. One professional felt there needs to be *"a good range of options for activities [that] service users can get involved in, that are meaningful and can give a sense of pride too, such as work experience, and aim high for people with a learning disability."*

However, staff also provided examples of good practice, such as tailoring care to the individual. Furthermore, day centres were reported to be places providing good support to citizens. *"There are many with dietary needs, hoisting needs, and other disabilities, that only get sorted at the centre."*

### 5.2.5 Impact of COVID-19

Positive impacts of the pandemic include having smaller groups, which allows staff to provide services which are more personal. Health and safety being a priority was also identified as a positive impact. However, a deterioration in mental health for some clients was a negative impact and staff shortages are a continuing problem since the pandemic. Healthcare was felt to be inadequate during the pandemic. *"Healthcare provision wasn't up to scratch."*

***"There is not enough support and recognition from managers outside the day centre. They need to visit more and see the good work the staff are doing."***

Birmingham health professional.

***"I do get support and feel I have a good staff group around me. Dealing with bereavements, early onset dementia, and challenging behaviour can sometimes take their toll, so emotional support is very important."***

Birmingham health professional.

# 6 Opportunities for Action

This section identifies areas of need, to be addressed through commissioning or other actions by local organisations.

## 6.1 What Would We Like to Achieve?

The aim of this deep dive report is to establish an evidence base to inform actions to reduce inequalities in outcomes experienced by those living with learning disabilities. This includes supporting the *Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change (2022-32),* through identifying the level of need in the population, and the gaps and barriers in service provision. A broad range of evidence has been used to explore the needs of citizens living with learning disabilities in Birmingham. This evidence shows the work being carried out to support the needs of these populations, and the vast array of services that are available across the city. Nevertheless, there are gaps in data, gaps in service provision and ultimately there continues to be unmet need and inequalities for these people.

This chapter will outline the key findings of this deep dive and will provide key recommendations for each of the findings, which hope to address the areas of unmet need for these groups. Focused work on the wider determinants of health among people with learning disabilities will support the reduction of health inequalities and enable these citizens to live well in the community.

## 6.2 Key Findings and Recommendations

Here we set out the key findings from this deep dive and make recommendations as to how local partners can help us achieve positive change.

Key Finding 1: There is demand for strengthening the ‘whole system approach’ for coordinating and supporting the health and wellbeing of citizens living with learning disabilities.

Key Finding 2: There is currently insufficient data to gain a full understanding of the size and needs of the local learning disabilities population.

Key Finding 3: There are opportunities in frontline healthcare to improve identification and assessment of citizens living with learning disabilities.

Key Finding 4: There is demand for improved learning disability services, through person-centred and consistent care across the city.

Key Finding 5: There is a need for more research to support the evidence base around health inequalities for citizens living with learning disabilities.

## 6.3 Key Finding 1: There is Demand for Strengthening the ‘Whole System Approach’ for Coordinating and Supporting the Health and Wellbeing of Citizens Living with Learning Disabilities.

> ***“Organisations need to be better connected to help spread awareness of the help and support that’s out there.”***
>
> Birmingham health professional.

In Birmingham, there is a gap concerning a whole system approach to learning disabilities. A whole system approach involves identifying the components of a system and evaluating links and relationships between each of them. The complexity of the multifactorial drivers of societal and health problems associated with learning disabilities indicates that a whole system approach is needed, supported by a joint commissioning framework. Rather than focusing on an individual’s circumstances separately and providing support in an isolated fashion for each issue, a whole system approach provides a contextual perspective which incorporates all societal and healthcare levels when considering a person’s learning disabilities. This is particularly important because the city’s population continue to navigate challenges and inequalities intensified through the COVID-19 pandemic.

Placing the individual at the centre of this approach acknowledges their needs, capabilities, beliefs, behaviours and motivations. These are generally already considered and should continue to be the focus of healthcare and support. However, the whole system approach should progress this model and look to understand how the social environment (e.g., relationships, families, social networks and support groups), organisations (e.g., schools, health care, charities and clubs), physical environment (e.g., transport, housing, built and green spaces), and policy around individuals influence their health, wellbeing, support and care.

This deep dive has identified an absence of an accreditation scheme for primary care providers in Birmingham, which would support a whole system approach including allowing a pathway for further training to occur. The Southern Health NHS Trust’s *Learning Disability Friendly Award Scheme* provide good practice guidelines for primary care staff and would potentially provide a template for a similar scheme in Birmingham.

The evidence suggests that there are large inequalities across many domains and stages of life for citizens with learning disabilities, including education, housing, employment and healthcare. Further work is needed to address these, supported by a joint commissioning framework with a shared vision across health and social care for citizens with learning disabilities. To address the gaps in services and available support, and to increase ownership and coordination of services, we recommend:

| Number | Recommendation |
|---|---|
| K1.1 | A ‘learning disabilities friendly’ GP accreditation scheme to be taken on board which can take forward the recommendations around training of staff (e.g., Oliver McGowan training and notifying patient deaths to the LeDeR programme). Other functions of this scheme include improving data collection, consistency of services, promoting adverse weather advice, raising awareness of the importance of cancer screening among patients with learning disabilities and their carers, and the development of a network of primary care learning disability champions who will support these functions. |
| K1.2 | Prisons in the local area to identify a learning disability champion to raise awareness of learning disabilities in prison, train staff and support prisoners. |
| K1.3 | A standardised hospital passport be agreed and utilised across the West Midlands, which includes a DNACPR decision instruction. |
| K1.4 | Improve information sharing between professionals where appropriate to communicate about diagnoses of learning disabilities, communication needs, and reasonable adjustments required (e.g., hospital passport and suitably updating medical records held by the GP). |
| K1.5 | Holistic support for parents with learning disabilities in the preparation stages before parenthood and throughout to develop parenting skills and support the wider needs of the family. |
| K1.6 | A whole system approach to supporting the development of employment skills for citizens with learning disabilities is required, including employment skills development in day service opportunities and formally supported employment programmes. This needs to be underpinned by partnerships with third sector, commercial and voluntary organisations, to increase employment opportunities. |
| K1.7 | Consideration to an Easy Read website being developed and maintained to provide a user-friendly web directory of available learning disabilities services within Birmingham. This could potentially be built upon existing website infrastructure (e.g., the all age autism service directory). |
| K1.8 | Action to ensure that citizens with learning disabilities have access to affordable long-term housing, which is safe and comfortably habitable, enabling these individuals to live well in the community. This should include options around housing for citizens. |
| K1.9 | Continue to support the areas of priority identified in the Birmingham and Solihull LeDeR programme 3-year strategy and raise awareness of the LeDeR programme locally. (See section 1.7.7) |
| K1.10 | Integrated care systems to work collaboratively with local authorities, within a joint commissioning framework. Joined up processes throughout health, education and social care systems will support a holistic approach. Interagency teams between education, health and social care services to facilitate coordinated support across these sectors. |

| | |
|---|---|
| K1.11 | Continued emphasis on citizens with learning disabilities to be identified in priorities as part of CORE20PLUS5 model. |

### 6.3.1 What Next?

The authors of this Learning Disabilities Deep Dive have worked with stakeholders from across Birmingham's healthcare system, services and voluntary sector and listened to the voices of lived experience to produce the report's recommendations. The following table outlines the stakeholders, who have agreed to take forward each of the report's recommendations concerning Key Finding 1.

| Number | Action to be Taken |
|---|---|
| K1.1 | To be taken forward by the Birmingham & Solihull Integrated Care Board. |
| K1.2 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K1.3 | To be taken forward by NHS Birmingham and Solihull. |
| K1.4 | To be taken forward by NHS Birmingham and Solihull. |
| K1.5 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K1.6 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K1.7 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K1.8 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K1.9 | To be taken forward by the Learning Disabilities and Autism Transformation Programme Lead in Adult Social Care, Birmingham City Council. |
| K1.10 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K1.11 | To be taken forward by the Birmingham & Solihull Integrated Care Board. |

## 6.4 Key Finding 2: There is Currently Insufficient Data to Gain a Full Understanding of the Size and Needs of the Local Learning Disabilities Population.

The lack of available data, which is detailed, accurate, local, and complete, makes it difficult to fully understand the needs of people living with learning disabilities in Birmingham.

More data on substance misuse is required to understand the inequalities and unmet need in this area. Similarly, there was a lack of available data relating to how many people with learning disabilities have contact with the criminal justice system. A lack of data on these topics were barriers to providing a full picture of need.

Valuable information regarding people living with learning disabilities was provided by the *Health and Care of People with Learning Disabilities dataset*. While this was available at CCG level, it did not cover 100% of GPs in the area. Furthermore, data exploring the number of inpatients with learning disabilities and/or autism was available nationally (through the *Mental Health Services dataset*), but not locally. Similarly, national data provided an understanding of how NHS trusts perform against the learning disability improvement standards. However, a local view of this is needed. These gaps lead to challenges in presenting a whole picture of need in Birmingham.

Anonymised Birmingham GP data (accessed through the ICB) was useful to the authors of this deep dive report in understanding the age, gender and ethnicity of local citizens with learning disabilities, registered with Birmingham GPs. It would be helpful if routine data could also include demographic and familial data (outlined below) and also be made available to public health researchers and LeDeR reviewers. This would improve our understanding of the needs of specific groups, such as citizens with learning disabilities from ethnic minority backgrounds, citizens from LGBT+ communities, and those who may have parents with learning disabilities.

Service providers (including healthcare, education, employment, transport and charities) should provide a consistent approach to collecting data for individuals with learning disabilities (e.g., age, gender, ethnicity, co-morbidities and sexual orientation), which would highlight gaps in care and enable improved service provision. Routine data should also be expanded to include demographic data (e.g., age, gender, ethnicity, disability and sexual orientation) for individuals with learning disabilities. This should be made available for public health analysis at a lower geographic level (e.g., ward level).

The authors of this deep dive report recognise that data are often limited in availability and as such do not account for or show intersectionality or comorbidities. This is due to significant limitations in currently available data and is included in the recommendations section as an area for future research to explore.

These gaps limit the ability to present a comprehensive picture of prevalence in Birmingham, thus also limiting our knowledge of where there may be need. Understanding the demographic profile by ward or constituency would enable an analysis of wider determinants of health in more depth, for example by comparing deprivation with prevalence across the city.  As can be seen throughout this chapter, citizens with learning disabilities consistently show poorer health outcomes than the general population. Furthermore, data shows that people with learning disabilities are less likely to access the healthcare services that they are entitled to. Further research to understand barriers to these services for those living with learning disabilities in Birmingham would help reduce these inequalities.

A whole system approach (outlined above) would enable the facilitation of data recording and identification across primary care services working with citizens living with learning disabilities.

To improve our understanding of the local learning disabilities population, we recommend that:

| **Number** | **Recommendation** |
|---|---|
| K2.1 | GPs be more proactive in identifying citizens with learning disabilities within their practice populations, and record it on the QOF register, regardless of the patient’s age. |

| | |
|---|---|
| K2.2 | Read Code flags be used to identify parents with learning disabilities, the children of parents with learning disabilities and parents of children with learning disabilities. |
| K2.3 | Develop and share data across our system to shape further our future commissioning priorities and data should be made available for public health analysis. |
| K2.4 | In accordance with LeDeR recommendations, future JSNAs should publish data on the needs of citizens with learning disabilities, with particular attention to inequalities between ethnic groups. |
| K2.5 | Local data to be consistently gathered around how Birmingham performs against the NHS Learning Disability Improvement Standards. |
| K2.6 | To utilise a primary care read code to identify patients with learning disabilities with substance misuse, enabling an accurate prevalence to be created. In addition to this, service providers to continue recording citizens with LD who are undergoing treatment. |
| K2.7 | Routine data should also be expanded to include demographic data (e.g., age, gender, ethnicity, disability and sexual orientation) for individuals with learning disabilities. |
| K2.8 | The Cabinet Member for Health and Social Care to write a letter to the Health Secretary to lobby for cancer screening databases to include learning disability flags, letters to be produced in Easy Read and to pilot the effectiveness of using these in follow-ups and with non-responders. Aligned to this, the Director of Public Health to take similar action with OHID. |

### 6.4.1 What Next?

The authors of this Learning Disabilities Deep Dive have worked with stakeholders from across Birmingham's healthcare system, services and voluntary sector and listened to the voices of lived experience to produce the report's recommendations. The following table outlines the stakeholders, who have agreed to take forward each of the report's recommendations concerning Key Finding 2.

| Number | Action to be Taken |
|---|---|
| K2.1 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K2.2 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K2.3 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K2.4 | To be taken forward by Birmingham City Council Public Health. |
| K2.5 | To be take forward by NHS Digital. |
| K2.6 | To be taken forward by Change Grow Live. |
| K2.7 | To be taken forward by the Birmingham & Solihull Integrated Care Board. |
| K2.8 | To be taken forward by the Cabinet Member for Health and Social Care and the Director of Public Health. |

## 6.5 Key Finding 3: There are Opportunities in Frontline Healthcare to Improve Identification and Assessment of Citizens Living with Learning Disabilities.

> ***"People say he doesn't 'look' like he has anything wrong with him'. 'Not understanding, they say a lot of disabilities are hidden, and I think people with a learning disability are side-lined because people assume a disability has to be visible."***
>
> Birmingham parent.

> ***"There's no support for professionals to be able to gain knowledge and information to then provide effective support for people with learning disabilities."***
>
> Birmingham health professional.

Knowledge and awareness are key to any role which contributes to the care and support of individuals with learning disabilities. This allows caregivers and support staff to meet individuals' needs, further identify new cases, and understand those already known. Research collated in this deep dive exposes the unmet training needs of health and social care staff. More training is required for those supporting and caring for people with learning disabilities, both in terms of raising awareness of learning disabilities, and training in recognising and identifying these conditions.

There is a need for frontline healthcare professionals to be able to be proactive in identifying learning disabilities among those who access their services and to clearly record on medical records whether someone has a diagnosis. This is particularly important due to Public Health England's estimate that only 23% of people with a learning disability are recorded on their GP's QOF register. This will provide the dual benefit of providing access to accurate local data and will enable the needs of these individuals to be met by these services. It should be the collective responsibility of all services to ensure staff are adequately trained to identify those with possible learning disabilities and record any reasonable adjustments needed.

We recognise that a whole system approach would be required to improving identification and assessment of citizens with learning disabilities and that this would be supported by widespread uptake of recognised training such as the Oliver McGowan training. Uptake of this training by frontline staff across Birmingham City Council services (e.g., adult social care), cancer screening services and community services (e.g., sexual health services) will support an increased understanding of learning disabilities among staff. In addition to this, there may also be an opportunity for the training to be undertaken to raise awareness in wider staff teams (e.g., Birmingham City Council employees).

Raising awareness of the LeDeR portal for notifying deaths of citizens with learning disabilities will support more professionals from health and social care to use this. Improving the reporting of the deaths of all citizens with learning disabilities will allow for improved understanding of the health inequalities experienced by these citizens.

To improve identification and assessment of learning disabilities we recommend that:

| Number | Recommendation |
|---|---|
| K3.1 | Support system-wide rollout of the Oliver McGowan training (including reporting of patient deaths to the LeDeR programme, and other recognised training) to health, social care, emergency services, criminal justice system staff, and healthcare staff responsible for cancer screenings. This will raise awareness and understanding of learning disabilities, so that staff can identify citizens more quickly. |
| K3.2 | Reciprocal training for frontline staff working with citizens with a learning disability to be aware and able to identify domestic abuse, and staff working with people who have experienced domestic abuse to be aware and able to identify learning disabilities. |
| K3.3 | To sustain the increase in access to quality health checks (in accordance with the Birmingham Health and Wellbeing Strategy), and to ensure consistent quality of these. |
| K3.4 | Raise awareness among professionals of wider health and support needs (e.g., health conditions, mental health needs, experience of domestic abuse or ‘mate crimes’). |
| K3.5 | The LeDeR programme to raise awareness of their portal for reporting the deaths of citizens with learning disabilities. |

### 6.5.1 What Next?

The authors of this Learning Disabilities Deep Dive have worked with stakeholders from across Birmingham’s healthcare system, services and voluntary sector and listened to the voices of lived experience to produce the report’s recommendations. The following table outlines the stakeholders, who have agreed to take forward each of the report’s recommendations concerning Key Finding 3.

| Number | Action to be Taken |
|---|---|
| K3.1 | To be taken forward by Paddie Murphy (Bham Community Healthcare Trust on behalf of the BSOL ICS). Furthermore, the Oliver McGowan training will also be taken up by Change Grow Live, Adult Social Care, Umbrella and by professionals working within educational travel. |
| K3.2 | To be taken forward by the Learning Disabilities and Autism Transformation Programme Lead in Adult Social Care, Birmingham City Council. |
| K3.3 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |

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|---|---|
| K3.4 | To be taken forward by the Learning Disabilities and Autism Transformation Programme Lead in Adult Social Care, Birmingham City Council. |
| K3.5 | To be taken forward by the LeDeR Programme. |

## 6.6 Key Finding 4: There is Demand for Improved Learning Disabilities Services, through Person-Centred and Consistent Care Across the City.

> ***“Our regular GP makes an effort to talk to my daughter, whereas others don’t make that effort. They talk to me, and I end up having to say, ‘she’s there’ and ‘she’s old enough to understand herself’ which really frustrates me.”***
>
> Birmingham parent.

> ***“People with disabilities should have key visible roles and should have an input on the decisions that affect them.”***
>
> Birmingham health professional.

The life expectancy of citizens with learning disabilities is lower than the general population, as is the expected number of years lived in good health. Furthermore, citizens with a learning disability are more likely to experience a range of comorbidities, including mental health conditions, and conditions such as epilepsy, asthma, hypothyroidism and diabetes, having lower levels of physical activity, as well as being less likely to access routine cancer screenings. While good work is being done within the health sector to reduce the overmedication of people with learning disabilities (e.g., STOMP), the data we have presented still highlights inequalities, showing that more work is needed in this area. With the recent experience of the COVID-19 pandemic, inequalities for citizens living with learning disabilities have been intensified further and work to address these is required.

The evidence presented in this deep dive points to an unmet need for improved services to tackle these health inequalities and to provide consistent and high-quality care in all areas of the city, including continuity of care. This can be facilitated through the uptake of a primary care scheme to support services in their development, which has been previously mentioned. This could enable a network of learning disability champions across the city to be developed, which could work towards improving services through partnership working.

One aspect of service improvement that is needed is continuity of care, particularly during times of transition (e.g., when someone moves between a hospital and community setting or when transitioning to adult services). Improved service coordination may mean citizens do not need to repeat their story multiple times and that services are equally accessible city-wide. There is a need to improve the EHCP process and waiting times for SEND services, such as EHCP applications and SEND therapists. These may be achieved with alignment to the changes outlined in the SEND and Alternative Provision (AP) Improvement Plan (2023).[338] Similarly, Universal Credit applications require simplification for citizens who need additional support. One way to improve service coordination may be through co-production.

Another is through improving systems and processes which are lengthy, complex and difficult to navigate for citizens living with learning disabilities. Research suggests that the Universal Credit system is difficult to navigate, and that there are barriers to entering employment, which stem from the application process. Citizens attending day centres and young people with SEND may be well-placed to be supported in developing employment skills. Improving these systems would support greater independence and opportunities among citizens, reducing inequalities. This deep dive has also explored opportunities for improvements in accessible communication, through the use of Easy Read and video formats. The use of these could be expanded to provide information around accessing and using key locations within the community (e.g., hospitals), and to support independent travel (e.g., when using train stations and airports).

Person-centred care should also recognise the unique needs of citizens, such as those identifying as LGBTQ+, those with mental health problems, or those with community language requirements. This includes reasonable adjustments, communication adaptations and equipping staff with the knowledge to recognise where these are needed. While some services are providing patient focused care, this is not the case everywhere and further work is needed to embed this within everyday practice. Furthermore, the needs of specific groups require further attention, including citizens with a learning disability from an ethnic minority background, parents with learning disabilities, and LGBTQ+ citizens with learning disabilities. Experts by experience should be involved in co-producing services at every level to help develop patient focused care.

With the understanding that some groups may have specific needs, we recommend that specific services are developed to support those with learning disabilities who are from a minority ethnic background, as well as those with learning disabilities who are LGBTQ+. Other services of benefit may be substance misuse services for people with learning disabilities, parental services for parents with learning disabilities and services supporting people with both learning disabilities and autism. The development of specialist services should be informed by local research. Services may find it helpful to undertake an annual audit of protected characteristics including learning disabilities and how they are meeting this need.

In July 2023, Birmingham City Council's cabinet approved the provision of the Independent Travel Training Programme across Children's services, and the provision of travel support to programmes promoting travel independence to clients of Adult Social Care services.[339] Continuation of this will support citizens living with learning disabilities of all ages to learn independent travel skills.

Services play a large role in reducing inequalities and our recommendations aim to prevent there being gaps in learning disabilities service provision across the city. This work on improving services requires the whole system approach to be impactful.

To improve learning disabilities provision, we recommend:

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[338] HM Government. (2023). Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan. Accessed Jun 2024.

[339] Birmingham City Council. Children and Young Person's Travel Service. Accessed Nov 2022.

| Number | Recommendation |
|---|---|
| K4.1 | To support children with SEND into adulthood. Align local practice to the national guidance on supporting children and young people through transition. |
| K4.2 | Attention to be paid to ensure information about services is accessible to those with a learning disability (e.g., Easy Read and other accessible formats). |
| K4.3 | Existing services should be adapted, and new services should be developed for groups with specific needs such as citizens from the LGBTQ+ community and those with community language preferences. This should be aligned with findings from local research. |
| K4.4 | Review the findings and learning from the Pregnancy to Parenthood Project (CASBA), with a view to making the pathway a city-wide offer. |
| K4.5 | The mental health needs of citizens with learning disabilities should be recognised and identified. Services should recognise that citizens with learning disabilities may require in-person appointments in order to meet communication needs. |
| K4.6 | Breast and bowel cancer screening services to be able to rapidly provide cancer screening information packs in Easy Read to patients with learning disabilities, or their carers, upon request by GPs, and also to consider the implementation of learning disabilities champions. |
| K4.7 | Citizens with learning disabilities should be supported where possible with continuity of care, (e.g., people should not have to tell their story over and over). |
| K4.8 | There should be equal access to services across the city, from early years through to adulthood, no matter which part of the city someone resides in. |
| K4.9 | To support a revolution in family help, working to reduce the handovers of families between services and to increase support, in accordance with the recommendations from the *Independent Review of Children's Social Care.* |
| K4.10 | Continue work on making the EHCP process easier to understand, and increasing transparency around how decisions are made and how families can appeal these. |
| K4.11 | Align local practice to the National SEND and Alternative Provision Improvement Plan to continue to work on improving waiting times in SEND services. |
| K4.12 | The Cabinet Member for Health and Social Care to write a letter to the Work and Pensions Secretary to lobby for national action to simplify application forms involving Universal Credit and financial support, with more support given to citizens throughout these processes. |
| K4.13 | The value of experts by experience should be recognised and utilised through being embedded in the process of service development, training of staff, service evaluation, and staff recruitment. Experts by experience should be appropriately recompensed for their time. |
| K4.14 | Improvement of locally supported employment programmes for those individuals who want to work and an increase in accessible applications. |

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| | Specifically, citizens within day centres to be supported with more opportunities to develop employment skills and seek employment opportunities and for employment opportunities to be advertised and available in an Easy Read format. Additionally, further work to continue to identify how improvements can be made to support employment opportunities for citizens with learning disabilities. |
| K4.15 | Improved support to explore possible employment options in the SEND local offer, in alignment with the new national SEND and Alternative Provision Improvement Plan. |
| K4.16 | Continued Independent Travel Training offer to all ages of citizens with learning disabilities in Birmingham. |
| K4.17 | Increased opportunities to be physically active and participate in sport in the community. |
| K4.18 | Improvements in community services support the care of citizens with ambulatory care sensitive conditions is needed to reduce unnecessary and lengthy hospital stays. |
| K4.19 | Increased dementia care services for citizens with learning disabilities due to the increased rates among this group compared with the general population. |
| K4.20 | Uphold the ambitions of the Palliative Care for People with Learning Disabilities Network and NHS England to deliver improved end of life care for people with learning disabilities. |

### 6.6.1 What Next?

The authors of this Learning Disabilities Deep Dive have worked with stakeholders from across Birmingham's healthcare system, services and voluntary sector and listened to the voices of lived experience to produce the report's recommendations. The following table outlines the stakeholders, who have agreed to take forward each of the report's recommendations.

| **Number** | **Action to be Taken** |
|---|---|
| K4.1 | Adherence to the SEND and Alternative Provision Improvement Plan. |
| K4.2 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K4.3 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K4.4 | To be taken forward by CASBA. |
| K4.5 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K4.6 | To be taken forward by Andrew Dalton (Screening and Immunisation Lead, NHS England). |
| K4.7 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K4.8 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K4.9 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |

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| K4.10 | Adherence to the SEND and Alternative Provision Improvement Plan. |
| K4.11 | Adherence to the SEND and Alternative Provision Improvement Plan. |
| K4.12 | To be taken forward by the Cabinet Member for Health and Social Care. |
| K4.13 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K4.14 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K4.15 | Adherence to the SEND and Alternative Provision Improvement Plan. |
| K4.16 | To be taken forward by the Children and Young Peoples' Travel Service. |
| K4.17 | To be taken forward by the Public Health Physical Activity Team (Birmingham City Council). |
| K4.18 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K4.19 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |
| K4.20 | Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change. |

## 6.7 Key Finding 5: There is a Need for More Research to be Commissioned to Support the Evidence Base around Health Inequalities for Citizens with Learning Disabilities.

> ***"There is a big gap in transition from day services to employment. Citizens should have the opportunity to learn skills for the job they wish to apply for, and staff who know them well should be allowed to support them."***
>
> Birmingham health professional.

> ***"We previously had to deal with a number of staff losses before the pandemic. Coming back to the service after the pandemic, there hasn't been adequate support for this, and the response is visible."***
>
> Birmingham health professional.

There is a need for more research to build the evidence-base around health inequalities for citizens with learning disabilities, including a greater understanding of differences in life expectancy between males and females and in different geographical locations around the UK. Birmingham's inpatient data revealed that around half of hospital admissions were for individuals aged 19 and under, suggesting that age differences may require further exploration. Additional research to understand comorbidities and their impact on citizens with learning disabilities is also needed. Other research required includes greater understanding of pain management, end of life care, and inequalities in accessing cancer screenings.

Further research to understand specific demographic groups is needed. These include citizens identifying as LGBTQ+, citizens with learning disabilities who have experienced transition from children's to adults' services, women with learning disabilities and their experiences of maternity care, and parents with learning disabilities. It is also recognised that focus groups were unable to take place with children, young people and older adults, and that research with these groups is needed to understand experiences across the life course. Birmingham carers data also revealed a larger proportion of carers from a black or ethnic minority background, compared with white ethnicity. This requires more research to understand the differences in caring between ethnic groups. There are also lower numbers of adults from an Asian ethnic background who are supported by Adult Social Care (20.6%), compared with the proportion of people from an Asian ethnic background as reported by the 2021 Census (31%). This requires further research to understand.

Furthermore, local research to understand the experience of those with learning disabilities during and after the pandemic is needed, because this event exposed wide inequalities, particularly health inequalities for this group. This research should explore life beyond the lockdown restrictions and how citizens feel these inequalities continue to exist in everyday life.

Intersectionality highlights the barriers people face based on protected characteristics, such as ethnicity, sexual orientation, age, religion, gender, and disability. Rather than these factors that make up a person's identity existing separately, they intersect and can magnify the discrimination and marginalisation the person might experience. There appears to be a gap in the evidence base on people with learning disabilities, who are from underrepresented and marginalised groups in society. Birmingham has a diverse and multicultural population, so it is important that future research in the city is undertaken with intersectionality as a key component of the analyses. This will generate data that are more representative of Birmingham's diverse population, whilst also taking the first steps in fully understanding to what extent protected characteristics and sociodemographic factors impact upon the life experiences of people who have learning disabilities. The findings of this research are intended to provide an evidence base which can be used to inform policy, practice and training.

A review of the 'liveable neighbourhoods' pilot in Bordesley Green and the impact on citizens with learning disabilities is needed. Associated with this is the need to provide local affordable homes, which support the diverse needs of citizens. These 'liveable neighbourhoods' could foster additional opportunities in supporting the wellbeing of citizens with learning disabilities, through having identified Safe Places and having local hubs where citizens are able to engage with local services and access community groups and classes.

In the focus groups commissioned for this deep dive, the experience of having a parent in a residential care home and being unable to visit as frequently as desired was highlighted by one citizen (see section 5.1). More research is required to understand the experiences of citizens with learning disabilities who transition from family to professional care settings and who have parents who live in care settings. This research should seek to explore these experiences and how best to support citizens affected by these circumstances, to ensure smooth transitions between different types of care and to ensure family relationships are upheld with frequent visits and communication.

To address local gaps in learning disabilities research, we recommend consideration to the following research themes:

| Number | Recommendation |
|---|---|
| K5.1 | The experience of comorbidities for citizens with learning disabilities, the underlying causes of death for citizens with learning disabilities, and the wider determinants associated with those causes of death. |
| K5.2 | The topic of suicide and learning disabilities, with a view to understanding how to promote early detection and intervention. |
| K5.3 | The cumulative impact of multiple comorbidities on the disability pay gap experienced by citizens with learning disabilities. |
| K5.4 | The age differences in Birmingham inpatient admission rates. |
| K5.5 | The gender inequalities that exist within SEND prevalence and life expectancy, among those with learning disabilities (see section 1.5.3). |
| K5.6 | The geographical differences in average life expectancy. |
| K5.7 | The experiences of maternity care for parents with learning disabilities. |
| K5.8 | The experience of parents with learning disabilities and children in care. |
| K5.9 | The experiences of citizens with learning disabilities throughout the COVID-19 pandemic and the continuing impact on service provision. This has been highlighted by our focus group research with Mencap. |
| K5.10 | The experience of citizens with learning disabilities in the cost of living crisis. |
| K5.11 | The impact of adverse weather on people living with learning disabilities. |
| K5.12 | The intersection of learning disabilities and mental health, with the aim of providing an evidence-base for the support of those with unmet need. |
| K5.13 | The experience of ageing family carers of citizens with learning disabilities, with focus upon support for both parties when the carer is unable to continue caring, due to entering professional care settings. |
| K5.14 | Review the findings of the 'Liveable neighbourhoods' pilot in relation to how this may support citizens with learning disabilities across a range of outcomes (e.g., access to diverse and affordable housing, and access to local services). |
| K5.15 | Evaluate the benefits of the Safe Places National Network and how it could best support citizens with learning disabilities in Birmingham. |
| K5.16 | Evaluate the benefits of local hubs and how they could best support citizens with learning disabilities in accessing local services and community activities. |
| K5.17 | Review the cancer screening evidence following the changes made to lowering the age of bowel cancer screening by NHS England and the impact on citizens with learning disabilities. |
| K5.18 | Further local research into understanding the prevalence of learning disabilities among those experiencing homelessness in Birmingham. This |

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| | research should seek to understand the unique challenges faced by this group and support needs. |
| K5.19 | Further research into groups for whom we were unable to commission focus groups for this deep dive, including citizens with learning disabilities who have come into contact with the criminal justice system, LGBTQ+ citizens, citizens with learning disabilities who are of working age and independent means, citizens with learning disabilities who have recently experienced transition, and professionals working with citizens with a learning disability, who have had contact with the criminal justice system. This also includes children and young people, and older adults in order to be able to explore experiences across the life course, including experiences of individuals living with learning disabilities and dementia, and the experience of end of life care in Birmingham. |
| K5.20 | We recommend that this deep dive into the health and wellbeing of citizens with learning disabilities is refreshed in 5 years. |

### 6.7.1 What Next?

The research recommendations in Key Finding 5 highlight the gaps in research relating to citizens living with learning disabilities. Therefore, this research team have listed these research gaps with the aim of encouraging other researchers to carry out their own investigations. In addition, Birmingham City Council's Public Health Division have committed to refreshing this Deep Dive in five years, and also to utilising the learning from this deep dive to inform future JSNAs.

Birmingham
City Council

> ***"A person with a learning disability has to repeat their story over and over because the cross over between different services isn't good enough."***
>
> Birmingham health professional.

**Learning Disabilities in Birmingham JSNA Deep Dive Report (2024)**

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