BIRMINGHAM CITY COUNCIL

BIRMINGHAM HEALTH AND WELLBEING BOARD

THURSDAY, 09 MAY 2024 AT 10:00 HOURS
IN COMMITTEE ROOMS 3 & 4, COUNCIL HOUSE, VICTORIA SQUARE, BIRMINGHAM, B1 1BB

A G E N D A

1 **NOTICE OF RECORDING/WEBCAST**

The Chair to advise/meeting to note that this meeting will be webcast for live or subsequent broadcast via the Council's Public-I microsite (please click this link) and that members of the press/public may record and take photographs except where there are confidential or exempt items.

2 **DECLARATIONS OF INTERESTS**

Members are reminded they must declare all relevant pecuniary and other registerable interests arising from any business to be discussed at this meeting.

If a disclosable pecuniary interest is declared a Member must not participate in any discussion or vote on the matter and must not remain in the room unless they have been granted a dispensation.

If other registerable interests are declared a Member may speak on the matter only if members of the public are allowed to speak at the meeting but otherwise must not take part in any discussion or vote on the matter and must not remain in the room unless they have been granted a dispensation.

If it is a 'sensitive interest', Members do not have to disclose the nature of the interest, just that they have an interest.

Information on the Local Government Association's Model Councillor Code of Conduct is set out via http://bit.ly/3WtGQnN. This includes, at Appendix 1, an interests flowchart which provides a simple guide to declaring interests at meetings.

3 **APOLOGIES**

To receive any apologies.

4 **DATE AND TIME OF NEXT MEETING**

To note the dates of formal meetings of the Board commencing at 1000 hours.

5 **MINUTES AND MATTERS ARISING**

5 - 12

To confirm and sign the Minutes of the last meeting held on 28 March, 2024,

5A **COMMISSIONERS REVIEW AND COMMENTS ON THE AGENDA**

13 - 14

To note any comments.

6 **ACTION LOG**

15 - 16

To review the actions arising from previous meetings.

7 **CHAIR'S UPDATE**

To receive an oral update.

8 **PUBLIC QUESTIONS**

(1015-10120) - Members of the Board to consider questions submitted by members of the public.
The deadline for receipt of public questions is 1500 hours on 2 May, 2024.
Questions should be sent to: HWBoard@Birmingham.gov.uk.
(No person may (submit more than one question)
Questions will be addressed in correlation to the agenda items and within the timescales allocated. This will be included in the broadcast via the Council's Public-I microsite (please click this link)
NB: The questions and answers will not be reproduced in the minutes.

9 **CREATING A CITY WITHOUT INEQUALITY FORUM ANNUAL UPDATE**

17 - 40

Monika Rozanski (Inclusion Health Service Lead, Public Health, Birmingham City Council) will present this item.
Report to Follow

10 **LEARNING DISABILITIES DEEP DIVE REPORT**

41 - 166

Luke Heslop (Evidence Service Lead Public Heath, Birmingham City Council) will present this item

167 - 182

11 **COMPASSIONATE CITIES UPDATE**

Becky Pollard (Assistant Director, Adults & Older Adults, Birmingham City Council) will present this item.

183 - 190

12 **PLACE COMMITTEE UPDATE**

Mike Walsh/Prof. Graeme Betts (Adult Social Care, Birmingham City Council) will present this item.

191 - 202

13 **BETTER CARE FUND QUARTER 3 REPORT**

Mike Walsh (Head of Service - Commissioning, Adult Social Care, Birmingham City Council) will present this item.

203 - 204

14 **CREATING A BOLDER HEALTHIER CITY (2022-2030) - INDICATOR UPDATES**

205 - 214

15 **HEALTH AND WELLBEING BOARD FORWARD PLAN**

16 **OTHER URGENT BUSINESS**

To consider any items of business by reason of special circumstances (to be specified) that in the opinion of the Chair are matters of urgency.

BIRMINGHAM CITY COUNCIL

BIRMINGHAM HEALTH AND WELLBEING BOARD MEETING TUESDAY, 28 MARCH, 2024

MINUTES OF A MEETING OF THE BIRMINGHAM HEALTH AND WELLBEING BOARD HELD ON TUESDAY, 28 MARCH, 2024 AT 1000 HOURS IN COMMITTEE ROOMS 3 AND 4, COUNCIL HOUSE, BIRMINGHAM, B1 1BB

PRESENT: -

Councillor Rob Pocock Acting Cabinet Member for Health and Social Care
Dr Clara Day (Vice-Chair) Chief Medical Officer, NHS Birmingham & Solihull ICB (In the Chair)
Councillor Karen McCarthy, Cabinet Member for Vulnerable Children and Families
Dr Justin Varney, Director of Public Health
Helen Price, Director of Education and Skills
Andy Cave, Chief Executive Officer, Healthwatch Birmingham
Anne Coufopoulos, Executive Dean, UCB
Professor Catherine Needham, University of Birmingham
Stephen Raybould, Programmes Director, Ageing Better, BVSC

ALSO PRESENT:-

Louisa Nisbett,Committee Services
Aidan Hall,Service Lead, Governance
Helen Harrison, Assistant Director Healthy Behaviours and Communities
Becky Pollard, Assistant Director, Public Health, Birmingham City Council
Tom Richards, Public Health
Tonye Sickabofori,Deputy Chief Medical Officer
Mike Walsh, Head of Service, Commissioning, Adult Social Care
Ibrahim Subdurally, Plon
Humera Sultan,Public Health, BCC
Rob Checketts, Chief Officer for Policy, Birmingham and Solihull ICB

Several people attended the meeting online.

****

NOTICE OF RECORDING/WEBCAST

762 The Chair advised that this meeting would be webcast for live or subsequent broadcast via the Council's Public-I microsite (please click this link) and that

members of the press/public may record and take photographs except where there were confidential or exempt items.

The business of the meeting and all discussions in relation to individual reports are available for public inspection via the web-stream.

DECLARATIONS OF INTERESTS

763 The Chair reminded Members that they must declare all relevant pecuniary and other registerable interests arising from any business to be discussed at this meeting. If a disclosable pecuniary interest was declared a Member must not participate in any discussion or vote on the matter and must not remain in the room unless they have been granted a dispensation.

If other registerable interests were declared a Member may speak on the matter only if members of the public are allowed to speak at the meeting but otherwise must not take part in any discussion or vote on the matter and must not remain in the room unless they have been granted a dispensation. If it is a 'sensitive interest', Members do not have to disclose the nature of the interest, just that they have an interest.

Information on the Local Government Association's Model Councillor Code of Conduct is set out via http://bit.ly/3WtGQnN

This includes, at Appendix 1, an interests flowchart which provides a simple guide to declaring interests at meetings.

There were no declarations made.

APOLOGIES

764 Apologies for absence were submitted on behalf of:-

Councillor Matt Bennett, Opposition Spokesperson on Health and Social Care
Jo Tonkin, Assistant Director (KEG), BCC (in place of Justin Varney)
Richard North, Chief Superintendent, WMP
Joanna Statham, DWP
Riaz Khan
David Melbourne, NHS Birmingham and Solihull CCG
Natalie Allen Chief Executive SIFA FIRESIDE

MINUTES AND MATTERS ARISING

765 The Minutes of the meeting held on 28 November, 2023, having been previously circulated, were confirmed and signed by the Chair.

COMMISSIONERS REVIEW AND COMMENTS ON THE AGENDA

766 There were no comments submitted by the Commissioners in relation to any of the agenda items.

DATES OF MEETINGS

767 The Board noted the dates of future meetings of the Committee for the remainder of the municipal year commencing at 1000 hours:

9 May, 2024.

ACTION LOG

768 No outstanding actions were raised for the Action Log.

CHAIR'S UPDATE

769 Dr Clara Day, Deputy Chair (Chairing the meeting) reported as follows:-

- There had been a significant measles outbreak in Birmingham and Solihull. The number of cases had now reduced, however there were still new cases every week. This had put extra pressure on Health Services. The reason was that immunisation rates were 75% and 80%.
-

There had been very significant casework regarding the uptake of MMR in the City. Uptake at Practices had doubled since Christmas. There had been focussed work at schools with the lowest uptake.

Very significant engagement work had been undertaken to address why people were not taking up immunisation in the first place. In spite of the financial restrictions HWB would focus on priorities and look ahead to future needs.

Councillor Pocock gave a brief financial update on BCC. The Commissioners were now in place in the City. Savings were to be made over a 2-year period. Proposals to Cabinet Committee in February had been agreed at the City Council meeting in March.

There had been an increase in the Adult Social Care budget. However, it was still short of what was needed. The impact of the cuts on HWB and BCC was an ongoing piece of work.

It was noted that Deborah Cadman, former Chief Executive had now left BCC and that Graeme Betts was now Acting Chief Executive.

Justin Varney was welcomed back to the Committee and Jo Tonkin was thanked for standing in for him.

PUBLIC QUESTIONS

770 The Chair advised that the Board welcomed questions, any questions should be sent to HealthyBrum@Birmingham.gov.uk.

There were no questions.

DIRECTOR OF PUBLIC HEALTH ANNUAL REPORT 2023-2024

The following report was submitted:-

(See document attached)

Dr Justin Varney (Director of Public Health), Birmingham City Council presented this report and gave a summary of the report for endorsement by the HWB.

The Director of Public Health (DPH) had a statutory duty to write an independent, evidence-based annual report detailing the health and wellbeing of our local population. This was an opportunity to look at census data and changes.

Some of the headlines were:-

- The decline in birth rates in Birmingham
- Growth of the 50 – 59 age group by 20%
- Ethnicity
- Diversity
- Immigration
- Housing
- Employment
- Work with Students to design the cover – Design Competition

The efforts of Public Health to engage with the public and fund activities was acknowledged. Councillor Pocock said that the HWB would benefit from receiving a briefing. The report would be submitted to the Cabinet for approval. Justin Varney undertook to discuss work focussed on the 50-59 age group with Mike Walsh.

771 **RESOLVED**:-

i. That the HWB note the findings of the Director of Public Health Annual Report 2023-24; and

ii. That the HWB endorse the Director of Public Health Annual Report 2023-24 for wider dissemination.

BIRMINGHAM AND SOLIHULL ICB JOINT FORWARD PLAN UPDATE

The following report was submitted:-

(See document attached)

Rob Checketts (Chief Officer for Policy, Birmingham and Solihull ICB) presented this item to update the Committee on the process and plan for updating the Joint Forward Plan (JFP) and responded to questions from Members. An update would be submitted to the Committee in June. Following some comments about public satisfaction with the NHS and the engagement strategy, Clara Day said that there would be further discussion at the next meeting.

The Board was asked to support the approach being taken to developing the updated JFP and delivery plan

772 **RESOLVED**:-

That the HWB note the process and plan to update the Joint Forward Plan for 2024/25.

CREATING AN ACTIVE BIRMINGHAM STRATEGY - CONSULTATION FINDINGS AND FINAL STRATEGY

.
The following report was submitted:-

(See document attached)

Justin Varney, Humera Sultan / Ibrahim Subdurally-Plon attended to present the findings of the Creating an Active Birmingham Strategy (CABS) consultation and the Final strategy following the consultation and to advise Health and Wellbeing Board members about the intention to seek Cabinet's ratification. The main findings were reported.

Humera Sultan gave more detail about the Citizenship Forum. Helen Price offered assistance if required with regard to Children and Young People. More work was needed with regard to families in most acute need and community organisations. It was noted that the Small Grant Programme had been launched this week.

773 **RESOLVED**:-

i. That HWB members note the CABS Consultation findings; and

ii. That HWB members support the Final Strategy and Implementation Plan

---

BIRMINGHAM AND LEWISHAM AFRICAN CARIBBEAN HEALTH INEQUALITIES REVIEW (BLACHIR) PROGRESS UPDATE

The following report was submitted:-

(See document attached)

Helen Harrison (Assistant Director of Public Health, Birmingham City Council), assisted by Officers joining the meeting online presented this item providing an update to the Board since the previous report in March 2023 regarding the Health and Care system implementation of the recommendations and advised of the next steps. Justin Varney added that they were aware they needed to change the way they worked for example when looking at different communities, so that it was embedded in the business rather than as an add on.

774 **RESOLVED**:-

That the HWB note the progress being made to implement the BLACHIR opportunities for action and the 7 key priority areas highlighted within the Review and for Board members to continue to support in the system delivery of the key actions

PHARMACEUTICAL NEEDS ASSESSMENT (PNA) UPDATE – SUPPLEMENTARY STATEMENT

The following report was submitted providing an update on the changes to the availability of pharmaceutical services in Birmingham.

(See document attached)

A PNA was a statutory requirement of Health and Wellbeing Boards (HWB) in England; its purpose was to assess the current provision of pharmaceutical services in an area and the 'need' for such services now and in the future. Members were concerned about the capacity of the service and the lack of pharmacies opening on a Saturday. Clara Day added that maybe the HWB should look to re-establish the PNA Group who could look at the reduction in hours.

775 **RESOLVED**:-

i. That the HWB note the changes to pharmaceutical provision since the publication of the PNA and agree to publish a supplementary statement; and

ii. That the HWB agree to re-establish the PNA Steering Group (details and terms of reference will be presented to Health and Wellbeing Board).

HEALTH AND WELLBEING BOARD – EXECUTIVE BOARD PAPERS (DECEMBER 2023)

The following report was submitted:-

(See document attached)

Dr Clara Day presented this item and following a brief discussion it was:-

776 **RESOLVED**:-

That the HWB note and approve the recommendations from the Executive Board.

INFORMATION ITEMS

The following written updates were on the Agenda for information only.

BIRMINGHAM AND SOLIHULL CHILD DEATH OVERVIEW PANEL (CDOP) ANNUAL REPORT 2022-23

(See document attached)

777 **RESOLVED**:-

That the written updates be noted.

CREATING A BOLDER HEALTHIER CITY (2022-2030) - INDICATOR UPDATES

(See document attached)

778 **RESOLVED**:-

That the written updates be noted.

HEALTH AND WELL BEING BOARD FORWARD PLAN

779 The Forward Plan was noted.

(See document attached)

OTHER URGENT BUSINESS

780 No other urgent Business was raised.

The meeting ended at 1150 hours.

…….
CHAIR

Birmingham City Council
Health and Wellbeing Board
9 May 2024

Commissioner Review

The Commissioners support the recommendations in the reports.

Action Log 2023/24

Rag rating:

Overdue
In progress
Complete

Index no.	Date of Entry	Agenda Item	Action or Event	Named Owner	Target Date	Date Complete	Outcome/Output	Rag
1	18/07/2023	11. Children and Young People's Plan	Agree a future HWB meeting date for Children and Young People's Plan update.	Aidan Hall	26/09/2023	26/09/2023	Added to the HWB Forward Plan.	
2	18/07/2023	12. Birmingham and Solihull Joint ICB Forward Plan	Agree a future HWB meeting date for 'Joint Forward Plan' for the ICS 10-year strategy.	Aidan Hall	26/09/2023	26/09/2023	Added to the HWB Forward Plan.	
3	18/07/2023	10. Health and Wellbeing Board Development 2023-24	Defer the HWB Development item to the next meeting.	Aidan Hall	26/09/2023	26/09/2023	Item refined and brought back to the following meeting.	
4	18/07/2023	20. Exclusion of the Public	'Private' Minutes will be deferred to the next meeting and HWB will be given access	Louisa Nisbett	26/09/2023	26/09/2023	Private minutes circulated to members via email	
5	26/09/2023	9. Health and Wellbeing Board Development	Review Executive Board after 6 months.	Aidan Hall	26/03/2023			
6	26/09/2023	10. Joint Strategic Needs Assessment (JSNA) Update	Agree a future HWB meeting date for the Deep Dive Programme and JSNA update.	Aidan Hall	28/11/2023	28/11/2023	Added to the HWB Forward Plan (24/25).	

7	26/09/2023	11. Draft Birmingham and Solihull Enabling Primary Care Strategy	Agree a future HWB meeting date for the Enabling Primary Care Strategy	Aidan Hall	28/11/2023	28/11/2023	Added to the HWB Forward Plan (24/25).	

	Agenda Item: 9
Report to:	**Birmingham Health & Wellbeing Board**
Date:	**9 May 2024**
TITLE:	**CREATING A CITY WITHOUT INEQUALITIES FORUM ANNUAL REPORT 2023-24**
Organisation	**Birmingham City Council**
Presenting Officer	**Monika Rozanski**

Report Type:	**Information**

1. Purpose:

This report takes stock of the Forum's activity since September 2022 when the existing forward plan started to be delivered through to the end of February 2024 and aims to:

1.1. Promote a wider understanding of the forum's activity and achievements.

1.2. Set out plans for the forum's refresh and strengthening its focus on inclusion health.

2. Implications (tick all that apply):

Creating a Bolder, Healthier, City (2022-2030) – Strategic Priorities	Closing the Gap (Inequalities)	x
	Theme 1: Healthy and Affordable Food	
	Theme 2: Mental Wellness and Balance	
	Theme 3: Active at Every Age and Ability	
	Theme 4: Contributing to a Green and Sustainable Future	
	Theme 5: Protect and Detect	
	Getting the Best Start in Life	
	Living, Working and Learning Well	
	Ageing and Dying Well	
Joint Strategic Needs Assessment		

3. Recommendation

3.1. The Health and Wellbeing Board notes the work of the Creating a City without Inequalities Forum, supports its future direction and considers what other related agendas and representatives would strengthen its work on inclusion health[1].

4. Report Body

4.1. The Creating a City without Inequalities Annual Report 2023-24 represents a pivotal moment in the CCWIF's journey, highlighting its renewed dedication to tackling health inequalities. It provides an overview of the Forum's activities from September 2022 through to February 2024, outlining the progress made in the delivery of the current forward plan, which is focussed on the five health inequality priority areas within the joint health and wellbeing strategy 'Creating a Bolder Healthier City 2022-30" linked to deprivation, disability, inclusion health, ethnicity and locality.

4.2. The forum continues to be managed by the Public Health Division (with its running costs covered through the ring-fenced public health grant funding) and serve as a wider system platform for fostering collaboration among strategic partners across various sectors and organisations, working towards a shared objective of reducing health inequalities in these areas.

4.3. The forum recognises the financial challenges faced by the Birmingham City Council, therefore it has made considerable efforts to focus its work on the most disadvantaged populations, and it continues to strengthen collaboration between forum member organisations and services to avoid duplication and enable effective and efficient action that supports the delivery of the Council's Improvement and Recovery Plan as well as the Early Intervention and Prevention agenda.

4.4. Over the 15-month period between September 2022 and February 2024, the forum explored and discussed the first four of the above five priorities with the last one being explored at the Integrated Care System locality basis through the Primary Care Networks' inequality initiatives, with which the forum is strengthening its links.

4.5. When discussing the inequality priority areas linked to deprivation, disability, inclusion health and ethnicity, the forum examined intersectionality of experiences and needs across all of those communities, leading to a deeper exploration of inclusion health needs and the marginalisation within those communities, with a focus on the homeless, people experiencing multiple disadvantages and migrants amongst other vulnerable groups where the health inequalities are the greatest.

4.6. The progress updates within the report are structured against the existing three core functions of the forum which includes the direct delivery of projects and

[1] Inclusion health is an umbrella term used to describe people who are socially excluded, who typically experience multiple interacting risk factors for poor health, such as stigma, discrimination, poverty, violence, and complex trauma. People in inclusion health groups include people who experience homelessness, people with drug and alcohol dependence, vulnerable migrants and refugees, Gypsy, Roma, and Traveller communities, people in contact with the justice system, victims of modern slavery, sex workers and other marginalised groups (NHSE 2023). https://www.england.nhs.uk/long-read/a-national-framework-for-nhs-action-on-inclusion-health/

programmes that through the forum report to the HWB. The other function of shining the light on key issues enables the forum to take a deeper look at specific health inequalities or specific communities experiencing the deepest disparities in their health outcomes. Finally, through the enabling function, the forum explores the ways in which it can, collectively or through individual members, facilitate better engagement with communities of experience and identity, development of joint protocols and actions, building capacity and capability within the system to improve our response to tackling health inequalities in the city.

4.7. it is worth highlighting some key achievements and progress updates such as the BLACHIR project, the gender health inequalities work, Birmingham Poverty Truth Commission, the forum's work on inclusion health, community health profiles and efforts to improve data capture to better understand and respond to the health and wellbeing needs of our most vulnerable citizens.

4.8. The Birmingham Poverty Truth Commission is a form of immersive learning experience where people with current lived experience of poverty are brought together with people of influence from the civic world, build trusting relationships over time, share their experiences and perspectives on topics related to poverty, explore opportunities to make a difference and, as individuals as well as a group, advocate and influence decision making that affects communities affected by poverty. This project has now been concluded with the legacy from the commission living on, and the impacts varying from personal successes of the community participants to impact on engagement, co-production, and policy development at a local and national levels. The evaluation of this project is scheduled to be completed in June 2024.

4.9. Highlights from the public health led gender health inequalities project include a completion of the women's health needs report with recommendations to be published in April 2024 with the work on men's health already under way; the completion of the sex worker needs analysis to be launched this spring, work on the period literacy toolkit for the homelessness sector which is in its final stages of development and the forum's contribution to the development of the domestic abuse prevention strategy.

4.10. It is worth highlighting the commitment that the forum has made to the inclusion health agenda in alignment with the wider ICS priorities that has been strengthened further by the publication of the National Framework for NHS – Action on Inclusion Health (NHSE 2023). Some notable achievements include integration of the homelessness and health legacy from the third sector led HealthNow Alliance initiative, continuous roll out of the Safe Surgeries and veteran friendly surgeries initiatives through the city's PCNs. The significance of these achievements lies in the fundamental access it guarantees for patients, particularly migrants, asylum seekers, ex-service people and other vulnerable populations, to healthcare, and this work has also been recognised nationally. Development of the inclusion health co-production coalition with the continually evolving Making Every Adult Matter (MEAM) programme led by the Birmingham Voluntary Service Council (BVSC) is another highlight that demonstrates the partnerships' commitment to the inclusion health agenda.

4.11. This report also provides a roadmap for the future of the forum, highlighting the strategic direction planned for 2024 and beyond. The forum recognises the pressing need to prioritise the health and wellbeing of inclusion health groups

and is planning to redirect its efforts towards addressing their needs in strong alignment with the BSol ICS' priorities and in the context of the financial recovery of the Council, which it supports through strengthening collaboration between partners and a better, including a shared use of available resources. The forum is currently working through the new terms of reference and forward plan as part of the wider review of the Health and Wellbeing Board's sub-groups and further reports will be submitted in due course.

5. Compliance Issues
5.1. HWBB Forum Responsibility and Board Update
The annual report has been approved by the CCWIF Chair, Cllr Nicky Brennan and disseminated to forum and board members.
5.2. Management Responsibility
Helen Harrison – Assistant Director for Healthy Behaviours and Communities, Deputy Chair, Creating a City without Inequalities Forum Monika Rozanski – Service Lead – Inclusion Health
5.3. Finance Implications
Management and administration of the forum is covered by the Public Health ringfenced grant.
5.4. Legal Implications
n/a
5.5. Equalities Implications (Public Sector Equality Duty)
The forum, through its activity, aims to reduce health inequalities in the city.

6. Risk Analysis

Identified Risk	Likelihood	Impact	Actions to Manage Risk
Capacity of forum members to continue their commitment and progress action on inclusion health	Medium	High	• Forum workshops and discussions to prioritise future activity; a refresh of the forum's terms of reference • The forum's refresh as part of the wider HWB sub-forum review

Appendices

Appendix 1 – CREATING A CITY WITHOUT INEQUALITIES FORUM ANNUAL REPORT 2023 - 2024: Recognising Achievements, Charting a New Way Forward Appendix A - CCWIF Opportunities for Action Matrix 2023-24 (within Appendix 1)

Background Papers
Creating a City without Inequalities Annual Report 2022-23

CREATING A CITY WITHOUT INEQUALITIES FORUM ANNUAL REPORT 2023 - 2024:

Recognising Achievements, Charting a New Way Forward

Birmingham Health and Wellbeing Board

May 2024

Inclusion Health Team – Birmingham Public Health

Contents

1. Introduction

The Birmingham Joint Health and Wellbeing Strategy 'Creating a Bolder, Healthier City 2022-2030' acknowledges the pressing issue of health inequalities that persist within our communities. These inequalities have far-reaching consequences, impacting the health and wellbeing of individuals throughout their lives. Recognising the need for targeted action, the Creating a City Without Inequality Forum (CCWIF) has centred its efforts on addressing key health inequalities outlined in the 2022-2030 Joint Health and Wellbeing Strategy:

- Inequalities linked to deprivation
- Inequalities affecting communities with disabilities
- Inequalities affecting inclusion groups (e.g. people experiencing homelessness)
- Inequalities affecting different ethnic communities
- Inequalities of locality (i.e. variation/inequalities between wards).

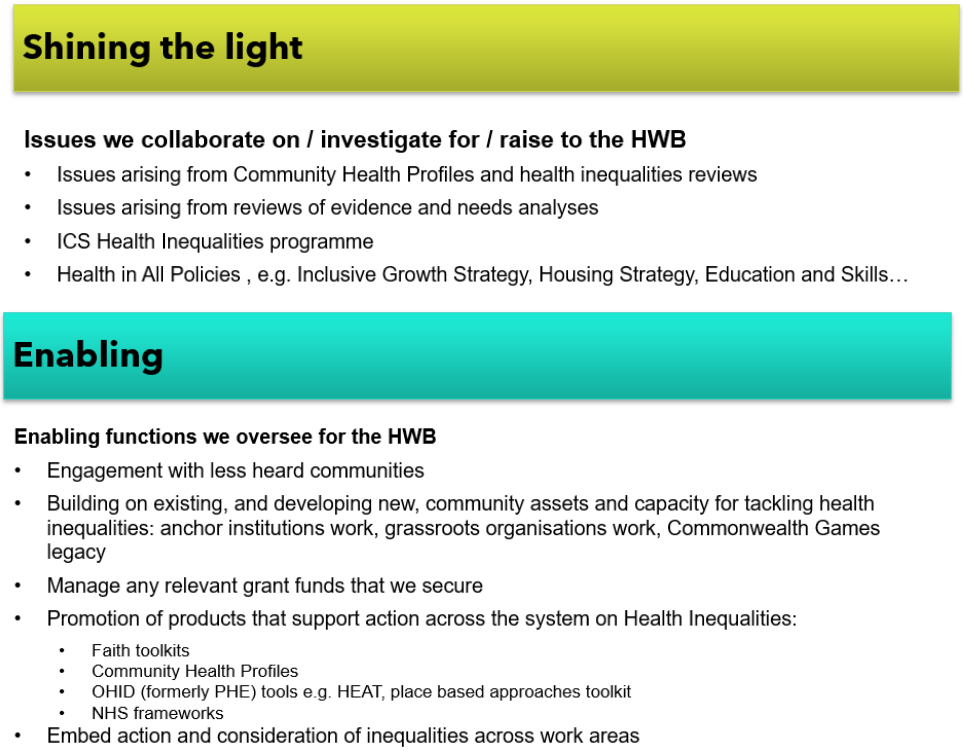
This annual report represents a pivotal moment in the CCWIF's journey, highlighting its renewed dedication to tackling health inequalities. It provides an overview of the Forum's activities from September 2022 through to February 2024, outlining the progress made in the delivery of the current forward plan. The forum continues to be managed by the Public Health Division (with its running costs covered through the ring-fenced public health grant funding) and serve as a wider system platform for fostering collaboration among strategic partners across various sectors and organisations, working towards a shared objective of reducing health inequalities in these areas.

The forum recognises the financial challenges faced by the Birmingham City Council, therefore it has made considerable efforts to focus its work on the most disadvantaged populations and it continues to strengthen collaboration between forum member organisations and services to avoid duplication and enable effective and efficient action that supports the delivery of the Council's Improvement and Recovery Plan as well as the Early Intervention and Prevention agenda. As evident in this report, a significant progress has been made to address the key health inequality priorities; however, we recognise that there is still more work to be done, particularly for the communities that experience the deepest inequalities and needs.

This report also provides a roadmap for the future of the forum, highlighting the strategic direction planned for 2024 and beyond. In the report, we acknowledge the pressing need to prioritise the health and wellbeing of inclusion health groups and will redirect our efforts towards addressing their needs through the platform provided by the forum.

1.1 Approach to achieving forum objectives

At present, the CCWIF's approach focuses on delivering effective programmes, creating awareness, and providing essential support to drive positive change in addressing health inequalities in Birmingham through the delivery of the following three key functions:



2. Programme delivery: key achievements

2.1 BLACHIR Implementation Project

With the support of the BLACHIR Implementation Board (BLACHIRIB), the BLACHIR ICS taskforce, community engagement partners, and other external stakeholders, the project team has made a significant progress. The Implementation Board has been actively working on the seven key themes identified in the project review and has been building upon the recommendations to strengthen evidence-based and co-production approaches.

Notable progress has been made in three of these themes:

1. Trust and Transparency: Focused on Cultural Competency as an umbrella term for developing culturally intelligent organisations and policies, and culturally humble and safe front-line practices. Two co-production sub-groups were created to progress with this work.
    i. Cultural Intelligence – to develop cultural competency at a strategic, leadership and population level
    ii. Cultural Humility and Safety – to develop cultural competency at an interpersonal level.

1.1 Cultural Intelligence

The Birmingham Cultural Intelligence Framework (BCIF) is the main output from the Cultural Intelligence workstream that addresses and reaches beyond the BLACHIR communities. BCIF is a toolkit to help individuals and organisations to develop, strengthen and evidence their deeper understanding and approach to enabling and empowering different communities of identity and experience.

Expression of interests have been advertised for organisations to apply to pilot the BCIF. It is aimed to recruit 3-5 partner organisations to pilot, refine and enhance the framework over a period of 12-18 months, starting May 2024. The pilot will focus on 10 specific communities of identity: 5 ethnic communities, 2 faith, 2 disability and 1 LGBTQ+. Staff members within Public Health will be required to complete 2 domains as part of their annual personal development plan. Public Health have also advertised for an independent evaluation

for the BCIF. The evaluator will assess if, within the pilot, the framework is reaching its intended outcomes and is making a meaningful difference in comparison to already available EDI provisions.

1.2 Cultural Humility and Safety

The Birmingham Cultural Humility and Safety framework (BCHSF) is the key output from the Cultural Humility and Safety workstream. The BCHSF aims to standardise CHS training across the system, specifically acting to improve the quality and reach of the CHS training offer in Birmingham. The framework is designed for commissioners of CHS Training and providers who deliver the training. It aims to both provide a minimum standard of training, and also provide a framework to enable organisations to evaluate and further develop their training programmes through a process of continuous evaluation.

Expression of interests have also been advertised for organisations to apply to pilot the CHS Framework. It is aimed to recruit 3-5 partner organisations to pilot, refine and enhance the framework over a period of 12-18 months, starting in May 2024. The CHS Framework aims to partner with a wide range of organisations including universities, hospital trusts, primary care, BCC departments, voluntary sector organisations, and others. An independent evaluator will also be commissioned for the CHS Framework, starting May 2024.

Alongside the pilot, all Public Health colleagues and at least one other Council Directorate with public-facing staff members will be offered CHS training. This will be delivered by a provider commissioned by Public Health.

2. Better Data: A set of standard demographic questions has been co-created and will be integrated into Birmingham City Council's data collection efforts. These questions, incorporating BLACHIR recommendations and developed based on national standards, have been tested with a citizen involvement panel. The integration of these questions will provide valuable insights into the demographics of consultations, surveys, and services, ensuring a more inclusive and accurate representation of the community.

3. Health Checks and Campaigns: A rapid evidence review was conducted to explore access and quality of health checks for global majority communities, specifically focusing on Black African and Black Caribbean communities. The review led to recommendations such as community outreach, engagement, and education, increasing accessibility of health checks, administering multimethod invitations, providing culturally and religiously sensitive approaches, and conducting ethnic-specific focus groups. These recommendations will inform targeted pilot programs aimed at addressing barriers to health checks and improving outcomes for these communities.

Engagement partners have been actively contributing to the BLACHIR Implementation project's progress. The Allies Network has delivered community engagement sessions and webinars, shining the light on innovative approaches to address health inequalities in African communities. The Black Heritage Support Service has been finalising a Caribbean Health Exhibition to educate and engage the Caribbean community on health-related issues. Mindseye Development has participated in various meetings and events focused on addressing health inequalities for Black African and Black Caribbean citizens, coordinating efforts and raising awareness within these communities.

Looking ahead, The BLACHIR project has outlined planned activities in key thematic areas. These include piloting cultural intelligence and cultural humility frameworks, integrating new Equality, Diversity, and Inclusion (EDI) question sets into core public health services, commissioning focus groups to improve access and quality of health checks, and developing key principles for future targeted health campaigns for Black African and Black Caribbean communities. Additionally, efforts will be made to address early interventions, healthy behaviours and health literacy as well as fairness, inclusion, and respect themes.

2.2 Gender Health Inequalities Project - addressing women's and men's health inequalities

Over the last year, the Public Health led Gender Health Inequalities Project has advanced steadily and made notable strides with the phase 1 focused on women's health nearing completion and the implementation of its findings to be disseminated across the relevant parts of the system, and the phase 2 focused on data and evidence review for Birmingham men's health, using the parliamentary research briefing on men's health as a framework, already in progress. The below summaries provide a snapshot of what has been achieved.

1. Women's Health Report: The findings of the women's health gaps and needs analysis have been signed off, the report with recommendations will be published shortly (currently in design process) and disseminated through a variety of groups and stakeholders, including the women's health working group, CCWIF, ICS Inequalities Board, and other, as appropriate. The working group will determine the next steps for implementation, including links to existing work or ongoing initiatives such as women's health hubs. The core themes in the report were based on the National Women's Health Strategy for England (2022) and build the local picture of women's health needs in the city. The findings and 26 recommendations provide valuable insight into disparities in health outcomes between women compared to men, and women nationally, women's health across the life course and women's experience of the local healthcare system. The working group has started to examine the findings linked specifically to women's health literacy in more detail and develop proposals for implementation and co-production to drive this work forward. Work has already been progressed against at least 8 recommendations through dedicated new (e.g. women's health hub), or existing initiatives (e.g. BLACHIR, sex worker needs analysis etc.).

2. Sex Workers - Analysis of Health Needs (SWAN): The outputs from the SWAN studies, including key findings and recommendations, will be published in April 2024. Plans for their launch and further engagement of stakeholders to raise awareness about the health needs of sex workers in Birmingham are currently being developed. However, the dissemination of findings has started in November 2023 with the summaries being presented to the CCWIF partners, informing commissioning of sexual health services, Domestic Abuse Prevention Strategy development and improving data capture on the inclusion health needs of this group. Key findings relating specifically to LGBTQ+ communities have also been disseminated as part of the LGBT+ Health Conference led by Public Health throughout the month of February 2024.

3. Period Literacy Toolkit: The development of the Period Literacy Toolkit for the Housing and Homelessness Sector will be completed and published in April-May 2024 (subject to design timescales). This toolkit will provide valuable resources and support for addressing period poverty and literacy among homeless females.

4. Men's Health: Building on the priorities outlined in the All-Parliamentary Party Group (2022) proposal for a national men's health strategy, an initial rapid desktop evidence review is currently underway. This review will emulate the approach from Phase 1, producing a comprehensive report on men's health in Birmingham to provide an insight into men's health inequalities in Birmingham, with a focus on intersectionality and inclusion health. Simultaneously, mapping of existing services, current activities, and stakeholders related to men's health has begun, allowing for a comprehensive understanding of the existing landscape.

5. Webinars on Gender Health Project: Following the success of the Inclusion Health, Sex Work and the LGBTQ+ community webinar, the Inclusion Health Team will deliver further webinars on the Gender Health

Project. The webinars will highlight intersectionality and focus on specific gender inclusion health groups, emphasising the importance of addressing health inequalities within these communities.

6. **Domestic Abuse Prevention Strategy:** The forum supported raising awareness and provided a platform to share and gather valuable feedback for the development of the Birmingham Domestic Abuse Prevention Strategy, with the aim to strengthen its ambitions for primary, secondary and tertiary prevention with a specific focus on children and young people, and behaviour change, including through targeted interventions aimed at perpetrators.

2.3 Birmingham Poverty Truth Commission

The Poverty Truth Commission has concluded its activities in October 2023, holding its final meeting and legacy planning session. The commission celebrated its achievements and presented the feedback and outputs from its sub-groups during the last listening event in July 2023.

Since April 2023, the commission concluded its four workstreams on housing, food, health and family poverty, with four listening events that gathered system leaders and influential civic leaders from across the city. During those events, the community (lived experience) and civic (representatives of the civic and professional world immersed in the poverty truth experience) commissioners shared their experiences and learning from being part of the project as well as their ambitions for how this immersive model of engagement and learning from the lived experience can evolve.

During the commission's legacy phase, which has started in July and will conclude with the publication of the evaluation of the project in May 2024, the focus is on incorporating the value of all of the commissioners' journey and utilising their skills and commitment beyond the commission itself.

The highlights of the BPTC legacy work include:

- At a national level, the BPTC community members continue to engage with the national Poverty Truth Network, which aims to influence the way, in which national policies are shaped to ensure they contribute to alleviating, not exacerbating the impacts of poverty. The BPTC had four sessions with the APPG Poverty Strategy Commission, exploring the concept of the "Cost of Living" and its impact on individuals. The discussions revealed the challenges faced by commissioners in balancing rising prices and their incomes, as well as the hidden costs of setting up a home.
- The commission also organised a Listening & Conversation Event with the Department for Work and Pensions (DWP), where commissioners shared their stories and questions related to the treatment of individuals within the welfare system. The conversation aimed to explore how the system could humanise itself better, particularly in relation to sanctions imposed on families.
- The commission also collaborated with the Spring Housing Association to explore a different (immersive) approach to customer service and involvement. Through relational facilitation, the aim has been to create a safe space for commissioners and participants to share stories and co-design a customer involvement strategy. This legacy project is still ongoing.
- Some commissioners remain engaged with the Birmingham City Council's Housing Team to provide insights regarding homelessness prevention, contributing to the Birmingham's new Homelessness Prevention Strategy development. Commissioners also participated in a Community Conversation during Birmingham Housing Week, discussing how developers can effectively work with communities in shaping regeneration projects.
- Members of the commission are also collaborating with the private sector and were involved in the development of the city-wide Economic Justice Action Network (EJAN), exploring and promoting anti-poverty measures and economic growth.

- Some BPTC members continue to be engaged with the Marmot's Health Equity Collaborative within the BSol ICS focused on children and young people.

The BCC contract to deliver the BPTC with Thrive Together Birmingham is coming to an end in March 2024, however, it is evident that the legacy for this and the very first commission, will carry on through the ongoing activity of individual members of the BPTC#1 and BPTC#2 as well as their host organisation and the organisations and services that the commission has worked with. The commission's future plans include sustaining a group under the banner of Birmingham Poverty Truth to continue supporting initiatives in the city and amplifying the voices and insights of people with lived experience of poverty. The commission's legacy phase is focused on utilising the knowledge and skills gained during its activities to drive positive change and address issues related to poverty and inequality in Birmingham.

3. Shining the light: key achievements

3.1 The Cost-of-Living Programme

The Cost-of-Living Programme remains a key area of work with active involvement of the Inclusion Health Team, and through the CCWIF platform, we have ensured that the Cost-of-Living Programme takes into account the unique challenges faced by the inclusion health groups. These groups often experience higher levels of homelessness, poverty, and health disparities, making it critical to address their specific needs within the programme.

Through participation of the forum members and the Poverty Truth Commission members, we have successfully influenced the programme's development to incorporate measures that directly address their concerns. This includes improving access to advice on benefits, development of the warm spaces network, increasing energy efficiency to reduce costs, and ensuring an adequate supply of food through food banks. This support is crucial in ensuring that services are tailored and responsive to the diverse needs of our city's socially excluded residents.

3.2 Integration of the HealthNow Alliance legacy into the ICS programmes

The forum served as a platform for discussing and exploring the integration of the legacy from HealthNow Alliance, working to improve access to healthcare for the homeless population and embedding their voice in service design and improvement, into the relevant ICS plans and programmes. The project's legacy, including the outcomes from the peer advocacy and lived experience projects, has been embraced and incorporated into efforts to enhance pathways and accessibility to healthcare, particularly primary care, for the homeless population. This integration demonstrates a significant step towards addressing the healthcare inequalities faced by this marginalised group and ultimately working towards the goal of creating a city where everyone has equal access to essential services and opportunities.

3.3 ICS armed forces and veteran health provision

The CCWIF partnership played a key role in shining the light on the needs of all inclusion health groups, including the ex-service men and women. Through presentation of findings from the JSNA deep dive, discussions, and engagement, the forum effectively communicated the commitment of the BSol ICS to improving the health and wellbeing of this group.

To respond to the forum's recommendations, the ICS are supporting the armed service covenant and ensuring continuing of health provision for those still in service, improving awareness training and information for staff, improving mental health support and streamlining pathways. ICS legal obligations to the covenant will be followed through commissioning, procurement and contracting services. Work is already underway of GP accreditation for armed services support. The BSol ICS has already taken proactive measures to ensure the

continuity of health provision for those currently serving in the armed forces. This includes enhancing awareness training and information for primary care staff to better understand the unique needs and challenges faced by former service men and women. This project, also known as veteran friendly GP surgeries, is still in development, but demonstrates a commitment to reducing health inequalities affecting this inclusion health group.

3.4 Safe Surgeries initiative

Over the past year, an impressive achievement has been made in the creation and success of the Safe Surgeries initiative. This initiative, promoted by the Birmingham and Solihull Integrated Care System (BSol ICS), aims to address the barriers faced by individuals in vulnerable circumstances who struggle to access healthcare.

The initiative has gained significant traction, with 73 Safe Surgeries established the West Midlands, including Birmingham. This includes three Safe Super Partnerships and the first Safe Primary Care Network (PCN) nationally. The coverage of Safe Surgeries in diverse areas of the city ensures that safe access to healthcare is provided where it is needed the most.

The impact of the initiative has been recognised on a national level, as it is now recommended as one of the "menu of interventions" by NHS England and NHS Improvement to reduce health inequalities. Moreover, it was shortlisted for the General Practice Awards 2019, and the toolkit has received endorsements from the Royal College of Practitioners and the Royal College of Nursing.

The success of the Safe Surgeries initiative can be attributed to the commitment of practices in implementing the NHS registration principles and providing access for all. Some practices only required minor adjustments or a refresh of their existing policies to become more inclusive in their primary care services.

The significance of this achievement lies in the fundamental access it guarantees for patients, particularly migrants, asylum seekers, and other vulnerable populations. These individuals often face barriers to healthcare due to their living conditions, environmental factors, or fear of the hostile environment rules. The Safe Surgeries initiative provides a safe and welcoming environment, ensuring that patients can access the support they need. The initiative goes beyond medical care by offering a supportive network that can signpost patients to legal and social support services. This holistic approach recognises the importance of addressing patients' wider social and psychological needs, ultimately supporting their integration into the community.

The network continues to grow throughout the city, empowering healthcare professionals to fulfil their calling of treating patients without concern for housing or immigration status. This achievement represents a significant step forward in creating a city without inequalities and ensuring equitable access to healthcare for all residents.

4. Enabling: key achievements

4.1 Co-production coalition for involvement of those with multiple complex needs

The CCWIF served as a platform for initiating discussions about the creation of a co-production coalition. This coalition has been established collaboratively across the Making Every Adult Matter (MEAM) Programme, the Council and the CCWIF partnership. The co-production coalition serves as a collaborative platform that aims to actively involve individuals with multiple complex needs (MCN) in decision-making processes. These individuals face a range of challenges, including homelessness, substance abuse, mental health issues, and offending behaviour.

Moving forward, the forum remains committed to providing an avenue for the promotion of inclusivity and empowering individuals with MCN through supporting the growth of the co-production coalition and utilising its assets in making health and wellbeing services more accessible and responsive to the needs of those experiencing multiple disadvantages.

4.2 Community Health Profiles

The Communities Team in Birmingham City Council (BCC) has developed a further 11 Community Health Profiles that complement the originally published 14 profiles[1]. All the 14 profiles were peer reviewed by academic editors. The profiles were launched at live webinars, hosted on MS Teams between February and March 2024. Alongside publicising the profiles, the launch events also enabled opportunity for community feedback, including offering comments on the language and sensitivity of the information in the profiles and inclusion of any reports or other published source that could be added into the profiles.

Previous 14 profiles published between 2021 and 2022 are as follows:

- Bangladeshi
- Caribbean Commonwealth
- Indian
- Kenyan
- Muslim
- Nigerian
- Pacific Islands
- Pakistani
- Sikh
- Somali
- Deaf and Hearing Loss
- Sight Loss
- Lesbian
- Trans communities

The 11 profiles published between 2022 and 2023 are as follows:

- Gay Men and Men who have Sex with Men
- Bisexual
- Arab
- Central African
- South African
- Latin American
- Central and Eastern European
- Irish
- Gypsy, Roma and Traveller
- Chinese
- 16-24 Student Population.

Community Health Profile Evaluation

[1] Link to Community Health Profiles: https://www.birmingham.gov.uk/info/50305/community_health_profiles

The Communities Team is also currently working with an academic evaluator to provide process and impact evaluation on the Community Health Profiles programme. Evaluation of the programme will give opportunity for policy decision makers, authors, users of the profiles and engagement partners to provide feedback on the profiles. Data collection will be completed with qualitative and quantitative methodology. A final report will be published which summarises methodology and resources in writing the profiles, the suitability of the profiles, how well they have been used, dissemination and the impact of the completed engagement partner work. It is anticipated that the final evaluation report will be published in Q2 2025/26.

4.2 BSol ICS improved ethnicity coding

The forum has provided a space for discussions on the challenges and gaps in consistent collection of ethnicity coding, particularly in urgent admissions. Members of the forum have shared their experiences and insights, highlighting the need for improved frameworks and pathways for accurate ethnicity coding. These discussions within the forum help to raise awareness of the challenges and advocate for the necessary resources and capacity to address it.

A notable achievement in this area, is the development of the ICS digital strategy to enhance data collection, access, and utilisation as well as improve digital solutions offered for various services in Birmingham and their accessibility.

Local trust providers, like elective care at University Hospital Birmingham (UHB), have made significant progress in gathering ethnicity data at lower category levels. This includes categories such as Pakistani and Gypsy, which allows for a more detailed and accurate representation of the population. Efforts are also underway to establish routine reporting based on this data.

To further improve population trend analysis, a dedicated Population Health Management team has been established. This team is focused on exploring and supporting better analysis of population trends, including the enhancement of ethnicity coding and analysis. By improving the accuracy and depth of ethnicity data, it is expected that a more comprehensive understanding of the population's health needs can be achieved.

5. Looking ahead

The CCWIF is taking significant steps towards prioritising inclusion health groups in its efforts to reduce the deepest health inequalities in Birmingham. In line with the Birmingham Joint Health and Wellbeing Strategy ‘Creating a Bolder, Healthier City’, the previous Forward Plan of the CCWIF aimed to address a range of inequalities, including those linked to deprivation, disabilities, inclusion health groups, different ethnic communities and localities.

However, recognising the size, diversity and complexity of the inclusion health populations in the city, the forum has shifted the attention to exploring their specific challenges and needs. This shift will enable all system partners to gain a better understanding of the unique issues faced by these communities, both as individual groups and as a collective. By doing so, we can develop targeted efforts that effectively address these challenges.

It is important to note that this shift in focus does not represent a complete departure from our previous efforts. The forum and its members had already recognised the significance of addressing inclusion health needs at the local level and have already been carrying out this work and supporting inclusion health initiatives in the system accordingly. Further, this decision aligns with the publication of the National Health Service England’s (NHSE) National Framework for NHS - Action on Inclusion Health, strengthening the CCWIF partnership’s commitment to addressing the needs of inclusion health groups.

The forum will seek to address the needs of inclusion health groups experiencing more severe health and wellbeing challenges. We will continue to leverage the expertise and resources within the forum and its members, by facilitating targeted conversations, linking programme areas of work and recognising opportunities for action that address the unique challenges faced by inclusion health groups, building on those already identified and being implemented (see appendix 2).

Through this refreshed direction, the forum seeks to maximise its impact in addressing health inequalities and improving the overall health and wellbeing of the most vulnerable and marginalised populations across Birmingham.

6. Emerging priorities

During a February 2024 CCWIF Workshop, forum members and other key stakeholders convened to determine the primary areas of focus amidst the forum's transition towards inclusion health groups.

The workshop yielded the following key strategic priorities:

1. **Improve Data Collection and Action:** The participants stressed the importance of filling data gaps and collecting and disseminating intelligence to inform decision-making. They recommended collecting relevant data and analysing it effectively to gain insights into the challenges faced by inclusion health groups. It was suggested to take targeted actions based on data-driven approaches.
2. **Strengthen the High Intensity Intervention Programme:** This project is aimed at reducing demand from inclusion health frequent users of accident and emergency services. It involves developing targeted interventions and programmes that address the specific healthcare needs of frequent users, ultimately improving their overall wellbeing and reducing the strain on healthcare resources.
3. **Facilitate Co-Production:** Participants maintained the importance of true co-production, actively involving partners and individuals with lived experience in decision-making processes. It was suggested that clear expectations for communication and support should be set to ensure effective implementation of co-production.
4. **Ensure Cultural Awareness and Sensitivity:** The participants highlighted the need for cultural awareness and sensitivity when discussing future works and addressing the needs of inclusion health groups. Participants recommended considering cultural practices, beliefs and preferences in healthcare delivery to ensure inclusivity.
5. **Address Discrimination and Trauma-Informed Approaches:** The participants emphasised the need to actively champion cultural competence, promote inclusivity and address the impact of trauma on individuals. Some groups recommended providing training and resources to forum members and promoting best practices.
6. **Test and Innovate:** The participants suggested using the forum as a platform to test new ideas and be innovative in addressing the challenges faced by inclusion health groups. Participants also recommended experimenting with different approaches and strategies to identify effective solutions.

It is envisaged that the above priorities will be explored, and action plans will be developed through task and finish sub-groups. The terms of reference for the CCWIF are currently being revised to reflect this and the future direction for the forum. These will be shared alongside a new Forward Plan 2024-25 with the Birmingham Health and Wellbeing Board for ratification.

7. Conclusions and next steps

The CCWIF has made significant progress in addressing four out of the HWB five key inequality areas. Through the implementation of various projects and the development of new strategies, including the Gender Health

Inequalities Project, the Birmingham Poverty Truth Commission, BLACHIR, the Community Health Profiles, the ICS's and partners' commitment and action to improve engagement and services for the inclusion health groups, the forum and its members have taken concrete steps to address the unique needs of the most vulnerable citizens.

Looking ahead, the CCWIF recognises the need to adapt and ensure its organisational structure aligns with its renewed commitment in the context of the challenges across the ICS and the financial recovery of the Council, which it supports through strengthening collaboration between partners and a better, including a shared use of available resources. Therefore, a new set of terms of reference and a forward plan will be developed in the next month. These documents will reflect the refocus on inclusion health and provide a clear roadmap for the forum's future activities. The forum will strive to enable the delivery of programmes that accurately capture the needs of these communities and will continue to highlight initiatives that promote inclusion while supporting organisations within the system in their efforts to meet the growing needs of inclusion health groups.

In doing so, the CCWIF aims to create a city where every resident has equal access to health and care services and experiences improved health outcomes, regardless of their socio-economic status and background.

Authors:
Monika Rozanski – Service Lead – Inclusion Health, Public Health, Birmingham City Council
Fedalia Richardson – Public Health Senior Officer, Birmingham City Council

Appendix

Appendix A: CCWIF Opportunities for Action Matrix 2023-24

Item	Opportunity for action	HWB inequality priority area	Inclusion health group impacted	Owner	Current activity	Further action needed?	How will it be measured?	When will it be achieved?
A.	Develop a lived experience framework for Birmingham, increasing the involvement of inclusion health groups, and people with disabilities, in the co-production of solutions to tackle health inequalities and barriers in accessing healthcare.	Inequalities affecting inclusion health groups and communities with disabilities	All inclusion health groups plus people with disabilities	BCC public participation team / ICB comms and engagement team	- Lived experience co-production framework MEAM/BCC (in development) - ICS Community Engagement Strategy (in development) - Disability is an HR priority for the ICS - 'Disability confident' training for the ICB workforce			
B.	Co-produce and deliver training in cultural sensitivity and humility practice to front-line staff, including GPs, to meet the needs of disadvantaged groups and eradicate stigma and discrimination.	Inequalities affecting inclusion health groups / ethnic communities / communities with disabilities	All inclusion health groups	DPH BCC / ICS	- Cultural intelligence framework project (linked to BLACHIR) led by BCC - Cultural humility work for maternity care led by Flourish and maternity/ infant mortality and diabetes workstreams and other specific pilots (e.g. bowel cancer screening for Asian males) within the ICS - Community Co-production Framework for Personalised Care - ICB - MEAM Programme – focus on cultural humility and trauma informed practice in services for people with multiple disadvantage			
C.	Address digital exclusion among inclusion health population groups to	Inequalities affecting inclusion	All inclusion health groups	ICS	- Digital Inclusion Strategy – BCC - IT & Digital Strategy – ICS			

Item	Opportunity for action	HWB inequality priority area	Inclusion health group impacted	Owner	Current activity	Further action needed?	How will it be measured?	When will it be achieved?
	improve access to online healthcare information, advice and services that are available in easy read formats.	health groups			- ICS pilots around reasonable adjustments and preferences to improve accessibility of information, advice and support (these have already been successful in reducing DNAs and there are plans for scaling up)			
D.	Improve systematic data collection and quality by increasing its granularity so that ethnic minority and inclusion health groups' intersectionality is understood, and health and wellbeing needs are identified and addressed.	Inequalities affecting inclusion health groups & ethnic communities	All inclusion health groups	BCC/ Birmingham City Observatory / ICS Provider Collaboratives	- 'Better Data' work on ethnic coding linked to BLACHIR - Advocacy for better data collection across services, including the NHS, on inclusion health needs by the BCC PH Inclusion Health Team and via relevant needs assessments - Legal duty for ICS/ NHS to collate and publish data on protected characteristics – ICB's work with PCNs on improved data collection and sharing			
E.	Ensure the needs of inclusion health groups and people with disabilities are defined in Joint Strategic Needs Assessments (JSNA), enabling health services to be developed and effectively targeted.	Inequalities affecting communities with disabilities	All inclusion health groups (focus on people with disabilities)	BCC Public Health	- Vulnerable/ inclusion health groups incorporated into the latest JSNA projects/ outputs - Needs assessments for specific inclusion health groups progressed (e.g. sex workers, justice health) - ICB disability humility action plan for their workforce			
F.	Establish a community champions / advocates initiative across GP practices and the health system, advocating for the needs of the homeless and	Inequalities affecting inclusion health groups	All Inclusion health groups (with an additional focus on those	ICS	- PCN Health Inequalities Champions (could be further trained specifically for inclusion health groups) - HealthNow Alliance Programme (fixed term)			

Item	Opportunity for action	HWB inequality priority area	Inclusion health group impacted	Owner	Current activity	Further action needed?	How will it be measured?	When will it be achieved?
	supporting them and other inclusion health groups to access healthcare services.		experiencing homelessness)		- Making Every Adult Matter (MEAM) Programme (fixed term)			
G.	Embed the Making Every Adult Matter (MEAM) approach across the system, making Birmingham a trauma responsive city. Develop and implement a multiple disadvantage charter.	Inequalities affecting inclusion health groups	Those experiencing multiple disadvantages (two or more of the following – homelessness, substance misuse, mental health needs and offending)	MEAM Programme	- MEAM Programme - WMCA Trauma Informed Framework - Sex worker trauma informed toolkit (BSMHT) - HealthNow Alliance Programme - DPH Annual Report 2019-20 'Complex Lives, Fulfilling Futures'			
H.	Improve identification of individuals at risk of homelessness across the wider system and facilitate access to prevention and early intervention to mitigate the risk.	Inequalities affecting inclusion health groups	Those experiencing homelessness	Homelessness Partnership Board	- Homelessness Prevention Strategy led by BCC (in development)			
I.	Implement the legacy and learning from the HealthNow Alliance programme across the healthcare system, ensuring its sustainability and making sure homelessness is understood across every service.	Inequalities affecting inclusion health groups	Those experiencing homelessness	ICS	- HealthNow Alliance legacy plan and collaboration with ICS			

Item	Opportunity for action	HWB inequality priority area	Inclusion health group impacted	Owner	Current activity	Further action needed?	How will it be measured?	When will it be achieved?
J.	Adopt the S*upporting people experiencing homelessness and rough sleeping: Emergency Department pathway, checklist, and toolkit* within the healthcare system.	Inequalities affecting inclusion health groups	Those experiencing homelessness	NHS				
K.	Develop a system blockage tracker, outlining and collecting data on the barriers people with dual diagnosis experience when trying to access health services.	Inequalities affecting inclusion health groups, disable communities and ethnic communities	All inclusion health groups (substance misuse and mental health needs)	TBD	- Dual diagnosis 'deep dive' - MEAM Programme - Provider collaboratives			
L.	Develop a GP accreditation scheme to increase the awareness and understanding of learning disabilities, enabling support to be provided more quickly and effectively.	Inequalities affecting disabled communities	People with Learning disabilities (not a clear Inclusion Health Group)	PCNs / LD & A Partnership	- LDA register and health check process - LDA passport scheme in development by the ICB - ICS reasonable adjustments and preferences scheme			
M.	Establish an easy read website which provides a user-friendly directory of local learning disability	Inequalities affecting disabled communities	People with Learning disabilities (not a clear	LD & A Partnership	- 'The Waiting Room' - NHS Choices - ICS Communication and Engagement strategy (in development)			

Item	Opportunity for action	HWB inequality priority area	Inclusion health group impacted	Owner	Current activity	Further action needed?	How will it be measured?	When will it be achieved?
	services and resources in Birmingham.		Inclusion Health Group)		- Disability confident scheme at the ICB			
N.	Provide employers training and targeted information campaigns to challenge the stigma and attitudes towards people with disabilities, whilst also outlining the benefits of hiring staff with disabilities and the support that is available.	Inequalities affecting disabled communities	All inclusion health groups (focus on people with disabilities)	DWP / LD & A Partnership	- Disability confident scheme and humility programme at the ICB - PURE Project - Disability Advisors at DWP			
O.	Define consistent accessibility standards and implement them across the city.	Inequalities of locality	All inclusion health groups	TBD	- Disability confident schemes (BCC/ ICB) & disability humility programme (ICB) - Accessibility standards at BCC - Health literacy programme (PH)			
P.	Provide health screening services in community settings where inclusion health groups can access services without barriers.	Inequalities affecting inclusion health groups	All inclusion health groups	ICB	- Series of targeted cancer and diabetes programmes in community venues across areas of high prevalence, deprivation and concentration of specific ethnic communities - Flourish outreach in schools for childhood asthma - Vaccination and immunisation outreach programmes - ICS Communications and Engagement Strategy (in development)			

	Agenda Item: 10
Report to:	**Birmingham Health & Wellbeing Board**
Date:	**9th May 2024**
TITLE:	**LEARNING DISABILITIES DEEP DIVE REPORT**
Organisation	**Public Health, Birmingham City Council**
Presenting Officer	**Luke Heslop – Service Lead for Evidence**

Report Type:	**Approval**

1. Purpose:

1.1. To present the board with the completed Learning Disabilities Deep Dive Report. This is the third in a series of deep dive reports, that provide deeper insight into inequalities to complement the Joint Strategic Needs Assessment (JSNA).

2. Implications (tick all that apply):

Creating a Bolder, Healthier, City (2022-2030) – Strategic Priorities	Closing the Gap (Inequalities)	✓
	Theme 1: Healthy and Affordable Food	
	Theme 2: Mental Wellness and Balance	✓
	Theme 3: Active at Every Age and Ability	✓
	Theme 4: Contributing to a Green and Sustainable Future	
	Theme 5: Protect and Detect	✓
	Getting the Best Start in Life	✓
	Living, Working and Learning Well	✓
	Ageing and Dying Well	✓
Joint Strategic Needs Assessment		✓

3. Recommendation

3.1. It is recommended that the Health and Wellbeing Board support the implementation of the report's recommendations and provide approval for the Learning Disabilities Deep Dive to be published.

4. Report Body

4.1 Context

This is the third JNSA Deep Dive Report to reach completion. It is presented for comment and for approval to publish.

The report focuses on citizens living with learning disabilities (LD) in Birmingham.

There are 10,389 patients living with LD registered on GP records in Birmingham, which is just under 1% of the population. However, this is probably a significant underestimate due to un-diagnosed cases. Citizens living with LD endure significant health and wellbeing inequalities throughout the life course. In the West Midlands, life expectancy is significantly reduced to 59 years, which is a reduction of 16.8 years for males and 22.8 years for females. Citizens with LD are also significantly more vulnerable to health conditions, such as asthma, obesity, diabetes and epilepsy, as well as dementia, despite the lower life expectancy. Citizens with LD also endure significant other inequalities, including service provision, deprivation, adversity and social indicators (e.g. education, employment and housing).

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.

The Public Health Evidence Team reviewed the available evidence (e.g. strategies, data, epidemiological research and service provision) and also commissioned qualitative research to capture voices of lived experience from targeted research demographics. These included:

- Citizens living with LD and autism.
- Black and ethnic minority citizens living with LD.
- Parents of children who have LD.
- Parents of adult-children who have LD.
- Parents who have LD.
- Healthcare professionals who work with Parents with LD.

- Day centre staff.

The views of Birmingham's citizens helped to inform the key findings of the deep dive report, which are summarised in the five key findings below.

4.2 Key Findings

Recommendations and stakeholder ownership are detailed in Chapter 6 of the deep dive report.

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

The deep dive has also informed the *Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change (2022-32).*

4.3 Next Steps / Delivery

This document will be published on the Birmingham Council website and disseminated widely amongst stakeholders. An Easy Read version and an infographic will be published alongside the report.

Board members are asked to review the recommendations and stakeholder ownership and support implementation, which are detailed in Chapter 6 of the deep dive report.

5. Compliance Issues
5.1. HWBB Forum Responsibility and Board Update
The development of the JSNA, both core and deep dives, is managed by the JSNA steering group.
5.2. Management Responsibility
Luke Heslop, Service Lead for Evidence.
5.3. Finance Implications

The report provides an evidence base around learning disabilities in Birmingham and makes recommendations for actions. It is not a decision report and as such does not have direct financial implications.
5.4. Legal Implications
This report is part of the Public Health Team's statutory duty to provide specialist public health advice and support to the NHS under the Health and Social Care Act 2012. It is also part of the local authority's statutory duty, through the Health and Wellbeing Board, to produce the Joint Strategic Needs Assessment. There are no legal implications arising from this report.
5.5. Equalities Implications (Public Sector Equality Duty)
This report is part of the Public Health Team's statutory duty to reduce health inequalities, by providing specialist public health advice and support to the NHS under the Health and Social Care Act 2012. It is also part of the local authority's statutory duty, through the Health and Wellbeing Board, to produce the Joint Strategic Needs Assessment.

6. Risk Analysis

Identified Risk	Likelihood	Impact	Actions to Manage Risk
That the recommendations are not implemented.	Low	Low	The team has carried out substantial engagement with stakeholders to assign ownership of the recommendations.
That the evidence is not applicable.	Low	Low	Local evidence was obtained and analysed, lived experience data was captured and the team worked closely with stakeholders.
That there is no improvement in outcomes (relating to inequalities) for citizens living with learning disabilities.	Low	Low	The report's recommendations work across the whole system to influence positive action. There is also a recommendation for the Deep Dive team to refresh this deep dive in 5 years.

Appendices

Appendix 1 - Learning Disabilities Deep Dive Report
Appendix 2 - Learning Disabilities Deep Dive – Easy Read Version

Background Papers

The following people have been involved in the preparation of this board paper:
Luke Heslop, Service Lead for Evidence.
luke.heslop@birmingham.gov.uk

Learning Disabilities in Birmingham JSNA Deep Dive Report (2024)

Pre-production draft document. Awaiting approval by the Health and Wellbeing Board.

Contact

luke.heslop@birmingham.gov.uk

Research Champions

Richard Kirby (Executive Director, Birmingham Community Healthcare NHS Foundation Trust) and Stephen Raybould (Director, Birmingham Voluntary Service Council).

Lead Researcher

Luke Heslop (Service Lead Evidence, Public Health Division, Birmingham City Council).

Research Team

Bethany Parkes	Senior Public Health Officer	Birmingham City Council
Jeanette Davis	Senior Public Health Officer	Birmingham City Council
Dr Alexander Dallaway	Senior Public Health Officer	Birmingham City Council
Zoe Wright	Senior Public Health Officer	Birmingham City Council
Manuela Engelbert	Public Health Officer	Birmingham City Council
Tariro Mandisodza	Public Health Officer	Birmingham City Council
Eleanor Fry	Public Health Officer	Birmingham City Council

Acknowledgements

With thanks to the Birmingham & Solihull Learning Disability and Autism Operational Board, Midland Mencap, Birmingham Strategic Commissioning Group, Birmingham Children's Trust, Birmingham Autism and ADHD Board, Birmingham City Council Adult Social Care, POhWER, Advocacy Matters, Hodge Hill Neighbourhood Network Scheme, Sutton Coldfield Neighbourhood Network Scheme, Dr Justin Varney (BCC), Samantha Lowe (Coventry & Warwickshire Partnership Trust), Linda Harper (BCC), Joseph Martin (NHS Birmingham and Solihull), Olivia Brown (Black Autism), Natalie Stewart (BCC), Mohan Singh (BCC), Dr Albert Prats-Uribe (University of Oxford), Dr Mary Orhewere (BCC), Julie Harrison (BCC), Julie Bach (BCC), Katie Meah (Birmingham and Solihull CCG), Vanessa Wright (LeDeR), Emma Pickering (LeDeR), Dawn Garbett (Black Country Healthcare NHS Foundation Trust), Deborah Towle (BCC), Ginny Cullen (CASBA), Jennifer Brown (CASBA), Samantha Russell (expert by experience), Ashleigh Jones (Mencap), Alison Montgomery (Birmingham Children's Trust), Rachael Lickley (Birmingham Children's Trust), Joann Bradley (BCC), Rachael Garvey (Birmingham Community Healthcare NHS Foundation Trust), Tom Mullen (BCC), Theresa O'Borne (DWP), Alex Quarrie-Jones (BCC), Shiraz Sheriff (BCC), Dr David Ellis (BCC), Chung Au-Yeung (BCC), Jo Tonkin (BCC), Rhys Boyer (BCC), Aidan Smith (Leeds Council), James Turner (Leeds Council), Rosemary Armitage (Leeds Council), Joanne Smith (UHB), Tom Parker (BCC), Saba Rai (BCC), Fharat Rehman (BCC), Juliet Grainger (BCC), Lottie Drury (BCC), Julia Pauschardt (BCC), Andrew Lindop (BCC), Karl Beese (BCC), Linda Sutton-Howard (BCC), Jayne Harlow (BCC), Maureen Black (UHB), Nadine Coughlan (UHB), William Aldridge (NHS Midlands & Lancashire Commissioning Support Group), Rebecca Howell-Jones (BCC), Jo Carney (NHS), Heather Wood (BCC), Andy Kimber (BCC), Linda Lockwood (NHS), David Stringfellow (Birmingham Children's Trust), Dave Rogers (Midland Mencap), Lynda Bradford (BCC), Humera Sultan (BCC), Sumyra Ul-Hassan (BCC), Paddie Murphy (Birmingham Community Healthcare Trust on behalf of BSOL ICB), Andrew Dalton (NHS England), Dr Kirsten Blackford (Cofton Medical Centre), Adrian Weissenbruch (BCC).

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.

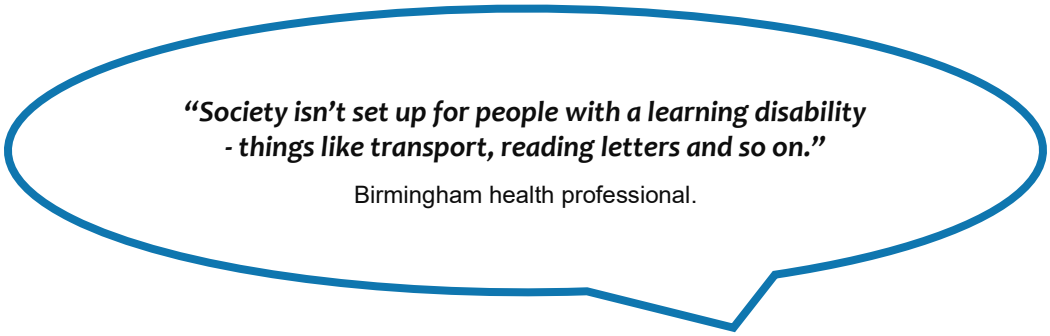
We all have a responsibility to care for those most vulnerable in society, and this deep dive opens the conversation about how we are currently doing this for our citizens and where we can create positive actions for change. Across our city, we want to develop communities and organisations who can openly 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



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.

[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]

[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.

Many countries use the term 'intellectual disability' rather than 'learning disability', but these terms have the same meaning and are interchangeable.[9] (

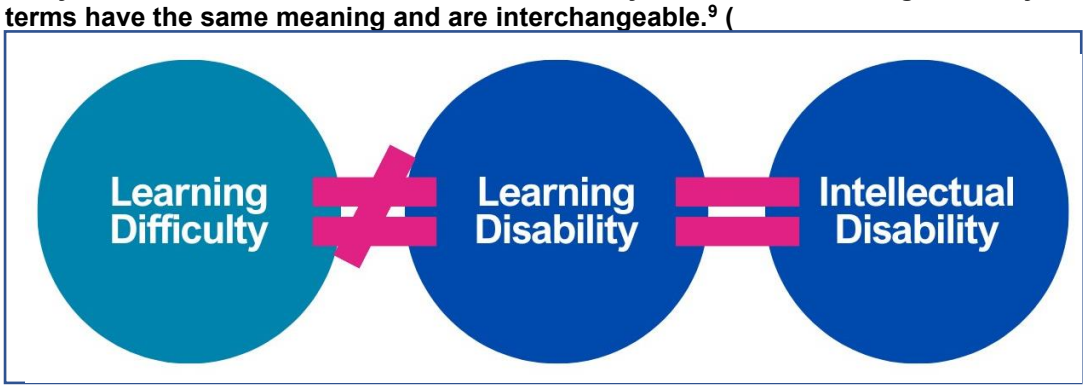


Figure 1). Health conditions which are associated with learning disabilities include autism, cerebral palsy, dementia, Down syndrome, epilepsy, Fragile X syndrome, Williams syndrome and mental health problems.[10]

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

Source: Produced Internally.

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. 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.

[9] Emerson, E. et al. A Working Definition of Learning Disabilities. Accessed Dec 2022.
[10] Mencap. Learning Disability and Conditions. Accessed Feb 2022.
[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.

- 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 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.

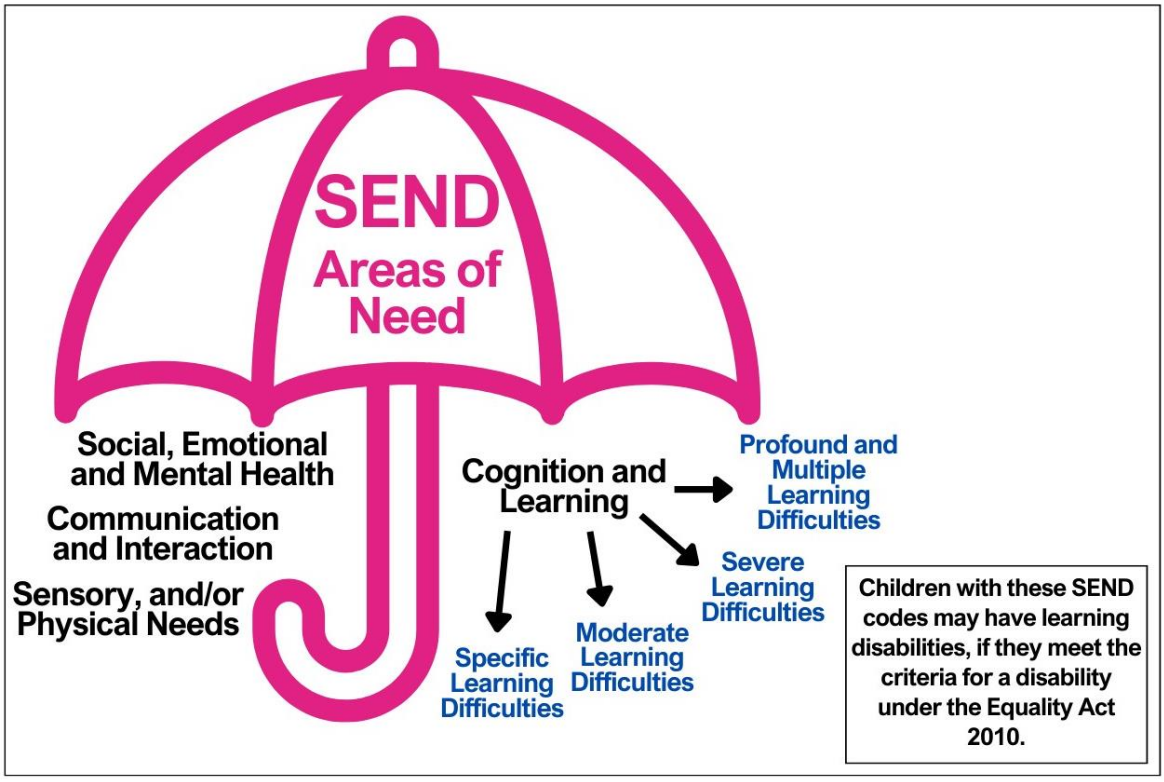


Figure 2: SEND Areas of Need.

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.

[14] BILD. (2011) Factsheet: Learning Disabilities. Accessed Feb 2022.
[15] Bristol University. Learning Disabilities: A Working Definition. Accessed Dec 2022.
[16] Information reviewed with the Children and Families Directorate, Birmingham City Council.

- 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.
- 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

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

'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).

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.

[22] GOV.UK. (2018). Reasonable Adjustments for People with a Learning Disability. Accessed Oct 2022.
[23] NHS England. Reasonable Adjustments. Accessed Oct 2022.
[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.

Error! Reference source not found. 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]

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 special educational needs (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 learning disability SEN codes include 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

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

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.

1.5.2 Projections

National projections for adults living with a learning disability or Down syndrome can be seen in **Error! Reference source not found.**. 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).

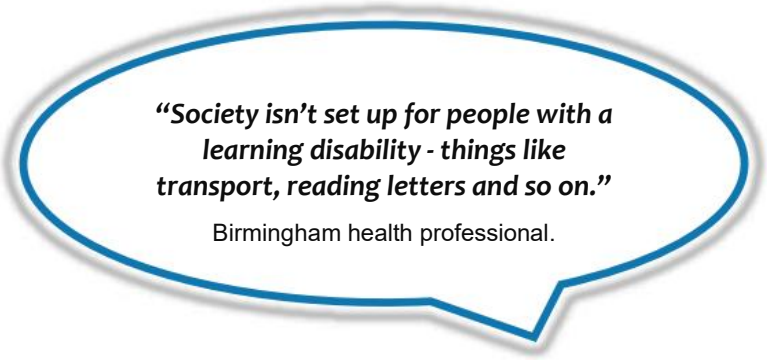
Type of Disability	2020	2025	2030	2035	2040
Learning Disability	1,318,401	1,351,529	1,391,883	1,427,237	1,448,961
Down Syndrome	21,661	21,902	22,068	22,189	22,292
Total	**1,778,395**	**1,825,129**	**1,880,479**	**1,928,850**	**1,959,438**

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]

[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.
[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 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.

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*.

[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.

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 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]

[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.
[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.

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]

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

[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.
[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.

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]

The ***SEND Review: Right Support, Right Place, Right Time (2022)*** highlighted three key challenges that the SEND system faces. Firstly, outcomes are poor for children with special educational needs or who are in alternative provision. Secondly, navigating the SEND system and alternative provision is difficult for children and families. Parents face difficulties seeking the right support for their children and delays are a common experience for families. During 2020-21, in England there were 8,600 registered SEN appeals to the tribunals, a figure which has increased year on year. Thirdly, the system does not deliver value for money, despite unprecedented investment.[60]

Within the system, there are inconsistencies between services across different parts of the country, resulting in unclear expectations around service provision. For those who do require an *Education, Health and Care Plan* (EHCP) or specialist placement, this should be accessed with minimal bureaucracy. This report proposed the introduction of a standardised and digitised EHCP process and template to support this. Proposals from this review include a

[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.
[60] HM Government. (2022). SEND Review: Right Support Right Place Right Time. Accessed Jun 2022.

national SEND system with national standards, a review and update of the SEND code of practice, new investments into school budgets and an updated SEND Inspection Framework.[61]

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 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.[62]

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.[63]

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.[64]

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.[65]

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

[61] GOV.UK. Open Consultation. SEND review: right support, right place, right time. Accessed Jun 2022.
[62] MacAlister. (2022). Independent Review of Children's Social Care. Accessed Jun 2022.
[63] Mind. Sectioning. Accessed Jan 2023.
[64] Equality and Human Rights Commission. The Human Rights Act. Accessed Jan 2022.
[65] Gov.UK. Equality Act 2010: Guidance. Accessed Nov 2021.

safeguarding framework was outlined which set out how local authorities and other relevant professionals should protect adults from abuse and neglect.[66]

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.[67]

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.[68]

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.[69]

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.[70]

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. [71] 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.[72]

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.[73]

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:

---

[66] Department of Health and Social Care. (2016). Care Act Factsheets. Accessed Jan 2022.
[67] Information, Advice and Support Programme. Factsheet: An Introduction to Part 3 of the Children and Families Act 2014. Accessed Nov 2022.
[68] Local Government Association. Reforming the Mental Health Act white paper 2021. Accessed Apr 2022.
[69] UK Parliament. Down Syndrome Act 2022. Accessed Jun 2022.
[70] NHS. (2018). The Learning Disability Improvement Standards for NHS Trusts. Accessed Mar 2022.
[71] NHS. The Learning Disability Improvement Standards for NHS trusts. Accessed Jan 2022.
[72] NHS. Performance against the learning disability improvement standards Findings from the benchmarking exercise July 2019. Accessed Jan 2022.
[73] NHS. (2019). The NHS Long Term Plan. Accessed Mar 2022.

- 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.[74]

1.6.5 National Institute for Health and Care Excellence (NICE)

NICE guidelines are evidence-based recommendations for health and care in England.[75] 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).[76]

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.[77]

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).[78]
- Social work with adults experiencing complex needs (NG216, 2022).[79]

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.

[74] PCPLDD Network and NHS England. (2017). Delivering high quality end of life care for people who have a learning disability. Accessed Mar 2022.
[75] NICE. NICE guidelines. Accessed Feb 2022.
[76] NICE. People with Learning Disabilities. Accessed Feb 2022.
[77] NICE Impact. (2021). People with a learning disability. Accessed Jan 2022.
[78] 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.
[79] NICE. (2022). Social work with adults experiencing complex needs. Accessed Nov 2023.

- 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.
- 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.[80]

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.[81]

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:

[80] 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.
[81] 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.

- 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 healthcare (including reasonable adjustments digital flag), and implement recommendations from the *Lives and Deaths of People with a Learning Disability Review*.[82]

1.6.6 Core20PLUS5 Model

The Core20PLUS5 is a national NHS England approach to reducing health inequalities at national and local levels.[83] 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.[84] 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.

[82] NICE Impact. (2021). People with a learning disability. Accessed Jan 2022.
[83] NHS England. Core20PLUS5 (adults) – an approach to reducing healthcare inequalities. Accessed Dec 2022.
[84] Birmingham City Council. Our Future City Plan 2021. Accessed Nov 2022.

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.[85]

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.[86]

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.[87]

1.7.5 Birmingham SEND Strategy (2023-28)

This Strategy was co-produced with stakeholders and identifies eight priority areas:[88]

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.

[85] Birmingham City Council. Creating a Bolder, Healthier City (2022 to 2030), Accessed Nov 2022.
[86] Birmingham City Council. Birmingham's Levelling Up Strategy. Accessed Nov 2022.
[87] Birmingham and Solihull Integrated Care System. Our Priorities. Accessed Aug 2023.
[88] Local Offer Birmingham. SEND and Inclusion Strategies Overview. Accessed Sep 2023.

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.

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.[89] 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.[90]

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.[91]

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).[92]

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

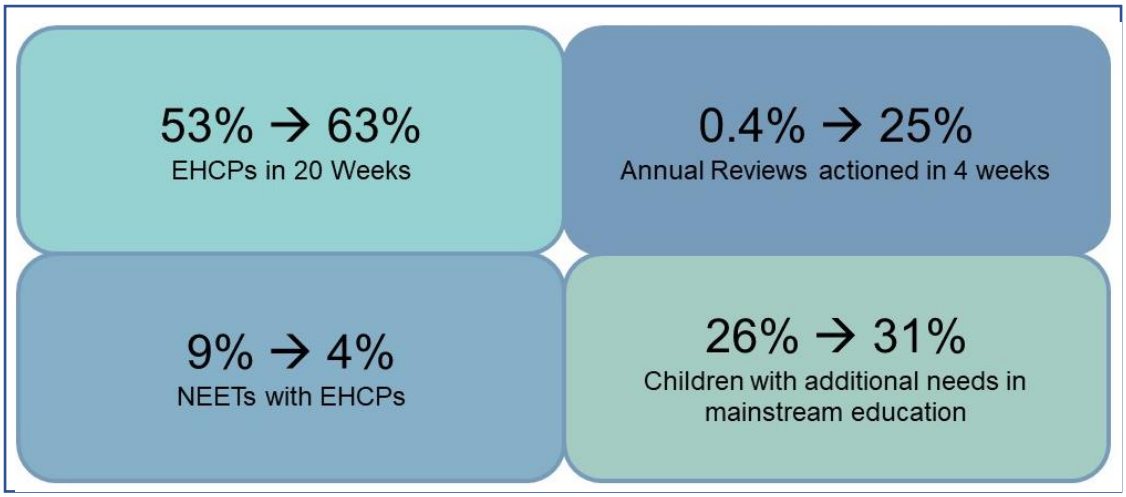


Figure 4: Birmingham SEND Updates, 2021-22.

Source: Birmingham City Council SEND Improvement Update.

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:[93]

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.

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

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.[94] 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).

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.[95] 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),[96] 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.

[94] Data supplied by BSoL LeDeR programme.
[95] NHS England and NHS Improvement. Children and Young People's Mental Health and Emotional Wellbeing Local Transformation Plan 2021/22 Birmingham. Accessed Dec 2022.
[96] NHS England. Dynamic support registers and Care (Education) and Treatment Review code of practice. Accessed Nov 2023.

''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.[97]

[97] 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.[98] 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.[99]

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.[100] 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.[101]

[98] Source: Business Intelligence BSOL ICB January 2023. Accessed Nov 2023.
[99] NHS Digital. (2021). Quality and Outcomes Framework, 2020-21. Accessed Oct 2021.
[100] BBC News. (2011). Domesday Reloaded: Mental asylums to care in the community. Accessed Nov 2023.
[101] 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.

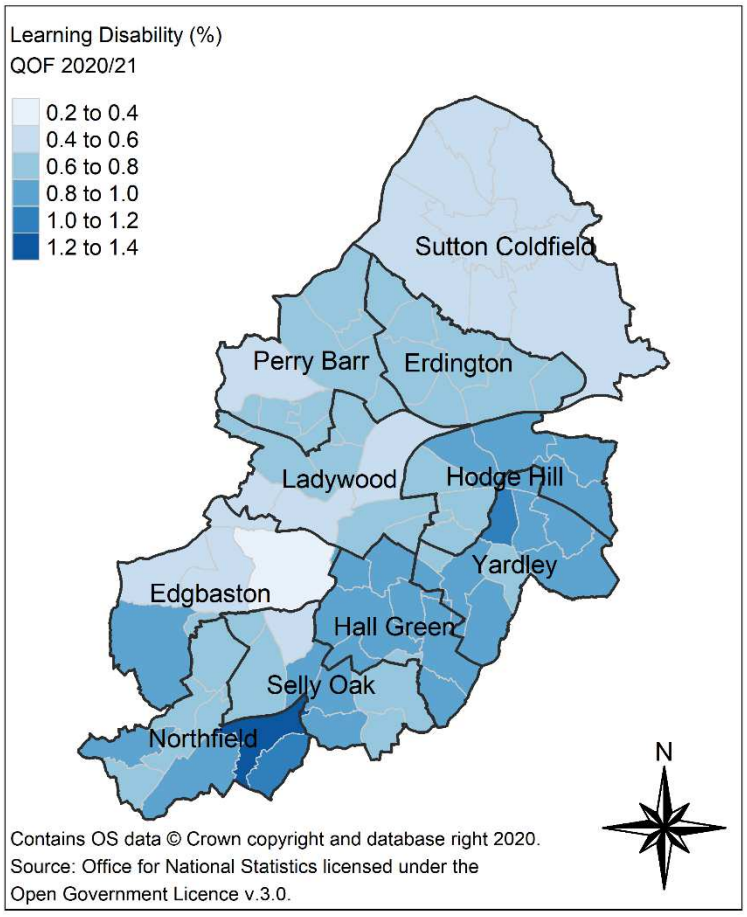


Figure 5: Learning Disabilities QOF Prevalence by Ward (2020-21).

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

Figure 6: Population Pyramid Displaying Age Range of Birmingham Patients Living with Learning Disabilities (January 2023). Figure 6 provides an age summary of these patients. 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.[102]

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

Age Group	Number of LD Patients	%
Under 20	2,556	25%

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

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).

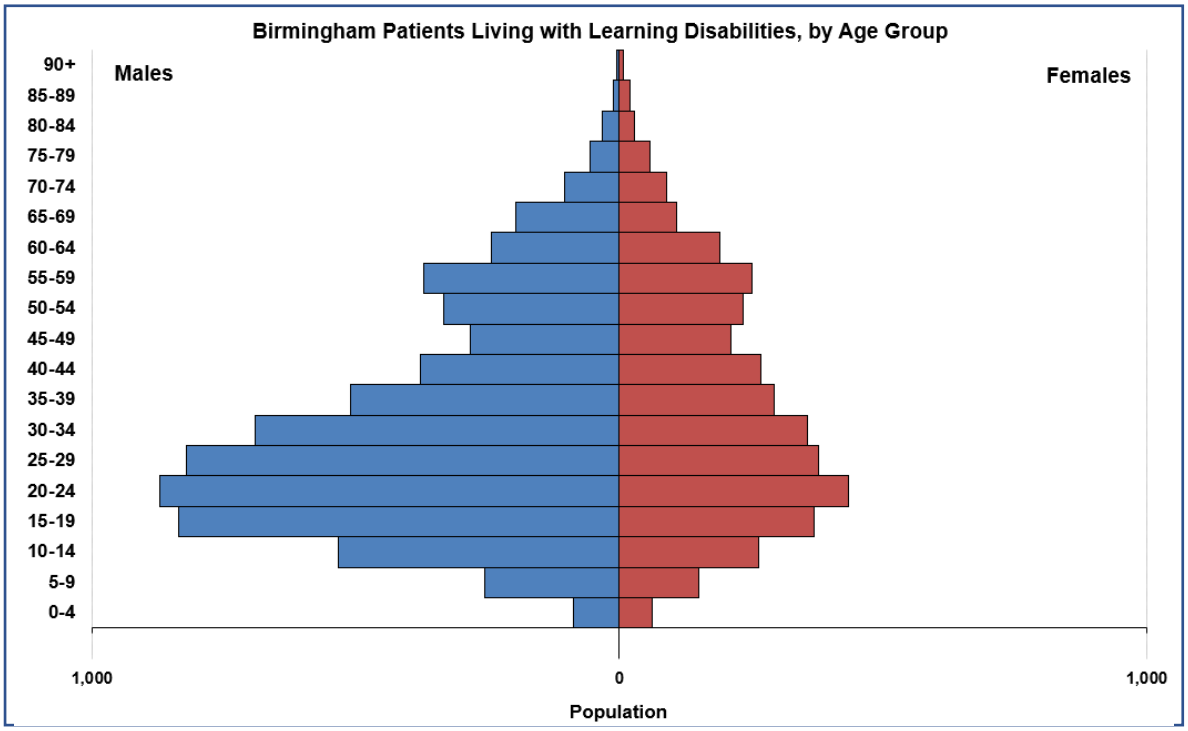


Figure 6: Population Pyramid Displaying Age Range of Birmingham Patients Living with Learning Disabilities (January 2023).

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.[103] 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%

[103] ONS. 2021 Census. Accessed Jan 2023.

Not known	1,390	13%	0%

Source: Business Intelligence BSOL ICB Jan 2023, [104] and 2021 Census.

2.2 Projections

***PANSI*[105] and *POPPI*[106] provide projection figures for Birmingham residents (aged 18+) with various vulnerabilities, including learning disabilities. Projections cover 2025 to 2040 and are for varying degrees of learning disabilities, ranging from moderate to severe, with Down syndrome recorded separately.[107] 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**

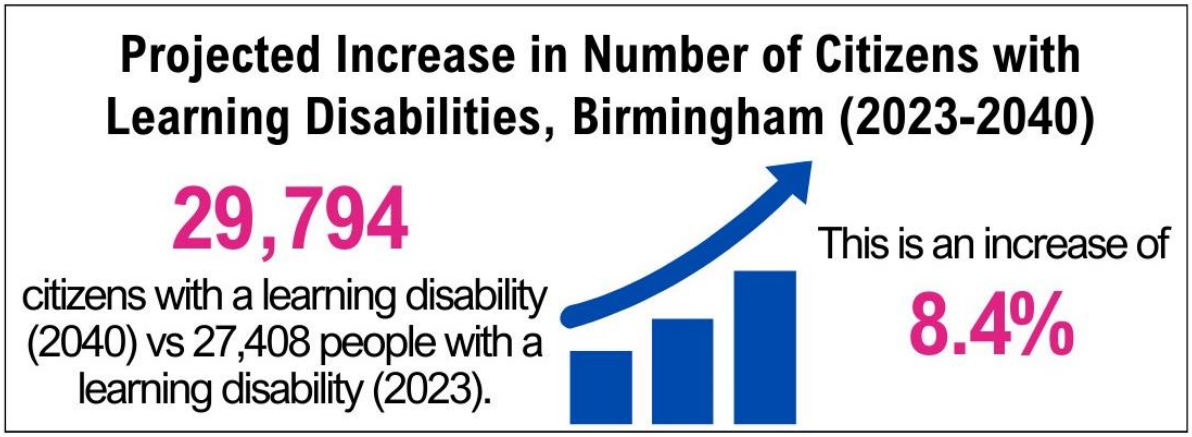


Figure 7). The projections are based on 2021 Census.

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).

[104] Information supplied by Business Intelligence BSOL ICB. January 2023. Accessed Jan 2023.
[105] PANSI. Projecting Adult Needs and Service Information. Accessed Aug 2023.
[106] POPPI. Projecting Older People Population Information. Accessed Aug 2023.
[107] Information confirmed by email from PANSI. Accessed Sep 2021.

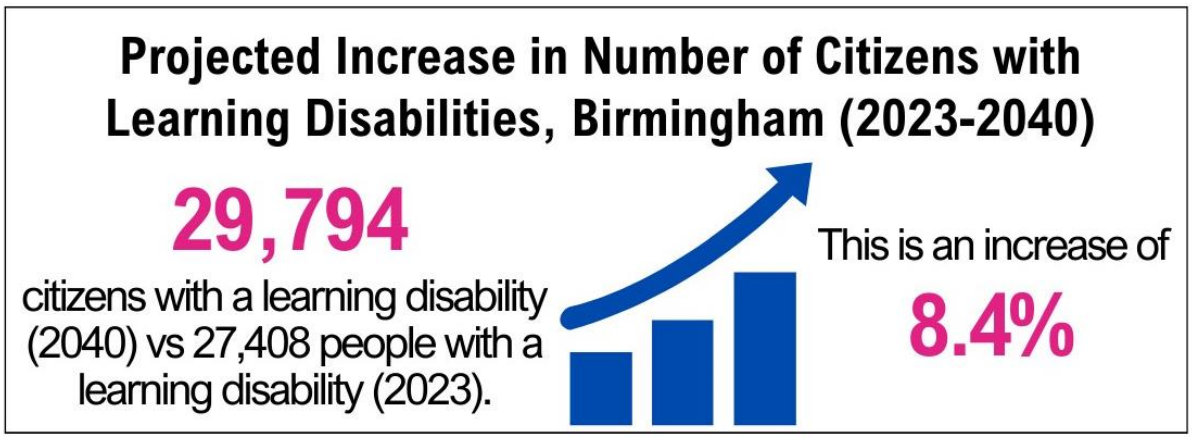


Figure 7: Projections of Citizens with Learning Disabilities (2023-2040).

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 from infants to 80+ years, indicating that people with Down syndrome have had increased life expectancies over time, but often with health complications.[108]

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.[109] 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. Blue numbers represent the life expectancy of the general population in the ward, and red represents the difference in years for life expectancy for citizens living with a learning disability.

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

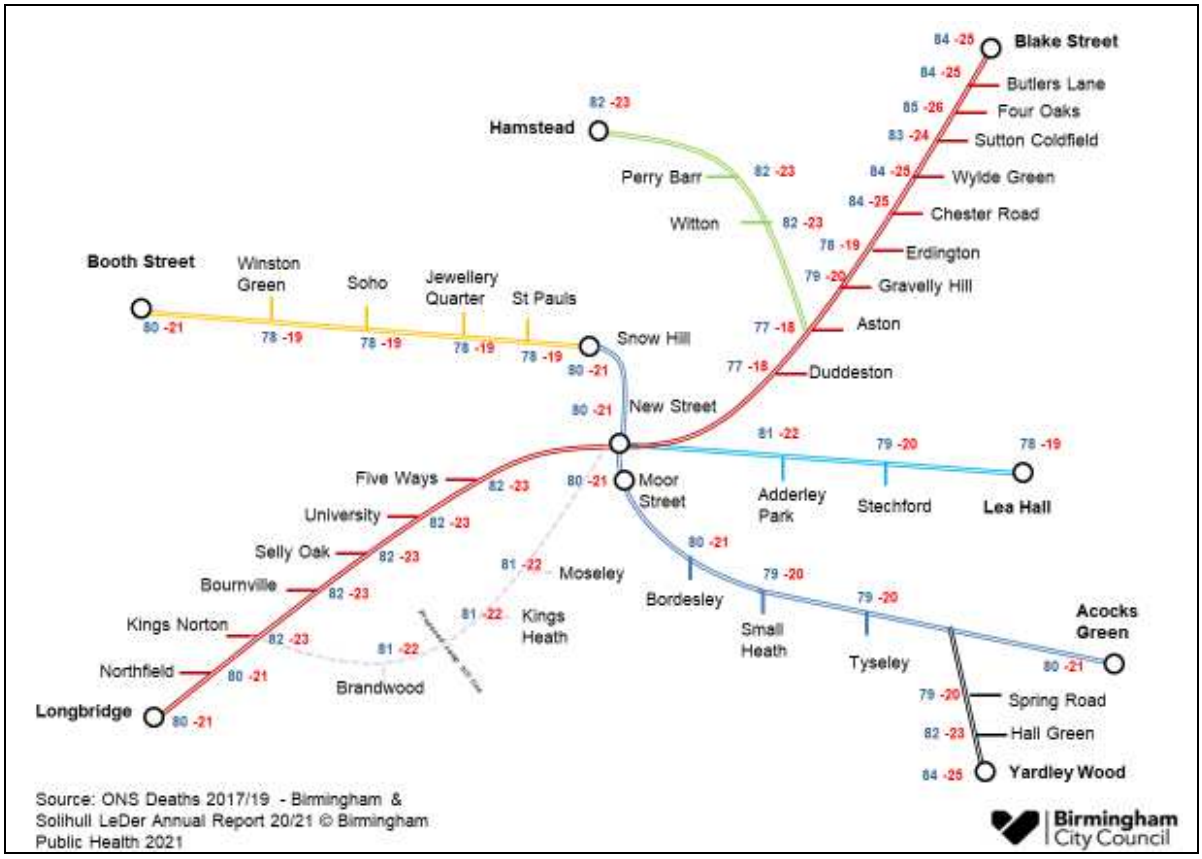


Figure 8: Life Expectancy Gap for Citizens with Learning Disabilities Compared to General Population, by Railway Stations.

3 Health and Wellbeing Inequalities

3.1 Health Inequalities

Health inequalities are avoidable and unfair differences in health status between groups of people.[110] 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.[111] 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.[112] 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.[113]

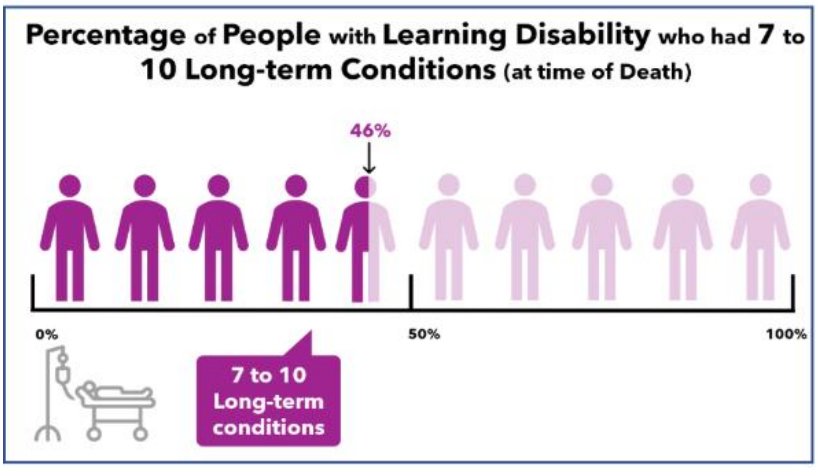


Figure 9: Percentage of People with a Learning Disability who had 7 to 10 Long-Term Conditions at Time of Death.

Source: LeDeR *Annual Report.*[114]

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%).[115]

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 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

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

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%).[116]

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%).[117]

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.[118]

19% of citizens of Birmingham with learning disabilities had epilepsy, 12.1% had ADHD and 1% had dementia (Table 8: Long-Term Health Conditions amongst Learning Disability Patients (January 2023).Table 8).

Table 8: Long-Term Health Conditions amongst Learning Disability Patients (January 2023).

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).

[116] King's College London. (2023). LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People. Accessed Dec 2023.
[117] NHS Digital. (2021). Health and Care of People with Learning Disabilities. Accessed Sep 2021.
[118] 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.[119] 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 (January 2023).

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 (January 2023).

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: Diabetes Prevalence among Learning Disability Patients (January 2023).

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

Source: Business Intelligence BSOL ICB (Jan 2023).

[119] 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

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,[120] where 1 in 6 adults (16.6%) experience symptoms of common mental health problems.[121]

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).[122] 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.[123]

Despite the high prevalence of mental health problems in people with learning disabilities, they continue to be under-recognised,[124] and subsequently remain largely untreated.[125] Diagnostic overshadowing may exacerbate the problem, leading to a lack of suitable care and prolonged distress for the person with learning disabilities.[125] The prevalence of mental health problems and challenging behaviour may be influenced by the underlying cause of the person's learning disabilities.[126] 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.

---

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

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 estimated to have a severe mental illness (all ages, 2011-22).[127] 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).[128]

Table 12: Mental Health Conditions of Patients with Learning Disabilities (January 2023).

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).[129]

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).[130]

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%).[131] 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.[132,133] 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.[131] Research has also shown that a higher proportion of female adolescents with learning disabilities report suicidal attempts (9%) compared to their male

[127] Office for Health Improvement and Disparities. Mental Health Profile. Accessed Nov 2023.
[128] *Locally calculated by Business Intelligence BSol ICB (January 2023).*
[129] Information supplied by Business Intelligence BSOL ICB. January 2023. Accessed Jan 2023.
[130] NHS Digital. (2021). Health and Care of People with Learning Disabilities. Accessed Sep 2021.
[131] Fuller-Thomson et al. (2018). Suicide Attempts Among Individuals with Specific Learning Disorders: An Underrecognized Issue. Accessed Dec 2021.
[132] Bender et al. (1999). Stress, Depression, and Suicide among Students with Learning Disabilities: Assessing the Risk. Accessed Dec 2021.
[133] BOND Consortium. Children and young people with learning difficulties – understanding their mental health. Accessed Dec 2021.

counterparts (4%).[134] 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 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;[131] 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.[132] 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.[135]

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%).[136]

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.[137]

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.[138] For further information on cancer and cancer screenings, please see section 4.4.

---

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

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 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.[139] 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.[140]

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.

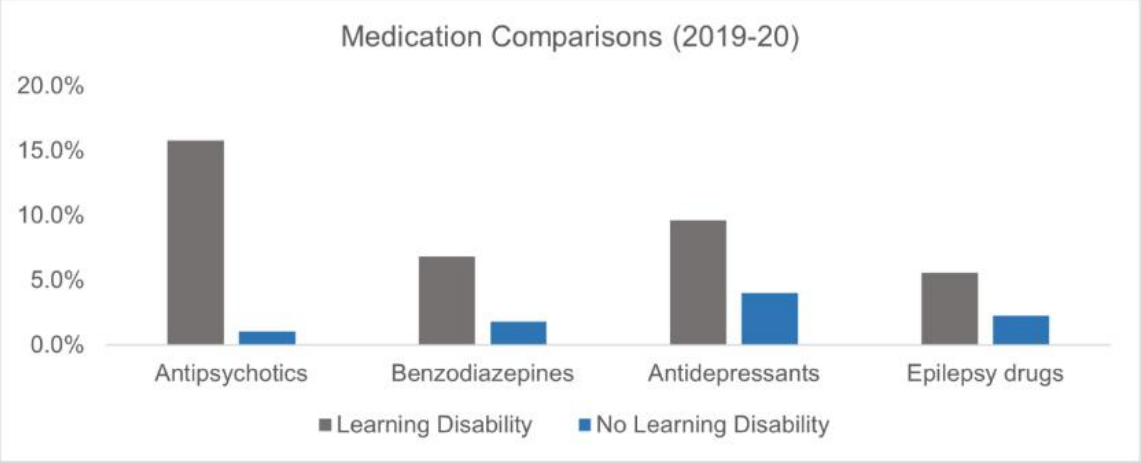


Figure 10: Medication Comparisons in Birmingham: Antipsychotics, Benzodiazepines, Antidepressants (in Absence of a Diagnosis of Depression) and Epilepsy Drugs (in Absence of a Diagnosis of Epilepsy).

Source: Health and Care of People with Learning Disabilities (2019-20).[141]

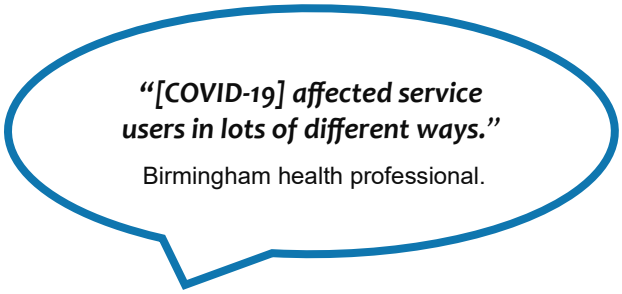
[139] Public Health England. (2015). Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England. Accessed Jan 2022.
[140] NHS. Stopping Over Medication of People with a Learning Disability, Autism or Both). Accessed Dec 2021.
[141] NHS Digital. (2021). Health and Care of People with Learning Disabilities. Accessed Sep 2021.

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 programme to individuals from an ethnic minority background.[142] 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.[143]

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.[144]

3.1.4 Long-term Impact of the COVID-19 Pandemic



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).[145]

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

[142] Birmingham Community Healthcare Foundation Trust. Multicultural STOMP (MC-STOMP). Accessed Nov 2022.
[143] Birmingham Community Healthcare Foundation Trust. Useful Resources. Accessed Nov 2022.
[144] Glover and Evison. (2013). Hospital Admissions That Should Not Happen. Accessed Feb 2022.
[145] 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.[146] Figure 11 highlights some of the key findings from this survey.

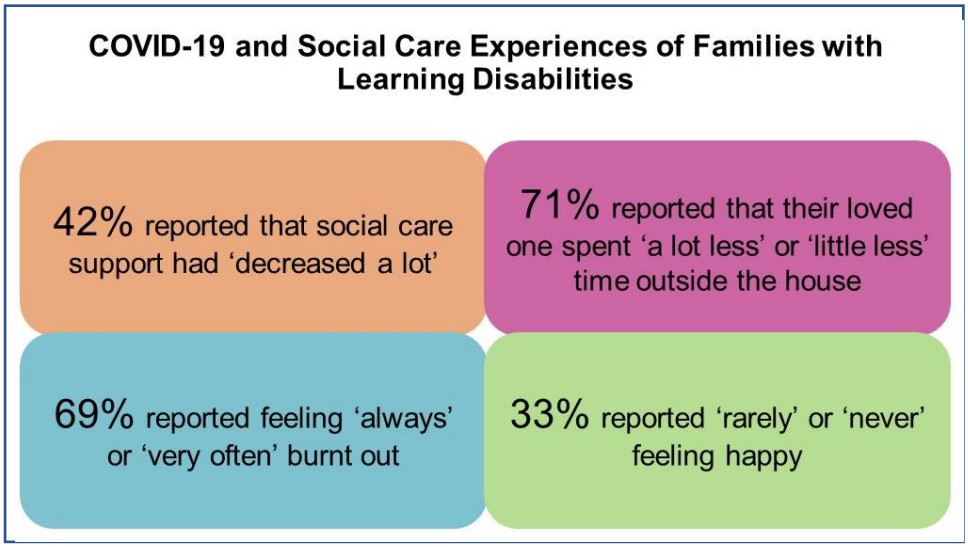
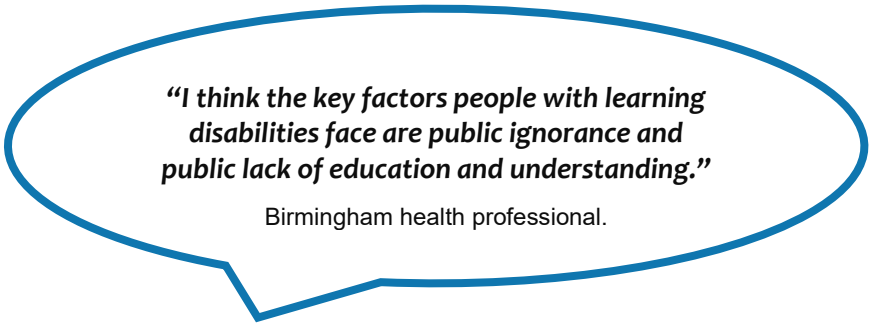


Figure 11: Responses to Survey on COVID-19 Pandemic and Social Care Experiences of Families with Learning Disabilities.

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

3.2 Wider Determinants of Health



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 were exposed to income poverty at multiple time points, compared with 47% of children in the general population.[147]

[146] Mencap. (2022). Let Behind and Locked Down – New Figures from Mencap Highlight how Social Care has been 'Ravaged by the Pandemic'. Accessed Jul 2022.
[147] Public Health England. (2015). The determinants of health inequities experienced by children with learning disabilities. Accessed Dec 2022.

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.[148]

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.[149]

3.2.3 Physical Activity

Low physical activity is the 4th highest behavioural cause of disease and disability in England.[150] Engaging in physical activity is a protective factor for health with benefits to both mental and physical health and wellbeing.[151,152] 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.[153,154]

3.2.4 Transport

The *National Disability Strategy* (2021) recognises that everyday journeys are still not accessible for many people with disabilities, especially spontaneous journeys. This strategy 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.[155]

---

[148] Hft. Lockdown on Loneliness. Accessed Dec 2022.
[149] Scope. (2018). The Disability Perception Gap. Policy Report. Accessed Dec 2021.
[150] 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.
[151] Warburton and Bredin. (2017). Health benefits of physical activity. A systematic Review of Current Systematic Reviews. Accessed Dec 2021.
[152] Lukács et al. (2018). Physical activity and physical fitness as protective factors of adolescent health. Accessed Dec 2021.
[153] 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.
[154] Dairo et al. (2016). Physical activity levels in adults with intellectual disabilities: A systematic review. Accessed Dec 2021.
[155] HM Government. National Disability Strategy. Accessed Dec 2021.

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.[156]

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).[157]

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 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

[156] Department for Education. (2021). Special educational needs and disability: an analysis and summary of data sources. Accessed Jan 2022.
[157] Public Health England. Proportion of Supported Working Age Adults with Learning Disability in Paid Employment. Accessed Aug 2021.

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*.'[158]

In 2017-18, the majority of those in work (68.3%) were working less than 16 hours per week.[159] *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%).[160]

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.[161]

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 parents. This takes away their independence, causes them to be reliant on others, reduces their confidence to live independently and adds stress to their careers.[162]

[158] Cheetham et al. (2019). Impact of Universal Credit in Northeast England: a qualitative study of claimants and support staff. Accessed Nov 2022.
[159] Public Health England. (2020). Chapter 2: paid employment. Accessed Dec 2021.
[160] 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.
[161] Gov.UK. Reasonable adjustments for workers with disabilities or health conditions. Accessed Jan 2022.
[162] Mencap. Housing for People with a Learning Disability. Accessed Dec 2021.

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.[163]

The Learning Disability and Autism Housing Network[164] (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.

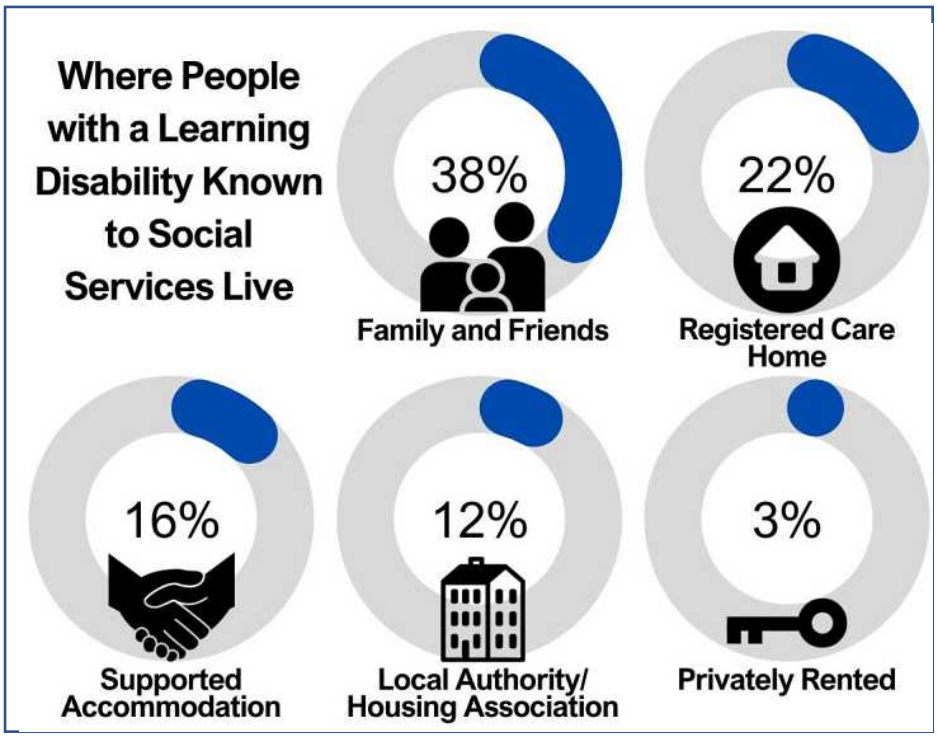


Figure 13: Where People with a Learning Disability Known to Social Services Live.

Source: Mencap Housing Report v7.

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

[163] Bonnefoy. (2007). Inadequate housing and health. Accessed Jan 2022.
[164] Advance. Learning Disability and Autism Housing Network Launch Charter. Accessed Jan 2022.

care and support. Examples of the good practice that has filtered into the many forms of their work 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.[165]

Through the Maze is an Easy Read website providing information and highlights services in Leeds aimed at citizens with learning disabilities, their family carers and professionals. This provides a comprehensive resource for citizens to access, presented in an Easy Read format.[166]

Being Employed is an Easy Read website, collating paid and voluntary work opportunities for citizens with learning disabilities.[167]

Forum Central is the collective voice of Leeds' third sector and is a network of learning disability organisations in Leeds. This has over a hundred third sector organisations as members, which work to improve services and opportunities for people with learning disabilities in Leeds. The focus of the work of this board is around the 'Being Me' Strategy. The work is divided into task groups which are themed: Being Well, Being Social, Being Safe, and Employment and Travel. Forum Central lead on the Employment Task Group, which takes a city-wide partnership approach and includes experts by experience, representatives from third sector organisations (e.g., Lighthouse Forward Trust) and employers. This group co-ordinate activities across the city to engage more citizens with learning disabilities into employment.[168]

3.2.9 Adverse Weather

People living with learning disabilities are vulnerable to the impact of both hot and cold adverse weather.[169] 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.[170]

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

[165] Leeds Learning Disability Partnership Board Strategy. Being Me. Accessed October 2022.
[166] Through the Maze. Accessed Oct 2022.
[167] Being Employed Leeds. Accessed Nov 2022.
[168] Forum Central. About the Learning Disability Network. Accessed Oct 2022.
[169] King's College London. (2022). LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People. Accessed Dec 2023
[170] UK Health Security Agency. (2023). Cold-Health Alert action card for health and social care providers. Accessed Dec 2023.

patients in accessible ways.[171] 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.[172]

The Adverse Weather and Health Plan aims to reduce deaths and morbidity from adverse weather.[173] Weather warnings occur in England when there is a possibility that the weather impacts on health and wellbeing.[174] 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.[175]

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.[176] In this sample, a third of inpatients (32%) with a planned discharge date experienced an overdue discharge, with common reasons including awaiting care home placements or support accommodation availability. Over half of the 3,490 inpatients had been admitted for over a year.[177]

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.[178]

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.[179] It has also been reported that people with learning difficulties may experience more intensive coercive control from perpetrators.[180]

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

[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] Public Health England. (2014). Heatwave Plan for England. Accessed Dec 2023.
[173] UK Health Security Agency. (2023). Adverse Weather and Health Plan. Accessed Dec 2023.
[174] UK Health Security Agency. (2023). Supporting vulnerable people before and during hot weather: social care managers, staff, and carers. Accessed Dec 2023.
[175] UK Health Security Agency. (2023). Weather-Health Alerting System. Accessed Dec 2023.
[176] NHS Digital. (2021). Learning Disability Services Monthly Statistics, AT: October 2021, MHSDS: August 2021 Final. Accessed Nov 2021.
[177] NHS Digital. (2022). Learning Disability Services Monthly Statistics, AT: December 2021, MHSDS: October 2021 Final. Accessed Feb 2022.
[178] NHS. (2019). NHS Long Term Plan. Learning Disability and Autism. Accessed Feb 2022.
[179] ONS. (2022). Disability and Crime. Accessed Nov 2023.
[180] Safe Lives. (2017). Disabled Survivors Too: Disabled people and domestic abuse. Accessed Nov 2023.

violence, the majority felt unsupported and experienced problems in seeking help, especially those who had children.[181]

As of 2015, only 13% of refuges could provide temporary personal care assistants.[182] 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.[183] 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.[184] 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.[185]

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.[186]

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.[187] Children with disabilities were more likely to have experienced being the victim of crime (21%), compared with non-disabled children (10%).[188]

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

[181] 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.
[182] Public Health England. (2015). Disability and Domestic Abuse. Accessed Oct 2022.
[183] Youde. (2018). Inside the only refuge specifically for women with learning disabilities. Accessed Sep 2021.
[184] 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.
[185] Information supplied directly by Change Grow Live. (2021).
[186] Public Health England. (2017). Substance misuse and people with learning disabilities: making reasonable adjustments to services. Accessed Dec 2022.
[187] ONS. (2022). Disability and Crime. Accessed Nov 2023.
[188] ONS. (2019). Disability and Crime, UK: 2019. Accessed Mar 2022.

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.[189]

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.[190]

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.[191]

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.

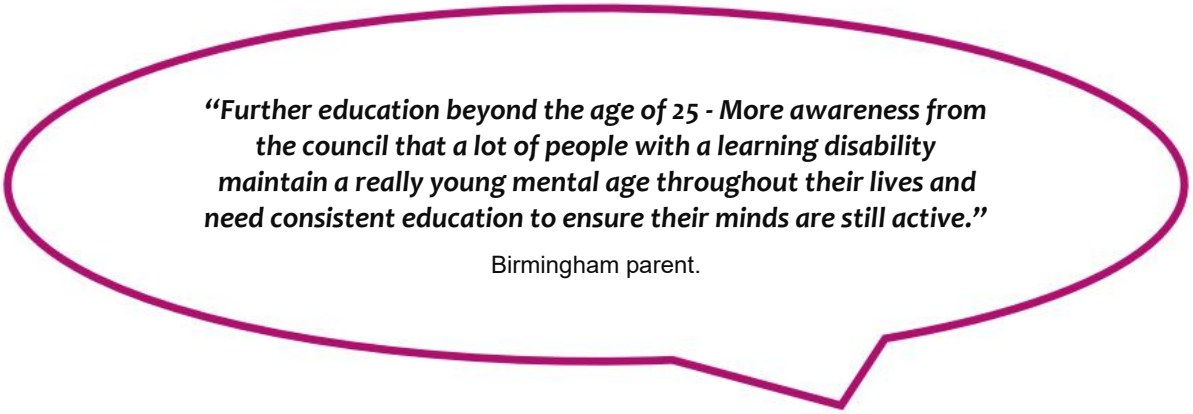
3.3.1 Transition

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.[192]

[189] Landman. "A counterfeit friendship": mate crime and people with learning disabilities. Accessed Mar 2022.
[190] Criminal Justice Joint Inspection. (2021). Neurodiversity in the Criminal Justice System. A review of evidence. Accessed Dec 2021.
[191] NHS. (2021). Meeting the healthcare needs of adults with a learning disability and autistic adults in prison. Accessed Mar 2022.
[192] Hughes et al. (2013). Secondary school transition for children with special educational needs: a literature review. Accessed Nov 2022.

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.[193] 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.[194]

3.3.2 Parents and Carers of Children and Adults with Learning Disabilities



Learning disabilities can be diagnosed either during pregnancy or during the first formative years of a child's life,[195] 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.[196]

[193] NHS. Getting Support: Learning Disabilities. Accessed Nov 2022.
[194] Mencap. Transition into adulthood. Accessed Feb 2022.
[195] Public Health England. NCARDRS Congenital anomaly statistics report 2018. Accessed Jan 2022.
[196] Gant and Bates. (2019). 'Cautiously optimistic': Older parent-carers of adults with intellectual disabilities – Responses to the Care Act 2014. Accessed Jan 2022.

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.[197]

3.3.3 Maternity Care for Citizens 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% 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.[198]

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

[197] Forrester-Jones. (2019). People with learning disabilities and/or autism and their carers getting older. Accessed Feb 2022.
[198] Redshaw et al. (2013). Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. Accessed Jan 2022.

identification of their disabilities, difficulties and conditions, and places an emphasis on reasonable adjustments, prevention and early support.[199]

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.[200]

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.[201] Evidence from national research has suggested that parents with learning disabilities are over-represented in child welfare cases.[202] 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%).[203]

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 judged more stringently than other parents. Advocates may be an important source of support and help for parents throughout this process.[204]

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.[205] 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),[206], 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

[199] Leeds Maternity Care Pathway for Women with Learning Disabilities. (2016). Accessed Sep 2022.
[200] CASBA Advocacy. Pregnancy to Parenthood. Accessed Dec 2023.
[201]. CHANGE and PEN. Hidden Voices of Maternity. Accessed Dec 2021.
[202] Booth et al. (2005). The prevalence and outcomes of care proceedings involving parents with learning difficulties in the family courts. Accessed Jan 2022.
[203] Birmingham City Council. Children and Young People JSNA (2024).
[204] 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.
[205] Born in Bradford. Born in Bradford Family Cohort. Accessed Dec 2023.
[206] Olubunmi et al. (2019). A review of the reproductive consequences of consanguinity. Accessed Dec 2023.

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.[207]

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.[208] 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.[209]

Table 13**Error! Reference source not found.** 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.[210]

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%	*
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.[211]

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

[207] Born in Bradford. Brilliant Bradford. Accessed Dec 2023.
[208] Sheridan. (2013). Risk factors for congenital anomaly in a multiethnic birth cohort: an analysis of the Born in Bradford study. Accessed Dec 2023.
[209] Born in Bradford. Evidence Briefing, Genes and Health: Inheritance and Risk. Accessed Dec 2023.
[210] NHS. University of Bristol LeDeR annual report 2020. Accessed Nov 2021.
[211] NHS. University of Bristol LeDeR annual report 2020. Accessed Nov 2021.

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.[212]

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.[213] 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.[214]

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. [215] 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 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.[216]

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.[217] 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

[212] King's College London. (2023). LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People. Accessed Dec 2023.
[213] NHS. Learning disability mortality review (LeDeR): Action from learning report 2020-21. Accessed Feb 2022.
[214] Birmingham and Solihull ICB. The LeDeR Programme. Accessed Jan 2023.
[215] The Migration Observatory. (2020). The Health of Migrants in the UK. Accessed Dec 2023.
[216] 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.
[217] Birmingham LGBT. (2011). Out and About. Accessed Dec 2021.

throughout England, but this is not currently extended to Birmingham**Error! Reference source not found.**.[218] 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.[219] 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).[220]

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.[221] However, at the time of writing, there was no local data available on this.

[218] Choice Support. Find support near you. Accessed Dec 2023.
[219] NHS. Action from learning: What happens with reviews once they are completed? Accessed Feb 2022.
[220] University of Bristol. (2021). LeDeR Annual Report 2020. Accessed Feb 2022.
[221] 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.

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.[222]
- 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.[223]

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.[224] Health checks can help recognise co-morbid conditions as early as possible and work to maintain good health.[225] 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%).[226]

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.

[222] Birmingham Community Healthcare NHS. Birmingham LD Service for Adults. Accessed Nov 2021.
[223] Birmingham Community Healthcare NHS. Special Care Dentistry for professionals. Accessed Nov 2021.
[224] NICE Impact. (2021). People with a learning disability. Accessed Jan 2022.
[225] LeDeR Programme. Annual Report 2020. Accessed Jan 2022.
[226] 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.[227]

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. [228]

4.1.2 Barriers to Accessing Healthcare

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.[229] 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.[230]

A review of research exploring professional carers' experiences of caring for individuals with both learning disabilities and dementia was published in 2017.[231] 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*.[232] The Standard directs organisations to ask people about their communication needs and flag the

[227] Mencap. My Health, My Life: Barriers to healthcare for people with a learning disability during the pandemic. Accessed Jun 2022.
[228] Public Health England. (2017). Quality Checking Health Checks for People with Learning Disabilities. Accessed Apr 2022.
[229] Heslop et al. (2013). Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Assessed Dec 2022.
[230] NICE Impact. (2021). People with a learning disability. Accessed Jan 2022.
[231] Cleary et al. (2017). Professional carers' experiences of caring for individuals with intellectual disability and dementia: A review of the literature. Accessed Jan 2023.
[232] 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,[233] 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.[234] 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.[235] 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.[236]

The system-wide rollout of the Oliver McGowan training by BSOL will affect over 100,000 staff in the health and care system who require this training. The majority will require Tier 2 level training. It is aimed that the 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.[237]

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

[233] 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.
[234] NHS Health Education England. The Oliver McGowan Mandatory Training on Learning Disability and Autism. Accessed Sep 2023.
[235] Department of Health and Social Care. Learning disability and autism training for health and care staff. Accessed Sep 2023.
[236] Oliver McGowan Mandatory Training in Learning Disability & Autism. Monthly newsletter for stakeholders in Birmingham and Solihull - Oct 2022. Accessed Nov 2022.
[237] Information supplied internally by NHSE. (2023).

personal details, the type of medication being used and any pre-existing health conditions. 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.[238] 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.[239]

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.[240] It is hoped that capability will be made available for wider use across health and care in the future.[241] 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 are providing awards to GPs in that area.[242] 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 of steps taken in each of these areas 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).

[238] Mencap. Health Guides. Accessed Jun 2022.
[239] 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.
[240] NHS Digital. (2020). Patient record flag can positively affect care of people with learning disabilities. Accessed Dec 2021.
[241] NHS Digital. Reasonable Adjustment Flag. Accessed Dec 2021.
[242] NHS Southern Health NHS Foundation Trust. Learning Disability Friendly GP Award. Accessed Jan 2022.

- Communication: add communication alert on system, ensure implementation of the alert across all practice staff.

4.1.4 Veterans Friendly Framework

The Veteran Friendly Framework 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 (VFF) is a programme led by the Military Care Home Providers: The Royal British Legion (RBL) and Royal Star and Garter (RS&G). The initiative aims to equip care and nursing homes across 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.[243] 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).[244]

[243] GOV.UK. Armed Forces Covenant: guidance and support. Accessed Dec 2023.
[244] NHS. Mental health support for veterans, service leavers and reservists. Accessed Dec 2023.

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.

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.[245,246]

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.[247]

[245] VFF. Supporting guidance, hints & tips for completion of the VFF application. Accessed Dec 2023.
[246] VFF. Framework process flow chart. Accessed Dec 2023.
[247] NHS Digital. Learning Disability Services Monthly Statistics, AT: October 2021, MHSDS: August 2021 Final. Accessed Nov 2021.

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%).

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).

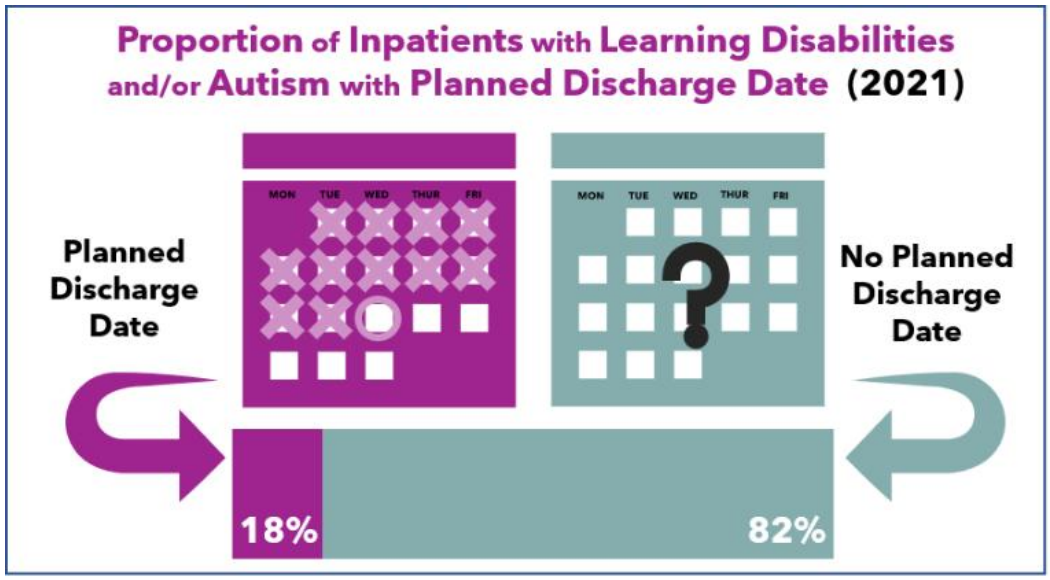


Figure 15: Inpatients with Learning Disabilities and/or Autism with and without a Planned Discharge Date.

Source: Mental Health Services Dataset.[248]

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%

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

10+ years	205	6%
All patients	**3,490**	**100%**

Source: Mental Health Services Dataset.[249]

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.[250]

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.[251,252]
- The Birmingham Women's and Children's NHS Foundation Trust provides a *Learning Disability Liaison Nurse* at Birmingham Women's Hospital.[253]
- 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.[254]

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.[255]

- Youth First is a community mental health service for children and young people, provided by Birmingham and Solihull Mental Health NHS Foundation Trust.[256]
- Birmingham Community Healthcare NHS Foundation Trust provide a *Community Forensic Learning Disability Team* for adults with moderate to severe learning disabilities with forensic needs.[257]
- 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.[258]

[249] NHS Digital. (2022) Learning Disability Services Monthly Statistics, AT: December 2021, MHSDS: October 2021 Final. Accessed Feb 2022.
[250] NHS. (2020). Learning disability and autism – adult inpatient rates by TCP Accessed Nov 2021.
[251] Birmingham Women's and Children's Trust. Forward Thinking Birmingham. Accessed Nov 2021.
[252] Birmingham Women's and Children's Trust. Health in Mind. Accessed Nov 2021.
[253] Birmingham Women's and Children's Hospital. Learning Disabilities. Accessed Nov 2021.
[254] Birmingham and Solihull Mental Health Trust. Reach Out Provider Collaborative. Accessed Feb 2022.
[255] 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.
[256] Birmingham and Solihull CCG. Birmingham Children and Young People's Mental Health and Wellbeing Refresh Local Transformation Plan 2020-21 Accessed Nov 2021.
[257] Birmingham Community Healthcare Trust. Birmingham Learning Disability Service for Adults. Accessed Jan 2022.
[258] Birmingham and Solihull Mental Health NHS Foundation Trust. Criminal Justice Liaison and Diversion Team. Accessed Feb 2022.

4.3 Social Care Services

4.3.1 Children's Social Care

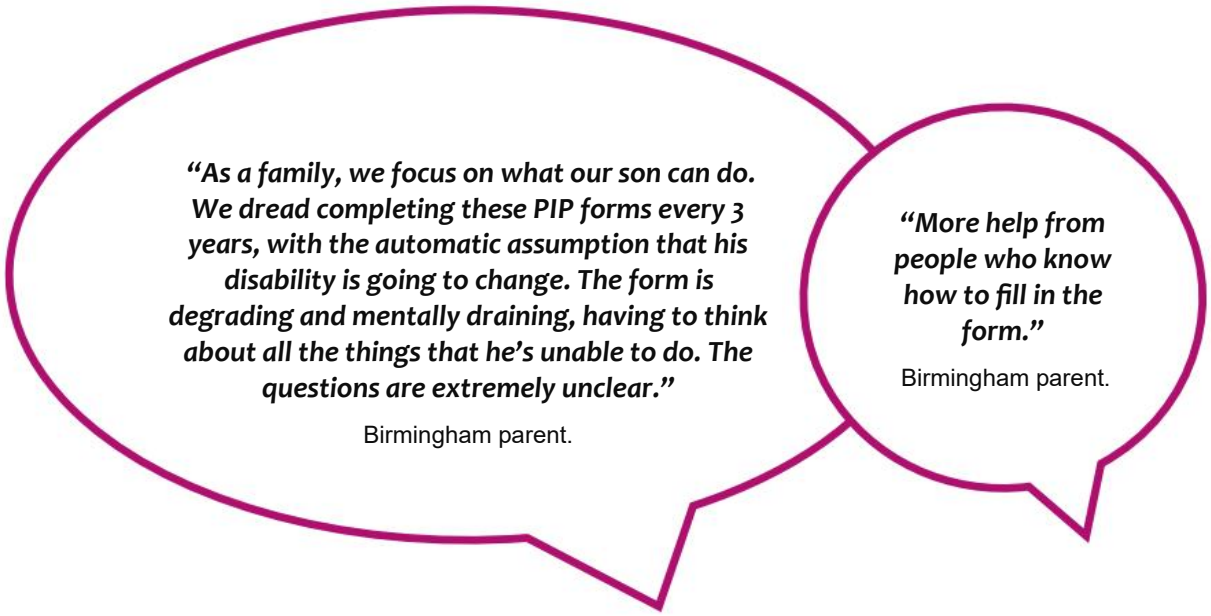
Birmingham Children's Trust provide the *Children with Disabilities Service,* which provides support for families caring for a child aged 0-18 years, with complex or critical needs. This service is provided for children with a disability and all disabled children come under the category of 'children in need'. Children termed 'children in need' can access Disabled 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.[259] 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.[260] 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.[261]

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.[262]

4.3.3 Social Care Funding



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*.[263]

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

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.[264]

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

- 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).[265]

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.[266] 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.

[264] NHS. When the Council Might Pay for your Care. Accessed Nov 2021.
[265] Local Offer Birmingham. Benefits. Accessed Dec 2022.
[266] Source: Business Intelligence BSOL ICB Jan 2023. Accessed Nov 2023.

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 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.[267]

4.3.5 Transport

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

[267] ARC England. ARC England Learning Disability Research Unit. Accessed Sep 2022.

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.[268]

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.[269] 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).

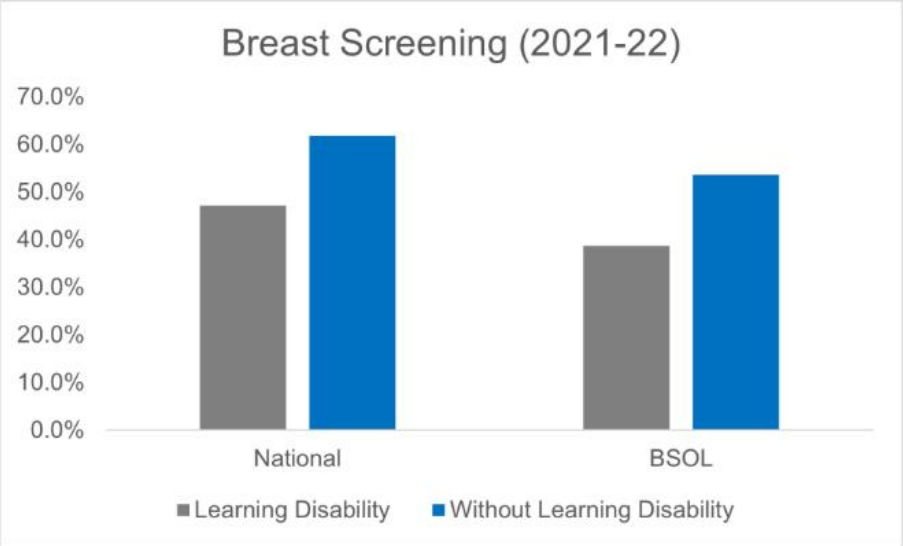


Figure 16: Breast Cancer Screening of Women Aged 50-69 with and without a Learning Disability (2021-22).

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

[268] Birmingham City Council. Children and Young Person's Travel Service. Accessed Nov 2022.
[269] NHS Digital. (2022). Health and Care of People with Learning Disabilities Experimental Statistics 2021 to 2022. Accessed Aug 2023.

disability were significantly less likely to receive adequate cervical cancer screening (31.3%), compared to women without a learning disability (61.7%).[270]

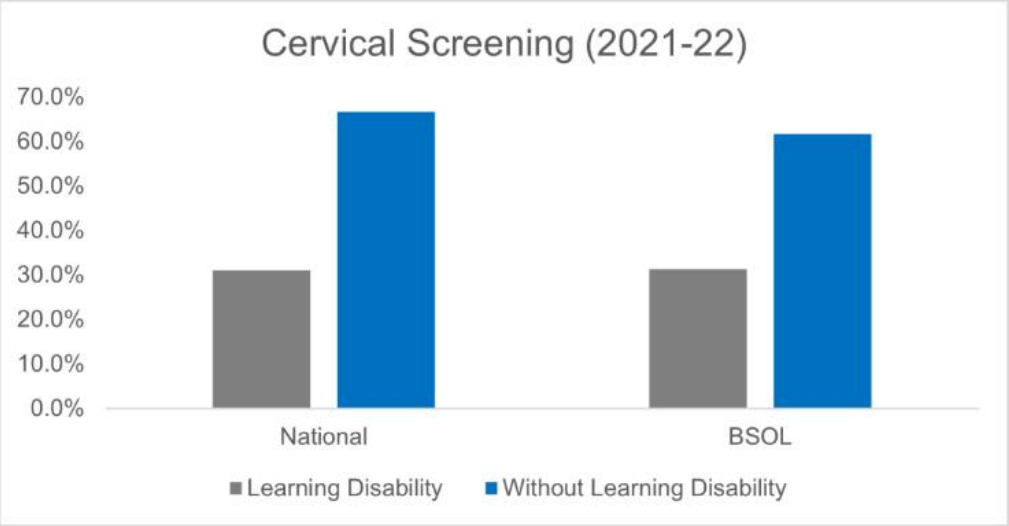


Figure 17: Cervical Cancer Screening of Women Aged 25-64 with and without a Learning Disability (2021-22).

Source: Health and Care of People with Learning Disabilities.

4.4.3 Colorectal Cancer Screening

Error! Reference source not found. 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%).[271]

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

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

Source: Health and Care of People with Learning Disabilities.

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.[272]

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.[273]

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.[274] Providers of adult short break services include Priory's Learning Disability service,[275] Real Life Options,[276] Respite Breaks,[277] Birmingham Community Healthcare NHS Foundation Trust[278] and Mencap.[279]

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.[280]

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.[281]

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

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

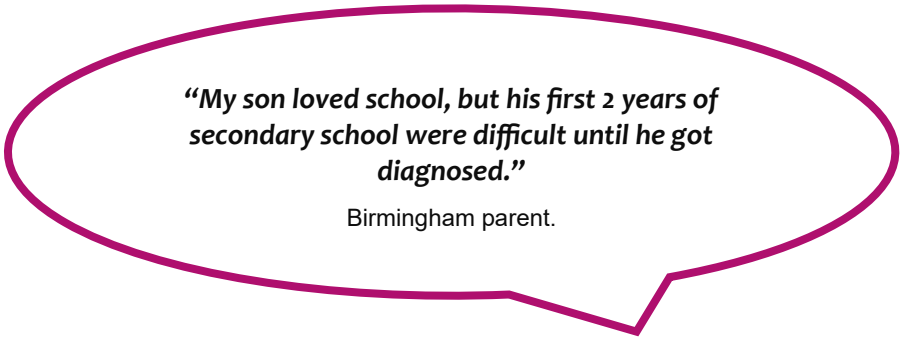
Area	%
Birmingham	69.0
England	77.3

Source: Learning Disability Profiles.

Providers of adult care residential and supported living services for citizens with learning disabilities include Priory,[282] Real Life Options,[283] Trident Reach,[284] Mencap,[285] Green Square Accord[286] and Birmingham Rathbone.[287]

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.[288]

4.7 Education



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.[289] 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).[290]

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

[282] Priory Adult Care. Autism Support and Care. Accessed Aug 2021.
[283] Real Life Options. Supporting You. Accessed Aug 2021.
[284] Trident Reach. Learning Disabilities Services. Accessed Aug 2021.
[285] Midland Mencap. Supported Living Services. Accessed Aug 2021.
[286] Green Square Accord. Learning Disability. Accessed Sep 2022.
[287] Rathbone Rathbone Birmingham Accessed Dec 2023.
[288] Birmingham City Council Adult Social Care. Local Calculations.
[289] Birmingham City Council. Education, Health and Social Care Plan. Accessed Apr 2022.
[290] 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.[291]

Birmingham City Council lists 27 special schools in the directory of schools within Birmingham,[292] and a further 42 schools with resource bases for children with SEN.[293]

Providers of education services for citizens living with learning disabilities aged 16+ include Care First,[294] Community Prospects,[295] Queen Alexandra College,[296] Argent College,[297] Heart of Birmingham Vocational College,[298] Hive College[299] and Sense College.[300]

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.

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

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.[303]

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*.[304] *The Pupil and School Support Service* are a team of teachers who work with children and young people with cognition, learning and language difficulties.[305]

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.[306]

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.[307]

Birmingham Community Healthcare Trust's *SEND Therapy Team* are a team of occupational therapists and speech and language therapists.[308] They work with mainstream schools,

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

4.7.1.4 SEND Parent and Carer Surveys

In May 2022, Birmingham SEND services carried out a survey with parents and carers.[310] 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

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.[311]
- Remploy is a national organisation supporting individuals with disabilities to access employment opportunities.[312]

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

- Disability Resource Centre provide employment, training and volunteering opportunities and have a local branch in Yardley.[313] Disability Resource Centre run *Opportunities for Life* courses which aim to tackle barriers that disabled people face in accessing employment and training opportunities.[314]
- Better Pathways is a mental health charity which supports citizens with poor mental health and those with learning difficulties and disabilities with employment support.[315]
- Birmingham Rathbone[316] 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.[317]

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.[318]

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.[319] 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.[320]

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

[313] Disability Resource Centre. Accessed Aug 2021.
[314] Disability Resource Centre. Employment Training and Volunteering Opportunities. Accessed Sep 2022.
[315] Better Pathways. What We Do. Accessed Sep 2022.
[316] Birmingham Rathbone. Accessed Aug 2021.
[317] Birmingham Careers Service. About Us. Accessed Jan 2022.
[318] Birmingham Women's and Children's Trust. Employment for People with a Learning Disability. Accessed Feb 2022.
[319] Disability Resource Centre. Yardley Neighbourhood Network Scheme (NNS). Accessed Aug 2021.
[320] Connect to Support. Accessed Oct 2022.

flexible support, enabling people to pursue their interests in an accessible way. This work has been focused in Hodge Hill, Erdington and Hall Green.[321]

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.[322]

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.[323]

[321] Community Catalysts. Birmingham: The Story So Far. (2019). Accessed Dec 2023.
[322] BSOL CCG. Small Supports. Accessed Aug 2021.
[323] 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.[324]

4.10 Services for Carers and Families

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.[325] CASBA work in partnership with the Alzheimer's Society and Mencap and are exploring a national rollout of further work based on this pilot.[326-327]

Forward Carers is a West Midlands based carer and family support organisation.[328] Their local Birmingham Carers Hub provides a range of services, including a *Young Adult Carer Service*,

[324] 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.
[325] CASBA. Supporting carers with learning disabilities. Accessed Feb 2024.
[326] Information provided directly from CASBA advocacy. Accessed Feb 2024.
[327] Alzheimer's Society. Supporting Dad after his dementia diagnosis as a person with a learning disability. Accessed Feb 2024.
[328] 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.[329]

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.[330]

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.[331]

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.[332] 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.[333]

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.[334]

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.[335]

[329] Forward Carers. Impact Review 2019. Accessed Aug 2021.
[330] Birmingham Parent Carer Forum. What is Birmingham parent carer forum Accessed Dec 2021.
[331] POhWER. Birmingham Advocacy Hub. Accessed Nov 2021.
[332] Information supplied directly from CASBA. Accessed Sep 2022.
[333] CanDo Doulas CIC. About Us. Accessed Sep 2022.
[334] Dudley Lodge. Parenting Services. Accessed Sep 2022.
[335] 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."*

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.

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 Birmingham City Council Learning Disabilities and Autism Transformation Programme Lead.
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, Dr. Justin Varney 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 Councilor Mariam Khan (Cabinet Member for Health and Social Care) and Dr Justin Varney (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.

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 Birmingham City Council Learning Disabilities and Autism Transformation Programme Lead.
K3.3	Inclusion in the Birmingham and Solihull Learning Disabilities and Autism Framework for Transformational Change.
K3.4	To be taken forward by the Birmingham City Council Learning Disabilities and Autism Transformation Programme Lead.
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.

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. 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.[336] 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:

Number	Recommendation
K4.1	Develop comprehensive strategy and services to support children with SEND into adulthood.
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).

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

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	Continue to work on improving waiting times around SEND services. a) continue to improve waiting times for health interventions. b) adhere to the 20-week timeliness statutory indicator for EHCPs.
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. 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, which is currently difficult for families to understand.

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	To be taken forward by SEND.
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.
K4.10	To be taken forward by SEND.
K4.11	To be taken forward by SEND.
K4.12	To be taken forward by Councillor Mariam Khan (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	To be taken forward by SEND.
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 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 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.
K5.19	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.

Learning Disabilities in Birmingham JSNA Deep Dive Report (2024)

Contact: luke.heslop@birmingham.gov.uk

Birmingham City Council

Easy Read

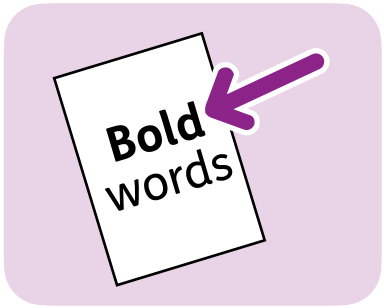
Learning Disabilities in Birmingham (2024)

What we found out

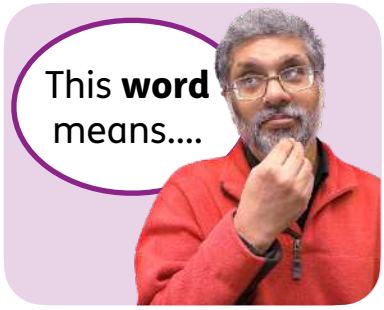
Easy Read

This is an Easy Read booklet of some of the information in the report ‘Learning Disabilities in Birmingham (2024)'. It may not include all of the information but it will tell you about the important parts.

This Easy Read booklet uses easier words and pictures. Some people may still want help to read it.



Some words are in **bold** - this means the writing is thicker and darker. These are important words in the booklet.



Sometimes if a bold word is hard to understand, we will explain what it means.

Blue and underlined words show links to websites and email addresses. You can click on these links on a computer.

What is in this booklet

About this report

This report is from the Public Health team at Birmingham City Council.

We know that people with learning disabilities often have worse health and **wellbeing** than other people.

Wellbeing means feeling happy and healthy in your body and mind.

We talked to people with learning disabilities, their families and people who work with them to find out more.

The report will tell you what we found out.

What we found

We found that people with learning disabilities have lots of problems in different areas, like:

- Their health, and not living as long as other people.

- Getting the support they need.

- School or college.

- Work.

- Where they live.

A lot of the problems do not need to happen.

Some services are giving really good help.

But more could be done to help people.

In 2023, there were more than 10 thousand people with a learning disability in Birmingham.

About the health of people with learning disabilities

Health inequalities are unfair differences in health between groups of people that do not need to happen.

People with learning disabilities have a lot of health inequalities.

The health inequalities start when they are young.

People with learning disabilities sometimes have other health conditions that last for a long time.

Some people with learning disabilities do not get checked for cancer when they should.

We think that services should tell people with learning disabilities how and when to get checked for cancer.

Because people with learning disabilities often do not have the support they need at home, they:

- Go to hospital when they could be treated at home.

- Stay in hospital for longer than they need to.

People with learning disabilities should get checked by their doctor every year.

This is called an **Annual Health Check**.

The Annual Health Check helps:

- People with learning disabilities stay healthy.

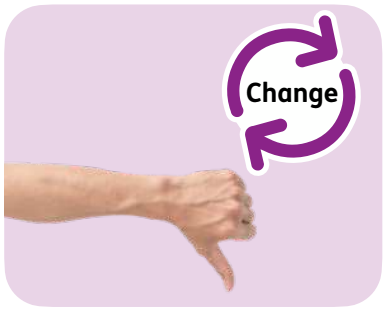
- Doctors find other health problems people with learning disabilities might have, so they can get treatment.

At the moment, 3 out of 4 people with learning disabilities have an Annual Health Check, but more need to.

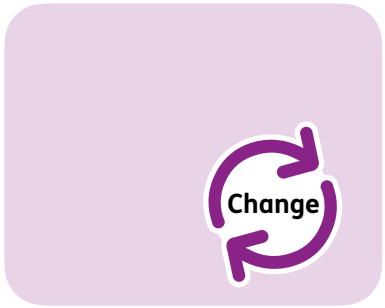
What makes the health of people with learning disabilities worse?

The health of people with learning disabilities can be made worse by:

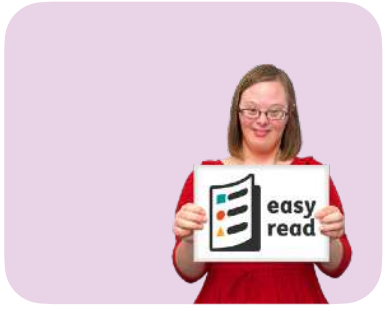
- Problems getting healthcare.



- Problems getting **reasonable adjustments**.



Reasonable adjustments are changes that places and services can make so that disabled people can take part like everybody else.



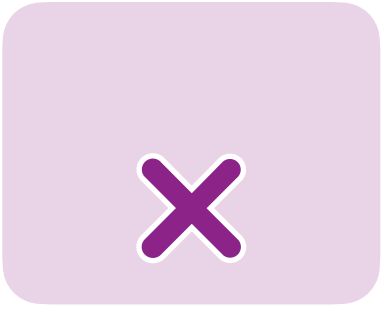
For example, getting information from the doctor in Easy Read.

The health of people with learning disabilities is also made worse by:

- Not having much money.

- Not being able to travel on their own.

- Not having the right support at school.



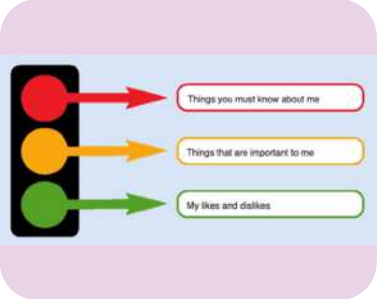
- Not being able to get a job.

- Not being able to get a good place to live.

Some organisations are helping people with learning disabilities, by:

- Having learning disability nurses who work with doctors.

- Using **hospital passports**.



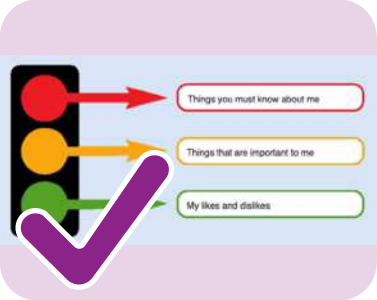
A **hospital passport** is a booklet that tells the hospital about your healthcare and how to make things easier for you.

- Giving travel training to young people.

We think that medical practices should:

- Do more to support their patients with learning disabilities.

- Become **accredited** - this means they have a certificate to show they support patients with learning disabilities.



We think that all hospitals in Birmingham should use the same hospital passport which has up-to-date information.

We think that organisations should:

- Give more help to women with learning disabilities who become pregnant.

- Give more training to healthcare staff about how to help people with learning disabilities, like the Oliver McGowan training.

- Help people with learning disabilities to get a job if they want one.

- Do more to help people with learning disabilities live on their own and look after themselves.

- Give travel training to more people with learning disabilities in Birmingham.

Groups who need extra support

Some of the groups that we know need extra support are:

- People with learning disabilities who are having a lot of change in their life, like children who are changing school or leaving school.

- Parents of people with learning disabilities, especially as the parents get older.

- People with learning disabilities who have children.

Other groups that we know need extra support are:

- Women with learning disabilities who are pregnant.

- People with learning disabilities from black and **ethnic minorities**.

  An **ethnic minority** is a small group of people of the same race, in a place where most other people are a different race.

- People with learning disabilities who are **LGBTQ+**.

  LGBTQ+ is used to describe people with different sexualities, like gay and bisexual. It also includes people who have changed their gender or feel themselves to be a different gender.

COVID-19

The COVID-19 pandemic has made **health inequalities** bigger for people with learning disabilities.

Remember, **health inequalities** are unfair differences in health between groups of people that do not need to happen.

We need to find out from people with learning disabilities about how the pandemic has affected them, so we understand what they need now.

Find out more

You can look at our website here:
https://www.birmingham.gov.uk/

You can contact us by email:
luke.heslop@birmingham.gov.uk

This Easy Read booklet was produced by easy-read-online.co.uk
The booklet includes images licensed from Photosymbols & Shutterstock.

	Agenda Item: 11
Report to:	**Birmingham Health & Wellbeing Board**
Date:	**9th May 2024**
TITLE:	**COMPASSIONATE CITIES BIRMINGHAM**
Organisation	**Compassionate Communities UK and Birmingham City Council**
Presenting Officer	**Dr Emma Hodges**

Report Type:	**Information**

1. Purpose:

1.1. To promote a wider understanding of its aims and objectives across the wider health and wellbeing system.

1.2. To set out the recent and planned activities of Compassionate Cities Birmingham.

2. Implications (tick all that apply):

Creating a Bolder, Healthier, City (2022-2030) – Strategic Priorities	Closing the Gap (Inequalities)	x
	Theme 1: Healthy and Affordable Food	
	Theme 2: Mental Wellness and Balance	x
	Theme 3: Active at Every Age and Ability	x
	Theme 4: Contributing to a Green and Sustainable Future	
	Theme 5: Protect and Detect	
	Getting the Best Start in Life	
	Living, Working and Learning Well	
	Ageing and Dying Well	x
Joint Strategic Needs Assessment		x

3. Recommendation

3.1. The Health and Wellbeing Board notes the work of Compassionate Cities Birmingham supports the communications and gathering of stories to promote its work and considers what other representative or linked agendas would strengthen its work

4. Report Body

4.1 The Compassionate City Charter was launched in 2015, endorsed by United Nations and was initially developed as a correction to the Healthy Cities programme that was silent on death, dying and loss.

4.2 The Compassionate City Charter promotes 13 areas of action that cities, towns or villages may take to publicly recognise those who are dying, caregiving or grieving and to make their locality a supportive and open place for these processes to take place in. These are set out below:

Charter Domains – Areas of Action and Principles/Enablers

- Schools and Young People
- Places of Worship
- Workplaces and Trade Unions
- Health and Care organisations
- Neighbourhoods
- Museums and Art Galleries
- Homelessness
- Prisons
- Memorials
- Equity, Diversity and Inclusion
- PR / social media
- Stories telling / competitions
- Incentives / Awards

4.3 The two fundamental principles of a Compassionate City/Community are 1) equity and inclusion and 2) the recognition of the 95% rule. Only 5% of the time when someone is terminally ill or grieving is spent with a Healthcare professional, most of the time is spent in their community, at work, with family and friends, on the school playground, walking the dog etc. The Public Health Approach to Palliative Care focuses on the 95% and work with the 5% to help reorientate healthcare.

4.4 The accreditation framework was launched by Compassionate Communities UK in 2020 with Birmingham becoming the first accredited city in February 2021.

4.5 Birmingham's approach

4.5.1 The Compassionate Cities Birmingham network is formed of individuals and organisations working in this space that act to guide the direction of the work. The aim is to have broad representation in order to reach into the many other forums / boards in the city that are relevant to the aspirations of a Compassionate City.

4.5.2 Work has taken place to map these forums and boards alongside the membership of the Compassionate Cities Birmingham Network and to create a governance structure and overall programme plan.
4.5.3 Compassionate Cities Birmingham is a programme of social and system change and transformation. It is not a short-term project, and the aim is for the ethos of compassionate communities, cities, and public health palliative care to become business as usual via education, training, influence, and discussion. In addition, the programme seeks to bridge the space between grass roots compassion and system design. However, building trust and networks at this level takes time.

4.6 What has been happening

4.6.1 Governance

The Compassionate Cities Birmingham Network has been supported by Birmingham City Council's Public Health Team to ensure structure, governance and admin support is in place.

4.6.2 One Day Conference

A one-day conference was held in 2023 which was attended by over 70 delegates. It showcased Compassionate Cities Birmingham work, including art, inequity, neighbourhood networks, street connectors, BrumYODO etc. The event evaluated positively.

4.6.3 Death Literacy Index (DLI)

4.6.3.1 A key aim for 2023 was to better understand death literacy in Birmingham's citizens. An internationally validated survey tool, The Death Literacy Index (DLI), was used to conduct a survey across the city. The first results will form a baseline from which to understand the city's various communities.

4.6.3.2 Birmingham is an early adopter of the DLI, and there are opportunities to lead the way in which this can be combined with other outcome measures, such as the Sustainable Development Goals (SDGs). Using this approach may allow correlation between death literacy and health and care outcomes, such as early identification and reduced hospital deaths.

4.6.3.3 The Birmingham sample consisted of 391 residents, which exceeded the target set by Public Health for statistical significance. The survey was via an online tool and circulated via Compassionate Birmingham Network members. It was acknowledged that this would not be a 'deep dive' into any particular community and would provide a broad initial perspective. As such, there is a desire to use the tool at a more local level, such as Ward/community level. The report has recently been analysed and is in draft form.

4.6.3.4 The key headline from the DLI results is that where people have had prior experience of death, dying and loss there is a level of confidence in talking about these topics with friends, GPs etc. The confidence around hands on care is more varied. However, when it comes to factual knowledge about the system, formal documentation, information around choices and access to community support groups the results shift significantly indicating lower confidence.

4.6.3.5 In addition to the standard questions that form part of the DLI, we collected demographic data and asked participants for their top three priorities with regards to palliative and end of life care. The results indicated the importance of emotional support and the time with family, friends, and their social connections. This provides a

strong argument for Compassionate Cities Birmingham and the need to both understand these figures at community level but also to ensure there is sufficient emotional and social connectedness in society due to their positive health and wellbeing impact.

4.6.3.6 These results will provide part of a roadmap for focused activity in Birmingham around communicating information to the public.
As an early adopter of this tool, Birmingham is facing similar challenges to many areas in seeking appropriate evaluation methods. Compassionate Communities UK are developing and reviewing ideas around evaluation, via the recent launch of a Research Academy with leading academics across several disciplines. Professor Cara Bailey (part of the Birmingham network) is a member of this academy. The use of the Death Literacy Index is a key element of this strategy with the aim of then considering the positive impact on sustainable development goals using the methodology proposed by SDG's that are centred around what matters most to citizens[i]. It was this next phase of consideration of evaluation methods that meant the prioritisation question (pie chart above) was added to the DLI survey.

4.6.3.7 Members of the Compassionate Birmingham Network, including Public Health, Birmingham University and Compassionate Communities UK, will be meeting early in 2024 to work through SDG methodology. In addition, there has been a mapping undertaken of the DLI questions and typical palliative and end of life care outcomes, an effort to look at whether increased death literacy correlate to traditional outcomes regarding palliative and end of life care.

4.6.4. Other Actions
Members of the network continue to work in a wide variety of ways that demonstrate Compassionate Cities Birmingham in action, including:-

- Increasing Children & Young Peoples engagement with a local hospice
- Bereavement Awareness Training for schools, colleges, and universities.
- Community Companion and Hospital Companion service - Marie Curie Companions.
- Support & Wellbeing Hub social support groups – Saturday Social, Men's Shed, Daff Caff.
- Life Cafes with range of communities such as , Project Echo – Learning Disabilities and Autism at the end-of-life network (mariecurie.org.uk).
- An End to be Proud of workshops with a LGBTQ+ focus.
- Commemorating people who have died including, World Aids Day and Transgender Day of Remembrance.
- Understanding of gaps in support and raising awareness of less well-known places to access help.
- Bereavement awareness and grief awareness training courses
- Death Cafes across various neighbourhood networks and other forms of initiating discussions.
- Homeless- to raise confidence and competency of support staff in the homeless sector to support those dealing with loss and grief.
- Prisons- to develop understanding and confidence of inmates to support other inmates who are dealing with loss and grief.
- Workplace- to help create compassionate workplaces.
- Community- developing the capacity and resilience of communities to support each in grief and loss. use of creative activities to encourage conversations about death, dying and end of life care planning.
- Annual festival with BrumYODO lots of activities each year across the city

- Focused work with communities often under-served by health and care organisations to build trust.
- Northfield Neighbourhood Network- spearheading a compassionate community approach, building connections, hosting events, and creating spaces for people to talk about grief supported by their community.

4.7 International Links

4.7.1 Birmingham is cited as an example of a Compassionate City globally, in presentations by Allan Kellehear. Additionally, Dr Emma Hodges has presented Birmingham as a Compassionate City in Rotterdam (European Association of Palliative Care conference) and Japan (Sendai conference) as part of a knowledge exchange in Matsuzaki.

4.7.2 Leipzig and Denmark have shown interest in the approach. In November, a delegation from Singapore was hosted by members of Compassionate Birmingham and Dr Julian Abel. Birmingham will be featured in a book (subject to successful publication) of international examples of Compassionate Cities / Communities in Action.

4.8 Costs

Most of the activity related to Compassionate Cities Birmingham is undertaken as part of business as usual of network members. However, some specific funding has been provided by the Birmingham City Council to support this work, including hosting the conference, supporting neighbourhood networks and a death and dying arts project.

4.9 What's Next

The Birmingham Compassionate Cities Network will continue to capture and promote its work and to encourage greater participation in this programme.

We will share the Death Literacy Index results with relevant groups to inform future strategy. An agreed approach to the wider roll out of the Death Literacy Index will be discussed with the Compassionate Birmingham network to ‘deep dive’ into diverse communities.

The Compassionate Cities Birmingham Network will consider what else it can do to improve the Death Literacy Scores and how it can influence the various forums and Board it participates in.

There is a planned roll out of the approach taken by Northfield NNS and encourage further NNS to adopt a Compassionate Communities approach in Spring 2024.

A public focused report and communications plan will be produced to highlight our achievements and encourage more people to get involved in supporting their communities.

Consideration of Compassion Awards will be discussed as a way of celebrating the wonderful work happening in the city.

An event is being organised to remember those who died in the city with no one to attend their funeral in May 2024. The current planned location is St Martin’s Church. This will be a celebratory event of life stories, music, and stalls from appropriate

stakeholders in the city to engage with the public and each other. It will further raise the profile of compassionate Birmingham.

5. Compliance Issues
5.1. HWBB Forum Responsibility and Board Update
The forum has no responsibility. This can be a rotating annual update.
5.2. Management Responsibility
Becky Pollard - Assistant Director of Public Health (Adults and Odler People) Dr Emma Hodges – Specialist Adviser (Compassionate Cities Birmingham)
5.3. Finance Implications
Projects below are funded through the ring-fenced Public Health Grant • **2023 Compassionate Cities Conference** - £5,000 • **2024 Death Café / Bereavement / Grief Support** - £2,500 • **2024 A Life Lived Celebration (linked with Dying Matters Week and A Matter of Life and Death Festival** – estimated at £4,000 (max grant = £8,000) **Specialist Advisor's staff time** – 2023/24 cost of £28,800 was funded from the Adult Social Care (ASC) budget. The 2024/25 cost are estimated to be £28,800, ASC is funding £20,000 of this with the balance coming from the Public Health Ring Fenced grant.
5.4. Legal Implications
N/A
5.5. Equalities Implications (Public Sector Equality Duty)
As with all Public Health-driven initiatives, Compassionate Cities is an equality-driven piece of work. Much of the work we have done has reached out to the broader community, without focusing on minority communities, specifically. As such, much of what we have done has the tone of equality, but it is not equity. However, the next phase of the DLI will be reaching out to minority groups to better understand their experiences of death. Also, the 'A Life Lived Celebration' has intentionally reached out to several minority groups (Birmingham LGBT, Refugee Migrant Centre, LGBT migrant project, LeDeR, Age Concern, Forward Carers, for example) to create a welcoming space. Further working happening in Bartley Green will also seek to reach all members of that Ward, by using the Ward Profile (from the Birmingham City Observatory) as a guide. This work will, where possible, use an equity-based approach.

6. Risk Analysis			
Identified Risk	**Likelihood**	**Impact**	**Actions to Manage Risk**
Capacity of network members may impact progress	Likely	Significant	Continuing to build the network and establish business as usual change. Developing evaluation measures to demonstrate impact
A failure to weave the opportunities of Compassionate Cities into relevant strategies	Possible	Significant	The network and key members of the team continue to try to create connections with these strategies. Further work following the publication of the DLI report will be undertaken to strengthen this.
Lack of communication of activities that impacts the 'social movement' of improving confidence and experience in the community	Likely	Moderate	A comms group has been set up to review ways to disseminate activities. NNS and Ward Forums are a key target for communications going forward
A lack of communication of the Compassionate Cities work.	Possible	Moderate	A comms plan is being developed to improve visibility of Compassionate Cities Birmingham and to broaden the scope of our communications.

Appendices
Appendix 1 – Death Literacy Index presentation slides

Background Papers

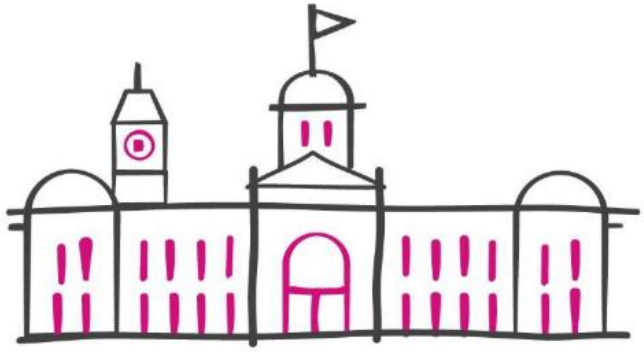
The following people have been involved in the preparation of this board paper:

Dr Emma Hughes

Paul Campbell
Edward Roberts
Becky Pollard

Compassionate Birmingham

Death Literacy Index
April 2024



RESET RESHAPE RESTART

Contents

- Key Points
- Themes
- Graphical Representation
- Summary

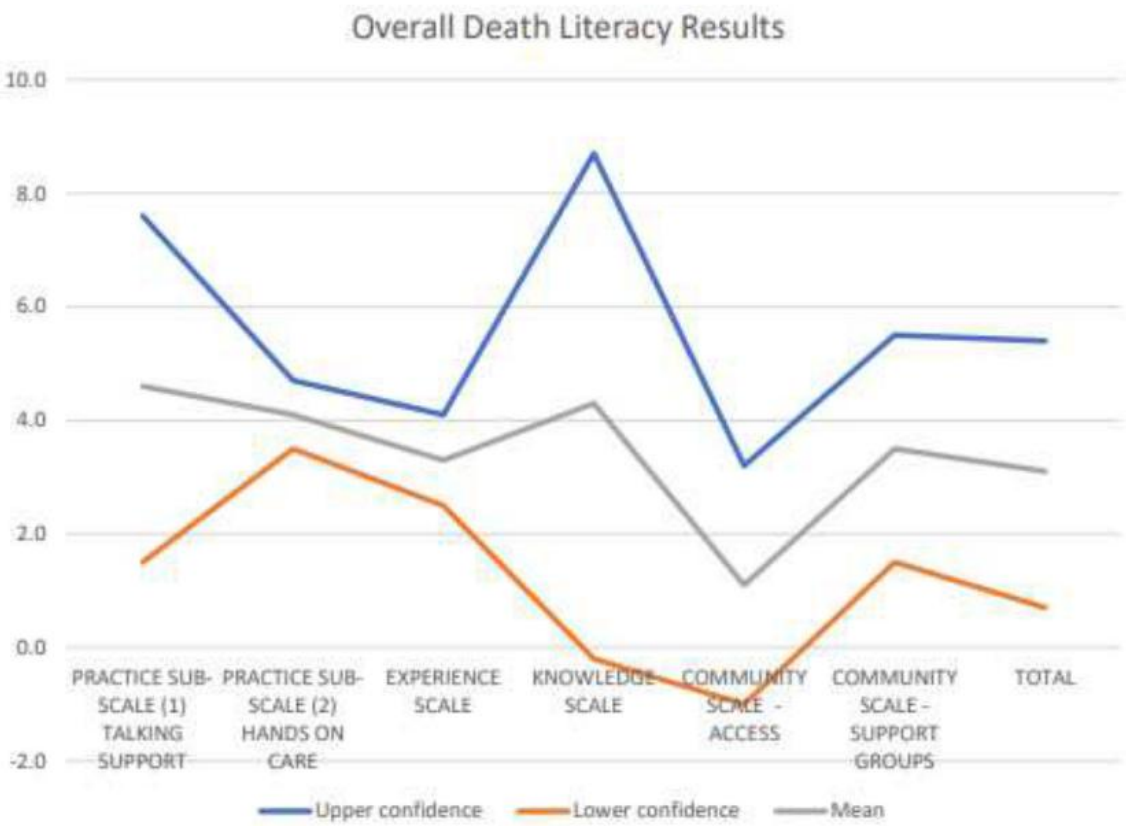
Key Points

- The Death Literacy Index (DLI) is an internationally validated tool to measure the confidence of citizens in issues relating to serious illness, dying and grief. It is also validated for use in the UK.
- A broad Birmingham sample of 391 people completed the survey.
- This was an initial scoping to understand the value of the DLI prior to further rollouts.
- The data demonstrates areas of confidence and where there is more work to do.
- Next stages are to focus on specific wards and communities starting with LGBTQIA+ to ensure a representative and inclusive perspective of DLI.

DLI Themes (based on prior personal experience):-

- Practical Knowledge (e.g. confident in providing to others).
  - Talking Support.
  - Providing hands on care.
- Experiential Knowledge (e.g. development of skills & knowledge).
- Factual Knowledge (e.g. access to formal services, dying at home).
- Community Knowledge.
  - Support groups (e.g. bereavement, carers groups).
  - Accessing help (e.g. emotional and cultural support or equipment).

Results Summary



Summary for Birmingham's initial results

- Providing **talking support** or some elements of **hands-on care** based on previous personal experience performed well.
- Wide variation on the **knowledge scale** which can be further analysed. **Access to support in the community** didn't score as highly and provides some insight into future actions for members of Compassionate Birmingham network.
- The results are broad but provide a roadmap for further work in Birmingham.
- An agreed approach to the wider roll out of the Death Literacy Index will be discussed with the Compassionate Birmingham network to 'deep dive' into diverse communities.

@BhamCityCouncil

@birminghamcitycouncil

@birminghamcitycouncil

birmingham.gov.uk

Questions?

	Agenda Item: 12
Report to:	**Birmingham Health & Wellbeing Board**
Date:	**9th May 2024**
TITLE:	**BIRMINGHAM PLACE COMMITTEE UPDATE**
Organisation	**Birmingham City Council**
Presenting Officer	**Richard Doidge**

Report Type:	**Discussion**

1. Purpose:

1.1. To update the Health and Wellbeing Board on the activities of the Birmingham Place Committee.

2. Implications (tick all that apply):

Creating a Bolder, Healthier, City (2022-2030) – Strategic Priorities	Closing the Gap (Inequalities)	
	Theme 1: Healthy and Affordable Food	
	Theme 2: Mental Wellness and Balance	X
	Theme 3: Active at Every Age and Ability	X
	Theme 4: Contributing to a Green and Sustainable Future	
	Theme 5: Protect and Detect	
	Getting the Best Start in Life	
	Living, Working and Learning Well	X
	Ageing and Dying Well	X
Joint Strategic Needs Assessment		

3. Recommendation

3.1. To note the activity of the Birmingham Place Committee.

4. Report Body

Executive Summary

4.1 This paper summarises the items received by the Birmingham Place Committee at its meetings in January and March 2024, and summarises key activities carried out within the remit of the committee.

4.2 The paper also summarises key updates from the Fairer Futures Fund (FFF), and the Birmingham Strategic Commissioning Group (SCG).

4.3 Place Committee Action Plan

The Committee reviewed implementation against the action plan that was developed at the joint Birmingham and Solihull Place Committee workshop held in September 2023. Two of the key actions are being developed by ICB colleagues. These are:

- Develop a scheme of responsibilities and delegation to improve clarity of governance and sequencing, including clarity of roles/responsibilities of each committee.
- Clarify roles and responsibilities for strategic commissioning programmes, including what will be retained by the ICB, what will be delegated to the Collaboratives and Local Authorities and what will be delivered jointly. This will include identifying any gaps (in priorities or resourcing) and risks/issues in the transition from the ICB to other parties.

Upon completion, a revised TOR will be drafted (with Solihull) for endorsement at Place Committee and approval at ICB Board.

Place Committee also noted that regular reporting to the Birmingham Health and Well-being Board will be introduced.

4.4 Birmingham City Council Savings Plan and Collaborative response to the financial challenges

The Committee received a presentation setting out the financial challenges facing the local authority and the actions that are progressing to agree a savings plan. The presentation highlighted the intervention that has now been made by the Secretary of State. In particular, the wide-ranging powers and responsibilities of the commissioners that have been appointed to work with the Council's leadership team were detailed.

The financial position was outlined. Over the next two financial years, the Council must find savings of £300m (at time of Place Ctte). All service area functions and services will need to be reviewed which will result in the likelihood of potential downsizing of the workforce (or in some cases, ceasing) to make smaller teams / functions to meet the savings targets. Difficult decisions need to be made within service areas in order to get finances back on track and in a healthy position for the long-term benefit of residents and colleagues.

The Committee welcomed the presentation and the clarity of the message – committing to working with the Council on opportunities to mitigate impact on services and citizens.

4.5 Community Care Collaborative and Integrated Locality Hubs

The Committee received an update report on the Community Care Collaborative (CCC), setting out the progress of the work undertaken to date and the development of the Full Business Case.

The CCC is still in the 'build phase' of development, and there are currently two live programmes of work being progressed: Integrated Teams and Intermediate Care. The Strategic Outline Case was approved by the ICB in November, and the Full Business Case is now being developed for May 2024.

The CCC is leading on the development of Local Delivery Partnerships (LDPs), following approval by Place Committee in December. LDPs will be accountable through the CCC Steering Group to Place Committee and will have responsibility for implementing the objectives of the CCC within the 5 localities of Birmingham (comprised of pairs of constituencies) and Solihull. The form of LDPs is still in development but there is agreement that they should be a unit of delivery with a local GP as chair, supported by an Executive Officer from one of the ICS anchor organisations. In Birmingham LDPs will also have delegated responsibility to develop a delivery plan for Locality Partnership Fairer Futures Fund.

Operationally, work continues on the development of 6 Integrated Locality Hubs across Bsol, covering all four pillars of the proposed CCC model, with the immediate priority being the 'Locality Care Co-ordination' model for the East, West and Solihull Localities. Birmingham Community Healthcare Trust (BCHC) is to undertake the role of lead provider for the Integrated Locality Hubs.

It was noted that a positive quarterly review had taken place with ICB colleagues, noting different areas of scope to focus on, including end of life care. It was also noted that there is a particular need to ensure effective engagement and liaison with GP provider organisations, and to ensure that the interface between the CCC and Primary Care is developed effectively.

The Committee agreed the importance of working to achieve synergy through the continuing development of the Community Care Collaborative, and that securing engagement and commitment from partners to the overall approach is key.

4.6 Proposed Transfer of Commissioning Responsibilities for Learning Disabilities and Autism

The Committee received a report setting out the ICB's strategies commissioning position in relation to Learning Disabilities and Autism, making recommendations to the Committee in respect of a proposed commissioning model for adult LD and Autism in line with the ICS Operating Framework.

The scope of the paper covers ICB commissioning relating to the following areas of service for adult people with learning disabilities and autism:

- Community services;

- Specialist community healthcare services for adults with learning disabilities including Community Forensics Team, Intensive Support Team, Occupational Therapy, Salt;
- Respite Care;
- Advocacy and support services;
- In patient services.

Not in scope are the following: Children's Community Services; Mental Health Services including assessments for children and adults ADHD pathways; Section 117 provision for people with LDA; Primary Care Contracting; CHC Packages of care; LDA provision commissioned by local authorities.

The paper goes on to describe national and local strategic contexts in relation to LDA and draws attention to the **BSOL Strategic Vision for LDA** which forms the key local driver for change.

The paper summarises available local population health needs in relation to the LDA cohort and identifies key health inequalities affecting the LDA population. It is noted that health needs analysis is limited in this area. The paper goes on to describe current performance in relation to key targets and deliverables. A system wide recovery plan is in place concerning inpatient performance with progress updates reporting into the ICB System Oversight Group for Performance.

The paper sets out the current ICB organisational resource aligned to the commissioning and oversight of LDA and LDA programmes of work.

Forward Plan

The ICS has previously set out its future Operating Framework which seeks to achieve greater integration and subsidiary through the devolution of commissioning responsibilities to 'service integrators' or via joint commissioning with local authorities. In line with this approach the paper sets out a series of options for the future commissioning of NHS-funded LDA services for adults.

The ICB Executive have confirmed that the preferred commissioning model is the transfer of responsibilities to BSMHFT. LDA will represent an expansion of the existing commissioning portfolio held by BSMHFT as part of the Mental Health Provider Collaborative.

The committee agreed with the following recommendations:

- Through a transfer of commissioning responsibility process BSMHFT is nominated as Lead for the commissioning of Adult Learning Disability and Autism Services, with continued oversight through existing system oversight structures
- A robust commissioning and delivery plan for the service be developed in advance of transfer;
- A steady state of the current arrangements while we work through transition assurance process and governance.
- That the transition timeline, governance and assurance arrangements outlined in the project plan are established.
- That the timeline for transfer of staff on 1 June 2024 (subject to formal HR processes) is endorsed.

4.7 East/ West Locality Health Inequality Reports

The Committee received a presentation and report setting out a new suite of information and resources on health inequalities in Birmingham, detailing the key findings, impacts and recommendations. The paper presents findings from a collaboration between Aston University, Birmingham Community Healthcare NHS Foundation Trust (BCHC) and Citizens UK.

The report highlighted useful areas of demographic intelligence, including on gaps in equality and access to services. It was noted that the report provided a valuable resource that can be of use in ongoing development of programmes across the ICS, including the Community Care Collaborative.

It was agreed that a group would be established to bring together issues arising from the report, so that they could be directed into useful actions, and take forward development issues raised. A Chair for this group was nominated.

4.8 Accelerating Reform Fund

A paper was presented to update the Committee on the proposals submitted by Birmingham and Solihull Councils, for funding from the Government's Accelerating Reform Fund. This is a fund offered to all ICS areas in England, inviting bids to be submitted for short-term projects focusing on priority areas including support for unpaid carers, self-directed support and community-based models of care.

Birmingham and Solihull have been successful in their bid and have been allocated £1.12 million in funding (covering 2024/25). This will be used to fund two projects aimed at improving the lives of carers and those cared-for across the ICS system. These are:

Shared Lives: Expansion of the Shared Lives programme. Birmingham will lead a programme to expand the operational capacity of Shared Lives for both Birmingham and Solihull. This will involve extra staffing resource to enable the recruitment and support of additional Shared Lives carers, and to expand the number of people cared for by this service.

Unpaid Carers. Both Birmingham and Solihull will expand the support and assessment offer available to unpaid carers, to improve the identification of carers, their needs, and to improve the identification of support.

4.9 Fairer Futures Fund

A variation to an existing contract between BCC and Heart of England Community Foundation has been agreed for the delivery of the City-wide Small Grants Fund. This has a value of £2.46m. FFF leads are working with Heart of England in preparation for the launch of the fund in March/April (date TBC). Mobilisation activity includes agreement of the application process and communications material.

The Birmingham Fairer Futures Fund programme board have approved funding of £105k to enable a selection process – managed by BVSC - for a voluntary sector lead for each locality to drive the development of a delivery plan for each locality's

Partnership Fund (total value of £5.74m). The following organisations have been appointed:

West – Flourish

North – Witton Lodge Community Association

East – Disability Resource Centre

A process is ongoing to appoint suitable lead organisations for South and Central Localities. These leads will have a responsibility for connecting statutory and VCFSE partners to develop projects within the locality that address specific inequalities in respect of the thematic priorities of the FFF. It is envisaged that each delivery plan will have 5-6 impactful projects running over a 3 year period.

As the most established partnership, West Locality Delivery Partnership are piloting the development of a locality FFF delivery plan. The locality have held a prioritisation session and will shortly launch an Expression of Interest phase.

Robust evaluation is a key element of the Fairer Futures Fund. Birmingham and Solihull leads have been progressing work on an evaluation framework and have engaged with Birmingham Health Partners from the University of Birmingham in respect of over-arching programme evaluation utilising ICB resource that has been allocated for this purpose.

4.10 Strategic Commissioning Group

The Strategic Commissioning Group (SCG) is currently overseeing four main programmes of work:

1) Regulated Care Market: Three Task and Finish Groups have been established:
    a. Joint Strategy and Development Task and Finish Group, working to implement the scope, aims and objectives and outcomes for the workstream.
    b. Market Engagement, focussing on best practice research and mapping, and establishing a joint market shaping approach.
    c. Cost of Care Task and Finish Group established to develop best practice approach and project plan.
2) Learning Disabilities and Autism (as discussed in specific LDA update in section 4.6 of this report)
3) Children and Young People: Refresh of timeline, action plan and risk register will take place, following re-setting of scope by strategic management. Further updates to the plan and timescale will be reported back to SCG in April.
4) Continuing Health Care (CHC): Improvement Group and Pathways Group established to maintain pace of change and consistency across the system. Elements of the CHC programme have been merged with the Regulated Care Market workstream to ensure consistency. Elements of the CHC programme will also be aligned to the Childrens and Young Peoples' workstream, to ensure Childrens CHC aligns correctly.

The SCG also received a paper outlining Birmingham's strategic approach to Carers support, showing the work conducted since the establishment of the Carers Strategy in 2018, and the plans for development of a refreshed strategy and governance

arrangements. Proposed governance is that the Carers Partnership Group reports progress to the SCG, which will in turn escalate and report into the Place Committee.

The SCG received a presentation on the development of the three NHS Provider Collaboratives and held a discussion on their role and the integration of Provider Collaboratives with the SCG and other governance structures within the ICS partnership. A representative of the Mental Health Provider Collaborative (which is the furthest-progressed of the three) has now become a member of the SCG, to ensure cohesion and co-operative working. Further developments will be reported to future SCG meetings.

5. Compliance Issues

5.1. HWBB Forum Responsibility and Board Update

5.1.1. The Place Committee will provide regular updates to the Health and Wellbeing Board.

5.2. Management Responsibility

5.2.1. Mike Walsh (Head of Service – Commissioning, Adult Social Care, BCC)

5.3. Finance Implications

5.3.1. The ICB has made arrangements to support the Place Committees in their exercise of delegated functions.

5.4. Legal Implications

5.4.1. The 2022 Health and Care Act made provision for the formation of place-based committees.

5.5. Equalities Implications (Public Sector Equality Duty)

5.5.1. The Place Committee is committed to equality and reducing health inequalities in Birmingham (e.g. through work such as the Fairer Futures Fund).

6. Risk Analysis

Identified Risk	Likelihood	Impact	Actions to Manage Risk
N/A	N/A	N/A	N/A

Appendices

1. None

	Agenda Item: 13
Report to:	**Birmingham Health & Wellbeing Board**
Date:	**9th May 2024**
TITLE:	**BETTER CARE FUND QUARTER 3 UPDATE**
Organisation	**Birmingham City Council**
Presenting Officer	**Richard Doidge**

Report Type:	**Approval**

1. Purpose:

1.1. To update the Health and Wellbeing Board on the activities of the Better Care Fund, following the Quarter 3 submission.

2. Implications (tick all that apply):

Creating a Bolder, Healthier, City (2022-2030) – Strategic Priorities	Closing the Gap (Inequalities)	
	Theme 1: Healthy and Affordable Food	
	Theme 2: Mental Wellness and Balance	X
	Theme 3: Active at Every Age and Ability	X
	Theme 4: Contributing to a Green and Sustainable Future	
	Theme 5: Protect and Detect	
	Getting the Best Start in Life	
	Living, Working and Learning Well	
	Ageing and Dying Well	X
Joint Strategic Needs Assessment		

3. Recommendation

3.1. To note the activity of the Birmingham Better Care Fund and provide accountable body approval for the Q3 return.

4. Report Body

Following discussion at the BCF Programme Board and approval for the BCF Commissioning Executive, Birmingham submitted the Better Care Fund Quarter 3 return to NHS England on schedule. Attached to this cover report are PDF extracts of the submitted return document. Health and Well-being Board is the statutory accountable body for the BCF. As such NHS England (NHSE) require formal approval for BCF planning and monitoring returns from Health and Well-being Boards.

Update from last report

- Financial pressures on the BCF remain, due to an overspend on the EICT contract for home care discharge. The working group, established to transform the performance and efficiency of the EICT workstream, has been developing and implementing a series of actions to reduce the impact of this, and to transform the operational performance.

- Progress in the first few months of the group's work are positive, with length of stay, transfers and assessments all moving in a positive direction. This is in turn showing a positive reduction in the associated costs of the service.

- The BCF Board has considered an application for funding for a Single Handed Care programme, which if implemented will also help to significantly mitigate the pressures on the EICT service.

- A revised BCF plan for 2024/25 is being developed, which will be submitted once deadlines and templates have been received from the national Better Care Fund Team. (Addendum: BCF Planning Requirements have now been received. A revised Financial Template must be submitted by 10 June 2024. This will be taken to the BCF Commissioning Executive prior to approval. Final approval will be required from the H&WBB)

Summary of the BCF Q3 Return:

- Avoidable admissions (unplanned hospitalisation for chronic ambulatory care sensitive conditions) currently not on track to meet the national target, however levels are dropping. We have conducted a deep dive analysis onto the contributing factors for this, showing which localities contribute disproportionately to this metric. In addition, the specific conditions of asthma and COPD have been identified as disproportionately contributory factors responsible for higher admissions.
- In response to this, we took a targeted approach to tackling this for the remainder of the performance year, and will continue to track forward into 2024/25.

- Discharge to normal place of residence (percentage of people who are discharged from acute hospital to their normal place of residence) is on track to achieve target.

- Falls target (Emergency hospital admissions due to falls in people aged 65 and over) is on track to achieve target.

- Residential admissions (rate of permanent admissions to residential care homes per 100,000 population) is on track to achieve target.

- Reablement (proportion of older people who were still at home 91 days after discharge from hospital into reablement or rehabilitation services) is also on track to achieve target

5. Compliance Issues

5.1. HWBB Forum Responsibility and Board Update

5.1.1. The Birmingham Better Care Fund team will provide regular updates to the Health and Wellbeing Board.

5.2. Management Responsibility

5.2.1. Mike Walsh (Head of Service – Commissioning, Adult Social Care, Birmingham City Council)

5.3. Finance Implications

5.3.1. The BCF is sourced from ring-fenced budgets from the NHS Integrated Care Board (ICB) allocations, and funding paid directly to local authorities.

5.4. Legal Implications

5.4.1. The BCF requires Integrated Care Boards (ICB's) and local government to agree a joint plan, owned by the Health and Wellbeing Board (HWB), governed by an agreement under Section 75 of the NHS Act 2006.

5.5. Equalities Implications (Public Sector Equality Duty)

5.5.1. The BCF Plan adheres to the Public Sector Equality Duty.

6. Risk Analysis

Identified Risk	Likelihood	Impact	Actions to Manage Risk
N/A	N/A	N/A	N/A

Appendices

Appendix 1 - Birmingham BCF Q3 Return

Better Care Fund 2023-25 Quarter 3 Quarterly Reporting Template

1. Guidance for Quarter 3

Overview

The Better Care Fund (BCF) reporting requirements are set out in the BCF Planning Requirements document for 2023-25, which supports the aims of the BCF Policy Framework and the BCF programme; jointly led and developed by the national partners Department of Health (DHSC), Department for Levelling Up, Housing and Communities (DLUHC), NHS England (NHSE), Local Government Association (LGA), working with the Association of Directors of Adult Social Services (ADASS).

The key purposes of BCF reporting are:
1) To confirm the status of continued compliance against the requirements of the fund (BCF)
2) In Quarter 2 to refresh capacity and demand plans, and in Quarter 3 to confirm activity to date, where BCF funded schemes include output estimates, and at the End of Year actual income and expenditure in BCF plans
3) To provide information from local areas on challenges, achievements and support needs in progressing the delivery of BCF plans, including performance metrics
4) To enable the use of this information for national partners to inform future direction and for local areas to inform improvements

BCF reporting is likely to be used by local areas, alongside any other information to help inform Health and Wellbeing Boards (HWBs) on progress on integration and the BCF. It is also intended to inform BCF national partners as well as those responsible for delivering the BCF plans at a local level (including ICBs, local authorities and service providers) for the purposes noted above.

BCF reports submitted by local areas are required to be signed off by HWBs, including through delegated arrangements as appropriate, as the accountable governance body for the BCF locally. Aggregated reporting information will be published on the NHS England website.

Note on entering information into this template

Throughout the template, cells which are open for input have a yellow background and those that are pre-populated have a blue background and those that are not for completion are in grey, as below:

Data needs inputting in the cell

Pre-populated cells

Not applicable - cells where data cannot be added

Note on viewing the sheets optimally

To more optimally view each of the sheets and in particular the drop down lists clearly on screen, please change the zoom level to between 90% - 100%. Most drop downs are also available to view as lists within the relevant sheet or in the guidance tab for readability if required.

The row heights and column widths can be adjusted to fit and view text more comfortably for the cells that require narrative information.

Please DO NOT directly copy/cut & paste to populate the fields when completing the template as this can cause issues during the aggregation process. If you must 'copy & paste', please use the 'Paste Special' operation and paste 'Values' only.

The details of each sheet within the template are outlined below.

Checklist (2. Cover)

1. This section helps identify the sheets that have not been completed. All fields that appear as incomplete should be complete before sending to the BCF team.
2. The checker column, which can be found on the individual sheets, updates automatically as questions are completed. It will appear 'Red' and contain the word 'No' if the information has not been completed. Once completed the checker column will change to 'Green' and contain the word 'Yes'

3. The 'sheet completed' cell will update when all 'checker' values for the sheet are green containing the word 'Yes'.
4. Once the checker column contains all cells marked 'Yes' the 'Incomplete Template' cell (below the title) will change to 'Template Complete'.

5. Please ensure that all boxes on the checklist are green before submitting to england.bettercarefundteam@nhs.net and copying in your Better Care Manager.

2. Cover

1. The cover sheet provides essential information on the area for which the template is being completed, contacts and sign off. Once you select your HWB from the drop down list, relevant data on metric ambitions and capacity and demand from your BCF plans for 2023-24 will prepopulate in the relevant worksheets.
2. HWB sign off will be subject to your own governance arrangements which may include a delegated authority.
4. Please note that in line with fair processing of personal data we request email addresses for individuals completing the reporting template in order to communicate with and resolve any issues arising during the reporting cycle. We remove these addresses from the supplied templates when they are collated and delete them when they are no longer needed.

3. National Conditions

This section requires the HWB to confirm whether the four national conditions detailed in the Better Care Fund planning requirements for 2023-25 (link below) continue to be met through the delivery of your plan. Please confirm as at the time of completion.
https://www.england.nhs.uk/wp-content/uploads/2023/04/PRN00315-better-care-fund-planning-requirements-2023-25.pdf

This sheet sets out the four conditions and requires the HWB to confirm 'Yes' or 'No' that these continue to be met. Should 'No' be selected, please provide an explanation as to why the condition was not met for the year and how this is being addressed. Please note that where a National Condition is not being met, the HWB is expected to contact their Better Care Manager in the first instance.

In summary, the four national conditions are as below:
National condition 1: Plans to be jointly agreed
National condition 2: Implementing BCF Policy Objective 1: Enabling people to stay well, safe and independent at home for longer
National condition 3: Implementing BCF Policy Objective 2: Providing the right care in the right place at the right time
National condition 4: Maintaining NHS contribution to adult social care and investment in NHS commissioned out of hospital services

4. Metrics

The BCF plan includes the following metrics:
- Unplanned hospitalisations for chronic ambulatory care sensitive conditions,
- Proportion of hospital discharges to a person's usual place of residence,
- Admissions to long term residential or nursing care for people over 65,
- Reablement outcomes (people aged over 65 still at home 91 days after discharge from hospital to reablement or rehabilitation at home), and;
- Emergency hospital admissions for people over 65 following a fall.

Plans for these metrics were agreed as part of the BCF planning process.
This section captures a confidence assessment on achieving the locally set ambitions for each of the BCF metrics.
A brief commentary is requested for each metric outlining the challenges faced in achieving the metric plans, any support needs and successes in the first six months of the financial year.
Data from the Secondary Uses Service (SUS) dataset on outcomes for the discharge to usual place of residence, falls, and avoidable admissions for the first quarter of 2023-24 has been pre populated, along with ambitions for quarters 1-4, to assist systems in understanding performance at HWB level.

The metrics worksheet seeks a best estimate of confidence on progress against the achievement of BCF metric ambitions. The options are:

- on track to meet the ambition
- not on track to meet the ambition
- data not available to assess progress

You should also include narratives for each metric on challenges and support needs, as well as achievements.
- In making the confidence assessment on progress, please utilise the available metric data along with any available proxy data.

Please note that the metrics themselves will be referenced (and reported as required) as per the standard national published datasets.

No actual performance is available for the ASCOF metrics - Residential Admissions and Reablement - so the 2022-23 outcome has been included to aid with understanding. These outcomes are not available for Hackney (due to a data breach issue) and Westmorland and Cumbria (due to a change in footprint).

5. Spend and Activity

The spend and activity worksheet will collect cumulative spend and outputs in the year to date for schemes in your BCF plan for 2023-24 where the scheme type entered required you to include the number of output/deliverables that would be delivered.

Once a Health and Wellbeing Board is selected in the cover sheet, the spend and activity sheet in the template will prepopulate data from the expenditure tab of the 23-25 BCF plans for all 2023-24 schemes that required an output estimate.

You should complete the remaining fields (highlighted yellow) with incurred expenditure and actual numbers of outputs delivered to the end of the third quarter (1 April to 31 December).

The collection only relates to scheme types that require a plan to include estimated outputs. These are shown below:

Scheme Type	**Units**
Assistive technologies and equipment	Number of beneficiaries
Home care and domiciliary care	Hours of care (unless short-term in which case packages)
Bed based intermediate care services	Number of placements
Home based intermediate care services	Packages
DFG related schemes	Number of adaptations funded/people supported
Residential Placements	Number of beds/placements
Workforce recruitment and retention	Whole Time Equivalents gained/retained
Carers services	Number of Beneficiaries

The sheet will pre-populate data from relevant schemes from final 2023-24 spending plans, including planned spend and outputs. You should enter the following information:
- **Actual expenditure to date in column I.** Enter the amount of spend from 1 April to 31 December on the scheme. This should be spend incurred up to the end of December, rather than actual payments made to providers.
- **Outputs delivered to date in column K**. Enter the number of outputs delivered from 1 April to 31 December. For example, for a reablement and/or rehabilitation service, the number of packages commenced. The template will pre-populate the expected outputs for the year and the standard units for that service type. For long term services (e.g. long term residential care placements) you should count the number of placements that have either commenced this year or were being funded at the start of the year.
- **Implementation issues in columns M and N.** If there have been challenges in delivering or starting a particular service (for instance staff shortages, or procurement delays) please answer yes in column M and briefly describe the issue and planned actions to address the issue in column N. If you answer no in column M, you do not need to enter a narrative in column N.

More information can be found in the additional guidance document for tab 5, which is published alongside this template on the Better Care Exchange.

HM Government

NHS England

Better Care Fund 2023-25 Quarter 3 Quarterly Reporting Template

2. Cover

Version 2.0

Please Note:

- The BCF quarterly reports are categorised as 'Management Information' and data from them will published in an aggregated form on the NHSE website. This will include any narrative section. Also a reminder that as is usually the case with public body information, all BCF information collected here is subject to Freedom of Information requests.

- At a local level it is for the HWB to decide what information it needs to publish as part of wider local government reporting and transparency requirements. Until BCF information is published, recipients of BCF reporting information (including recipients who access any information placed on the Better Care Exchange) are prohibited from making this information available on any public domain or providing this information for the purposes of journalism or research without prior consent from the HWB (where it concerns a single HWB) or the BCF national partners for the aggregated information.

- All information will be supplied to BCF partners to inform policy development.

- This template is password protected to ensure data integrity and accurate aggregation of collected information. A resubmission may be required if this is breached.

			Checklist Complete:
Health and Wellbeing Board:	Birmingham		Yes
Completed by:	Mike Walsh		Yes
E-mail:	michael.walsh@birmingham.gov.uk		Yes
Contact number:	07730 281349		Yes
Has this report been signed off by (or on behalf of) the HWB at the time of submission?	No		Yes
If no, please indicate when the report is expected to be signed off:	Thu 28/03/2024	<< Please enter using the format, DD/MM/YYYY	Yes

Question Completion - when all questions have been answered and the validation boxes below have turned green you should send the template to england.bettercarefundteam@nhs.net saving the file as 'Name HWB' for example 'County Durham HWB'. This does not apply to the ASC Discharge Fund tab.

Complete	
	Complete:
2. Cover	Yes
3. National Conditions	Yes
4. Metrics	Yes
5. Spend and activity	Yes

<< Link to the Guidance sheet

^^ Link back to top

Better Care Fund 2023-25 Quarter 3 Quarterly Reporting Template

3. National Conditions

Selected Health and Wellbeing Board: Birmingham

		Checklist Complete:
Has the section 75 agreement for your BCF plan been finalised and signed off?	Yes	Yes
If it has not been signed off, please provide the date the section 75 agreement is expected to be signed off		Yes

Confirmation of National Conditions			
National Conditions	**Confirmation**	**If the answer is "No" please provide an explanation as to why the condition was not met in the quarter:**	
1) Jointly agreed plan	Yes		Yes
2) Implementing BCF Policy Objective 1: Enabling people to stay well, safe and independent at home for longer	Yes		Yes
3) Implementing BCF Policy Objective 2: Providing the right care in the right place at the right time	Yes		Yes
4) Maintaining NHS's contribution to adult social care and investment in NHS commissioned out of hospital services	Yes		Yes

Better Care Fund 2023-25 Quarter 3 Quarterly Reporting Template

4. Metrics

Selected Health and Wellbeing Board: Birmingham

National data may be unavailable at the time of reporting. As such, please use data that may only be available system-wide and other local intelligence.

Challenges and Support Needs Please describe any challenges faced in meeting the planned target, and please highlight any support that may facilitate or ease the achievements of metric plans

Achievements Please describe any achievements, impact observed or lessons learnt when considering improvements being pursued for the respective metrics

Metric	Definition	For information - Your planned performance as reported in 2023-24 planning				For information - actual performance for Q1	For information - actual performance for Q2	Assessment of progress against the metric plan for the reporting period	Challenges and any Support Needs in Q3	Q3 Achievements - including where BCF funding is supporting improvements.	Checklist Complete:
		Q1	Q2	Q3	Q4						
Avoidable admissions	Unplanned hospitalisation for chronic ambulatory care sensitive conditions (NHS Outcome Framework indicator 2.3i)	302.8	291.7	330.2	310.9	368.0	356.8	Not on track to meet target	We have conducted a deep dive analysis into the contributing factors for the relatively high level of ACSC (Avoidable Admissions); showing which localities contribute disproportionately to the metric. In addition to specific localities, we have also identified asthma and COPD as the reasons for admission that are largely responsible for the higher figures. We are taking a targeted approach to tackling this for the remainder of the year, and will track it forward into 2024/25.	N/A	Yes
Discharge to normal place of residence	Percentage of people who are discharged from acute hospital to their normal place of residence	94.4%	94.8%	94.3%	93.3%	94.6%	94.7%	On track to meet target	None	N/A	Yes
Falls	Emergency hospital admissions due to falls in people aged 65 and over directly age standardised rate per 100,000.				2,212.2	507.4	532.8	On track to meet target	None	N/A	Yes
Residential Admissions	Rate of permanent admissions to residential care per 100,000 population (65+)				679	2022-23 ASCOF outcome: 587.2		On track to meet target	None	N/A	Yes
Reablement	Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement / rehabilitation services				80.4%	2022-23 ASCOF outcome: 80.8%		On track to meet target	None	N/A	Yes

Better Care Fund 2023-25 Quarter 3 Quarterly Reporting Template

6. Spend and activity

Selected Health and Wellbeing Board: Birmingham

Checklist						Yes		Yes		Yes	Yes
Scheme ID	Scheme Name	Scheme Type	Sub Types	Source of Funding	Planned Expenditure	Actual Expenditure to date	Planned outputs	Outputs delivered to date (estimate if unsure) (Number or NA)	Unit of Measure	Have there been any implementation issues?	If yes, please briefly describe the issue(s) and any actions that have been/are being implemented as a result.
1	Pathway 1 - Home First	Assistive Technologies and Equipment	Community based equipment	Minimum NHS Contribution	£5,261,599	£6,729,100	200,000	180003	Number of beneficiaries	No	Please note: the figures for line 1 are inclusive of the spend and performance for lines 2, 3 and 4
2	Pathway 1 - Home First	Assistive Technologies and Equipment	Community based equipment	DFG	£542,824	£0		0	Number of beneficiaries	No	
3	Pathway 1 - Home First	Assistive Technologies and Equipment	Community based equipment	Additional LA Contribution	£1,172,219	£0		0	Number of beneficiaries	No	
4	Pathway 1 - Home First	Assistive Technologies and Equipment	Assistive technologies including telecare	Local Authority Discharge Funding	£500,000	£0		0	Number of beneficiaries	No	
5	Pathway 1 - Home First	Home-based intermediate care services	Reablement at home (to support discharge)	Minimum NHS Contribution	£2,562,918	£10,251,400	6,541	6407	Packages	No	Please note: the figures for line 5 are inclusive of the spend and performance for lines 5, 6, 7 and 8
6	Pathway 1 - Home First	Home-based intermediate care services	Reablement at home (to support discharge)	Additional LA Contribution	£4,643,520	£0		0	Packages	No	
7	Pathway 1 - Home First	Home-based intermediate care services	Reablement at home (to support discharge)	iBCF	£3,259,376	£0		0	Packages	No	
8	Pathway 1 - Home First	Home-based intermediate care services	Reablement at home (to support discharge)	Local Authority Discharge Funding	£0	£0		0	Packages	No	
18	Pathway 1 - Home First	DFG Related Schemes	Adaptations, including statutory DFG grants	DFG	£12,400,268	£7,233,000	8,000	8492	Number of adaptations funded/people supported	No	
22	Pathway 1 - Home First	Assistive Technologies and Equipment	Community based equipment	Minimum NHS Contribution	£827,379	£483,000	1,639	1230	Number of beneficiaries	No	
24	Pathway 2 - Intermediate Care Bed	Bed based intermediate Care Services (Reablement, rehabilitation, wider short-	Other	Additional LA Contribution	£2,763,734	£9,767,000	189	142	Number of placements	No	Please note: the figures for line 24 are inclusive of the spend and performance for lines 24, 25, 26 and 27
25	Pathway 2 - Intermediate Care Bed	Bed based intermediate Care Services (Reablement, rehabilitation, wider short-	Other	Minimum NHS Contribution	£3,832,286	£0		0	Number of placements	No	
26	Pathway 2 - Intermediate Care Bed	Bed based intermediate Care Services (Reablement, rehabilitation, wider short-	Other	Minimum NHS Contribution	£6,177,557	£0		0	Number of placements	No	
27	Pathway 2 - Intermediate Care Bed	Bed based intermediate Care Services (Reablement, rehabilitation, wider short-	Other	ICB Discharge Funding	£3,346,067	£0		0	Number of placements	No	
33	Community Services	Carers Services	Carer advice and support related to Care Act duties	Additional LA Contribution	£1,349,427	£780,560	2,000	1154	Beneficiaries	No	Please note: expenditure for lines 33 and 34 have been aggregated
34	Community Services	Carers Services	Carer advice and support related to Care Act duties	Minimum NHS Contribution	£1,691,000	£993,440	8,000	8000	Beneficiaries	No	
46	Care Act Duties	Residential Placements	Other	iBCF	£44,341,210	£49,847,000	1,783	1337	Number of beds/placements	No	Please note: the figures for line 46 are inclusive of the spend and performance for line 47
47	Care Act Duties	Residential Placements	Other	Minimum NHS Contribution	£22,121,701	£0		0	Number of beds/placements	No	
48	Care Act Duties	Home Care or Domiciliary Care	Domiciliary care packages	iBCF	£14,780,403	£16,634,500	1,246,650	934988	Hours of care (Unless short-term in which case it is packages)	No	Please note: the figures for line 48 are inclusive of the spend and performance for line 49
49	Care Act Duties	Home Care or Domiciliary Care	Domiciliary care packages	Minimum NHS Contribution	£7,397,504	£0		0	Hours of care (Unless short-term in which case it is packages)	No	
50	Care Act Duties	Workforce recruitment and retention		Local Authority Discharge Funding	£3,500,000	£0		0	WTE's gained	No	No output delivery target measure has been identified against this scheme.
52	Technology Enabled Care	Assistive Technologies and Equipment	Assistive technologies including telecare	Local Authority Discharge Funding	£300,000	£251,250	2,000	1675	Number of beneficiaries	No	
53	Care Home Development	Home Care or Domiciliary Care	Other	Additional LA Contribution	£408,526	£306,400	-	0	Hours of care (Unless short-term in which case it is packages)	No	Note that this has been incorrectly identified as scheme type "Home Care or Domicillary Care". This funding relates to specific posts to provide additional quality support for nursing/residential care homes.

BIRMINGHAM HEALTH AND WELLBEING BOARD

Item 14 - Creating a Bolder Healthier City (2022-2030): Indicator Updates

The Health and Wellbeing Strategy has a series of ambitious targets for 2030. Each ambition is linked to an indicator that will be used to monitor progress and measure our impact. This update informs the Health and Wellbeing Board (HWB) of data that has been recently updated (since the previous HWB). The Power BI dashboard, which contains data for all indicators (including trends) can be viewed by clicking on the image below.

Click to view the dashboard

Recent Updates: 02 February – 15 April 2024

Indicator	Theme	Date updated
TB incidence (three-year average)(Persons, All ages)	Theme 5: Protect and Detect	25th March 2024
Under 75 mortality rate from heart disease (Persons, 3 year range)	Life Course: Living, Working and Learning Well	25th March 2024
Hospital admissions due to asthma in young people under 19 yrs	Life Course: Getting the Best Start in Life	28th February 2024
Percentage of adults from ethnic communities with Type 2 Diabetes	Life Course: Living, Working and Learning Well	28th February 2024
Percentage of people with Type 2 Diabetes aged 40 to 64	Life Course: Living, Working and Learning Well	28th February 2024
Smoking prevalence in adults with a long-term mental health condition (18+)	Theme 2: Mental Wellness and Balance	28th February 2024
Children aged 11-15 killed or seriously injured in road traffic accidents (Persons, 11-15 yrs)	Life Course: Getting the Best Start in Life	27th February 2024

Smokers that have successfully quit at 4 weeks	Life Course: Living, Working and Learning Well	23rd February 2024
Infant mortality rate	Life Course: Getting the Best Start in Life	22nd February 2024

Birmingham Health and Wellbeing Board
Board Membership and Work Programme 2023-24

Board Members:

Name	Position	Organisation
Councillor Mariam Khan (Board Chair) Councillor Rob Pocock	Cabinet Member for Adult Social Care and Health Acting Cabinet Member for Adult Social Care and Health	Birmingham City Council
Dr Clara Day (Vice Chair)	Chief Medical Officer	NHS Birmingham and Solihull Integrated Care Board (ICB)
Councillor Karen McCarthy	Cabinet Member for Vulnerable Children and Families	Birmingham City Council
Councillor Matt Bennett	Opposition Spokesperson on Health and Social Care	Birmingham City Council
Dr Justin Varney	Director of Public Health	Birmingham City Council
Professor Graeme Betts	Director for Adult Social Care	Birmingham City Council
Helen Price	Director - Strategy, Commissioning and Transformation Children and Families	Birmingham City Council
David Melbourne	Chief Executive	NHS Birmingham and Solihull Integrated Care Board (ICB)
Richard Beeken	Chief Executive	Sandwell and West Birmingham NHS Trust
Andy Cave	Chief Executive of Healthwatch	Healthwatch Birmingham
James A Thomas	Chief Executive of Birmingham Children's Trust	Birmingham Children's Trust
Anne Coufopoulos	Executive Dean (School of Health, Sport and Food)	University College Birmingham

Professor Catherine Needham	Professor of Public Policy and Public Management	University of Birmingham
Richard Kirby	Chief Executive	Birmingham Community Healthcare NHS Foundation Trust
Dr Douglas Simkiss	Medical Director and Deputy Chief Executive of Birmingham Community Healthcare NHS Foundation Trust	Birmingham Community Healthcare NHS Foundation Trust
Mo Hussain	Chief Executive	University Hospitals Birmingham NHS Foundation Trust
Chief Superintendent Richard North	Chief Superintendent	West Midlands Police
Joanna Statham	Inclusion and Engagement Partnership Manager	Department for Work and Pensions
Peter Richmond	Chief Executive of Birmingham Housing Trust	Birmingham Social Housing Partnership
tbc	tbc	Birmingham Chamber of Commerce
Co-optee		
Natalie Allen	Chief Executive of SIFA Fireside	SIFA Fireside
Patrick Nyarumbu	Executive Director Strategic Partnership	Birmingham and Solihull Mental Health Trust
Stephen Raybould	Programmes Director (Ageing Better)	Birmingham Voluntary Services Council
Karen Creavin	Chief Executive of TAWS	The Active Wellbeing Society (TAWS)

Committee Board Manager
Landline: 0121 303 9844
Email: Louisa.Nisbett@birmingham.gov.uk

Business Support Manager for Governance & Compliance
Landline:0121 303 4843

Mobile: 07912793832
Email: Tony.G.Lloyd@birmingham.gov.uk

Forward Plan: 2023/24

Date	Strategic Priority	Item	Lead	Purpose	Format	HWB Lead
HWB Meeting: 18 July 2023 Draft paper deadline: 21 June 2023	Getting the Best Start in Life	**Children and Young People's Plan 2023-28 - Update**	Colin Michel	Discussion	Report	Helen Price
	HWB Development	**HWB Development Day Feedback and Next Steps**	Dr Justin Varney	Discussion	Report	Councillor Mariam Khan
	Ageing and Dying Well	**Better Care Fund End of Year Plan**	Mike Walsh	Approval	Report	Prof Graeme Betts
	Ageing and Dying Well	**Better Care Fund Plan 2023-25**	Mike Walsh	Approval	Report	Prof Graeme Betts
	HWB Development	**ICB 5 year Joint Forward Plan**	Rob Checketts	Discussion	Presentation	David Melbourne
	Mental Wellness and Balance	**WM Police: Right Care, Right Person Model**	Chief Superintendent Kim Madill	Discussion	Presentation	Chief Superintendent Richard North
	Getting the Best Start in Life	**CDOP Annual Report 2021-22**	Mel McKenzie	Written Update	Report	Dr Clara Day
	Forum Themes	**HWB Forum Written Updates**	Aidan Hall	Written Update	Briefing	Dr Justin Varney
	HWB Development	**BSol Joint Capital Resource Plan**	Karen Kelly	Written Update	Report	David Melbourne

Date	Strategic Priority	Item	Lead	Purpose	Format	HWB Lead
HWB Meeting: 26 September 2023 Draft paper deadline: 29th August 2023	JSNA	**Joint Strategic Needs Assessment (JSNA) Update**	Rebecca Howell-Jones	JSNA Update	Report	Dr Justin Varney
	Protect and detect	**Fast Track Cities+ Update**	Becky Pollard	Update	Report	Dr Justin Varney
	HWB Development	**HWB Development Day Feedback and Next Steps**	Dr Justin Varney	Discussion	Presentation	Councillor Mariam Khan
	Mental Wellness and Balance; Protect and Detect; Ageing and Dying Well	**Primary Care Enabling Strategy**	Paul Sherriff / Dr Sunando Ghosh	Discussion	Report	Dr Clara Day
HWB Meeting: 28th November 2023 **Draft paper deadline: 31st October 2023**	Healthy and Affordable Food	**Creating a Healthy Food City Forum Annual Update**	Sarah Pullen	Update	Presentation	Dr Justin Varney
	Life Course	**Birmingham and Solihull Winter Pressures Update**	Mandy Nagra	Update	Report	Dr Clara Day
	Life Course	**Midlands Met Hospital Update**	Tammy Davies	Update	Presentation	Richard Beeken
	Active at Every Age and Ability	**Draft Physical Activity Strategy and Consultation**	Humera Sultan	Update	Presentation	Dr Justin Varney
	Getting the Best Start in Life	**Birmingham Children and Young People's Partnership Written Update**	Colin Michel	Written Update	Report	Helen Price

Date	Strategic Priority	Item	Lead	Purpose	Format	HWB Lead
	JSNA	**Creating a Bolder Healthier City (2022-2030) - Indicator Updates**	Aidan Hall	Written Update	Report	Dr Justin Varney
Executive Board - EB 18th October	HWB Development	**Terms of Reference and Model**				
	HWB Development	**Draft Ways of Working Agreement**				
	JSNA	**Pharmaceutical Needs Assessment Update**				
HWB Meeting: 30th January 2024 **Draft paper deadline: 2nd January 2024** **Cancelled**						
Executive Board – EB: Date TBC **Cancelled**						

Date	Strategic Priority	Item	Lead	Purpose	Format	HWB Lead
HWB Meeting: 26 March 2024 **Draft paper deadline:** 27th February 2024	HWB Development	**Financial Update**	Mohammed Sajid	Update	Presentation	
	Closing the Gap	**BLACHIR Update**	Helen Harrison	Update	Presentation	Dr Justin Varney
	HWB Development	**ICB 5 year Joint Forward Plan**	Rob Checketts	Discussion	Report	David Melbourne
	Active at Every Age and Ability	**Physical Activity Strategy**	Dr Mary Orhewere	Approval	Report	Dr Mary Orhewere
	JSNA	**Pharmaceutical Needs Assessment Update**	Aidan Hall	Approval	Report	Dr Justin Varney
	HWB Development	**Executive Board papers (Dec)**	Clara Day	Approval	Report	Clara Day
	JSNA	**DPH Annual Report 2023-24**	Dr Justin Varney	Discussion	Report	Dr Justin Varney
	Getting the Best Start in Life	**CDOP Annual Report 2022-23**	Mel McKenzie	Written update	Report	Clara Day
	JSNA	**Indicator Updates**	Aidan Hall	Written update	Report	
Executive Board - EB						

Date	Strategic Priority	Item	Lead	Purpose	Format	HWB Lead
9 May 2024						
HWB Meeting: 9 May 2024 **Draft paper deadline:** 9th April 2024	Closing the Gap	**Creating a City without Inequality Forum Annual Update**	Monika Rozanski	Update	Presentation	Dr Justin Varney
	Ageing and Dying Well	**Better Care Fund Q3 report**	Mike Walsh	Approval	Report	Prof Graeme Betts
	Ageing and Dying Well	**Compassionate Cities Update**	Becky Pollard	Update	Presentation	Dr Justin Varney
	JSNA	**Learning Disabilities Deep Dive (JSNA)**	Luke Heslop	Approval	Report	Dr Justin Varney
	HWB Development	**Place Committee Update**	Mike Walsh	Discussion	Presentation	Prof Graeme Betts
	JSNA	Indicator Updates	Aidan Hall	Written update	Report	

Standard Agenda

1. Notice of Recording
2. Notice of Potential for Public Exclusions
3. Declaration of Interests
4. Apologies
5. Minutes and Matters Arising
6. Action Log
7. Chair's Update
8. Public Questions
9. Presentation Items (see detail above)
10. Information Items (see detail above)
11. Forward Plan Review
12. Finalise Agenda for next Meeting
13. Date, Time and Venue of next Meeting
14. Notice of Recording Ceased
15. Private Items (see detail above)

Notes

Any agenda change request must form part of prior HWBB information item with as much lead in as possible but no later than the HWBB immediately prior to the agenda change request, including requests from sub-groups (see below).

Public Questions

Public questions are to be submitted in advance of the meeting. Questions should be sent to: HWBoard@birmingham.gov.uk