

Learning Disabilities in Tower Hamlets, Newham and City and Hackney

Report

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Executive summary

Goal

The East London Learning Disability Partnership commissioned a Health Needs Assessment (HNA) for individuals aged 14 and above with diagnosed learning disabilities in the boroughs of Tower Hamlets, Newham, and City and Hackney. The goal of the HNA is to provide a comprehensive needs assessment, strategies, and recommendations that will inform future service planning, commissioning, and identify opportunities for the transformation of learning disability services and tri-borough collaborations in East London. There was a particular focus to highlight inequalities in health and health outcomes within this population group. The conclusions and recommendations are based on data but also importantly, the views that service users and their families' and carers wanted us to highlight. There are different commissioning arrangements across the three boroughs that lead to variations in service provision and outcomes which are important to note when reading this report. This report should be seen in the context of North East London Integrated Care System plans and priorities to address inequalities in health for people with a learning disability.

Method

A mixed-methods approach was employed for this HNA, encompassing an extensive literature review. It also involved stakeholder interviews and focus group discussions with service users, carers and families, and service providers across the three boroughs and ELFT. Additionally, the HNA involved the analysis of national and local datasets to ensure a comprehensive understanding of the needs and challenges faced by individuals with learning disabilities in the three boroughs.

Key findings and recommendations

Prevalence: In Newham, Tower Hamlets, and City and Hackney, approximately 0.46% of the population has a diagnosed learning disability. However, the actual number is likely to be higher, as PANSI estimates an adult prevalence of 2.14%-2.27%. Most affected individuals are adults, and significant demographic variations exist between ethnic groups, with the highest prevalence in Asian or Asian British, White, and Black or Black British populations. Across the three boroughs the learning disability population consists on average of 60% male and 40% female. Analysis also shows that most of the learning disability population across all three boroughs live in the most deprived areas.

Recommendations include creating a system that helps find and recognise more people with learning disabilities who have not been officially identified as there seems to be delayed and missed diagnosis of people with learning disability across the system. This is especially the case for communities who are underrepresented in current learning disability services. By working together and sharing information, different organizations can make sure that these individuals are accurately identified in the central healthcare database and all health records. We also recommend "poverty proofing" learning disability services by maximizing their income and benefits entitlements through targeted strategies, including outreach programmes, awareness campaigns, and partnerships with relevant agencies, to enhance financial support and social inclusion.

Co-morbidity: Individuals with learning disabilities frequently experience multiple comorbidities, resulting in poorer overall health. In the tri-borough area, common comorbidities include cardiovascular diseases, diabetes, epilepsy, mental health issues, and other functional impairments. Current interventions often fall short in addressing the complex and evolving needs of this population, as evidenced by the less-than-optimal uptake of annual health checks and national screening programs. Perceived barriers to health service accessibility for individuals with



learning disabilities include communication challenges, inadequate facilities, rigid procedures, and a lack of cultural understanding.

Recommendations entail increasing collaboration with families, friends, and caregivers in decision-making and identifying/addressing health needs, as well as enhancing assistance, training, communication, and reasonable adjustments to improve access to health services.

Education: There is a perceived lack of adequate support for students with additional needs who do not attend specialist provisions. Furthermore, educational programmes in colleges lack efficient pathways for individuals to enhance their employment skills.

Recommendations include adopting a coordinated approach across the boroughs to effectively integrate special education needs support into mainstream education.

Transition between children and adult services: The findings from the HNA indicate that transition planning is often delayed and lacks effective collaboration. There is a poor understanding of the needs of individuals in transition, and information systems do not effectively connect across different agencies.

Recommendations include adopting a more integrated and data-driven approach, enhancing care coordination, and initiating statutory transition planning during the year 9 review when individuals are 13-14 years old.

Employment: A significant employment rate gap (71%) exists between the general population and those with learning disabilities, with the latter group expressing frustration at limited work experience opportunities.

Recommendations include promoting the availability of training programmes centred on developing vocational skills and roles and implementing strategies to increase representation and visibility of individuals with learning disabilities in the workforce. We also suggest securing funding from lottery or foundation sources or social impact bonds to create tailored employment opportunities for the learning disability population, promoting inclusion, independence, and an improved quality of life for this population

Accommodation and housing: Compared to their peers, younger individuals with learning disabilities are more likely to live in specialist accommodation facilities away from their family homes. There is a perceived shortage of high-quality providers and appropriate placements for those with greater needs, resulting in a significant number of out-of-borough placements.

Recommendations include making substantial investments in in-borough residential care and developing current and future housing strategies in collaboration with relevant agencies, considering the high and increasing demand for such accommodations.

Caring responsibility: During focus group discussions, carers expressed concerns about the lack of adequate recognition as experts in their clients' needs. They also perceived respite services to be insufficient, with gaps in support for those caring for individuals with mild to moderate needs. Furthermore, carers found career progression and wages to be unsatisfactory.

Recommendations include providing better resources and support for carers, as well as improving salaries in line with the London minimum wage.

Impact of COVID-19: The COVID-19 pandemic significantly affected service users and providers, increasing the risk of social isolation for individuals with learning disabilities, disrupting routines, and reducing access to healthcare services due to service delivery impacts or a shift to virtual appointments. A positive outcome was the expanded coverage of welfare checks through phone or video consultations, replacing in-person health checks.

Recommendations include maintaining in-person checks and providing additional accessibility support for this population when conducting virtual welfare checks and other remote services.



Conclusion and further recommendations

Based on the data and insights gathered from stakeholder engagements during the HNA, it is apparent that the three boroughs currently offer some valuable support for individuals with learning disabilities. Nonetheless, there remain unmet needs and opportunities for improvement that, if addressed, could significantly enhance the provision of services for the local learning disability communities and improve their health and wellbeing.

The HNA process underscores the need for improved and standardised data collection, analysis, and sharing across learning disability service providers in ELFT, NEL, and the three boroughs, with a focus on interagency collaboration and shared data collection frameworks. Additionally, enhancing staff training in data management and implementing Key Performance Indicators to track data collection improvements are crucial for ensuring data quality and completeness. In particular data collection and completeness in on ethnicity, employment, housing, sex etc are essential to understand and improve health and service equity.

Limitations

- The report faces limitations due to the absence of data concerning the utilization of support services by adults with learning disabilities, including direct payments, DLA, and attendance allowance, spanning from 2018 to 2022. Additionally, there is a lack of information about the preferences of individuals with learning disabilities between direct payments and commissioned services, as well as the absence of comprehensive data detailing care package recipients' demographics and service types across various East London boroughs.
- Where feasible we have used local data provided by NEL ICS data team as well as applying national estimates where these data weren't available. In line with national findings, the data quality and completeness of local learning disability data was variable making comparisons or analysis of inequity difficult. A key recommendation of this report is to develop systematic and shared data analysis for people with a learning disability.



1. Recommendations

The recommendations across all areas of our analysis are presented below and the rest of the report provide the findings and rationale for the recommendations below.

No.	Section	Recommendation
1.	Population	We recommend ensuring a system where different organizations work together to accurately identify individuals with learning disabilities. This would involve establishing rules and guidelines (cross-organizational protocols) to reduce the chances of missing these diagnoses in the community. Accurate identification would also be ensured by including information about individuals with learning disabilities in both the NHS central registration database and all health and care record systems.
2.	Population	Implement proactive planning by local services to accommodate the projected rise in the number of adults with learning disabilities and those reaching advanced age, while also addressing their unique needs, including the provision of diverse and adequate models of housing and support.
3.	Population	It is crucial to prioritize the needs of individuals with learning disabilities in deprived areas by adopting a proactive approach to "poverty proof" learning disability services. This can be achieved by implementing targeted strategies, including comprehensive outreach programmes, awareness campaigns, and partnerships with relevant agencies, to maximize income and benefits entitlements and promote social inclusion for individuals with learning disabilities and their families.
4.	Health of people with learning disabilities	The early identification of co-occurring health conditions in individuals with a learning disability can present a challenge. It is crucial to inform families of the increased risk in physical and psychological ill health so that they understand the importance of health checks. Involve families, friends, and caregivers in decision making and in the process of identifying and addressing these health needs. This can be through collaborative care planning, health assessments, health information and education and support groups.
5.	Health of people with learning disabilities	Given that a significant proportion of individuals with learning disabilities have co-occurring health conditions, it is important to emphasise the NHS key working principle of assigning a named healthcare coordinator for those with complex healthcare needs. This approach ensures that individuals receive comprehensive and coordinated care to address their diverse health requirements.
6.	Health of people with learning disabilities	The accuracy and comprehensiveness of data pertaining to comorbidities among individuals with learning



		disabilities raise concerns. To address this issue, it is imperative to focus on improving data collection, monitoring, and overall quality in relation to co-occurring conditions among this demographic.
7.	Health service use	At times there is a lack of availability of support staff to take people to appointments, lack of awareness surrounding the significance of health checks and lack of follow-up systems and processes are some of the cited reasons. Tackling these three barriers could improve health and lead to increased prevention of comorbidities.
8.	Health service use	It is of utmost importance that individuals with learning disabilities receive necessary assistance in accessing mainstream services through the provision of reasonable adjustments. Furthermore, it is advisable to consider the utilisation of specialised services as a supplementary measure to the existing services, to cater to the unique and individualised needs of each person with a learning disability.
9.	Health service use	GP surgeries and hospitals should invest in training and in diversifying and improving their communication and general offer to better accommodate the needs of their patients and visitors with learning disabilities. Examples of which include alternatives to online booking, easy-read health information documents, accessible physical environments, and education for practice staff.
10.	Health service use	As recommended by the Health and Care Act 2022, registered health and social care professionals are mandated to undertake training in learning disabilities and autism. The training should be considered a priority for all staff members to enhance their understanding and awareness of the intricacies associated with learning disabilities.
11.	Health service use	Promote the use and value of hospital or health passports to support workers, carers and GPs. Provide support to ensure passports remain up-to-date and comprehensive.
12.	Health service use	NHS NEL should aim to develop an improved mechanism for supporting and monitoring people that do not meet the eligibility criteria for learning disability support but have a high level of need to avoid these individuals 'falling through the gap'.
13.	Employment	Prioritise and promote the availability of training programmes that focus on the development of vocational skills and roles, with a specific emphasis on improving literacy and communication skills across the boroughs. This will help to ensure that individuals with learning disabilities have the necessary skills and training to prepare them for future employment opportunities.
14.	Employment	Efforts to increase the representation and visibility of individuals with learning disabilities in the workforce can challenge negative stereotypes. We recommend strategies to achieve this goal including continued



		employer awareness and training programs, job coaching and assistive technology support services, partnerships with disability organisations, and the creation of supportive and inclusive work environments through employee resource groups or diversity and inclusion committees. Examples of employment initiatives have been identified in the employment section of this report.
15.	Education	Effectively integrating special education needs support into mainstream education is important to meet the needs of students with mild to moderate learning disabilities. This requires a coordinated approach, including staff training and education on communication device tools and other reasonable adjustments and educating students to tackle stigma.
16.	Education	Ensure that students with learning disabilities are equipped with an effective development plan to assist with academic performance and general wellbeing and ensure the varying needs of each individual are taken into consideration.
17.	Housing and accommodation	Present and future housing strategies for individuals with learning disabilities should be devised through collaboration with relevant agencies, taking into account the high and growing demand for such housing.
18.	Housing and accommodation	Residential care needs substantial investment to ensure it is adequately resourced to meet the complex needs for individuals with more severe learning disabilities.
19.	Caring responsibilities	Ensure that carers and communities are better resourced to meet the complex needs of the learning disability population. This could include increased funding and prioritisation of day centres offering opportunities for individuals to socialise and meet other carers, but also opportunity for respite.
20.	Caring responsibilities	Ensure that carers receive a better salary (aiming for London Living Wage) as this will likely improve staff morale, in addition to hiring and retention.
21.	Caring responsibilities	Greater support should be given to carers, whilst encouraging them to be more wary of their own physical and emotional needs, which can often be neglected due to growing and demanding case loads
22.	Transition between children and adult services	A more integrated and data driven approach in order to monitor those with learning disabilities who are transitioning from children to adult services will offer service providers information to better plan for the population's needs.
23.	Transition between children and adult services	The transition between services for young adults with learning disabilities can be a source of stress. Children and adult services have varying service models and receive different levels of financial support, leading to a lack of synergy that can negatively impact the experience of accessing care for service users. It is crucial to prioritize improving the coordination of care and offering



		appropriate service provision for vulnerable populations, including planning service provision in a way that is tailored to their needs.
24.	Transition between children and adult services	To ensure a personalised and comprehensive approach, the statutory transition planning for individuals with disabilities should commence during the year 9 review at age 13-14. This planning should encompass various areas, including health, independent living, employment, and social inclusion, and should be centred on the individual.
25.	Impact of COVID-19	<p>Amid the COVID-19 pandemic, virtual appointments became the norm, causing health and social care professionals to encounter difficulties in identifying subtle clues related to mental health and wellbeing. As a result, there has been a rise in safeguarding concerns. To address this, it is crucial to ensure that essential in-person appointments, such as annual health checks, are maintained for individuals with learning disabilities. Moreover, health services that are now exclusively online require digital skills or additional accessibility support to be made available.</p> <p>However, it is important to realise that some individuals benefitted from on-line consultations and this knowledge should be used if people prefer or fail to attend their appointments.</p>



2. Background

2.1 Introduction

- 2.1.1 An estimated 1.5 million individuals in the UK have a learning disability.⁽¹⁾ Unfortunately, individuals with learning disabilities are particularly vulnerable to a range of adverse health outcomes. These include higher rates of physical and psychological disorders compared with the general population. They also have disproportionately lesser academic achievements, higher obesity levels and experience economic disadvantage when compared with their peers without a learning disability. Individuals with a learning disability from minority ethnic groups are even more disproportionately affected. Also, decreased life expectancy has historically been found among people with a learning disability compared to the general population.^(1–4)
- 2.1.2 Social factors are key facilitators of these health inequalities. Evidence indicates that those with learning disabilities can often face discrimination, which can hinder their ability to be active members of society.^(1,4) This is problematic as those with learning disabilities are equally capable of making important and meaningful contributions to society. Currently, the UK healthcare system struggles to meet the complex and changing needs of this population. This can be illustrated by the increasing rate of preventable comorbidities due to delays and obstacles in diagnosis, and a reduced likelihood to attend regular health checks and/or population screening programmes.^(2,3) Tackling the health and social inequalities pertinent to individuals with learning disabilities, particularly those from lower socio-economic backgrounds is an urgent public health matter and remains a key priority for the UK government.⁽⁵⁾

2.2 Definition of learning disability

- 2.2.1 For this report, we describe learning disabilities as an umbrella term for a significant, lifelong condition that first emerges during childhood and affects development across the lifespan. Whilst the NHS acknowledges that every presentation of learning disabilities is unique, certain overlapping themes emerge from the relevant literature.^(6–8) These include:
- Difficulty in understanding new and/or complex information.
 - A lower intelligence which has been classed as an IQ score of ≤ 70 .
 - Onset of learning disability presented in childhood and affects lifespan development.
- 2.2.2 For quite some time, the concept of a continuum of learning has been employed as an explanation for the diverse array of abilities observed among people with learning disabilities.
- Profound learning disability refers to individuals with an estimated IQ below 20, resulting in severely limited understanding. They often have multiple disabilities, including impairments in vision, hearing, and movement, along with additional challenges like epilepsy and autism. Communication



difficulties are prevalent, and extensive support is typically required for mobility and complex health needs.(6,9)

- Severe learning disability refers to individuals who primarily use basic words and gestures to communicate their needs. They require a high level of support for daily activities like cooking, budgeting, cleaning, and shopping, although they may be capable of managing some or all their personal care needs. Some individuals may have additional medical needs and require assistance with mobility issues.(9)
- Moderate learning disability is characterized by individuals who possess language skills that enable them to communicate about their daily needs and desires. They may require some support in self-care but are generally capable of carrying out day-to-day tasks with assistance.(9)
- Mild learning disability describes individuals who can engage in conversations and effectively communicate their needs and desires. They may require some support in comprehending abstract or complex ideas. People with a mild learning disability often exhibit independence in self-care and everyday tasks, typically possessing basic reading and writing skills. However, they may still require appropriate support for tasks such as budgeting and completing forms.(9)

2.3 Purpose of this report

- 2.3.1 The East London Learning Disability Partnership (NEL LD) has commissioned a comprehensive 'Health Needs Assessment' of individuals aged 14 years and above, residing in the London boroughs of Tower Hamlets, City and Hackney and Newham. This assessment aims to evaluate the health and social needs of individuals with learning disabilities living in these areas. The findings will be used to identify any gaps in existing service provisions and develop recommendations for future implementation. The goal is to inform future strategic service planning and commissioning while identifying opportunities for transformation within learning disability services and tri-borough collaborations across East London. This assessment is critical in ensuring that individuals with learning disabilities receive appropriate and effective support and resources to improve their quality of life.

2.4 Methodology

- 2.4.1 This report utilised a mixed-methods approach, incorporating evidence from literature reviews and both local and national datasets. Qualitative interviews were conducted with service providers, while focus group discussions took place with service users, carers, and family members across the three boroughs.
- 2.4.2 The primary themes explored were access, experiences, and outcomes related to learning disability services from the perspectives of service users and their families or carers, with a particular focus on inequalities in health and health outcomes. The findings from these focus group discussions and interviews are presented throughout the sections of the report. The organisations of contributors to the stakeholder engagements are listed in Appendix 1.



2.4.3 The scope and purpose of this needs assessment was agreed by the stakeholder liaison board. This consists of representatives from ELFT, individual local authorities, multi-agencies and departments.



3. National and local policy context

This chapter summarises key findings and recommendations from recent national and local documents relating to learning disabilities.

3.1 Building the right support for people with a learning disability and autistic people – Action Plan 2022 – Department of Health and Social care⁽¹⁰⁾

This action plan aimed at strengthening community support for individuals with learning disabilities and autism and reducing reliance on mental health inpatient care. The following are actions and recommendation from this plan:

- 3.1.1 Keep people with learning disabilities safe and provide a high level of health and social care by conducting regular reviews of care to ensure that inpatient care has as few restrictions as possible. Increased accountability and documentation of instances of force will maintain a progressive culture within inpatient services and result in a human rights approach and a workforce equipped with the relevant knowledge and skills to treat people with learning disabilities appropriately.
- 3.1.2 Reduce rates of hospital admissions for people with learning disabilities by updating the policy for Care and Treatment Reviews to emphasize the importance of maintaining good physical health for people in hospital. Providing local authorities with additional funding to mitigate any double running costs will help to increase discharge rates in England, as will creating proposals to introduce a new duty under the Mental Health Act which will see some restricted patients being discharged into the community.
- 3.1.3 Improve community integration for people with learning disabilities by promoting collaborative working between local agencies to provide a greater variety of support. This will allow for greater treatment flexibility which is important given the changes in condition and life circumstances reported by the learning disability population.
- 3.1.4 Ensure that people with learning disabilities are provided with equal opportunity to live a progressive and fulfilling life by providing early diagnosis to prevent negative health outcomes from manifesting, and equipping children and young people with an action plan to ensure a smooth transition into adulthood. This will prevent escalation of needs, mental health crises, and preventable hospital admissions.
- 3.1.5 Keep both local and national learning disability services accountable to ensure that high-quality care, support, and treatment is available for all. Integrating health and social care will help remove any barriers to accessing treatment offered by the NHS, while also improving collaboration between healthcare, social care, and public health services.



1.1 The NHS Long Term Plan (chapter: Learning Disability and Autism)⁽¹¹⁾

- 3.1.6 This chapter is made up of a series of key actions that will be taken by the NHS:
- 3.1.7 Action will be taken to tackle the causes of morbidity and preventable deaths in people with a learning disability and for autistic people. This will involve tackling health inequalities associated with learning disabilities by increasing the rate of annual health checks and preventing unnecessary medication through effective delivery of health programs such as STOMP (Stopping the Over-Medication of children and young people with a learning disability, autism, or both) and STAMP (Supporting Treatment and Appropriate Medication in Paediatrics). The LeDeR program can also provide tangible solutions to prevent avoidable deaths.
- 3.1.8 Secondly, the whole NHS will improve its understanding of the needs of people with learning disabilities and autism and work together to improve their health and wellbeing. To achieve this the plan is to provide information and training to NHS staff on supporting people with a learning disability and/or autism. Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) will be expected to ensure that all local healthcare providers make reasonable adjustments to support people with a learning disability or autism.
- 3.1.9 National learning disability improvement standards will be implemented over the next five years and will apply to all services funded by the NHS. These standards will promote greater consistency and address various themes such as rights, workforce, specialist care, and working effectively with people and their families. Additionally, a "digital flag" will be introduced in the patient record by 2023/24 to indicate if the patient has a learning disability or autism. The government also plans to improve awareness and support for children and young people with learning disabilities, autism or both, and to provide hearing, sight and dental checks for those in special residential schools.
- 3.1.10 As part of the efforts to improve services for children and young people with mental health needs, the plan includes a focus on reducing waiting times for specialist services for autism diagnosis. This will involve working with mental health services to explore and implement the most effective approaches. For example, by the year 2023/24, there will be a designated keyworker for children and young people with the most complex needs related to learning disability, autism or both.
- 3.1.11 To improve the quality of care for individuals with learning disabilities, the NHS will increase investment in intensive, crisis, and forensic community support. Additionally, the NHS will focus on improving the quality of inpatient care across both the NHS and independent sector. To achieve this, all care commissioned by the NHS will need to meet the Learning Disability Improvement Standards by 2023/24.

3.2 North East London LeDeR strategy 2022–2025⁽⁵⁾

- 3.2.1 The LeDeR (Learning Disabilities Mortality Review Programme) was established with the aim of improving the quality of health and social care



services provided to individuals with learning disabilities. This is achieved by facilitating reviews of the deaths of all such individuals within local areas. In the current strategy, data from eight local place partnerships, including Tower Hamlets, Newham, and City and Hackney, was analysed and evaluated to identify the key areas of focus for the period from 2022 to 2025. The findings of this analysis will inform the implementation of targeted interventions to enhance the quality of care and support provided to individuals with learning disabilities in these local areas.

3.2.2 Below are the key areas of focus for 2022-2025:

- Annual health checks: increase uptake, quality and effectiveness of annual health checks, ensure Health Action Plans are completed and shared with relevant professionals and ensure GP registers of persons with a learning disability are kept accurate and up to date.
- Provision of reasonable adjustments: raise awareness of the entitlement and provision of appropriate reasonable adjustments, ensure appropriate flexible appointments for all patients with learning disabilities, ensure there is sufficient provision of interpretation and translation services, ensure more GPs offer home visits to housebound and poor mobility patients to minimise “Did Not Attend” (DNAs).
- National Health Screening programmes: ensure fair access to routine health screening programmes.
- Mental Capacity Act across partner organisations: ensure improved application of mental capacity assessments and clear best interests decision-making process is evidenced where appropriate. Also, ensure regular social care reviews and increased use of independent mental capacity advocates (IMCA) to support patients with key making decisions.
- Advance Care Planning (End of Life care): actively support and encourage person centred care plans and health action plans to address immediate and future health deteriorations, ensure provision of end-of-life care is consistent across our local boroughs and increased staff awareness on supporting end-of-life patients.
- Recognition of deterioration and escalating appropriately: ensure all staff working with people with learning disabilities (including care staff) are trained to recognise, monitor and escalate early signs of deterioration or increased distress to health care professionals.
- STOMP/STAMP – overmedication with antipsychotic medicines: ensure STOMP pathways are developed to support medication reduction where appropriate and in patients’ best interest; ensure GPs are aware of pathway and able to refer and more social prescribing by GPs – introducing a range of local, non-medical activities, therapies, opportunities and support.
- DNACPR (Do not attempt cardiopulmonary resuscitation) application: ensure application of DNACPR is appropriately applied; ensure DNACPR process is discussed and completed in full consultation with families, carers and all those involved with the person’s care and DNACPR training to continue to be provided for frontline professionals.



- Care coordination across all services including discharge planning: ensure a well-planned transition process between primary and secondary care services and community services including hospital discharges, ensure services/ teams make use of health passports as this will improve information exchange between services.
- Missed health care appointments- 'Did Not Attend': ensure missed appointments are actively followed up, ensure the reasons behind DNAs are fully explored.
- Engaging with families and carers/support staff: encourage health and social care professional to foster good communication between teams and families, ensure carers are provided with the right information and support to understand the importance of carers' assessments and maximise partnerships with family and carers especially when persons with a learning disability are admitted to hospital settings by establishing clear roles and responsibilities.
- Black and global majority patients with a learning disability: ensure better understanding of the needs and demographics for these communities and how best to meet these needs and explore appropriate approaches to outreach and engagement with all parts of this community.
- Care for people with dysphagia/ swallowing problems: ensure appropriate and timely referrals to the Speech and Language Therapy (SALT) team and regular reviews.
- Improve blood testing for people with needle phobia: ensure more efforts around desensitisation (promoting use of exposure therapy has been recommended), promote closer working relationships between CLDS Teams, families and care providers.
- Body Mass Index and weight management: promote a more personalised approach in managing patients who are clinically overweight and obese, ensure more flexible options for exercise and healthy eating that include reasonable adjustments, close monitoring and reviewing of the effectiveness of exercise referrals to ensure they deliver outcomes for people with learning disabilities, dieticians to work more closely with GPs to discuss alternative ways of weight management and care staff to be trained on risks of poor nutrition including malnutrition and underweight.
- Rights based approach – personalised care: ensure all our local services are 'Learning Disability Friendly' by involving experts by experience, families and carers in this process, ensure the voices of persons with a learning disability shapes the way we deliver local care services, develop better ways of capturing the lived experience of persons with a learning disability and better ways of assessing whether their rights are actively being promoted in practice.
- Understanding additional health needs for people with learning disabilities: ensure GPs and healthcare professionals sets out ways of reducing clinical risks such as diagnostic overshadowing, increase awareness amongst care providers particularly on the common health issues and causes of death noted in our local reviews, increase awareness about the role of CLD teams and how to access them to provide support and ensure people with learning disabilities are able to access services they need.



- 3.2.3 This plan sets out the context of the North East London Learning Disabilities and Autism Programme, describes the Integrated Care Systems (ICS) and highlights the NEL ICS key priority areas for 2022/23.
- 3.2.4 This plan also highlights the progress achieved between 2021 and 2022. These include:
- Reduced reliance on inpatient settings. Following a significant peak in August, focused work was undertaken on increasing monitoring around the Dynamic Support Registers (DSRs) and increasing community (C(E)TRs); this has brought overall inpatient numbers down but not to pre-pandemic levels.
- 3.2.5 Secondly, a number of services have been developed in 2021/22, or have been scoped in preparation for delivery in 2022/23. These include:
- New and/or expanded autism diagnosis services for both adults and CYP, including pre- and post-diagnosis support.
 - Local autism hubs.
 - Out of hours crisis services and Intensive Support Teams.
 - Projects responding to findings from LeDeR, including initiatives to increase the uptake and quality of annual health checks, dietician services, and to support the uptake of flu and Covid-19 vaccinations.
- 3.2.6 A number of projects have been invested in to address health inequalities. Key examples of this include the roll out of Significant 7+ training¹, a number of projects to support weight management and co-produced training for primary care in reasonable adjustments and communication. Also, a number of boroughs have commissioned health check facilitators to increase the uptake of annual health checks; key work has begun to consider how improvements in quality can be made, and this will be a key priority for 2022/23.
- 3.2.7 Programme plans include:
- Reducing avoidable and preventable admissions to inpatient care. This will focus on key action and programme areas such as increasing use of personal health budgets, full scale diagnosis and continuing mobilisation of intensive and out of hours support, increased investment in intensive, crisis and forensic community support, additional support for discharge of long stay patients, an extended community forensic offer and mobilisation of the key working model in NEL.
 - Reduce mortality and preventable deaths. This will be achieved through the following actions/programmes: introducing a specific health check for people with autism, expanding the STOMP/STAMP programme, continuing the Continuing the Learning from Lives and Deaths Programme (LeDeR) and improving uptake and quality of annual health checks.

¹ Significant 7+ is an innovative training tool for Care Homes to ensure the prevention of avoidable A&E attendances and acute admissions for complex and frail patients.



- Improving Autism Diagnostic assessment and support. This will be achieved by reducing waiting times for Autism diagnosis of Children and Young People (CYP), providing pre-diagnosis support for CYP and their families with autism and other neurodevelopment disorders through the diagnosis process. As at the time of the writing of the plan, an LDA diagnostic piece has been commissioned across NEL to look at all community services while ASD diagnosis services are being expanded in BHR, Newham and Waltham Forest.
- Improving quality of care. This will be achieved through implementing recommendation of restricting the use of seclusion, long term segregation and restraint for all patients in inpatient settings; reducing inpatient length of stays and support earlier transfers of care from inpatient settings; implementing the '12-point discharge plan' to ensure discharges are timely and effective and reviewing and strengthening the existing Care, Education and Treatment Review (C(E)TR) and Care and Treatment Review (CTR) policies.
- COVID-19 and provision of virtual appointments: explore the potential benefits of the new ways of working and ensure this meets the needs for people with learning disabilities and quality of these appointments is not compromised, ensure that any technology that is being used as part of a virtual offer is accessible and appropriate for persons with a learning disability and promote a mix of face-to-face and virtual appointments to ensure physical assessments and examinations are continued.

3.3 The Adult Learning Disability Strategy 2017-2020 – Tower Hamlets Council⁽¹²⁾

- 3.3.1 Six overarching outcomes are outlined in this document. These include to be happy and healthy, live locally, be a member of the community and attend local activities, work or volunteer, have choice and the right support and be respected and safe.
- 3.3.2 In relation to these aims, six objectives were described. These include reduce health inequalities and the length of stay in hospital; increase the number of people living locally; increase the uptake of local and community activities; improve employment rates and the number of people who volunteer; increase the number of people reporting that they have choice of treatment and appropriate support and increase the number of people reporting who feel respected and safe.
- 3.3.3 An internal document by the health and adults' scrutiny sub-committee provides updates on the recommendations as per the learning disability strategy. There are 18 recommendations in this document. The recommendations and actions that were not finalized at the time this document was published, concerning health outcomes, employment, and education, are outlined here along with the progress made.
- 3.3.4 The first recommendation is that joint working between SEND, Children's and health services should aim to address the under representation of 14 - 17-year-olds on the learning disability primary care registers. This will ensure more effective coverage of primary care health checks for this group.



- Efforts are ongoing to identify more individuals with learning disabilities as the GP register has grown by over 300 people between 2020 and 2022.
 - A protocol was created to identify young people at age 14 for GP register inclusion when they start transition planning.
 - More young people with borderline learning disabilities will be assessed and potentially included on the GP learning disabilities register with provisional coding, while they are still in children's services.
- 3.3.5 Effective transition planning is addressed through the new learning disability strategy and joined up with the Children and Families Strategy and Child and Adolescent Mental Health Services (CAMHS) Transformation Plan. Also, identify and diagnose people with learning disability earlier and work with health provision to ensure that learning disability needs are being met effectively. Progress updates are summarised with the bullet points below:
- Children and adult services continue to prioritise a well-planned transition for young people, starting from age 14.
 - Transitions pathways are the focus of the newly constituted Transitions Board.
- 3.3.6 Increase further understanding of how to support those people who show signs of a learning disability but do not meet the initial Community learning disability service (CLDS) threshold through assessment. Progress updates include:
- An ongoing initiative within the transformation of community mental health services is in progress, aiming to guarantee that the requirements of individuals with mild and borderline learning disabilities are taken into account during the planning process.
 - Collaborative efforts are being made with conventional mental health services to facilitate access for individuals with mild learning disabilities and autism. This involves providing training, consultations, and fostering cooperation across different service sectors.
- 3.3.7 Utilise online platforms and develop (electronic) health passports for people with learning disabilities in Tower Hamlets and build into standard practice as part of Annual Health Check, initial assessments and annual reviews completed by CLDS. Progress updates:
- Significant work was undertaken by multiple partners including CLDS, the CCG and GP surgeries to raise awareness of hospital passports and this work continues.
 - A new system software which avoids double entries will be commissioned for electronic health passports as the old one has been decommissioned. Work is underway to understand the transition period from one system to the next.
 - Training will be provided to day services and supported living/residential services to support them in transferring existing paper health passports to the digital health passport system.



- 3.3.8 Tower Hamlets Council should lead by example and create more paid job opportunities for people with learning disabilities and set aspirational targets.
- Ongoing implementation of employment assistance and skill development initiatives will boost the number of people with learning disabilities seeking paid work.
 - Additional efforts will be made to promote the establishment of paid positions within the local council, and ambitious goals will be established and evaluated.
- 3.3.9 Get commitment from member organisations to employ more adults with a learning disability and incorporate the concept of supporting each other to develop a truly inclusive culture in their respective organisations.
- 3.3.10 The Health and Wellbeing Board, Partnership Executive Group and health organisations should create more job opportunities for adults with learning disabilities. The progress updates for the above are given below:
- The count of employers hiring individuals with learning disabilities experienced a consistent growth during 2019-2020, rising from 27 employers in the first quarter to 46 in the fourth quarter. The decrease observed throughout 2020-2021 can be predominantly attributed to the impact of the COVID-19 pandemic.
 - There has been enhanced employer engagement with new organisations recruiting and supporting people with learning disabilities to access employment and employment related benefits including:
 - Working with Airbnb, Coders for Covid and a FTSE100 company, the Compass Group.
 - Securing backing from the Forbes Charitable Foundation and the Department for Work and Pensions (DWP) will help facilitate kickstart employment opportunities for individuals with learning disabilities.
 - The ANZ Bank provided funding for more than 50 laptops and tablets, bolstering remote service offerings during the lockdown period.
 - The British Association for Supported Employment created opportunities for individuals with learning disabilities at Microsoft locations in London.
- 3.3.11 To ensure the supported employment programme set ambitious recruitment targets that are based on national benchmarking figures and population growth. Progress update below:
- The goals of the Employment Support contract stipulate that each year 110 new individuals (distinct from those in the previous year) will receive assistance in securing employment and further support throughout their time in the workforce. During 2019-2020, 126 individuals with learning disabilities received support to obtain employment. In 2020-2021, the service assisted a total of 121 people in finding jobs up to the third quarter, surpassing the yearly objectives.



- 3.3.12 The Tower Hamlets Accommodation Plan for people with LD should set ambitious targets for the development of local accommodation opportunities for people with a learning disability.
- 3.3.13 To secure funding and resources to support development of new supported accommodation schemes.
- 3.3.14 To work with Housing Providers and Housing Options and consider ways to increase supported accommodation capacity through capital programme/HRA funding. The progress updates for the above are given below:
 - Several adults have relocated back to the borough over the past two years, and more were planned to move during 2022.
 - The expansion of local housing alternatives and enhancement of services for individuals with more intricate needs will persist, with new projects planned for launch in August 2022 and October 2023.

3.4 City and Hackney Strategy for Learning Disabled People 2019-2024⁽¹³⁾

- 3.4.1 The City and Hackney Strategy for people with learning disabilities was formulated in collaboration with a diverse group of individuals, including those with learning disabilities, their caregivers, and organisations that work with people with learning disabilities in City and Hackney.
- 3.4.2 The fundamental vision for the strategy is that “learning disabled people are active and valued in a community which is accessible and enabling, with the same opportunities as anyone else in the community. They lead full, healthy and happy lives, achieving their potential.”
- 3.4.3 Eight outcomes are highlighted in this strategy:
 - People with learning disabilities have access to good quality housing and have a place they call home.
 - People with learning disabilities are able to get into and retain employment.
 - People with learning disabilities are able to have choice and control over the services they receive.
 - People with learning disabilities can access and use digital technology.
 - People with learning disabilities are valued for the contribution they make to society.
 - People with learning disabilities have good access to the health services they need.
 - People with learning disabilities are part of social networks.
 - People with learning disabilities are able to access life opportunities.



- 3.4.4 The first priority is focused on giving young people the best start in life. This involves:
- Seamless transition while preparing for and entering adulthood: The objective is to establish smooth and transparent pathways for individuals with learning disabilities, enabling them to achieve the highest possible level of independence, and ensuring they receive appropriate support in a timely manner when necessary.
 - Daytime activities or day opportunities – providing choice and control: The aim to provide an extensive selection of high-quality choices for individuals with learning disabilities. As part of this, the council will implement a variety of mechanisms that allow people to exercise varying degrees of decision-making autonomy, ensuring that their preferences are respected and valued.
 - Support for carers: The aim is to assist caregivers in their supportive roles and empower individuals with learning disabilities to reside close to or alongside their family and friends, fostering strong relationships and community ties.
 - Also, another goal is to engage carers in shaping services tailored for individuals with learning disabilities. Part of this process will be facilitated through the Learning Disabilities Partnership Forum, ensuring their valuable input is considered.
- 3.4.5 The second is on addressing health inequalities. This includes:
- Preventative health services – Improving access to universal/Public Health for learning disabled people: to ensure that individuals with learning disabilities have excellent access to mainstream preventive and health-promoting services, including initiatives focused on healthy eating and maintaining a balanced weight.
 - Reducing and preventing admission to hospitals: It is essential for individuals to actively participate in their communities, avoid unnecessary hospital admissions, maintain their independence by staying in their own homes as long as feasible, and prevent social isolation to promote overall well-being.
 - Getting the data right.
 - LeDeR programme – learning from mistakes and preventing future mistakes.
- 3.4.6 Getting a job/employment. This priority involves the following:
- Challenge expectations and transform attitudes, promoting the idea that individuals with learning disabilities participating in the workforce should be considered the norm
 - Supported employment – supporting and engaging with the work of the Supported Employment Network
 - Targeting City and Hackney’s big employers and supporting them to recruit and retain learning disabled people.
 - Supporting learning disabled people to find out and understand their employment options and act on these.



- The overall aim is to assist employers in becoming more accessible and employing a greater number of individuals with learning disabilities. To also ensure large employers in City and Hackney actively recruit and retain people with learning disabilities, fostering inclusivity and diversity in the workplace.

3.4.7 Making the community an integrated one. This will be achieved by:

- Personalisation – ensuring there are good offers and people can choose how they are supported, increasing the opportunity for people to take control of their personal budget/personal health budget.
- Ensuring there is a good choice of high-quality supported accommodation that offers settled accommodation and enable people with learning disabilities achieve their goals.
- Making sure people with learning disabilities are able to find out about and access activities in the community.
- The Learning Disabilities Charter – Partners will be encouraged to endorse this initiative, and it is expected that additional organisations may express interest in joining as well, further expanding its impact.

3.5 Adults with learning disabilities action plan 2022-25 – Newham⁽¹⁴⁾

- 3.5.1 The Newham Action Plan has been collaboratively designed with the goal of raising the profile of adult residents in the borough with a learning disability. The overarching objective is to promote increased community awareness and inclusion, while reducing inequalities for individuals with learning disabilities. This plan is divided into six broad sections: heard and valued, accommodation and housing, connected and involved, work and purpose, health and social care and carers.
- 3.5.2 The Heard and Valued action plan aims to raise awareness about learning disabilities and its impact on individuals. By improving attitudes towards individuals with learning disabilities, this initiative strives to foster greater inclusion and create opportunities for education, training, employment, and other important areas.
- 3.5.3 Other measures to support individuals with learning disabilities include ensuring the accessibility of key council and health information. Furthermore, efforts to refresh forums for people with learning disabilities will be undertaken, along with reviewing the effectiveness of the integrated advocacy service in meeting the needs of residents with learning disabilities.
- 3.5.4 The aim of the Accommodation and Housing plan is to provide appropriate support to residents with learning disabilities, ensuring that they are able to maintain their tenancies in general housing. In addition to this, the plan involves conducting reviews of shared lives offers and collaborating with housing providers to enhance access to social housing for individuals with learning disabilities. Needs, capacity, and opportunities assessments for care homes will also be carried out, alongside exploring new developments to increase the availability of accommodation options in-borough for residents with learning disabilities. Overall, this plan is intended to improve the housing



situation for individuals with learning disabilities and provide them with greater opportunities for independence and quality of life.

- 3.5.5 Some of the outcomes for this action plan includes suitable in-borough accommodation for residents with learning disabilities and more appropriate supported living services.
- 3.5.6 Connected and Involved action plan aims at co-developing key policies including learning disabilities non-exploitation policy; relationships policy and a policy and training programme for Health and Social Care professionals to support residents with Learning Disabilities to establish relationships. Other initiatives include employment of a support worker to specifically support residents with Autism and/or learning disabilities—with the aim of reducing social isolation and loneliness.
- 3.5.7 The Work and Purpose Action Plan aims to review the pathway from education to further education/employment for residents with learning disabilities, with the goal of identifying and addressing areas for improvement. The plan involves refreshing current day opportunities and the supported employment offer to better support individuals with learning disabilities in their pursuit of meaningful work and purposeful lives.
- 3.5.8 The Health and Social care aspect of the action plan focuses on developing and implementing a learning disability diagnostic service and increasing uptake of health checks for individuals with learning disabilities. The plan includes strengthening CETR, improving access to specialist health services for individuals with mild to moderate learning disabilities, reviewing the transition process for adults with learning disabilities to older adults, and improving end-of-life planning for individuals with learning disabilities.
- 3.5.9 The Carer action plan centres around planned respite support by developing appropriate in-borough respite services; emergency care and support that meets the needs of carers and the cared for and increased support for carers to reduced carer breakdown.

Shared priorities of Tower Hamlets, Newham and City and Hackney

Based on the review of the above local documents, here are some shared priorities across all three boroughs

- 3.5.10 Seamless Transition and Support for Young People:
- Establishing smooth and transparent pathways for individuals with learning disabilities during the transition to adulthood.
 - Prioritizing well-planned transitions and providing support from age 14 onwards.
 - Enhancing transition planning through collaboration between Children and Adult Services
- 3.5.11 Promoting Employment Opportunities:
- Challenging expectations, transforming attitudes, and promoting the inclusion of individuals with learning disabilities in the workforce.



- Supporting and engaging with the work of the Supported Employment Network.
- Creating paid job opportunities within local councils and member organizations.

3.5.12 Enhancing Health and Social Care Services:

- Improving access to health services and reducing health inequalities for individuals with learning disabilities.
- Increasing uptake of health checks and preventive health services.
- Strengthening diagnostic services and providing specialist health services for individuals with learning disabilities.

3.5.13 Creating Inclusive Communities:

- Fostering community awareness, inclusion, and valuing the contribution of individuals with learning disabilities.
- Enhancing access to community activities and social networks.
- Providing appropriate supported accommodation options and promoting settled living for individuals with learning disabilities.



4. Population

4.1 Key findings

- Recent reports indicate that an estimated 869,000 working-age adults in the United Kingdom have learning disabilities.
- Based on the Quality and Outcomes Framework (QOF) data as of April 2022, the prevalence of diagnosed learning disabilities in the London boroughs of Newham, Tower Hamlets, and City and Hackney ranges between 0.41% and 0.43% of the population.
- It is likely that the actual number of individuals with learning disabilities is significantly higher, as many remain undiagnosed or unknown to local authorities.
- The population and diagnostic estimates by Projecting Adult Needs and Service Information (PANSI) show that the prevalence of learning disabilities in adults is between 2.14% in Newham and 2.27% in Tower Hamlets. This is 2.21% in City and Hackney.
- Most of the learning disability population within these boroughs are adults aged 18 and above.
- The levels of learning disability severity differ across the boroughs; Newham has the highest rates of mild (178.43 per 1000 population), moderate (170.09 per 1000 population) and severe LD (145.08 per 1000 population) when compared to City and Hackney and Tower Hamlets. Tower Hamlets has the lowest rates across all three severities.
- There are demographic variations in the prevalence of learning disabilities among different ethnic groups. A higher proportion of people of Asian ethnicity have a learning disability.
- Most of the learning disability population across all three boroughs live in the most deprived areas.
- Despite the number of individuals with learning disabilities, the number of adults receiving long-term support from local authorities in the three boroughs remains below 3%, compared to a national average of 3.5%.
- By 2040, the number of people living in Tower Hamlets with a learning disability is expected to rise by 19%, 10% in Hackney while Newham is projected to experience a 6% increase. This can be attributed to enhanced diagnosis, increased visibility to local authorities, improved survival rates, better education access, and changing population demographics.



4.2 Recommendations

- We recommend ensuring a system where different organizations work together to accurately identify individuals with learning disabilities. This would involve establishing rules and guidelines (cross-organizational protocols) to reduce the chances of missing these diagnoses in the community. Accurate identification would also be ensured by including information about individuals with learning disabilities in both the NHS central registration database and all health and care record systems.
- Implement proactive planning by local services to accommodate the projected rise in the number of adults with learning disabilities and those reaching advanced age, while also addressing their unique needs, including the provision of diverse and adequate models of housing and support.
- It is crucial to prioritize the needs of individuals with learning disabilities in deprived areas by adopting a proactive approach to "poverty proof" learning disability services. This can be achieved by implementing targeted strategies, including comprehensive outreach programs, awareness campaigns, and partnerships with relevant agencies, to maximize income and benefits entitlements and promote social inclusion for individuals with learning disabilities and their families.

4.3 Learning disability population

- 4.3.1 There are a reported 1.5 million individuals living in the UK with learning disabilities, approximately 1.2 million of this population reside in England.(15,16) It is reported that there are 869,000 adults of working age with learning disabilities in the UK and 731,000 adults of working age with learning disabilities in England. Conversely, there are 351,000 children with a learning disability (0-17 years old) in the UK.(15–17)

4.4 Prevalence of learning disabilities in Newham, Tower Hamlets and City & Hackney

- 4.4.1 As per the QOF definition, in April 2022, 0.41% of Newham's total population is identified as having a learning disability. This is comparable to the prevalence rates in Tower Hamlets and City and Hackney, where 0.42% and 0.43% of the population, respectively, are reported to have a learning disability.(18) See figure 1 below.
- 4.4.2 In comparison to surrounding regions, the three boroughs exhibit a marginally lower prevalence of learning disabilities. The prevalence rate in these boroughs is somewhat lower than the national average of 0.50%, as stated by the NHS QOF 2019 data.(19) See figure 1 below.
- 4.4.3 Among those with a learning disability in Newham, 77.7% are aged 18 or above, with 9.2% falling in the age range of 14 to 17 years old. See figure 2 below.



4.4.4 Among those with a learning disability in City and Hackney there is a higher proportion of adults with a learning disability, with 85.3% aged 18 or above and 6.8% aged between 14 and 17. In Tower Hamlets, 82.6% are 18 or above, and 8.2% are aged between 14 and 17.(18) See figure 2 below.

4.4.5 The levels of learning disability severity differ across the boroughs; Newham has the highest rates of mild (178.43 per 1000 population), moderate (170.09 per 1000 population) and severe LD (145.08 per 1000 population) when compared to City and Hackney and Tower Hamlets. Tower Hamlets has the lowest rates across all three severities. See figure 3 below.

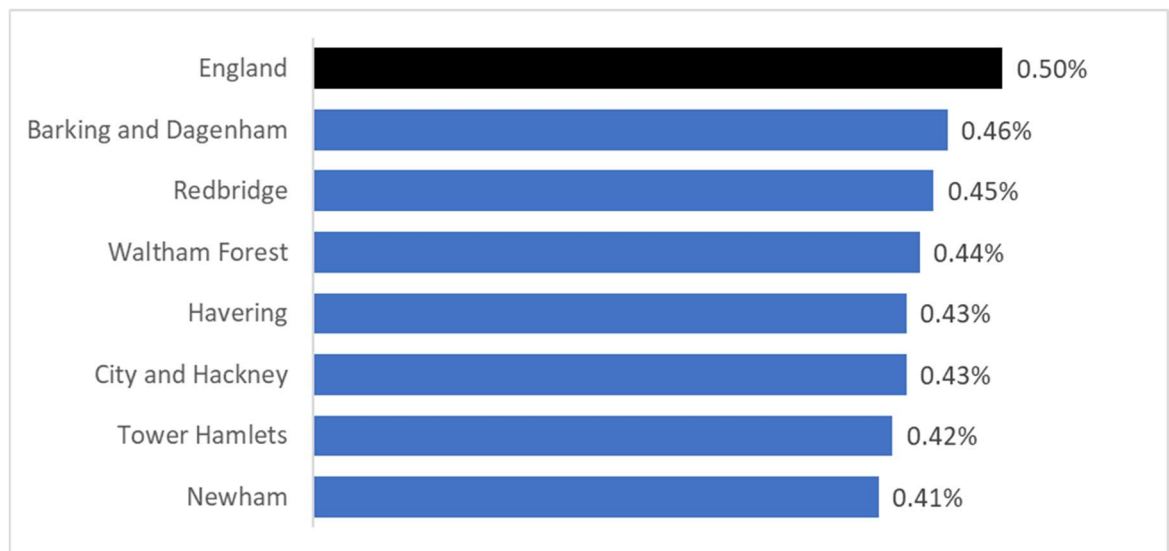
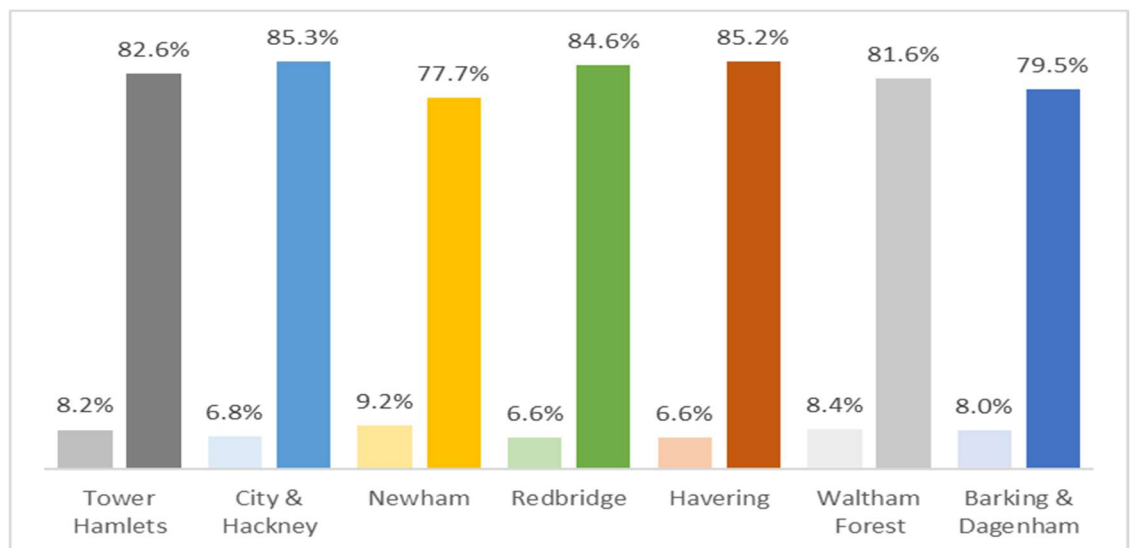


Figure 1: Prevalence of learning disabilities across the boroughs (QOF)



NB: Prevalence in children is represented by the shorter bars



Figure 2: Percentage of learning disabilities in children and adults out of the total learning disability population across the boroughs (QOF)

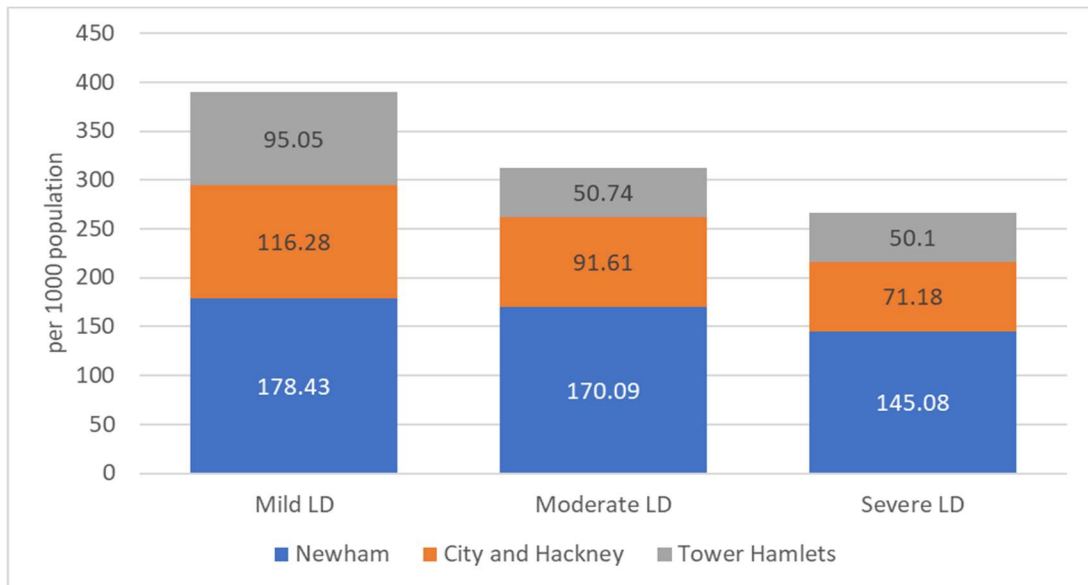


Figure 3: Severity of learning disabilities across the boroughs

4.4.6 The comprehensive dashboard developed by the North East London Integrated Care Board (NEL ICB) presents a marginally elevated and consistent prevalence of learning disabilities across the three boroughs as of April 2023. In Tower Hamlets, the prevalence rate stands at 0.44%, while Newham has a rate of 0.41% and City and Hackney 0.37%.⁽²⁰⁾ See figure 4 below.

4.4.7 It is important to note that these figures may not accurately reflect the true prevalence of learning disabilities, as many people are yet to receive a formal diagnosis, and existing GP records may be incomplete.

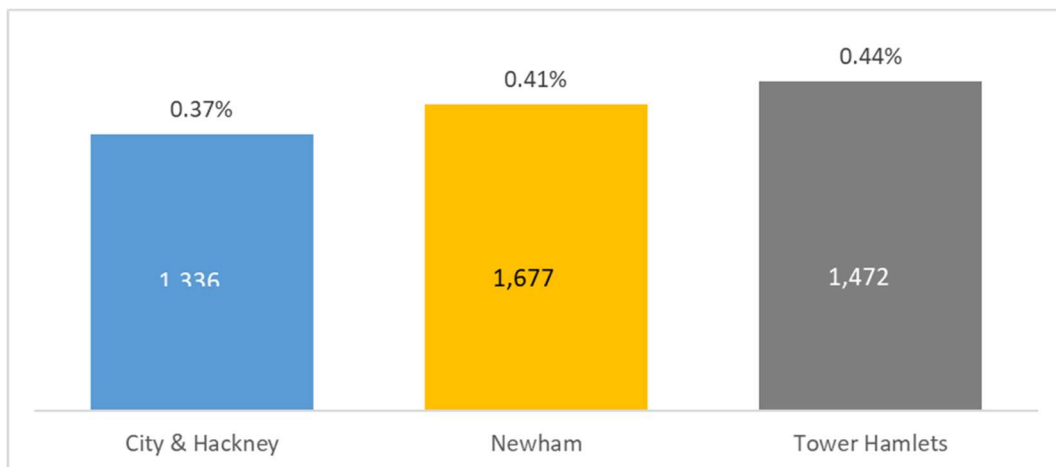


Figure 4: Prevalence of learning disabilities age 18-64yrs (NEL ICB)

4.4.8 Based on population and diagnostic estimates for 2022,⁽²¹⁾ the prevalence of learning disability for those aged 18-64 is predicted as 2.27% in Tower



Hamlets, 2.21% in City and Hackney and 2.14% in Newham.² The number of adults with a learning disability (aged 18-64) living in Tower Hamlets is 5846, City and Hackney is 4889 and Newham is 6005.

4.4.9 However, based on residents registered as having a learning disability as of April 2023, there were 1,472 individuals in Tower Hamlets who had a learning disability. This number was 1,336 in City and Hackney and highest in Newham with 1,677.(20) See figure 4 above.

4.5 Demographic profile of individuals with learning disabilities

Tower Hamlets

4.5.1 The prevalence of learning disabilities in Tower Hamlets by ethnic group is tabled below. Asian or Asian British individuals have the highest representation at 53.6%. This is followed by those of white ethnicity, with a representation of 30.1%, while individuals of Black or Black British ethnicity have a lower representation (9.8%). Other ethnic groups account for 3% of this cohort in Tower Hamlets. See table 1 below.

4.5.2 The learning disability population in Tower Hamlets is 61.2% male and 38.8% female.(20) See figure 5 below.

Table 1: Ethnicity of people with learning disabilities in Tower Hamlets

Ethnicity	Count	%
Asian or Asian British	837	53.6%
White	470	30.1%
Black or Black British	153	9.8%
Other Ethnic Groups	46	3.0%
Mixed	37	2.4%
Not Known	18	1.2%

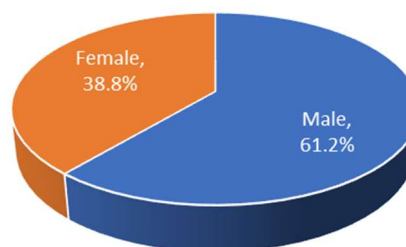


Figure 5: Gender of people with learning disabilities in Tower Hamlets

City and Hackney

4.5.3 In the City and Hackney area, individuals of White origin represent most of the learning disability population at 43.2%, followed by individuals of Black or Black British ethnicity at 30.2%. Individuals of other ethnicity represent 11.5%, and Asian or Asian British represent 9.3% of this population. See table 2 below.

4.5.4 Males are 59.9%, while females constitute 40.1% of the learning disability population in City and Hackney. See figure 6 below.

² Estimates derived from PANSI have been applied to Office for National Statistics (ONS) population projections.



Table 2: Ethnicity of people with learning disabilities in City and Hackney

Ethnicity	Count	%
White	610	43.2%
Black or Black British	426	30.2%
Other Ethnic Groups	162	11.5%
Asian or Asian British	131	9.3%
Mixed	59	4.2%
Not Known	23	1.6%

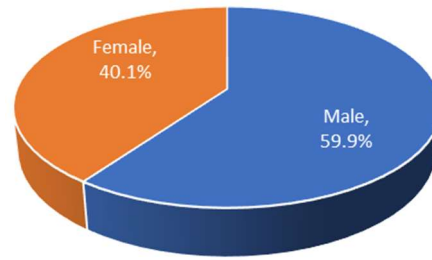


Figure 6: Gender of people with learning disabilities in City and Hackney

Newham

- 4.5.5 The learning disability population in Newham comprises 40.3% individuals of Asian or Asian British origin, 31.3% individuals of white ethnicity, and 21% individuals of Black or Black British ethnicity. Other ethnic groups represent 4% of this population. See table 3 below.
- 4.5.6 Within this population, males represent 61.9% while females represent 38.2%. See figure 7 below.

Table 3: Ethnicity of people with learning disabilities in Newham

Ethnicity	Count	%
Asian or Asian British	719	40.3%
White	558	31.3%
Black or Black British	375	21.0%
Other Ethnic Groups	72	4.0%
Mixed	47	2.6%
Not Known	14	0.8%

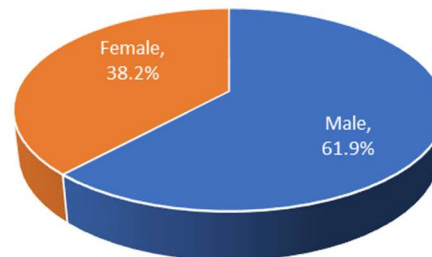


Figure 7: Gender of people with learning disabilities in Newham

Ethnic diversity of the population across the three boroughs

- 4.5.7 The 2021 census data highlights London as the most ethnically and religiously diverse region in England and Wales. In London, nearly two-thirds of the population identify with an ethnic minority group, a striking contrast to the North East where less than one in ten identify as such.(15) Newham, the most diverse borough in London, stands out with 69% of its residents being non-white, followed by Tower Hamlets and Hackney with figures exceeding 60% and 47%, respectively.(22) Notably, Tower Hamlets has the highest concentration of Bangladeshi or British Bangladeshi residents in any London Borough, making up 35% of the population. Additionally, Hackney hosts one



of Europe's largest Charedi Jewish communities, primarily residing in the borough's northeast, constituting 7% of the overall population.(23)

4.5.8 Research indicates that one's ethnic background can present barriers, potentially leading to less frequent utilization of specialized services within these demographics. Cultural perceptions about symptoms among ethnic minority patients may further hinder access, as their needs might be expressed differently. In the UK, ethnic minority groups experience challenges in accessing, engaging with, and achieving positive outcomes from mental healthcare services compared to the White British population.(24) This disparity significantly impacts the utilization of learning disability services, as ethnic minority communities exhibit lower engagement levels across the spectrum.

Age distribution of learning disability across the three boroughs

4.5.9 When considering all three boroughs collectively, much of the learning disability population falls within the age range of 15 to 39 years old, while the lowest numbers are observed among individuals over 70 years old.(20) This could be attributed to factors including reduced life expectancy for people with learning disabilities and improved support systems and healthcare which has enabled better identification, intervention and support from a younger age.

4.5.10 The prevalence of learning disability tends to increase with age from birth until the age group of 20-24 years old. From the age group of 25-29, the prevalence of learning disability appears to decrease until the age group of 50-54. It then slightly increases in the age group of 55-59 and continues to decrease until the age group of 85-89.(20) See figure 8 below.

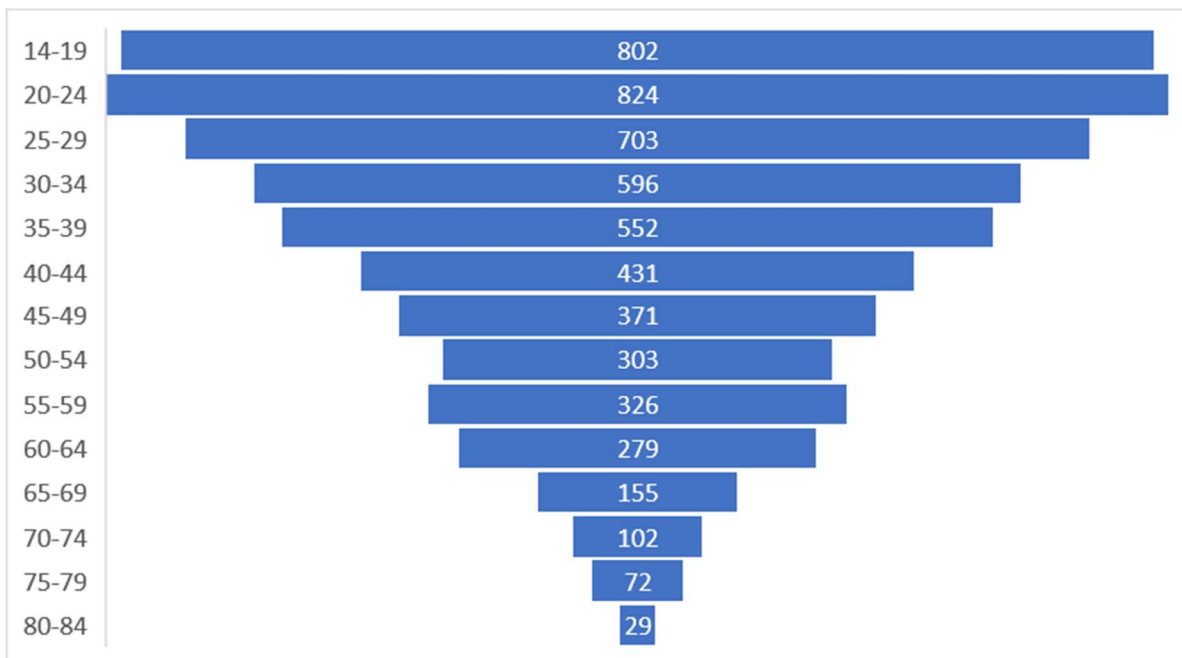


Figure 8: Age distribution of learning disability across the three boroughs combined



4.6 Deprivation

- 4.6.1 Recent evidence has shown that disability and poverty often coexist.(25) This is typically due to two main factors: high rates of unemployment and increased living costs associated with disability conditions.(26) In 2018, research indicated that there were around 6.6 million families in the UK living in poverty, all of which included at least one disabled adult.(27) According to the Institute of Health Equity, sufficient improvements in life expectancy for individuals with learning disabilities require targeted efforts to address poverty, inadequate housing, and discriminatory practices.(28)

Tower Hamlets

- 4.6.2 A high proportion of patients (70%) on the Learning Disability register for Tower Hamlets, live within the second and third most deprived neighbourhoods. There is a small catchment of patients (n=21) who live within more affluent parts of the borough (third least deprived neighbourhood) thus showing that patients are widely distributed.(20) See figure 9 below.

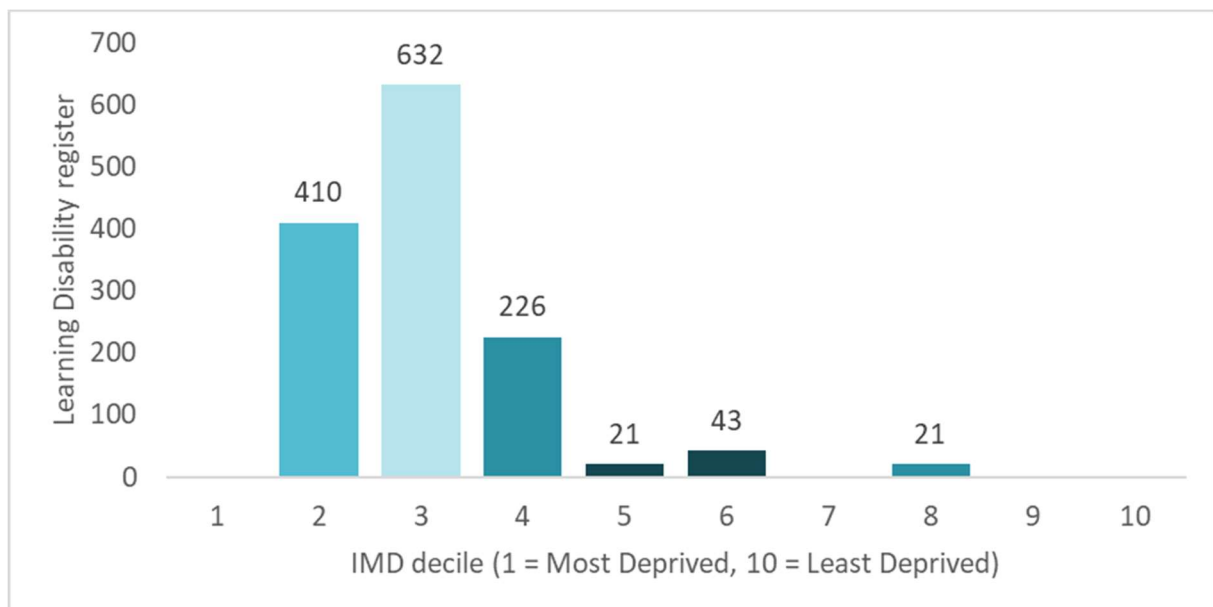


Figure 9: Deprivation distribution of learning disability across Tower Hamlets

City and Hackney

- 4.6.3 Across City and Hackney, 21% (n=274) of patients on the Learning Disability register live in the most deprived part of the borough. A further 69% (n=927) live within the second and third most deprived neighbourhoods.(20) See figure 10 below.



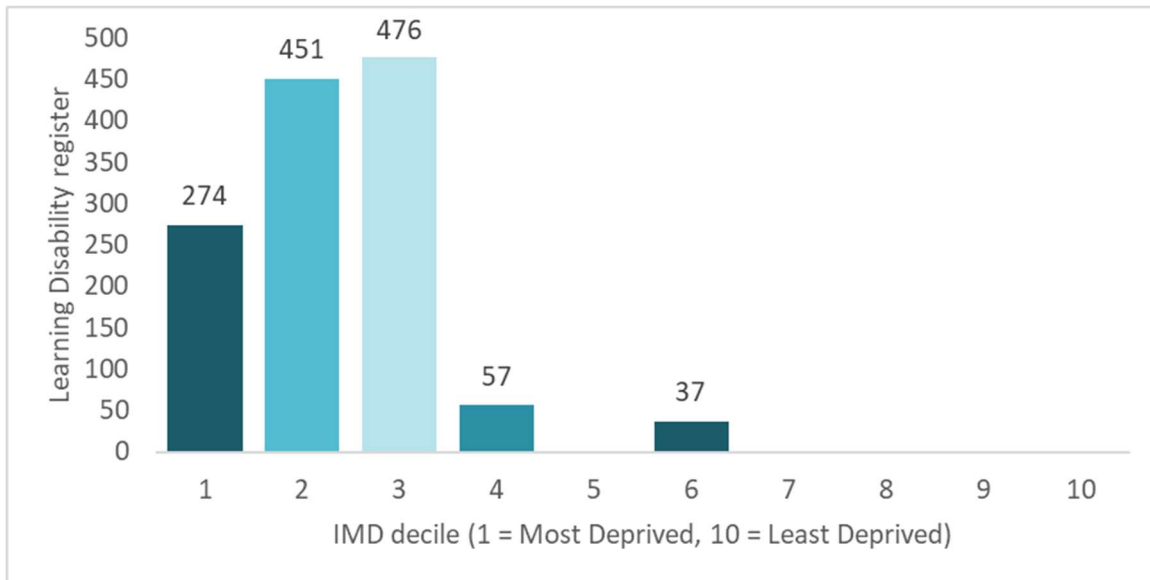


Figure 10: Deprivation distribution of learning disability across City & Hackney

Newham

4.6.4 Learning Disability registered patients in Newham live in the most deprived areas.(20) See figure 11 below.

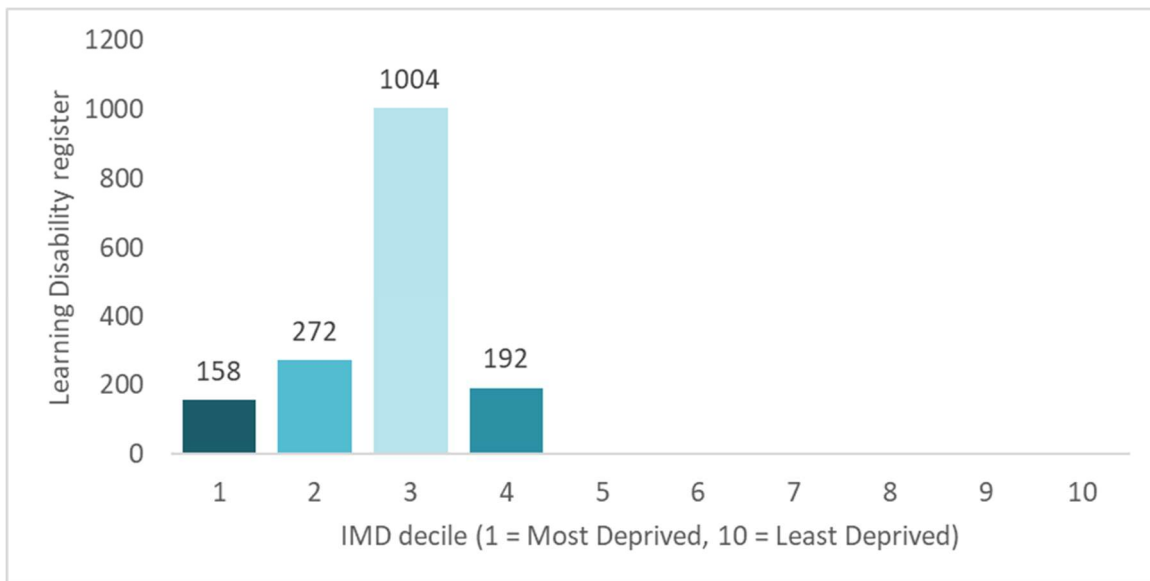


Figure 11: Deprivation distribution of learning disability across Newham

4.7 Adults with learning disability receiving long-term support from local authorities

4.7.1 Based on Fingertips data (2020)(19), the prevalence of adults with learning disabilities receiving long-term support³ across the three boroughs is 2.97%

³ This refers to working age adults that are known to the council with a primary support reason of learning disability support who received long term support during the year in the settings of residential, nursing and community but excluding prison.



in Tower Hamlets, 2.75% in City and Hackney and 2.83% in Newham. This is lower than the London average of 3.01% and the national average of 3.46%. This suggests that many individuals with learning disabilities may not be receiving the necessary support and resources needed to live independently or access appropriate healthcare services across the three boroughs.

4.8 Changing numbers with learning disabilities over time

Factors influencing the number of people with learning disabilities

- 4.8.1 Across most countries, the life expectancy of people with learning disabilities is increasing, leading to a larger aging learning disability population. There is also a growth in the number of younger adults with learning disabilities and care needs. Research indicates that the proportion of younger adults reporting a learning disability increased from 14% in 2007/08 to 18% in 2017/18, with a corresponding 35% increase when combined with population growth.(29)
- 4.8.2 There are multiple factors contributing to this significant growth in the number of people with learning disabilities in younger age groups, including better diagnosis and improved visibility by local authorities compared to previous decades. Others include improved survival rates, improved access to education and support services and changes in population demographics.

Expected change in the number of adults with learning disabilities

- 4.8.3 The prevalence of the learning disability population across Tower Hamlets, Newham, and City and Hackney is increasing. Based on data from PANSI, in 2020, 5,846 people aged 18-64 years living in Tower Hamlets were estimated to have a learning disability. This number is predicted to rise to 6,982 by 2040, representing a 19% increase. Similarly, by 2040, the number of people living in Hackney with a learning disability is expected to rise by 10%, while Newham is projected to experience a 6% increase.(21) See figure 12 below.
- 4.8.4 In 2020, the age group with the predicted highest number of individuals with a learning disability was 25–34-year-olds. This is predicted to remain the case for all three boroughs for the foreseeable future.
- 4.8.5 Despite the 25-34 age group having a higher number of people with a learning disability throughout the next two decades, the age group with the largest net change from 2020 to 2040 is the 55-64 population. For instance, in 2020, there were 501 people with a learning disability in the 55-64 age group in Tower Hamlets out of a total of 5,846 people. By 2040, this figure is expected to almost double, with an 89% increase.
- 4.8.6 This shift can also be observed in Newham (37%) and City and Hackney (44%), with the greatest net change in the number of people with a learning disability occurring in the 55-64 age group, although not to the same extent as in Tower Hamlets.(21) See figure 13 below.
- 4.8.7 Despite the 55-64 age group representing the smallest proportion of people living with a learning disability across the three boroughs, the increasing



prevalence and risk of comorbidities place additional importance on resource provision to ensure that the future needs of this group are adequately met.

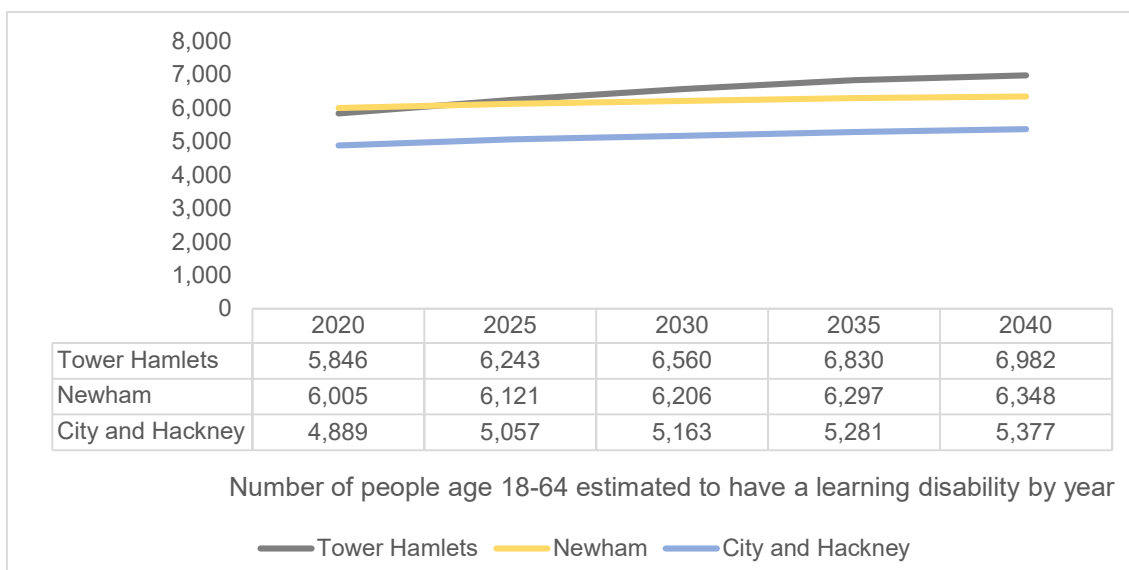


Figure 12: Estimated future population change for people aged 18-64 years with a learning disability by borough between 2020-2040

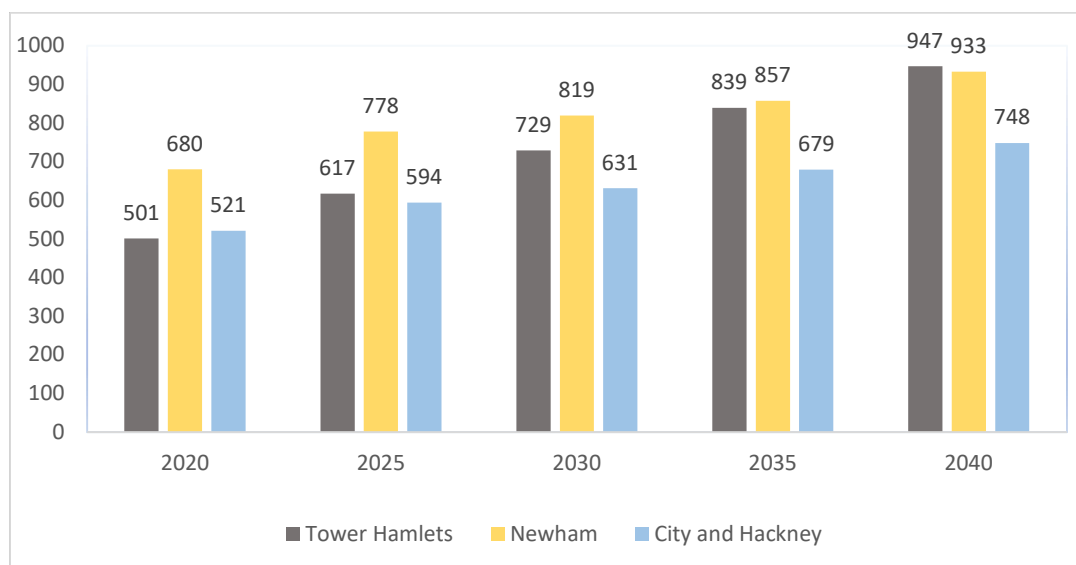


Figure 13: Estimated future population change for people with a learning disability aged 55-64

Total population aged 18-64 predicted to have a moderate to severe learning disability

4.8.8 The total number of individuals aged 18-64 years with moderate to severe learning disabilities is expected to increase across the three boroughs. In Tower Hamlets, the size of this group is projected to rise from 1,337 recorded in 2020 to 1,602 in 2040, representing a 20% increase. Newham and City and Hackney are also expected to experience a rise in the number of people with moderate or severe learning disabilities, increasing by 6% and 10%, respectively.(21)



Total population aged 18-64 predicted to have a severe learning disability

- 4.8.9 When examining the increasing prevalence of severe learning disabilities from 2020 to 2040, it is predicted that this population in Tower Hamlets will increase by 18%, while City and Hackney are expected to see a 10% increase. Unfortunately, data for the increasing prevalence of severe learning disabilities within the borough of Newham was not available. The age group with the greatest estimated net change in the prevalence of severe learning disabilities is the 55-64 age group for all three boroughs. However, the age group with the highest actual number of individuals with severe learning disabilities by 2040 is the 25-34 group.(21)

Total population aged 18-64 with a learning disability predicted to display challenging behaviour

- 4.8.10 In the next two decades, the number of individuals aged 18-64 years with learning disabilities prone to demonstrating challenging behaviour is expected to increase by 20% in Tower Hamlets, 6% in Newham, and 9% in City and Hackney. Within this group, those aged 55-64 years, followed by the 45-54 age group, are most likely to experience this change.(21)

Summary of expected changes in people with learning disabilities

- 4.8.11 Tower Hamlets is projected to experience the most significant growth in its learning disability population over the next two decades, and within that, the age group of 55-64 is expected to exhibit the highest net change in population over the same time period.
- 4.8.12 Among the three boroughs, Tower Hamlets is also expected to see the greatest population increase in those predicted to have moderate and/or severe learning disabilities and in those predicted to display challenging behaviour. This might be so because Tower Hamlets is experiencing larger population growth or influx of people including those with learning disabilities. Other reasons might include better identification individuals with learning disabilities and/or better access to specialised services.
- 4.8.13 There is a clear age-specific increase in prevalence, particularly among the 55-64 age group, which can be attributed to several factors, including increased survival rates among young people with severe and complex disabilities and reduced mortality among older adults with learning disabilities due to improvements in healthcare. As such, specific preparations and provisions need to be considered for this age group over the next two decades, with increasing resources required at a much greater rate than in previous decades.



5. Health of people with learning disabilities

5.1 Key findings

- Comorbidities common among those with learning disabilities include cardiovascular diseases (CVD), obesity, diabetes, dysphagia, cancer, epilepsy, mental health, respiratory disease, Sexually Transmitted Infections.
- Majority (40%) of individuals (aged 14 and over) with learning disabilities across the three boroughs have a coexisting condition. Of those with a coexisting condition, a substantial proportion, ranging from 45% in Tower Hamlets to 58% in Newham, have a cardiovascular disease. This is 11% for the general England population.
- Obesity as a co-existing condition has also been reported in this population. Of those with a coexisting condition, a substantial proportion, ranging from 10% in Newham to 14% in City and Hackney are obese. This is compared to the general England population at 9.7%

5.2 Recommendations

- The early identification of co-morbidities in individuals with learning disabilities can present a challenge. It is important to involve families, friends, and caregivers in decision making and in the process of identifying and addressing these health needs. This can be through collaborative care planning, health assessments, health information and education and support groups.
- Given that a significant proportion of individuals with learning disabilities have a co-morbidity, it is crucial to emphasise the NHS key working principle of assigning a named healthcare coordinator for those with complex healthcare needs. This approach ensures that individuals receive comprehensive and coordinated care to address their diverse health requirements.
- The accuracy and comprehensiveness of data pertaining to comorbidities among individuals with learning disabilities raise concerns. To address this issue, it is imperative to focus on improving data collection, monitoring, and overall quality in relation to co-occurring conditions among this demographic.

5.3 Life expectancy and mortality of people with learning disabilities

- 5.3.1 Research indicates that women with learning disabilities have a significantly lower life expectancy than those in the general population, with an average reduction of 17 years.(30) Similarly, men with learning disabilities experience



an average reduction of 14 years compared to men without learning disabilities.(30)

- 5.3.2 Studies highlight material deprivation, limited use of healthcare services, and poor health-related behaviours as key factors that contribute to the connection between learning disabilities and reduced life expectancy.(31,32) Moreover, research shows that 42% of deaths among individuals with learning disabilities are premature, with the most common causes attributed to difficulties with diagnoses or treatment.(33)

5.4 Common comorbidities of people with learning disabilities

Cardiovascular disease (CVD)

- 5.4.1 Research shows that people with learning disability are at greater risk of a range of physical and mental health disorders than the general population.(34) CVD affects around seven million people in the UK and is a significant cause of disability and death. It is also responsible for one in four premature deaths in the UK and accounts for the largest gap in health life expectancy in the general population.(34)
- 5.4.2 In the evaluation of the three boroughs, cardiovascular disease (CVD) emerged as the most prevalent co-existing condition. Nevertheless, this observation could be attributed to the fact that various types of CVD were collectively grouped together.
- 5.4.3 Specifically, within those with learning disabilities, the prevalence of CVD diagnoses ranged from 45.2% in Tower Hamlets to 57.9% in Newham. The prevalence of CVD among adults with learning disabilities in City and Hackney is 45.3%.(20) According to the British Heart Foundation the prevalence of CVD in the England general population is about 11%.(35)
- 5.4.4 Epidemiological research on age-related rates of CVD in people with learning disabilities is scarce and inconclusive.(36) However the primary care records of approximately 15,000 adults with learning disabilities in England revealed that compared to the general population, adults with learning disabilities have a lower likelihood (about 35% lower) of having a specific heart condition called ischemic heart disease. However, they have a higher likelihood (about 126% higher) of experiencing heart failure, and their chances of having a stroke or transient ischemic attack are also higher (about 74% higher).(36)
- 5.4.5 It is worthy of note that further analysis and investigation may be required to disaggregate findings based on the different cardiovascular diseases— ischemic heart disease, cerebrovascular disease, peripheral artery disease, and aortic atherosclerosis—and to develop effective interventions for prevention and management.(20) See figures 13-15 below.

Obesity

- 5.4.6 Data from GPs across England provides insight into the prevalence of excess weight in adults aged 18 and above with learning disabilities. Specifically, 27% of people with learning disabilities were classified as overweight, compared to 31.8% of people without a learning disability. However, there is a higher proportion of individuals classified in the more



severe category of being "obese" among people with learning disabilities, with 37% of individuals being classified as obese compared to 30.1% of individuals without learning disabilities.(35)

- 5.4.7 For many years, it has been acknowledged that individuals with learning disabilities have a higher likelihood of being overweight or obese compared to the general population. This is often due to a range of factors including medication with cardiometabolic side effects, poor dietary habits and a lack of physical activity. Unfortunately, this increased risk can lead to a range of health and social challenges.(37) Obesity significantly increases an individual's risk for numerous health issues, such as heart disease, hypertension, stroke, diabetes, various forms of cancer, and mobility difficulties.(37)
- 5.4.8 Obesity as a co-existing condition has been reported in the learning disability population across the three boroughs, with an incidence ranging 10.1% in Newham to 14.4% in City and Hackney.(20) The prevalence among people with learning disabilities in Tower Hamlets is 11.9%. See figures 14-16 below.
- 5.4.9 The prevalence of obesity, as derived from the QOF data, presents a more comparable perspective with the data from the three boroughs, as this data source focuses on all patients aged 18 or above registered with a GP practice. According to the QOF data, the prevalence of obesity among adults aged 18 and above stands at 9.7% in England.(37) This is lower when compared to the prevalence across the learning disability population in the three boroughs.

Diabetes

- 5.4.10 Diabetes as a co-existing condition has been reported in the learning disability population. However, data was only available for Tower Hamlets with a prevalence of 0.6% and 0.4% in City and Hackney among individuals with learning disabilities.(20) See figures 14-16 below.
- 5.4.11 Data from Diabetes UK shows that the prevalence among the general population is 7% in Tower Hamlets, 5.67% in City and Hackney, and 8.57% in Newham.(38)
- 5.4.12 The prevalence of diabetes based on QOF data is more comparable to the data from the boroughs as the data source is based on patients aged 17 or over registered with a GP practice. Based on this data, the prevalence of diabetes for those aged 17 and above in the general England population is 7.3% and has been on the increase since 2012.(39) The prevalence in the general London population is around 6.8%.
- 5.4.13 In comparing the prevalence of diabetes among the general population (aged 17 and above) in England, London, and the three boroughs to the prevalence among individuals with learning disabilities in these boroughs, it becomes evident that the prevalence is significantly higher than in Tower Hamlets (0.6%) and City and Hackney (0.4%).
- 5.4.14 Data for Newham was unavailable. As noted, there are issues with the quality of the existing data, which affects accuracy of these comparisons.



Dysphagia

- 5.4.15 Dysphagia refers to difficulty in swallowing and can be caused by different factors. Some individuals may have trouble swallowing certain types of food or liquids, while others may not be able to swallow at all. Dysphagia can occur at any stage of the eating, drinking, and swallowing process.(40)
- 5.4.16 Although it is widely accepted that people with learning disabilities are more likely to have dysphagia than the general population, there is currently no reliable data on the prevalence of dysphagia in people with learning disabilities. Historical estimates have ranged from 36% based on speech and language therapy caseloads to over 70% based on inpatient populations. However, recent studies have suggested that about 15% of adults with learning disabilities require support with eating and drinking, and 8% of those known to learning disability services have dysphagia. It is important to note that these figures may be an underestimate, as dysphagia can often be overlooked, particularly when it is mild.(40)
- 5.4.17 Prevalence of dysphagia among the learning disability population was 3.6%, 5.1% and 4% in Tower Hamlets, City and Hackney, Newham respectively.(20) See figures 14-16 below.

Epilepsy

- 5.4.18 Research shows that individuals with learning disabilities have a higher prevalence of epilepsy compared to the general population. About one in three people (32%) with mild to moderate learning disabilities also have epilepsy. Furthermore, the likelihood of having epilepsy increases with the severity of the learning disability. In contrast, around one in five people (20%) with epilepsy also have a learning disability.(41)
- 5.4.19 Based on QOF data, the prevalence of Epilepsy in England for those aged 18 and above is 0.8% and has remained so for over 10 years.(39)
- 5.4.20 In contrast, the prevalence of epilepsy among individuals with learning disabilities in the three boroughs demonstrates a higher rate. Specifically, the prevalence reaches 6.7% in Tower Hamlets, 6.1% in City and Hackney, and 3.5% in Newham.(20) See figures 14-16 below.

Respiratory Disease

- 5.4.21 Based on research, people with learning disabilities experience higher rates of respiratory disease, gastrointestinal problems and endocrine disorders.(34)
- 5.4.22 Research has shown that individuals with learning disabilities are at a higher risk of experiencing asthma, chronic obstructive pulmonary disease (COPD), and upper respiratory tract infections than the general population.(42) Furthermore, studies have reported that individuals with learning disabilities tend to have poorer measured lung function, which may contribute to a higher prevalence of respiratory conditions.(42)
- 5.4.23 A 2021 study conducted by the Scottish Learning Disabilities Observatory has revealed that individuals with learning disabilities face a significantly higher risk of premature death from respiratory disease compared to the



general population. The study, which analysed data from over 90,000 people with learning disabilities and 27,394 deaths, found that individuals with learning disabilities are nearly 11 times more likely to die prematurely from respiratory disease compared to those without learning disabilities. The findings of the study are based on a review of literature published over the past 24 years, which highlights the significant health disparity faced by individuals with learning disabilities.(43)

- 5.4.24 Across the three boroughs, prevalence of respiratory diseases among those with learning disabilities was 7.2% in Tower Hamlets, 2.6% in Newham and 6.9% in City and Hackney.(20) See figures 14-16 below.
- 5.4.25 In the general England population, approximately one in five people are affected by respiratory diseases, making it the third leading cause of death in England after cancer and cardiovascular disease.(44) The most common respiratory diseases that contribute to mortality rates include lung cancer, pneumonia, and chronic obstructive pulmonary disease (COPD). These conditions are responsible for a significant proportion of respiratory-related deaths in England.(44)
- 5.4.26 Further investigations and analysis are necessary to gain a better understanding of respiratory diseases among individuals with learning disabilities. It is essential to disaggregate the data and examine different types of respiratory diseases, including bronchitis, asthma, pulmonary hypertension, COPD, pneumonia, and others. By doing so, we can identify specific risk factors and develop targeted prevention and management strategies.

Sexually Transmitted Infection

- 5.4.27 There is little information available estimating the prevalence of sexual health issues amongst people with learning disabilities.(45) However, data from the boroughs for the prevalence of sexually transmitted infections for people with learning disabilities show a prevalence of 2.6% in Tower Hamlets and 0.9% in Newham.(20) There was no data available for City and Hackney.

Mental Health

- 5.4.28 Mental health problems encompass a range of conditions that can affect individuals, including common mental disorders such as depression and anxiety disorders, as well as more severe conditions like psychoses (e.g., schizophrenia and bipolar disorder), dementias, eating disorders, and alcohol and substance misuse. Other mental health problems include attachment disorders, sexually inappropriate behaviour, and various neuro-developmental conditions.
- 5.4.29 According to population-based estimates, individuals with learning disabilities in the UK experience significantly higher rates of mental health problems than those without learning disabilities. Approximately 40% of adults with learning disabilities (28% if problem behaviours are excluded) and 36% of children and young people with learning disabilities (24% if problem behaviours are excluded) experience mental health problems at any given time.



- 5.4.30 These rates are much higher than the rates observed in the general population. In addition, data from GP records in England in 2017/18 suggest that the number of patients with a recorded learning disability who had a GP diagnosis of severe mental illness was 8.3%, compared to 0.9% of individuals without learning disabilities.(46)
- 5.4.31 Individuals with learning disabilities have a greater risk of developing psychological disorders in comparison to the general population.(3) For this population, comorbidities often arise alongside mental illnesses thus making diagnosis difficult; particularly among those with more severe intellectual impairments.(47) Little is known about how learning disabilities affect mental health amongst young populations, which is surprising given that this period of life is where learning disabilities often arise.(48)
- 5.4.32 The prevalence of a mental illness in the learning disability population for the three boroughs is 1.4% in Tower Hamlets, 0.9% in City and Hackney and 0.5% in Newham.(20) See figures 14-16 below.
- 5.4.33 Based on comparative data from across the UK,(49) the observed prevalence across the three boroughs appears to be low, which could potentially indicate issues with data quality. There is need for more investigation and analysis on the different mental disorders listed above to better understanding and improve preventative and rehabilitative measures for this cohort.

Substance Misuse

- 5.4.34 Data from the Crime Survey for England and Wales indicates that around 9.2% of adults aged 16 to 59 years (equivalent to approximately 3 million adults) and approximately 18.6% of adults aged 16 to 24 years (equivalent to approximately 1.1 million adults) reported drug use, based on the data collected until June 2022.
- 5.4.35 Data from the NEL ICB was available for only Tower Hamlets and shows a substance misuse prevalence of 0.4% in the learning disability population.(20) See figure 14.

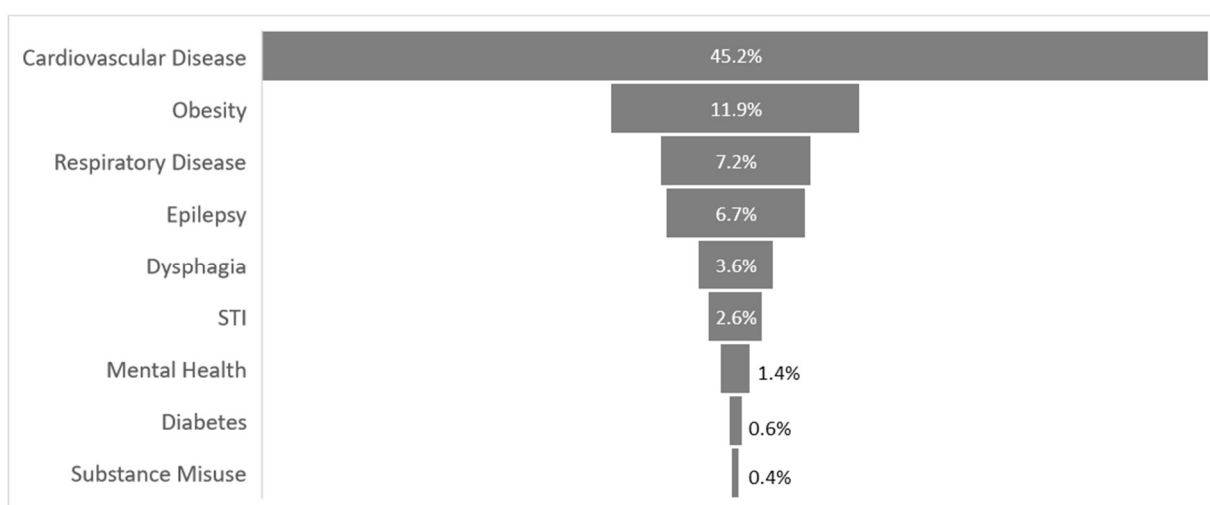


Figure 14: Proportion of patients on GP learning disability registers in Tower Hamlets with each comorbidity



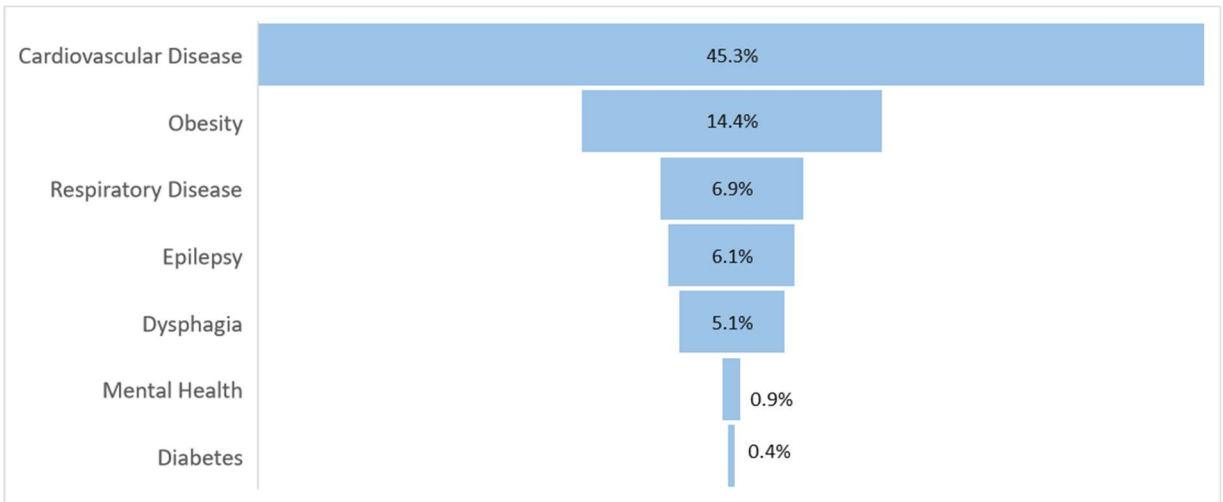


Figure 15: Proportion of patients on GP learning disability registers in City and Hackney with each comorbidity

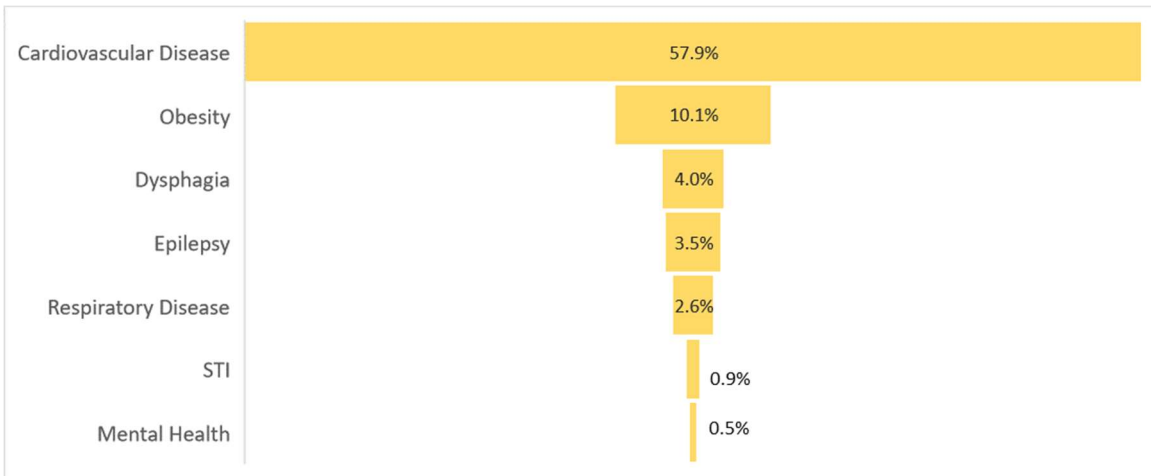


Figure 16: Proportion of patients on GP learning disability registers in Newham with each comorbidity



Table 4: Summary of prevalence of comorbidities compared to the general population

Comorbidity	Prevalence within those with learning disability (%) - NEL ICB			Prevalence in the general population (%)
	City and Hackney	Tower Hamlets	Newham	England
Cardiovascular Disease	45.3	45.2	57.9	11
Obesity	14.4	11.9	10.1	9.7
Diabetes	0.4	0.6	-	7.3
Dysphagia	5.1	3.6	4	-
Epilepsy	6.1	6.7	3.5	0.8
Respiratory Disease	6.9	7.2	2.6	20
STI	-	2.6	0.9	-
Mental Health	0.9	1.4	0.5	28
Substance misuse	-	0.4	-	9.2*, 18.6^

**This is for adults aged 16-59 years. ^This is for adults aged 16-24 years.*

NB: references for these figures are in the main body of the document.

Loneliness and boredom

- 5.4.36 According to a recent study conducted by the learning disability charity Mencap, individuals with learning disabilities in the UK are currently experiencing a mental health crisis due to the pandemic. The study showed that 88% of families and caregivers reported that their loved ones always or very often felt sad, while 82% felt lonely due to the limited ability to leave their homes.
- 5.4.37 In addition, almost a third (32%) of individuals were experiencing mental health issues such as low mood and low self-esteem. Unfortunately, 27% of those struggling with mental health problems were unaware of where to seek support, and there is still a common misconception that learning disability is a mental health condition in society.(50)
- 5.4.38 During the focus group discussions, service users across the three boroughs were asked how they spent their week. Young adults living with parents, when not at a day centre or college, said they went out with family members shopping or to visit other family or to places of worship. Variety was limited and some services had funding cut so day centres could only be accessed three days per week.
- 5.4.39 It was difficult to ascertain what happened on the other days. Some service users reported enjoying taking walks, while the majority reported being very inactive and spending most of their time sitting watching TV.

“One service user when asked what she did on other days said, I sit in my room and cry”



5.4.40 Most participants reported having very few if any friends outside of staff and family members directly involved in their care and that they were very lonely.



6. Health service use

6.1 Key findings

- There are challenges for the learning disability population in accessing health care services appropriately. This can be related to communication, inadequate facilities to meet their needs, rigid access procedures, lack of cultural understanding, lack of learning disability awareness and staff training, information inaccessibility (worsened by digital poverty). All of these can lower the uptake, coordination and accessibility of health services for the learning disability population.
- People with learning disabilities are more likely to attend hospital for something that could have been dealt with by a GP, and/or are more likely to take unnecessary medication(s).
- The learning disability population are less likely to attend regular health checks and national screening programmes when compared to the general population.
- Individuals with “borderline” learning disability often fall through the gaps in service without a system for monitoring individuals who have a high level of need but do not meet the eligibility criteria.

6.2 Recommendations

- It is of utmost importance that individuals with learning disabilities receive necessary assistance in accessing mainstream services through the provision of reasonable adjustments. Furthermore, it is advisable to consider the utilisation of specialized services as a supplementary measure to the existing services, to cater to the unique and individualized needs of each person with a learning disability.
- GP surgeries and hospitals should invest in training and in diversifying and improving their communication and general offer to better accommodate the needs of their patients and visitors with learning disabilities. Examples of which include alternatives to online booking, easy-read health information documents, accessible physical environments, and education for practice staff.
- As recommended by the Health and Care Act 2022, registered health and social care professionals are mandated to undertake training in learning disabilities and autism. The training should be considered a priority for all staff members to enhance their understanding and awareness of the intricacies associated with learning disabilities.
- Promote the use and value of hospital or health passports to support workers, carers and GPs. Provide support to ensure passports remain up-to-date and comprehensive.



- NHS NEL should aim to develop an improved mechanism for supporting and monitoring people that do not meet the eligibility criteria for learning disability support but have a high level of need to avoid these individuals 'falling through the gap.'

6.3 Access to healthcare

- 6.3.1 The accessibility and utilisation of healthcare services in the UK pose a persistent challenge for individuals with learning disabilities. Empirical research suggests that the underlying factors contributing to this challenge include poor communication channels, insufficient infrastructure, inflexible procedures, and a dearth of cultural sensitivity when engaging with those from ethnic minority backgrounds who have learning disabilities.(49)
- 6.3.2 These factors contribute towards a negative perception of healthcare professionals and services which further discourage this population from requesting and then receiving treatment. This negative perception further compounds the challenge faced by individuals with learning disabilities, discouraging them from seeking and receiving necessary treatment.
- 6.3.3 Consequently, this population is more prone to attending hospitals for conditions that could have been addressed by a GP, and/or taking excess medication when it is not necessary. These inequalities underscore the urgent need for multiple adaptations within UK healthcare services to ensure adequate accessibility for vulnerable populations, including individuals with learning disabilities.(49)

6.4 Digital poverty

- 6.4.1 The issue of digital poverty and exclusion is on the rise, particularly among individuals with learning disabilities. This is frequently due to a lack of access to digital devices and internet connectivity, as well as limited digital literacy.(51) Research indicates that learning disabilities play a significant role in determining digital exclusion.(51) An estimated 35% of individuals with learning disabilities lack essential digital skills, compared to 21% for the general population.(52) Such disparity presents multiple challenges for individuals with learning disabilities in their daily lives.
- 6.4.2 Stakeholder interviews for this health needs assessment; have revealed that a significant amount of information related to health needs and GP appointments is available exclusively online, which can present challenges for individuals with learning disabilities who often face digital poverty and exclusion. According to one interviewee, there is an evident lag in digital inclusion efforts and accessibility for individuals with learning disabilities.

6.5 Views of individuals with learning disabilities and their carers

- 6.5.1 The focus groups hosted by PHAST in the tri-borough area have gathered insights from individuals with learning disabilities and their caregivers regarding the challenges they face in accessing healthcare services.
- 6.5.2 The findings highlight the difficulties patients with learning disabilities face in accessing healthcare services through automated caller pathways and online



booking systems. They emphasize the need for direct access to healthcare professionals to address patient concerns effectively.

“It is difficult to get through to speak to a GP and then see a GP. They would be asked to call back at a particular time and that was a challenge.”

“I ring 111 because it is easier to get through to someone who will speak to you directly without paperwork or navigating automated caller pathways.”

- 6.5.3 There is significant impact of lengthy referral wait times on patient outcomes, including mobility deterioration and potentially fatal consequences, as reported by carers and individuals with learning disabilities.

“One of my clients had to wait six months for an appointment with a specialist, by which time she had sadly already died from the disease.”

“My client with osteoporosis had failed to receive timely physio support, leading to a rapid deterioration of her mobility, until eventually, she became completely bed bound.”

- 6.5.4 There are various challenges faced by patients seeking dental services. The fear of experiencing pain and the perception of high costs associated with dental services can discourage patients from seeking necessary care. Patients may also face uncertainty regarding the availability of free dental services and experience difficulties accessing dental appointments during times of crisis, such as the COVID-19 pandemic.

“It is sometimes unclear under what circumstances dental services are free.”

“There were difficulties getting dentist appointments during the pandemic.”

- 6.5.5 Challenges faced by patients accessing hospital care, include long waiting times, lack of privacy and poor treatment by staff. Additionally, patients and their caregivers may experience poor communication and coordination during the discharge process, leading to delayed or poorly timed discharges that can adversely impact patient well-being.

“Hospitals routinely fail to communicate and coordinate discharges; often holding the client longer than expected or dropping them off late at night when it is difficult to support them.”

“I was spoken to rudely and asked for private information in an open space causing significant distress.”



6.6 Views of service providers

- 6.6.1 In-depth interviews were held across NHS ELFT and with service providers and professionals across the three boroughs of Tower Hamlets, City and Hackney and Newham.
- 6.6.2 Interviewees reported a good level of collaboration and shared services across the three boroughs which helped meet the complex needs whilst improving inclusivity of the growing learning disability population.

“One of our key partnerships is that with our paediatric colleagues, and we are in the process of developing this partnership. Across the NEL CCG, we use a lot of the same services, and there is also ELFT conferences where everyone gets together and gets an opportunity to meet colleagues in other teams. I think that is very strong.”

- 6.6.3 Most interviewees in the three boroughs noted that health services were less accessible for people with learning disabilities when compared to the general population of the UK. This lack of accessibility was found to be linked with difficulties in facilitating better collaboration across the boroughs.

I think the issue is if you want to share physical resources that require collaboration by the commissioners. That sometimes proves a bit harder as each borough has its own pressures, their own budgetary issues.

- 6.6.4 Interviewees across the three boroughs reported a lack of adequate treatment provision for individuals with mild to moderate learning disabilities which, if left unattended, may result in more serious health conditions.

“Where we have a real issue is where you've got people coming through with a milder learning disability or someone under 18 who has not been formally diagnosed and they're not seen as somebody who needs a huge amount of planning. Also, depending on the borough, they may not quite meet thresholds for learning disability team services when they turn 18, and then they fall in this giant gap.”

- 6.6.5 Certain interviewees emphasized that there is a lack of comprehension regarding learning disabilities both in society and healthcare settings. This creates a considerable obstacle to treatment and a shortage of services for this specific population.

“There is definitely a big gap when it comes to GPs recognizing the level of need when they refer people onto hospitals” and “we don't have specialist learning disability beds in ELFT, so people access mainstream care”



Newham

- 6.6.6 In Newham, service providers demonstrate a commendable ability to meet the complex needs of individuals with learning disabilities in a collaborative, efficient, and adaptable manner. Key factors contributing to their success include specialized training in Positive Behaviour Support (PBS), an emphasis on holistic approaches, and a dedicated team of practitioners with expertise in the field.

“PBS virtual training was commissioned for providers, families, carers, to learn and understand the positive behavioural support approach or most of the point user’s framework. it has really made a difference. Care and Treatment Reviews are ongoing now on face-to-face and it involves a multidisciplinary team with a holistic approach including education, risks, future and current situations.”

- 6.6.7 Interviewees in Newham brought up a critical concern regarding challenges in recruiting and retaining staff. This issue may have adverse impacts on the quality of care provided, as well as staff morale, and increases the risk of burnout.

“Unfortunately, everything at the moment comes down to not having enough resources to put things into place” and “not having enough resources means you don’t have the best quality of staffing, then you’re unable to manage the number of individuals you are supporting”.

- 6.6.8 Individuals with learning disabilities in Newham may encounter greater difficulty in accessing healthcare services due to the shortage of expertise required to address the complex needs of this population.

“The kind of wraparound care that happens with people under the learning disability service isn’t available in quite the same way in community mental health services”.

City and Hackney

- 6.6.9 During stakeholder interviews conducted in City and Hackney, service providers were praised for their dedication and resilience in providing support for individuals with learning disabilities. Furthermore, the borough's successful implementation of cross-borough collaborations and co-produced services was also highlighted as contributing to their effectiveness in meeting the needs of the learning disability population.

“Carers are very dedicated we have interesting meetings on a quarterly basis and we’ve got a learning disability strategy which was co-produced with our users.”

- 6.6.10 City and Hackney's population is expanding, and local health services are often struggling to keep up with the increasing demands. As a result, many



individuals with learning disabilities transitioning from child to adult services face difficulties receiving adequate care. This situation causes exhaustion among service providers.

“The social care waiting list is enormous, it’s absolutely enormous. There are a number of staff on long term sick leave”.

- 6.6.11 Whilst services in City and Hackney are integrated, it was noted that they sometimes lack cohesion. This lack of synergy often results in unfair workloads being shared across services, with service providers aware that it may lead to low morale, longer waiting times and staff burnout.

“We work as an integrated service, health and social care, which I find it doesn’t always work in terms of coordination of care for the service user and that we come with different agendas and priorities. Most times it is the health side (of this integrated service) really carrying the team.”

Tower Hamlets

- 6.6.12 Interviewees reported Tower Hamlets learning disability service to have a “gold service.” This was mainly attributed to high level of investment, strong partnerships with private sector and the strong emphasis placed on culturally appropriate care.

“Tower Hamlets has got a gold service, they have absolutely everything and high investment as well. They have such a great gold service.”

“I think we’ve actually made huge gains in the last couple of months because we put a different equipment provider who’s going to help support some other logistics. We also have cultural advocates in the service that we have access to because it’s not just about the language barrier, it’s also the cultural religious aspects that we need to consider.”

- 6.6.13 Multiple interviewees indicated that many patients fail to attend health check-ups and other appointments with their GP. Also, Tower Hamlets frequently encounters low engagement from service users and there is a lack of history of robust service user participation and insufficient groups available to engage with.

“They are not attending their appointments; they are missing GP appointments as well.”

6.7 Annual health checks

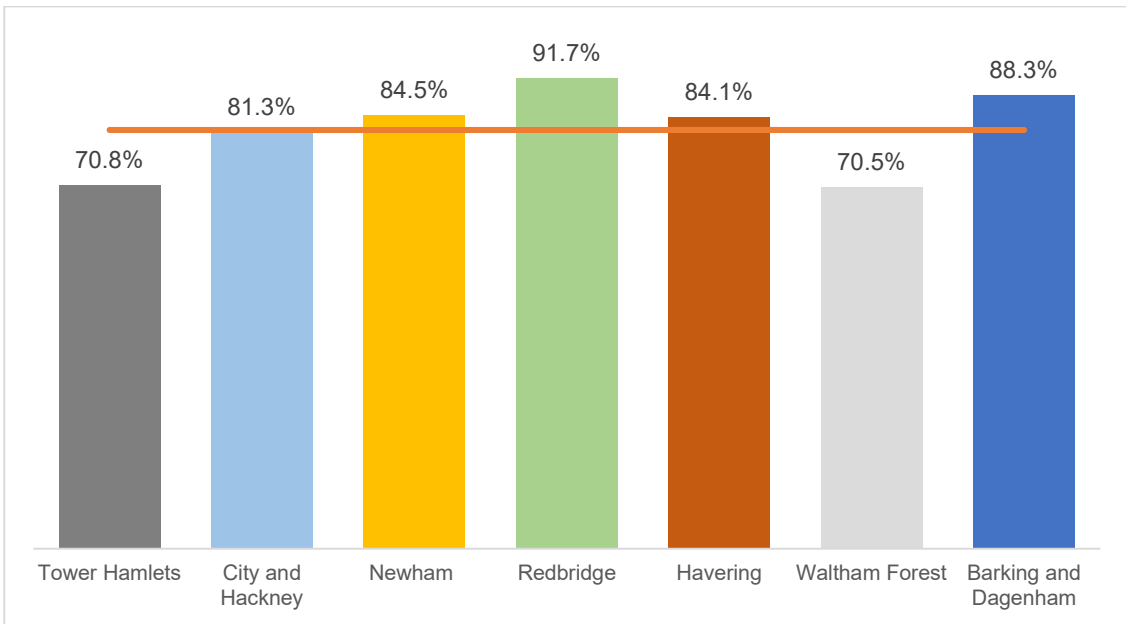
- 6.7.1 It is crucial for individuals with learning disabilities to receive a timely and accurate diagnosis from a registered healthcare professional. In England, individuals are advised to seek initial screening from their GP and may be



referred to specialized services as needed.(6) However, research indicates that individuals with learning disabilities are less likely to attend regular health check-ups and national screening programs, such as cancer screening, when compared to the general population.

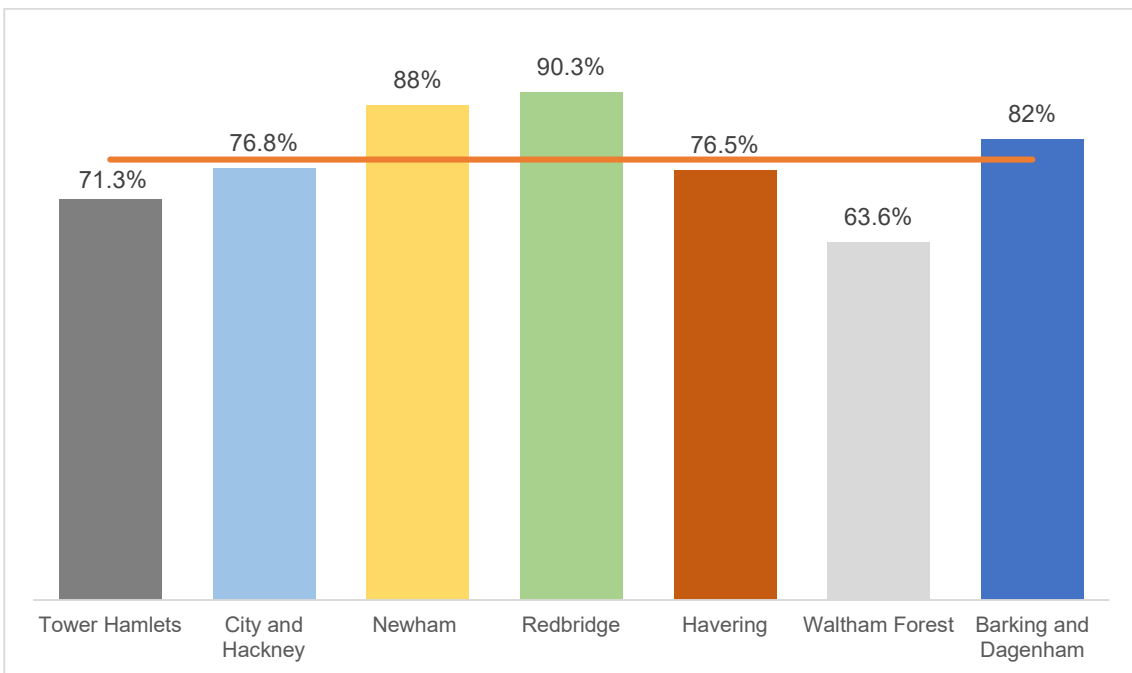
- 6.7.2 In light of these findings, it is expected that people with learning disabilities who are registered on their GP's disability list and are over 14 years old should undergo annual health checks in England. This is a mandatory requirement for GPs who receive funding based on their QOF.(53)
- 6.7.3 Annual health checks are a recognized evidence-based approach recommended by the National Institute for Health and Care Excellence (NICE) to facilitate early detection of undiagnosed health conditions, monitor the effectiveness of ongoing treatments, and ensure continuity of care.(53) These health checks enable healthcare professionals to address concerns and offer appropriate treatments or preventions when necessary. Additionally, health check action-planning provides an opportunity to promote uptake of cancer screening, immunizations, and healthy lifestyle behaviours.(53)
- 6.7.4 The NEL LeDeR 2020-21 report revealed that the percentage of individuals with learning disabilities receiving annual health checks was 66%, which is lower than the national average of 75%.(54) Furthermore, evidence suggests that the COVID-19 pandemic has further reduced the rate of annual health check performance among individuals with learning disabilities in North East London.(54)
- 6.7.5 Nationally reported factors associated with the declining annual health check figures among individuals with learning disabilities include, but are not limited to, the following:(54)
- Insufficient training for GPs in providing culturally competent care for individuals with learning disabilities.
 - Inadequate availability of support systems to facilitate transportation to appointments.
 - Limited awareness among individuals with learning disabilities regarding the importance of annual health checks.
 - Insufficient follow-up systems or processes to ensure timely and appropriate care.
 - Inadequate accommodations to meet the unique needs of individuals with learning disabilities.





NB: The line indicates the average uptake of annual health checks across the seven areas

Figure 17: Completed annual health checks for adults with a learning disability by borough



NB: The line indicates the average uptake of annual health checks across the seven areas

Figure 18: Completed annual health checks for individuals aged 14-17 with a learning disability by borough

Tower Hamlets

6.7.6 In Tower Hamlets, the percentage of 14 to 17-year-olds with learning disabilities who attended health checks in the last 12 months stands at 71.3%, while the corresponding figure for adults with learning disabilities is 70.8%.⁽¹⁸⁾ Both figures are also below the national target of 75% uptake of annual health checks for people with a learning disability and below the



average of 78.4% for the seven areas boroughs NEL.(54) See figures 17 and 18 above.

City and Hackney

- 6.7.7 In City and Hackney, the percentage of adults with learning disabilities attending health checks stands at 81.3%.(18) This is a relatively high percentage and might be indicative of the effectiveness of health services in this area.
- 6.7.8 Moreover, the data also highlights that adults with learning disabilities are more likely to attend health checks as compared to those aged between 14 to 17 years. This indicates that there may be specific challenges or barriers that prevent younger individuals with learning disabilities from attending health checks. The uptake for individuals above 14 years of age is higher than the national target but slightly lower than the average uptake across NEL.(54) See figures 17 and 18 above.

Newham

- 6.7.9 When it comes to conducting health checks for patients with learning disabilities, Newham has the best performance among the three boroughs examined. Both age groups, 14 to 17-year-olds and adults 18 years and above, have the highest percentage of completed health checks in the last 12 months compared to the other two boroughs. This was 88% for individuals aged 14-17 and 84.5% for adults. See figures 17 and 18.(18)
- 6.7.10 It is worthy of note that in all three boroughs examined, over 90% of patients who had a health check also had a health plan completed. Additionally, Tower Hamlets reported no instances of health checks being declined, while City and Hackney had a 3% decline rate and Newham had a 0.6% decline rate.(18)

NB: The figures used in accessing health checks are based on predicted population size and not on actual local QOF registers.

6.8 Screening and vaccination

- 6.8.1 Nationally, individuals with learning disabilities are at a disadvantage when it comes to cancer screening. Compared to the general population, they are less likely to be screened for cervical cancer, bowel cancer, and breast cancer. Of these, cervical cancer screening has the greatest disparity in uptake between individuals with learning disabilities and the general population.
- 6.8.2 According to 2019 data, only 33.5% of people with learning disabilities underwent cervical cancer screening, compared to 74% of the general population.(30) In terms of breast cancer screening, just under 50% of the UK's population with learning disabilities underwent this type of screening, while 82% underwent colorectal cancer screening.(30) These statistics highlight the need for increased efforts to improve cancer screening rates among individuals with learning disabilities, ensuring they receive the same access to essential healthcare services as the general population.



Cancer, bowel and cervical cancer screening

- 6.8.3 In the 12 months leading up to April 2022, the uptake of bowel cancer screening among patients with learning disabilities varied across the three boroughs. In Tower Hamlets, 22% of patients with learning disabilities underwent bowel cancer screening. In Newham, this figure stood at 35%, while in City and Hackney, 42% of the eligible learning disability population was screened for bowel cancer.(18) This uptake for eligible individuals is 70% in the general England population. See figure 15 below.
- 6.8.4 As of April 2022, data shows that the uptake of breast cancer screening among the learning disability population varied across the three boroughs examined. In Newham, 26% of the learning disability population underwent breast cancer screening. In Tower Hamlets, this figure stood at 25%, while in City and Hackney, the corresponding percentage was 20%.(18) This uptake for eligible individuals is 62% in the general England population. See figure 15 below.
- 6.8.5 Rates of undertaking a cervical screening for those with learning disabilities was similar across the three boroughs. As of April 2022, this figure stood at 33% in City and Hackney, 32% in Newham and 36% in Tower Hamlets.(18) This uptake for eligible individuals is 70%. See figure 19 below.

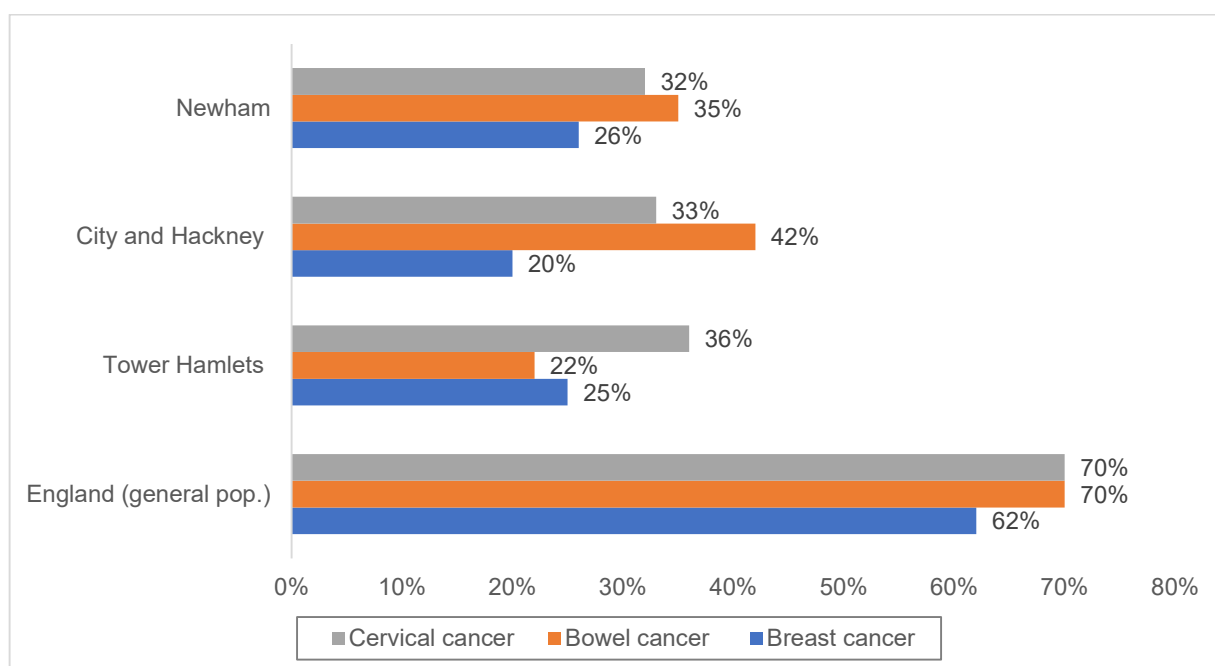


Figure 19: Uptake of screening programmes by borough, by adults with a learning disability (2022)

Flu vaccination

- 6.8.6 The uptake of seasonal flu vaccinations among the learning disability population aged 14-17 varies across the three boroughs. In City and Hackney, 28% of individuals in this age group received the vaccine in the 12 months leading up to April 2022, while the corresponding figure for adults was 49%.(18)



- 6.8.7 In Newham, 37% of the learning disability population aged 14-17 were vaccinated, with 57% of adults receiving the seasonal flu vaccine.(18)
- 6.8.8 In Tower Hamlets, 36% of the learning disability population aged 14-17 and 53% of adults were vaccinated for seasonal flu as of April 2022.(18)

COVID-19 Vaccination

- 6.8.9 During the early stages of the COVID-19 pandemic, individuals with learning disabilities who contracted COVID-19 were found to be at a significantly higher risk of hospitalization and death than the general population, likely due to the association between learning disabilities and comorbidities. This cohort was found to be five times more likely to be admitted to hospital and eight times more likely to die from the virus, in comparison to the general population.(55) As a result, this population was prioritized for COVID-19 vaccinations in the UK.(56)

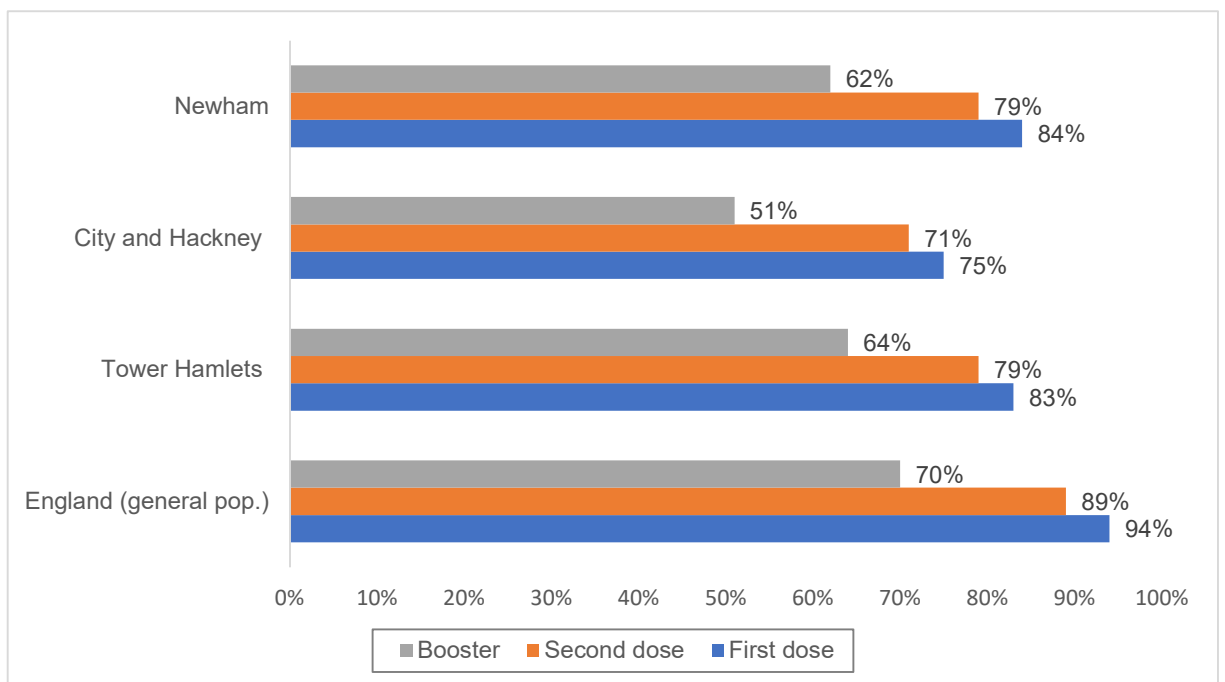


Figure 20: COVID-19 vaccination uptake by borough, 2022

- 6.8.10 While the national average for first-dose uptake of the COVID-19 vaccine stands at 94%, the average percentage uptake for those over 16 with learning disabilities across all North East London Boroughs is currently 84%. Newham and Tower Hamlets had the highest percentage uptake of first doses among adults with learning disabilities at 84% and 83%, respectively, while City and Hackney had a lower uptake rate of 75%.(57)
- 6.8.11 Despite the relatively high uptake of first doses among individuals with learning disabilities in these boroughs, there is a lower uptake of second and booster doses. Second-dose uptake was highest in Newham and Tower Hamlets, both with 79%, followed by City and Hackney with 71%.
- 6.8.12 The uptake of the booster vaccine was highest in Newham at 62%, followed by Tower Hamlets (64%) and then City and Hackney (51%).(57) Compared to the general population, which had a second-dose uptake rate of 75.3% as of February 2023, the uptake of second and booster doses among



individuals with learning disabilities needs to be improved.(57) This is particularly the case in City and Hackney which has fallen far below the NEL borough average. See figure 20 above.

6.9 STOMP – Stopping over medication of people with a learning disability, autism or both (STOMP)

- 6.9.1 "STOMP" is a program endorsed by NHS England that seeks to address the issue of overmedication of individuals with learning disability, autism, or both. The program aims to reduce the inappropriate prescription of psychotropic medication as a means of managing challenging behaviour in the absence of a documented mental health diagnosis.(58,59)
- 6.9.2 There have been longstanding concerns regarding the extent and potential overuse of psychotropic medication, specifically antipsychotics and antidepressants, in individuals with intellectual disability. These concerns were brought to light in the Serious Case Review conducted on Winterbourne View Hospital, which revealed the inappropriate use of medication. Subsequent reports emphasized the need for action, and Public Health England as of 2015 estimated that as many as 35,000 adults with intellectual disability are using psychotropic medication without having any health conditions that would warrant their use.(60)
- 6.9.3 Research shows that a significantly higher percentage of individuals with intellectual disability in community settings are prescribed antipsychotics and antidepressants compared to the general population. This finding has been established overtime.(61,62) NHS England set up the STOMP programme in 2015 to reduce overmedication in individuals with learning disabilities.

Tower Hamlets

- 6.9.4 In Tower Hamlets, there are a total of 191 patients on the psychiatric caseload. Initially, 64 patients were identified as STOMP-eligible. This number was reduced to 30 patients deemed most suitable for antipsychotic dose reductions. Factors taken into consideration included social support, past psychiatric history, and stability of the patient's condition.
- 6.9.5 The learning disability pharmacist has been working closely with the psychiatry team and collaborated with the nursing team to conduct follow-up STOMP medication reviews for patients who have undergone medication reductions. Since the start of the program, eight patients have had antipsychotic dose reductions, and three patients have stopped taking antipsychotics altogether. The overall reduction in antipsychotic doses is 45.4%. See table 5 below.

City and Hackney

- 6.9.6 Reports from the Hackney Integrated Learning Disability show that out of 165 patients on the Integrated Learning Disability Team Psychiatric Caseload, 36 were identified as fitting the criteria for a STOMP medication review. These patients were prescribed antipsychotic medication for challenging behaviour without a mental health diagnosis. Since the start of the program, five patients have had their antipsychotic doses reduced, and one patient has stopped taking antipsychotic medication altogether. See table 5 below.



- 6.9.7 After the 2020 STOMP Primary Care audit in Hackney, contact was made with the Primary Care Pharmacy team to obtain information on patients lost on follow-up identified in their report. The team provided 19 patient names, which were checked against the internal database and discussed with the Consultant Psychiatrists for Hackney.
- 6.9.8 Out of the identified patients, eight had a formal mental health diagnosis and were therefore not eligible for a STOMP review. Of the remaining 11 patients, nine were deemed potentially appropriate for a STOMP review.

Newham

- 6.9.9 To determine the extent of STOMP work needed in the London Borough of Newham, a Primary Care STOMP audit was conducted. The audit aimed to identify all patients with learning disabilities on their caseload who were prescribed antipsychotics. The audit was sent out to 46 GP practices in Newham in August 2021, and it was mostly completed by practice pharmacists in each practice. For five practices, access to EMIS was provided for the learning disability Pharmacist to complete the audits.
- 6.9.10 A total of 1,336 people with learning disabilities were identified in the audit, 1,094 of whom were adults over the age of 18. Out of these patients, 133 were deemed STOMP-eligible. Sixty-six of these patients were already on the Newham learning disability team psychiatric caseload, while the remaining 67 patients did not meet the Newham Learning Disabilities Team criteria. Out of the 66 STOMP-eligible patients identified in the Newham learning disability team, 17 have had antipsychotic dose reductions made. The cumulative dose percentage reduction in this cohort currently stands at 91.9% against the maximum daily dose. See table 5 below.

Table 5: STOMP-Eligible Patients and Psychiatric patients with medication changes

Borough	Learning Disability Psychiatry Caseload	Eligibility for STOMP (%)	STOMP-Related Antipsychotic Reduction	BNF Max Dose Reduction (%)	Patients with Stopped Medications
Tower Hamlets	191	30 (16)	8	45.4	3
City and Hackney	165	36 (22)	5	22.7	1
Newham	149	66 (44)	17	91.9	0

6.10 Variation in ELFT services across the boroughs

Aside from all the findings across the different sections of this report that show variation across the three boroughs, the table below highlights some of the variation in ELFT services across the three boroughs. Shared learning across the systems should be encouraged to identify better outcomes and best practice. This can help to reduce unwarranted variation in access and outcomes of local services and can help people with learning disabilities and their families / carers better navigate service provisions.



Table 6: Summary of variation of services across the three boroughs

Domain	Tower Hamlets Community Learning Disability service	Hackney Integrated Learning Disability service	Newham Health Team for Adults with Learning Disabilities
Service integration	The service is an integrated service between ELFT and the London borough of Tower Hamlets.	The service is an integrated service. The service is jointly commissioned by Hackney Council and the City and Hackney CCG.	The service is a standalone non-integrated service. Different to other boroughs, there is a separate adult social care team. LD services are commissioned by the CCG on the severe end of the spectrum. Only people with a moderate to severe learning disability are eligible for access.
Eligibility and Scope	The service provides support for individuals diagnosed with a learning disability across the whole learning disability spectrum.	The service provides support for individuals diagnosed with a learning disability across the whole learning disability spectrum.	The service provides specialized support for individuals who have significant, profound or severe learning disabilities along with communication, sensory, and mobility challenges. The mild learning disability population is excluded from the Newham specialist community health team.
Support services	The team consists of psychiatrists, clinical psychologists, occupational therapists, speech and language therapists, physiotherapists, art therapists, community nurses, and more.		
Best practice examples	The completion rate of Coordinate My Care Plans ⁴ in Tower Hamlets is significantly higher compared to several other boroughs.	Hackney has the first intensive support team in their service.	PBS virtual training was commissioned for providers, families, carers, to learn and understand the positive behavioural support approach.

6.11 Existing challenges and gaps in service provision

- 6.11.1 The NEL LeDeR 2020-21 report highlights that individuals with learning disabilities are not accessing the essential healthcare services they require, including health screening, weight management, oral care, and general healthcare. Several factors contribute to this, including a lack of culturally

⁴ An internet-based repository of care plans designed to offer assistance and support to individuals requiring moderate levels of aid.



competent care, limited support for seeking reasonable adjustments and accommodations, referral to inappropriate services, a lack of knowledge and awareness, and personal reasons such as anxiety or negative past experiences.(54)

- 6.11.2 The findings of this report couple with findings from this HNA process indicate a need for changes in the healthcare system to ensure that service providers have the necessary resources to meet the unique needs of individuals with learning disabilities. It is essential to address the barriers that prevent individuals with learning disabilities from accessing essential healthcare services, and to promote access to culturally competent care, effective communication, and appropriate referrals to services that meet their needs.
- 6.11.3 Overall, the recommendations outlined in the report emphasize the importance of creating a more inclusive and equitable healthcare system that is responsive to the needs of individuals with learning disabilities. By doing so, we can work towards ensuring that all individuals receive the care and support they need to maintain their health and well-being.



7. Education

7.1 Key findings

- Colleges' educational programs lack an efficient path for individuals to advance their employment skills, and there is a lack of a clear route to higher education or formal education.
- There is a perceived lack of suitable support for some students with additional learning needs who don't attend specialist provision.
- Individuals with learning disabilities often face challenges relating to memory and learning skills such as reading, writing, and math which can negatively affect educational attainment.

7.2 Recommendations

- Effectively integrating special education needs support into mainstream education is important to meet the needs of students with mild to moderate learning disabilities. This requires a coordinated approach, including staff training and education on communication device tools and other reasonable adjustments and educating students to tackle stigma.
- Ensure that students with learning disabilities are equipped with an effective development plan to assist with academic performance and general wellbeing and ensure the varying needs of each individual are taken into consideration.

7.3 Education of those with learning disabilities

- 7.3.1 Learning disabilities can impede cognitive function by obstructing the development of fundamental skills like reading, writing, and mathematics. They can also affect an individual's memory, ability to focus, and organisational skills, which can significantly hinder educational attainment.(63)

7.4 Views of individuals with learning disabilities and their carers

- 7.4.1 The focus groups hosted by PHAST in the tri-borough area have gathered insights from individuals with learning disabilities and their caregivers regarding the challenges they face in education.
- 7.4.2 The results from the focus groups revealed that the education provided by education colleges often has limited scope and inadequate progression opportunities for individuals to acquire crucial employment skills.



- 7.4.3 Lack of communication when service users are no longer eligible for education services, often causing significant upset and disturbance to routine for parents/carers and individuals.
- 7.4.4 Lack of training for education staff in communication device tools such as Eyegaze used by students with additional learning needs.
- 7.4.5 Eye-gaze assistive technology provides children with learning disabilities with opportunities to access a computer through control of eye movements, thereby to perform a range of activities for play, communication, and learning.(64)

“...she could use the communication device tool, Eyegaze, but the college tutor had not been trained in Eyegaze and there was no one-to-one support available other than her father.”

- 7.4.6 Eyegaze is just one example of a gaze-based assistive device for people with disabilities. There are several examples and models of eye tracking systems. For example, TM3 by EyeTech Digital Systems, IntelliGaze by Alea Technologies, EyeMax by DynaVox Mayer-Johnson and EcoPoint by Prentke Romich Company.(80)
- 7.4.7 Lack of suitable support for some students with additional learning needs.

“A couple of interviewees said that they think where there is a struggle is for those who don't attend specialist provision because of that, probably a lack of understanding of their needs.”

“Support workers employed by the Newham FE (Further Education) college for example work with moderate individuals not for the severe or profound.”

7.5 Views of service providers

- 7.5.1 Most service providers across the boroughs agree that further education colleges do not have a coordinated approach for educating their staff members on the unique needs associated with learning disabilities.

“Obviously education is a large gap for staff (education on learning disabilities), they all should have basic awareness around communication and reasonable adjustments—ensuring they know the MCA for instance.”

- 7.5.2 According to several service providers in Tower Hamlets, there is a lack of suitable education programs within the borough for individuals with learning disabilities, resulting in increased demand for special education needs schools.



“We have a few very good schools in Tower Hamlets... I think is a struggle for those who don't attend specialist provision first of all, because of that probably lack of understanding of their needs.”

- 7.5.3 Multiple interviewees emphasized the requirement for additional specialist schools for individuals with learning disabilities in Newham. Additionally, there is a need for more effective training programs to equip this population with the requisite skills for equal opportunity compared to the general population.

“We have a higher than average, for a borough, number of children with complex needs in mainstream education.”

“There are courses offered within the council service under the adult with autism and learning disability team. It could be ICT, cake decorating, drumming, drama, music, but they're 10 week rolling courses and once you've done it three times there's not much more you can learn from it.”



8. Transition between children and adult services

8.1 Key findings

- Findings show late and ineffective multi-agency transition planning with information systems not linking up well.
- There is no adequate understanding of who is transitioning.
- Reduced focus on empowering with life skills at transition.

8.2 Recommendations

- A more integrated and data driven approach in order to monitor those with learning disabilities who are transitioning from children to adult services will offer service providers information to better plan for the population's needs.
- The transition between services for young adults with learning disabilities can be a source of stress. Children and adult services have varying service models and receive different levels of financial support, leading to a lack of synergy that can negatively impact the experience of accessing care for service users. It is crucial to prioritize improving the coordination of care and offering appropriate service provision for vulnerable populations, including planning service provision in a way that is tailored to their needs.
- To ensure a personalized and comprehensive approach, the statutory transition planning for individuals with disabilities should commence during the year 9 review at age 13-14. This planning should encompass various areas, including health, independent living, employment, and social inclusion, and should be centred on the individual.

8.3 Transitioning into adulthood

- 8.3.1 Adolescence can be a challenging life stage for individuals with learning disabilities, as it can negatively impact health and other outcomes such as education and employment. Transferring from children to adult services can also be difficult, with a need for effective coordination and communication between services to ensure appropriate care is provided. The different service models and entitlement criteria used by children and adult services, as well as varying levels of financial aid, can further impair user experience and highlights the need for improved coordination of care for vulnerable populations.



- 8.3.2 A recent longitudinal study of young people with autism and learning disabilities observed changes in hospital admission rates before, during, and after transition into adult services. Planned admission rates for young people with a learning disability were highest before transition, reduced during, and remained consistent after transition into adult care. Unplanned admission rates increased before transition, remained consistent during, and continued to increase after transition.(65)

8.4 Views of service providers

- 8.4.1 Multiple interviewees reported that child services offer a more conducive environment for building social connections compared to adult services. They noted that the friendships established in child services tend to decline as individuals transition into adulthood.

“They do make the relationships in schools and colleges, and then they get to adulthood and it’s like, you are independent now, here is your own flat, and then they lose those connections.”

- 8.4.2 According to service providers there is still a gap where individuals with milder learning disabilities or those under 18 without a formal diagnosis are not considered in need of significant planning or support. Depending on the borough, they may not meet the threshold for learning disability team services upon reaching adulthood, resulting in a significant gap in service provision.

“Where we have a real issue is where you’ve got people coming through with a milder learning disability or someone under 18 who has not been formally diagnosed and they’re not seen as somebody who needs a huge amount of planning. And depending on the borough, they may not quite meet thresholds for learning disability team services when they turn 18, and then they fall in this giant gap.”

- 8.4.3 The majority of service providers in NEL/ELFT expressed feeling pressured to expedite placements for individuals with learning disabilities. This has led to incorrect referrals, delayed treatment, and suboptimal experiences for service users.

“Across NEL, we don’t have a huge amount of really good high-quality providers for this cohort (the learning disability population). So, again that kind of jarring shift from children to adults sometimes means that we don’t always get it right. The thing that we’re particularly bad at, I think, as part of transition, is supporting people with having an understanding of what is available and managing expectations.”



Tower Hamlets

- 8.4.4 One service provider from Tower Hamlets stated that a lack of resources and specialist care had a detrimental effect on the transition from child to adult services.

"Equipment poses a significant challenge," said one respondent. "For those who are neurotypical but have a learning disability, transitioning them to appropriate services can be difficult as there is a lack of dedicated resources."

City and Hackney

- 8.4.5 Most interviewees noted that the transition from child to adult services in City and Hackney was not smooth and required improvement. The primary reasons cited were insufficient early transitions, inadequate financial investment, and suboptimal service provisions.

"Starting transition planning early does not happen", "there's not always an allocated social worker. Social workers are fairly thin on the ground in adult services" and "one big technical problem, from our point of view is, who is managing money? Money becomes quite a big issue. They get paid more in children services than they do in adult services."

Newham

- 8.4.6 Numerous service providers expressed frustration over the absence of integrated services, which can result in longer waiting times for treatment and reduced access to a range of services for service users.

"There is not an integrated adult learning disability service that brings health and social care together, so people effectively have two transitions, a social care one and a health one and I don't think we do very well because we do offer services like musculoskeletal services, cardiac and neuro rehab service, but we probably don't make those services as accessible as they might be to people with learning disability."

- 8.4.7 There are issues with transitioning individuals with learning disabilities to adult services, with service providers expressing concerns about a lack of understanding and awareness of the transition process. There is also a need for more support and guidance for families and service users during the transition period.

"Transition is bad. Particularly because if we don't have an understanding, or even are aware of these guys who were transitioning and no work is done, or very little work is done when it comes to advising families on the support that our patients get around transitioning."



9. Employment

9.1 Key findings

- In 2020/21, 4.4% of women and 5.7% of men with learning disabilities were in paid employment in England; this figure stands at 77% for the general population.
- Most recent data from the UK Office for Health Improvement & Disparities shows that there is a 71% gap in the employment rate between those who are in receipt of long-term support for a learning disability (aged 18-64) and the overall employment rate.
- The employment gap (between those with learning disabilities and the general population) can be attributed to a lack of training and employability schemes, support in building self-esteem and awareness of what individuals with learning disabilities are capable of.
- The learning disability population reported frustration at limited work experience opportunities. Also highlighting difficulties in navigating online job applications and challenges in reading and writing as key barriers to securing paid employment.

9.2 Recommendations

- Prioritize and promote the availability of training programs that focus on the development of vocational skills and roles, with a specific emphasis on improving literacy and communication skills across the boroughs. This will help to ensure that individuals with learning disabilities have the necessary skills and training to prepare them for future employment opportunities.
- Efforts to increase the representation and visibility of individuals with learning disabilities in the workforce can challenge negative stereotypes. We recommend strategies to achieve this goal including continued employer awareness and training programs, job coaching and assistive technology support services, partnerships with disability organisations, and the creation of supportive and inclusive work environments through employee resource groups or diversity and inclusion committees.

9.3 Individuals with learning disabilities in employment

- 9.3.1 Data from the annual survey of adults with learning disabilities receiving long-term social care in England shows that the percentage of adults with



learning disabilities in paid employment has decreased from 6.0% in 2015 to 5.0% in 2021.(66)

- 9.3.2 According to NHS Digital's 2020 report, London and the South East have the highest proportion of adults with a learning disability known to their local authority in paid employment, at 7% and 6.9%, respectively. Yorkshire and the Humber have the next highest proportion, at 6.3%.(67)
- 9.3.3 Recent data shows that a higher proportion of men with learning disabilities are employed compared to women. In 2020/21, 5.7% of men with a learning disability were in paid employment, while only 4.4% of women with a learning disability were employed.(66) It is important to note that, in comparison, the general population had a much higher employment rate, with 77% of working-age individuals employed in 2020/21. However, this figure decreased by 1% from the previous year, largely due to the impact of the COVID-19 pandemic on the job market.(66)
- 9.3.4 A 2019 survey that explored the employment of people with learning disabilities and surveyed by level of support showed that 32% of those with the lowest support needs have a paid job, 9% of those with medium support needs have a paid job, fewer than 5% of those with the highest support needs have a paid job.(67)
- 9.3.5 The main reasons for the large employment gap between those with learning disabilities and the general population can be linked to:(67)
- Insufficient support to source and maintain employment.
 - Insufficient support in building confidence and skills around employment.
 - Employers' attitudes and general stigma surrounding learning disabilities.
 - Lack of awareness regarding what people with a learning disability can achieve when receiving adequate support.

Tower Hamlets

- 9.3.6 The Adult Learning Disability strategy indicates that Tower Hamlets planned that between 2017 and 2020, over 110 people with learning disabilities will be supported to reach an 11% employment rate within this population. Although critical appraisal of the initiatives from the learning disability strategy are yet to be published, this would represent a significant improvement compared to earlier years, when employment rates were much lower. For example, in 2013, only 7% of working-age adults with learning disabilities in Tower Hamlets were in paid or self-employment, with 70% of this group working less than 16 hours per week. Also, male cohorts were classified as more likely to be employed, as compared to their female counterparts. Similarly, in 2015, only 4.9% of the learning disability population in Tower Hamlets were employed full-time.(68)
- 9.3.7 Tower Hamlets' JET (Job, Enterprise, and Training) initiative is a program designed to serve individuals with learning disabilities and health conditions. Its primary objective is to boost the number of disabled individuals in long-term employment by offering a streamlined support system. Alongside employment and training assistance, JET manages several social enterprises in fields such as catering, information technology, and community



transport valeting. These enterprises supply supported work placements and paid job opportunities for local disabled residents, serving as a bridge to conventional employment.

City and Hackney

- 9.3.8 In 2015, only 2.9% of adults with learning disabilities who were in contact with Hackney's social services were employed by the end of the year. As at that time, these rates were lower than those of London and neighbouring areas, where the percentage of employed individuals with learning disabilities was around 6%.
- 9.3.9 To address this issue, City and Hackney have introduced ongoing employment services for individuals with learning disabilities. One such service is Hackney Council's Supported Employment Service, which provides individuals with the necessary tools and support to succeed in the workplace.
- 9.3.10 Other services in Hackney that seek to support people with learning disabilities into employment include:
- Hackney Council for Voluntary Service (HCVS) Supported Employment Network – this is a group of different third sector, council and voluntary organisations who want to support disabled people into employment.
 - Disability Employment Advisors at Job Centre Plus
 - Prospects (for young people)
 - Project Search
 - Working Capital pilot aimed at getting people with long term health conditions back into work.
 - Central London Works which is a programme to help Central London residents who have been unemployed for a long time as well as those with health conditions into work.
- 9.3.11 These employment services are important in promoting inclusive employment practices, providing reasonable adjustments, and offering career development opportunities for individuals with learning disabilities.

Newham

- 9.3.12 As of September 2021, Newham had a higher proportion of adults with learning disabilities in paid employment than the London average. Specifically, the proportion of adults with learning disabilities in paid employment in Newham was 5% higher than the average for London. The Newham Council has taken proactive steps to improve employment rates for individuals with learning disabilities by implementing and scaling up services targeted towards these populations. One such initiative is Our Newham Work, which provides skills training and resume building offerings to support individuals with learning disabilities in gaining access to paid employment opportunities.(69)



9.4 Views of individuals with learning disabilities and their carers

- 9.4.1 The focus groups discussions hosted by PHAST in the tri-borough area have gathered insights from individuals with learning disabilities and their caregivers regarding the challenges they face in accessing employment opportunities.
- 9.4.2 Individuals with learning disabilities often face frustration due to limited work experience opportunities. For example, young adults who attended college in Newham or attended services in Tower Hamlets shared their frustration at limited work experience opportunities which only seems available as part of college courses and end when the course has finished.
- 9.4.3 The shift towards online job applications has created additional barriers for individuals with learning disabilities in accessing employment opportunities. Some individuals with learning disabilities stated that they require additional support from key workers to navigate online job application processes, which can be time-consuming and complex. This can further limit access to employment opportunities and perpetuate inequalities in the workforce.

"I need help from my key worker to fill out application forms. Applying for jobs online makes it more difficult for me."

9.5 Views of service providers

- 9.5.1 In-depth interviews were held across NHS ELFT and with service providers and professionals across the three boroughs of Tower Hamlets, City and Hackney and Newham.
- 9.5.2 Several interviewees across the three boroughs pointed out the scarcity of employment prospects for individuals with learning disabilities in the three boroughs. The inequalities observed include a lack of recognition regarding the valuable contributions that this population can make, along with the disproportionate difficulties experienced during the COVID-19 pandemic.

"At time of recession, promoting employment opportunities for people with learning disability is going to become increasingly challenging. We have such a poor percentage level of individuals with learning disability into employment nationally. And these guys can be so supportive, so helpful within organisations."

Tower Hamlets

- 9.5.3 Although service providers in Tower Hamlets indicated that an employment scheme had been commissioned, they acknowledged that vulnerable populations, such as those with learning disabilities, faced a disproportionate impact during the COVID-19 pandemic when seeking employment.

"We do have an employment scheme here that is commissioned. It's obviously difficult particularly through the pandemic because a lot of those jobs are the ones that have



gone in the leisure and retail restaurants. So, we have a low number of people in employment, but we do have a contract with a local provider to do education and training and employment.”

City and Hackney

- 9.5.4 Most service providers in City and Hackney underscore the absence of incentives in the borough to encourage employers to hire individuals with learning disabilities. Consequently, this population experiences lower rates of employment pay compared to the general population.
- 9.5.5 Some service providers in City and Hackney stated that individuals with learning disabilities who are referred to the local employability service receive inadequate support. This may be attributed to the insufficient knowledge and training of the relevant service providers regarding learning disabilities.

“There is an employment service, but we've referred to them, and we don't get anything back. There is no patience and needed support and persistence from the service for people with learning disability.”

Newham

- 9.5.6 Several service providers in Newham pointed out that individuals with learning disabilities face significant challenges in progressing from education to paid employment.

“Once you go into adult services that all changes dramatically because, you might go to college, but when that ends there is very limited employment. Employment for people with learning disabilities is practically non-existent, you can either go to a day centre, but you won't get 5 days a week at a day centre, you might get 1 or 2 days a week.”

- 9.5.7 Certain interviewees mentioned that Newham commissions employment and training schemes that are more suitable for the general population rather than those with learning disabilities. The reasons for this social disparity were associated with insufficient support, time resources, and coaching.

“Yes, there are employment schemes but they are usually for just the most able, they tend to be run by the third sector, so charities or private organisations and they are generally referred to by the social worker. The reason why they are quite limited in their range is because most people require quite a high level of job coaching until they are able to work independently, so you will usually have people that go with them to work and then they will tail off, but obviously, it is very front-ended, you need to put in a lot of time and resources and then the person might be able to do that independently.”



10. Housing and Accommodation

10.1 Key findings

- Compared to the general population of the same age, younger individuals with learning disabilities are more likely to reside in specialist accommodation facilities, away from their family home.
- There is a perceived shortage of appropriate residential educational placements for children with learning disabilities who are unable to live with their families.
- Residential care in NEL is perceived to be inappropriate for individuals with learning disabilities, who are often placed at home or in a fully adapted accommodation, which often produce significant time and financial costs.
- There is a perceived scarcity of high-quality providers and suitable placements for individuals with a high level of need, leading to a substantial number of out-of-borough placements for this group.

10.2 Recommendations

- Present and future housing strategies for individuals with learning disabilities should be devised through collaboration with relevant agencies, taking into account the high and growing demand for such housing.
- Residential care needs substantial investment to ensure it is adequately resourced to meet the complex needs for individuals with more severe presentations of learning disabilities.

10.3 Housing and accommodation need for those with learning disabilities

- 10.3.1 Housing and accommodation requirements for individuals with learning disabilities often differ from those of the general population. This is apparent when comparing the proportion of people with learning disabilities residing with their parents to the general population at similar ages. For instance, young adults aged 16 to 24 years with learning disabilities are more likely to live away from their family home when compared to individuals in the same age group without a learning disability. Based on 2019 ONS data, specifically, 67.6% of those with learning disabilities live with their parent(s), while 73.1% of the general population do so.(70)
- 10.3.2 Nevertheless, beyond the age of 24, individuals with learning disabilities are more inclined to live with their parents than the general population, with a proportion of 28.8% compared to 24.1%.(70) Despite over a quarter of adults



with learning disabilities living with their parent(s), there are a range of other housing accommodation options available for individuals with learning disabilities.

10.4 Housing options for individuals with learning disabilities

Residential care

- 10.4.1 This form of housing offers a combined living space and personal care facility. It involves providing individuals with a room within a larger building, usually shared with four to eight other residents, along with meals. These accommodations are owned and managed by either public, private, or charitable organisations, and are registered under the Care Quality Commission. Typically, individuals are placed in this type of care by local authorities, based on an assessment when vacancies become available.(71)

Supported housing

- 10.4.2 Supported housing comes in various forms. As per the NHS, supported housing serves as an alternative for individuals who do not wish to reside in residential care. People may choose to live independently with support from others or share a home with several other individuals with similar disabilities. An employed staff member(s) provides assistance and care. Similar to residential care, individuals undergo an assessment through local social care departments to arrange for this type of housing.(72)

Shared lives

- 10.4.3 Shared Lives is a program where an individual with a learning disability is matched with a host family, becoming part of their household and family. The host family takes responsibility for providing both support and care for the selected individual.(71)

Mainstream market

- 10.4.4 Individuals with learning disabilities have the option to purchase a home if they have the financial means to do so. They can purchase through shared ownership with a housing association, friend, or family member, or independently if they have the means. Several programs in England support the co-ownership of a home, including the "Home Ownership for People with a Learning Disabilities" initiative. Additionally, individuals with learning disabilities can rent a "general needs" home on the open market, similar to the general population. This type of housing is suitable for those with milder diagnoses and is typically offered by local authorities, housing associations, or private landlords. Eligibility requires individuals to be on the local housing authority waiting list due to the significant and increasing demand for this type of housing.(71)
- 10.4.5 The estimate of housing need in England is published by the National Housing Federation.(73) The demand for social housing in England has escalated to 4.2 million people, translating to 1.6 million households. This figure exceeds the 1.1 million households documented on official waiting lists



by half a million, highlighting the significant need for additional social housing options.(73)

- 10.4.6 As of March 31, 2021, Tower Hamlets had 21,849 households on the social housing waiting list, while Newham had 33,246, City of London had 889, and Hackney had 8,235. Among all London Boroughs, Lambeth holds the longest waiting list with 33,640 households, followed by Newham, which has the second-largest list. Except for City and Hackney, both Tower Hamlets and Newham have social housing waiting lists that exceed the London average, indicating a higher demand for social housing in these areas compared to other London boroughs.(74) See figure 17 below.
- 10.4.7 Likely reasons for this include population growth, rising housing costs which may push lower-income households to seek affordable housing options, migration patterns or even increased employment opportunities in these areas attracting people seeking work and driving the demand on housing.

Tower Hamlets

- 10.4.8 Tower Hamlets provides various housing options to ensure sufficient choices for individuals with learning disabilities. Supported accommodation allows people to live independently or with a small group of others, with support workers who possess the necessary skills and knowledge of learning disability needs. Individuals are provided with a plan that outlines specific goals, including finances, life skills, personal relationships, and other developments. Supported accommodation is typically considered a temporary arrangement in Tower Hamlets while other forms of support are being arranged.(75)

City and Hackney

- 10.4.9 As of 2016, a noteworthy percentage of people with learning disabilities in Hackney are known to receive day care services, alongside supported living and home care. For those who are placed outside of the borough, the majority reportedly live in residential care settings. As of 2016, two-thirds of individuals were receiving residential or nursing care.(76)
- 10.4.10 As of March 2016, reports indicated that 135 adults with learning disabilities in City and Hackney were receiving residential care, with 114 of them placed outside of the borough. Additionally, 33% of adult individuals with learning disabilities were receiving housing with care or supported living, with the majority residing within the borough. Moreover, as part of their care package, fewer than five individuals were placed in nursing care homes in 2016.(76) We lack recent data to carry out adequate assessment.
- 10.4.11 Social housing is another housing option for residents who can apply or bid through a range of lettings. Available schemes prioritize individuals based on their level of need. As of 2016, there were about 72 households that included people with learning difficulties, although this may not accurately represent all individuals with learning disabilities. Floating support services are also available to assist vulnerable populations in managing these accommodations. These services offer one-to-one support, short-term interventions, or advisory sessions.(76)



Newham

- 10.4.12 Research suggests that 83.5% of Newham's residents with learning disabilities live within their own homes, which is approximately 6% higher than the national average.(77) The proportion of Newham residents with learning disabilities living in their own home has been higher than the national average since 2015. The majority of individuals living alone are reported to be between the ages of 35 and 44 and are more likely to be female.(77)
- 10.4.13 Newham offers day services, supported accommodation, and several other housing-related support services to individuals with learning disabilities. Supported living is available for individuals aged 18 and over with assessed needs, such as learning disabilities or mental health needs, and is provided by the Adult Social Care team. Supported living entails developing a personal support plan that maps specific needs and goals, such as finances, employment, personal relationship development, and life skills.(78)
- 10.4.14 Individuals with learning disabilities in Newham can access housing-related support services, which provide a lower level of support aimed at enabling them to live independently. This service can be provided within an individual's own home or in supported accommodation settings. However, these services are only available to Newham residents with a valid assessment of their needs, which is provided by the Adult Social Care team.

10.5 Views of service providers

Tower Hamlets

- 10.5.1 Several service providers in Tower Hamlets highlighted an accommodation gap because of limited in borough placements and service provision. Consequently, many individuals with learning disabilities tend to live out-of-borough.

“Most of our supported living are low-to-moderate needs, and if you have complex or challenging behaviours, they are not big enough. There are quite a few people who are placed out of area, who need to return to the borough but we don't have the provision. I don't think the borough has got enough resources to support people in-house and so they are usually taken outside into other services.”

City and Hackney

- 10.5.2 During the interviews, a significant number of participants expressed their frustration regarding the lack of appropriate accommodation available to the learning disability population, as well as other vulnerable groups in the City and Hackney area. The lack of available accommodation often results in the need to place residents outside of the borough, which can lead to various psychosocial issues and health conditions due to the lack of appropriate service provision.



“Some service users are placed out of the borough as far as West Sussex, Surrey because you cannot find providers to meet their complex needs. Some need 24 hours nursing support, suctioning, oxygen” and “challenges of having people placed out of borough are the distance of travel, internal problems of the placement (retaining staff) leading to a lack of seamless provision of services.”

- 10.5.3 Multiple interviewees raised a major concern about the overcrowded conditions that many residents in City and Hackney, a socially deprived neighbourhood, experience daily. This issue puts residents at a higher risk of developing psychological disorders compared to the general population in the UK.

“In Hackney, there is a high level of deprivation. This often leads people with learning disability to live in overcrowded settings which can negatively impact on their mental health.”

Newham

- 10.5.4 Interviewees who had experience operating placements in Newham reported difficulties in providing suitable accommodation for children with learning disabilities who were no longer able to live at home. The lack of specialist services made this task challenging for them, as children and adolescents often had to be placed in settings far from home as it was the only way to access specialist care.

“There is a significant lack of appropriate residential educational placement for children with learning disabilities who are not able to carry on living with their family” and “some of the difficulties sometimes we have is having to place people far away from home, if we don't have the right kind of specialist services.”



11. Caring responsibilities

11.1 Key findings

- Carers have expressed that there is a lack of adequate recognition of carers/support workers as client experts. They also reported experiencing some level of inappropriate treatments in hospitals.
- Parents/carers stated that they are not always aware of all the services available to them.
- There is a perceived gap in the support for people that are caring for individuals with mild, moderate needs.
- Respite offer is perceived as not sufficient by carers.
- There is no sufficient career progression for carers, and care workers are underpaid and feel undervalued.

11.2 Recommendations

- Ensure that carers and communities are better resourced to meet the complex needs of the learning disability population. This could include increased funding and prioritisation of day centres offering opportunities for individuals to socialise and meet other carers, but also opportunity for respite.
- Ensure that carers receive a better salary (aiming for London Living Wage) as this will likely improve staff morale, in addition to hiring and retention.
- Greater support should be given to carers, whilst encouraging them to be more wary of their own physical and emotional needs, which can often be neglected due to growing and demanding case loads

1.1 Number of carers of people with learning disabilities

- 11.2.1 In the UK, approximately 6.5 million people identified as carers in 2019, which is equivalent to one in eight adults. Among these carers, those who provide care for individuals with learning disabilities are more susceptible to experiencing other comorbidities.(79)
- 11.2.2 Data from 2018-2022 indicates that there were 18,000 carers in Hackney, 23,000 in Tower Hamlets, and 24,000 in Newham from 2019 onwards.(23,80,81) It is important to note that many carers are unpaid or not registered, which suggests that the actual number of carers in each borough may be higher than the reported figures.



1.2 Experiences of carers of people with learning disabilities

- 11.2.3 Raising children with learning disabilities presents numerous challenges that can affect the entire family, with carers experiencing physical, mental, and financial strain. Carers may have limited time to attend to their own health needs, leading to physical health problems.(82) Furthermore, those who care for individuals with challenging behaviour may experience high levels of stress and isolation, affecting mental health. This can negatively impact relationships, including marital, parental, sibling, and intergenerational relationships.(82)
- 11.2.4 Additionally, caring responsibilities can result in socio-economic difficulties, with families facing financial pressure due to lost earnings and increased household costs. The Carers UK Caring & Family Finances Report found that these pressures can have lasting effects on families taking on caring responsibilities.(83)
- 11.2.5 NICE guidelines outline the importance of involving families and carers in the development of support and care planning to allow them to feel heard, supported, whilst simultaneously increasing their confidence and skill delivery.(84)

Tower Hamlets

- 11.2.6 The most recent JSNA report from Tower Hamlets indicates some participation of carers in developing the Short Break (Respite Care) policy, although it is not specific to carers of individuals with learning disabilities.(85) The Tower Hamlets carer strategy highlights the importance of providing sufficient breaks for carers, who often experience health problems such as back and joint pain due to the physical demands of their caring responsibilities. In addition to physical health concerns, carers also report elevated levels of anxiety and stress, leading to emotional and physical exhaustion. Further research is necessary to further understand specific health needs of carers in Tower Hamlets.

City and Hackney

- 11.2.7 In 2015, a survey was conducted in Hackney through the Personal Social Services Survey of Adult Carers, in which 300 registered carers participated. Among the sample, 24% reported caring for an adult with a learning disability. However, it is important to note that the data collected did not differentiate between carers who cared for those with learning disabilities and those who did not.(76)
- 11.2.8 The survey revealed that 50% of carers in Hackney reported experiencing a health condition, while 20% felt socially isolated and neglected their own needs. Many carers reported not having sufficient time to engage in activities they value or feeling in control of their lives. Additionally, many carers reported experiencing distress and anxiety, with 37% being unemployed due to their caring responsibilities. Moreover, carers expressed dissatisfaction with the support they receive, and 25% indicated concerns for their personal safety.(76)
- 11.2.9 Efforts to identify the health needs of carers specifically caring for adults with learning disabilities were often redirected to the needs of those being cared



for. As such, further research is necessary to gain a greater understanding of the health needs of carers of individuals with learning disabilities in Hackney.(76)

Newham

- 11.2.10 According to the most recent JSNA report for Newham from 2016-18, carers' scores for health-related quality of life were reported to be lower compared to regional and national values, although these scores have been improving and are now becoming more comparable to national rates. Carers' scores for social care quality of life were found to be lower compared to England, with female carers reporting lower scores than male carers across England, London, and Newham.(86)
- 11.2.11 The number of carers in Newham who reported having sufficient social contact were similar to those at national and London levels. Further research is necessary to better understand the health needs of carers in Newham and their lower quality of life.(86)

1.3 Views of individuals with learning disabilities and their carers

- 11.2.12 The number of carer/key worker support hours for individuals living semi-independently seemed to have been reduced, particularly if the learning disability did not coexist with a physical condition like diabetes. As a result, some service users receive only one hour of key worker support per week, which is insufficient for meaningful engagement in activities like accompanied outings. These individuals report that the limited support is just enough to manage paperwork, such as bills.

“One young adult said he wanted help from his key worker with job applications but there was not enough time to do that.”

11.3 Views of service providers

- 11.3.1 Several service providers across NEL/ELFT have reported challenges in bringing carers together, particularly when accounting for sociocultural differences. They have expressed a need for more collaboration with council stakeholders and carers to address this issue.

“I think there is something about meeting the needs of the local cultural demographic, and there may be different needs from a carer’s perspective in terms of cultural background, the diversification of carers” and “we do run a group for carers of people with learning disability in collaboration with the carers centre, but in terms of the proportion of people that are known to us, it is very small.”

Tower Hamlets

- 11.3.2 Several service providers have emphasized the need for carers to be equipped with better resources to meet the complex needs of the learning



disability population. Interviewees have suggested that this could reduce the difficulties faced by carers while also improving access to appropriate healthcare for individuals with learning disabilities.

“We need to be able to offer more. I think particularly in terms of access to respite and those kinds of resources” and “So child care is something that can be complicated for these families and may interfere also in their ability to attend appointments because they've got other children that they need to care for and they can't get.”

City and Hackney

- 11.3.3 One interviewee highlighted the lack of efficacy in achieving patient information once they had been discharged from the hospital.

As a care manager, I have never received a discharge summary from a hospital. The carers get them and we rely on the carers to sort of photocopy them or scan them over to us. Technically I'm the registered manager, that should be coming to me. Never have!”

Newham

- 11.3.4 Some interviewees in Newham have reported difficulties in working with carers/parents when providing care for severe and profound cases of learning disability. Public service providers have expressed their need for more focused channels of communication when treating these individuals.

“In Newham it's a struggle, and one of the issues we have here is because our primary criteria is working with people with severe and profound learning disability, they are people the hardest to give a voice to. So, what you will find when you look at Tower Hamlets, they have a good service user forum with people with mild learning disabilities and people who can give feedback about their health experience and what they want from health services. With us it is different because their views will have to be expressed through their carers or parents.”

- 11.3.5 During the interviews a couple of interviewees expressed their discontent with the way carers were treated while accompanying someone to the hospital. Such treatment could exacerbate the mental health challenges and instances of burnout that are commonly experienced by carers.

“Hospitals making carers sit in a chair for hours, no access to a bed, no access to bathroom facilities or food (even if its hospital food) as they do not want to leave the service user” and “I guess some of the carers don't take all the respite that is offered to them.”



11.4 Future need for carers of people with learning disabilities

- 11.4.1 Approximately two-thirds of individuals with learning disabilities reside in their family homes. As both the individuals with learning disabilities and their family carers grow older, they are likely to encounter unique challenges and stresses. The impacts of aging affect both the family carers and the older individuals with learning disabilities they care for, and their situations are closely interconnected.(87)
- 11.4.2 As carers of individuals with learning disabilities grow older, they may experience age-related health problems and find it more challenging to provide the required care and support. This situation can lead to an increased demand for support services and residential care facilities. These services aim to address the needs of individuals with learning disabilities whose aging carers are no longer able to fulfil their caregiving responsibilities.
- 11.4.3 In the UK, various ongoing programs provide support for families and carers of children with learning disabilities. Short breaks are available in different forms, providing families and carers with the necessary time off from caring responsibilities. Every council is required to publish a list of available short breaks in their area. Additionally, longer breaks for quality respite care for carers may also be needed.(90)
- 11.4.4 Financial assistance is also available for parents and carers to provide adequate support for their child, including carers allowances, child benefit, universal credit, and child tax credits. Moreover, councils offer family support programs designed to provide support to groups and families with similar needs and experiences.(88)



12. Impact of COVID-19

12.1 Key findings

- The COVID-19 pandemic has had a significant impact on individuals with learning disabilities, both in terms of their clinical and non-clinical needs.
- Compared to the general population, individuals with learning disabilities were more likely to experience severe illness from the virus and up to eight times more likely to die.
- The pandemic and resulting lockdowns increased the risk of social isolation for this population. Many individuals also experienced disruptions to their routines and decreased access to healthcare services, either due to service delivery impacts or changes made to offer virtual appointments.
- There was a significant rise in safeguarding concerns for the learning disability population during the pandemic.

12.2 Recommendations

- During the COVID-19 pandemic, the shift to virtual appointments challenged health and social care professionals in identifying subtle cues related to mental health and wellbeing, resulting in increased safeguarding concerns. We recommend maintaining essential in-person appointments, such as annual health checks, for individuals with learning disabilities. Also, there should be adequate provision of digital skills training and additional accessibility support for online health services to ensure effective virtual welfare checks.

12.3 Views of individuals with learning disabilities and their carers

- 12.3.1 COVID-19 impacted service users negatively and has led to a cascade of other issues.

"A parent stated that her son left school during the pandemic, and she was unaware of available resources and services. She was recently advised to contact social services for help, but her son had lost confidence in going out, and she needed to accompany him everywhere."

- 12.3.2 Interviewees reported that a reduction in activities has resulted from a combination of factors, including cuts in funding and the impact of COVID-19. Service users expressed nostalgia for past training courses, such as first aid, wellbeing, healthy living classes, and walking groups.



- 12.3.3 Some carers reported difficulties accessing dental care during the COVID-19 pandemic. One respondent reported difficulties in obtaining dental appointments for their clients due to many dental practices closing during the pandemic. Support workers were uncertain about when service users would be eligible for free dental care, leading to further difficulties in accessing appropriate dental services.

12.4 Views of service providers

- 12.4.1 Multiple interviewees noted that the COVID-19 pandemic has resulted in a higher incidence of hospital admissions and mortality among the NEL/ELFT population, with current or underlying health conditions further exacerbated. The interviews indicated that individuals with learning disabilities were particularly vulnerable during this period.

“We have unmet needs surfacing because people were scared to access services during the pandemic, and these individuals became perhaps more unwell than they would have been ordinarily.”

- 12.4.2 Multiple interviewees noted longer waiting times, staff burnout, and closures of small services that were deemed financially unsustainable. These developments have had a negative impact on the experiences of both service users and providers.

“The last two years with COVID has really had a knock-on effect with just how stretched the staff team has become through absences or just natural attrition.”

- 12.4.3 An interviewee did mention a positive outcome resulting from the COVID-19 pandemic, as welfare checks were conducted over a wider area due to operational changes such as phone or video consultations replacing in-person health checks.

“So for some people it has opened up links that we never had before, because some families that might have been slightly isolated or less willing to engage, when we were doing our welfare checks during COVID, we called everyone on our caseload. You are suddenly making contact with families you never really had much to do with before and we were also checking that everyone had a hospital passport.”

City and Hackney

- 12.4.4 Despite demonstrating a commendable level of resilience during the COVID-19 pandemic, a significant number of service providers in City and Hackney reportedly experienced negative impacts on their wellbeing as a result of refusing to take breaks in order to manage the high caseload.



"During COVID, a challenge was the difficulty in taking regular breaks. This has led to enduring issues. While this may not be an unmet need at present, it is gradually resurfacing and causing a backlog. For carers, the pandemic has resulted in changes in routine, additional pressures, and increased stress on both physical and mental health."

- 12.4.5 As per several interviewees, service users faced significant challenges related to social isolation during the COVID-19 pandemic. Due to the substantial reduction in activities, their wellbeing, social relationships, and self-esteem were adversely affected.

"Individuals who face challenges in resuming activities that were shut down during COVID-19 may be experiencing social isolation, low mood, or anxiety. This may be particularly true for those who had limited support or became more isolated during lockdown. Moreover, many people have been isolated for an extended period due to COVID-19, leading to a loss of confidence and assurance."

Newham

- 12.4.6 According to several interviewees, the COVID-19 pandemic presented additional challenges in their role as service providers. Staff retention and recruitment shortages resulted in burnout among service providers.

I've been here four years, and for the last two, obviously COVID has not helped, we haven't had a patient participation officer to be able to do all service user works."

12.5 COVID-19 impacts

- 12.5.1 The COVID-19 pandemic had a significant impact on individuals with learning disabilities, affecting both their clinical and social well-being. Those with learning disabilities who contracted the virus were found to be at higher risk of hospitalization and death, with a five- and eight-times greater likelihood, respectively.(55) Additionally, missing Annual Health Checks could increase the risk of developing comorbidities, leading to further health complications and mortality.(89)
- 12.5.2 Socially, lockdowns disrupted routines, activities, and contact with family members and carers, leading to social isolation for individuals with learning disabilities. Moreover, digital poverty was exacerbated during the pandemic, as health services moved online, and many lacked the digital skills or access to technology necessary to access them.(52)
- 12.5.3 The COVID-19 pandemic had a profound effect on individuals with learning disabilities, disrupting their routine, activities, and contact with family members and carers due to lockdowns and enforced social isolation.(90) As previously noted, many individuals with learning disabilities also face digital poverty, which was exacerbated during the pandemic. With many health services shifting to online delivery, those without digital skills or access to technology were unable to access the necessary care and support.(52)



Impact on service delivery

- 12.5.4 Evidence suggests that during the peak of the COVID-19 pandemic, some specialist learning disability nurses who provided care in both the community and acute hospitals were redeployed to acute wards. This resulted in a gap in service provision for individuals with learning disabilities who may have required specialist nurse support.(91)
- 12.5.5 In addition, annual health checks for individuals with learning disabilities were postponed, and day centres and activities were closed, resulting in negative impacts on physical health and mental well-being. A recent report by the CQC indicated that individuals with learning disabilities experienced challenges in accessing services, including educational facilities, day services, respite care, GPs, and dentists.(92)
- 12.5.6 The disruption to services and routine caused by the pandemic led to psychological distress and negatively impacted well-being for some individuals with learning disabilities. Additionally, issues with care planning were exacerbated, and transition planning between child and adult services was found to be weak or non-existent in many areas, as reported by the CQC.(92)

Impact on service users

- 12.5.7 The COVID-19 pandemic had a significant impact on the learning disabilities population, exacerbating pre-existing and underlying conditions during the first wave of the pandemic. Individuals with learning disabilities experienced several health concerns and inequalities that were representative of the wider London population. Lockdowns implemented to slow the spread of the virus resulted in a loss of daytime activities, routine, and social contact with family and friends, which was particularly challenging for people with learning disabilities.(92) As noted by focus groups conducted by PHAST, there was a notable increase in mental health conditions due to isolation, as many individuals had limited social networks and limited digital access.

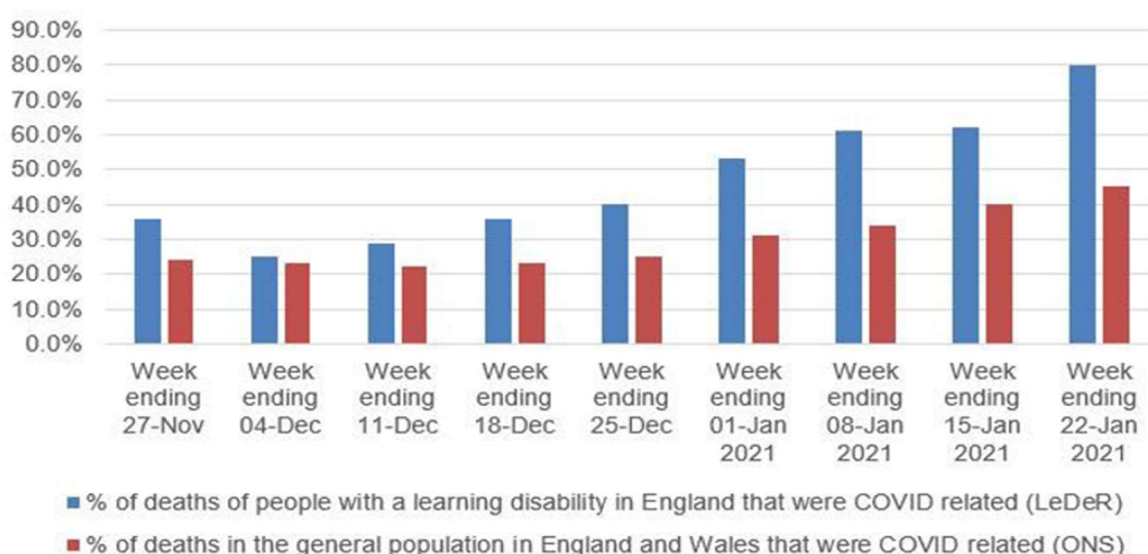


Figure 21: Proportion of COVID-19 deaths of people with a learning disability compared to the general population Nov 2019-Jan 2021(90)



- 12.5.8 Individuals with learning disabilities in clinical care settings faced a higher risk of mortality due to COVID-19, approximately 6.3 times more likely than the general population. The limited reach and adaptation of the COVID-19 vaccination resulted in fewer individuals with learning disabilities being vaccinated. There was a poor execution of service and care coordination due to inconsistent availability of liaison nurses working in acute hospitals or community-based roles.(91) In response to the impacts of the pandemic, this population experienced significant treatment delays and poor outcomes due to a decline in support staff, poor access to care, inadequate information, and inadequate adjustment to care in line with learning disability guidelines.(55)
- 12.5.9 Research has identified several other concerns regarding annual health checks during the pandemic. The shift towards digital delivery posed a risk of digital exclusion among specific populations. Although there is a clear target for the number of checks conducted, the quality of follow-ups and plans subsequently put in place is poor. A lack of understanding regarding annual health processes, compounded by knowledge gaps regarding the importance of checks among service users, resulted in a highly complicated uptake.
- 12.5.10 The COVID-19 pandemic had significant impacts on the mental health and well-being of individuals with learning disabilities and their families. Disruption to routines resulted in substantial feelings of confusion and isolation. Reports found a decline in mental health service users and increased challenging behaviours, placement breakdown, and need for short and long-term care during the pandemic. Online services may exclude individuals with poor digital literacy skills, and the virtual appointments made it more difficult for health and social care professionals to pick up subtle clues about mental health and wellbeing, leading to increased safeguarding concerns.(92) Carers took on significantly more care responsibilities, negatively impacting their own mental health and well-being. Typically, these individuals are not adequately trained to care for individuals independently, causing great stress and strain.(93)
- 12.5.11 The pandemic has also brought to light other health concerns affecting individuals with learning disabilities. There have been increased barriers to accessing oral health services, resulting in a greater risk of dental issues. Safeguarding concerns have also risen, with individuals potentially being more vulnerable due to the disruption of services and routine. High levels of obesity and poorer rates of cancer screening compared to the general population have also been identified as significant concerns.



13. Limitations

- 13.1.1 Despite our best efforts, we encountered significant limitations in obtaining data beyond a certain point for various sections of the report, which restricted our ability to provide a more comprehensive analysis. These limitations impacted the different sections of the report. Below, we summarize the specific limitations that hindered our data collection and analysis:

Population

- 13.1.2 Inability to access data related to the number and percentage of adults with learning disabilities receiving long-term support and their utilization of direct payments, disability living allowance (DLA), and attendance allowance from 2018-2022.
- 13.1.3 Unavailability of data on the number and percentage of people with learning disabilities choosing direct payments over commissioned services.
- 13.1.4 Lack of information regarding the number of people with learning disabilities receiving care packages from the local authority, disaggregated by age, gender, ethnicity, and type of service across different boroughs in East London.

Health

- 13.1.5 Inability to acquire data pertaining to the number and percentage of individuals with learning disabilities having comorbidities, categorized by learning disability type and those with multiple comorbidities.

Health service use section

- 13.1.6 Lack of data regarding the uptake of COVID-19 vaccinations by people with learning disabilities, their registration with dentists, attendance at annual oral health checks, and the number of A&E admissions categorized by learning disability type and cause of admission.

Education

- 13.1.7 Inability to access data regarding the number and percentage of people with learning disabilities accessing further education and skills-based training, students attending mainstream secondary schools/colleges versus specialist schools, and average educational attainment categorized by learning disability type.

Transition

- 13.1.8 Unavailability of data on the number and percentage of individuals who received child services but were unable or non-eligible for adult services (dropout rate from services at the point of transition), categorized by age, gender, ethnicity, and learning disability type.



Employment

- 13.1.9 Unavailability of data to assess the number and percentage of working-age adults with learning disabilities supported into full-time or part-time employment, as well as the number and percentage of unemployed individuals with learning disabilities, categorized by age, gender, ethnicity, and learning disability type across different boroughs.

Housing and accommodation

- 13.1.10 Lack of data on the number and percentage of people with learning disabilities residing in different types of accommodations, the associated costs, homelessness rates, out-of-borough placements, contracted accommodation/support service providers, the waitlist for housing support, and information on existing capacities and shortages.

Caring responsibilities

- 13.1.11 Inability to obtain data concerning the number of paid and unpaid carers, their demographic breakdown, types of employment, utilization of services such as short breaks, and average quality of life scores.

Impact of COVID-19

- 13.1.12 Lack of data on number of people with learning disability taking up COVID-19 vaccinations by age, gender and ethnicity across the three boroughs, number of people with learning disability registered with a dentist and attending annual oral health checks across the three boroughs
- 13.1.13 A&E admissions per year among people with learning disability, by learning disability category and cause of admission across the three boroughs and inpatients and outpatients with learning disability across the three boroughs



14. Conclusion and recommendations

14.1 Conclusion

- 14.1.1 Based on the data and feedback obtained through stakeholder engagement activities, it appears that while the three boroughs currently offer good support for individuals with learning disabilities, there remain areas of unmet need. Several opportunities for improving service provision for people with learning disabilities were identified.
- 14.1.2 As the number of adults with learning disabilities is expected to increase in the coming years, it is essential to prioritise the development of improved support and services to meet the growing demand. Additionally, the changing demographic of individuals with learning disabilities, shifting from a younger population to an older one, necessitates careful planning to ensure that services are tailored to meet the unique needs of this population. The provision of appropriate care and support services for older adults with learning disabilities will require a focus on specific age-related issues, such as age-related health conditions and comorbidities, and a consideration of their changing care and support needs over time. Such planning efforts will be critical to ensuring that individuals with learning disabilities receive the necessary support and care to achieve their full potential and live fulfilling lives.
- 14.1.3 Individuals with learning disabilities face significant challenges when accessing services including health, employment, housing and education due to communication barriers, inadequate facilities, rigid procedures, lack of cultural understanding and awareness, insufficient staff training, and information inaccessibility. The COVID-19 pandemic has had a severe impact on individuals with learning disabilities, who were at higher risk of severe illness and death compared to the general population. The pandemic also increased social isolation, disrupted routines, and led to decreased access to already poorly accessed services.
- 14.1.4 We make recommendations across the key sections of the report. We also highlight recommendations from key strategic local and national documents. A summary of major recommendations is presented at the beginning of the report.

14.2 Other recommendations

Improve data collection and analysis

- 14.2.1 The experiences gained during the HNA process highlight the potential for enhancing data collection, analysis, and sharing across various teams and organisations involved in learning disability services within ELFT and NEL NHS, and the three boroughs. To strengthen interagency collaboration, we recommend implementing clear data sharing agreements between the primary organisations, adoption of standardized data collection frameworks encompassing consistent definitions, data elements, and reporting formats.
- 14.2.2 We also suggest augmenting staff training to bolster comprehension and proficiency in data management. Furthermore, if not already established or



operational, Key Performance Indicators should be introduced to monitor the progress of data collection improvements, emphasizing data quality and completeness.

Asset mapping of available resources

- 14.2.3 Another recommendation is to undertake a comprehensive asset mapping initiative to catalogue and assess the available resources for learning disability services across the boroughs and within the NEL patch. This will aid service users to have a clear understanding of services available to them and will also enable stakeholders to effectively allocate resources, identify potential gaps, and foster collaboration among service providers, ultimately leading to enhanced service delivery and improved outcomes for individuals with learning disabilities.

Further work

- 14.2.4 We further recommend undertaking a follow-up project to address the gaps that could not be filled due to the constraints of this project's timeline and the limited data availability. This subsequent endeavour would focus on gathering additional data, refining the analysis, and providing a more comprehensive understanding of the learning disability services landscape.
- 14.2.5 We recommend exploring the possibility of securing funding from lottery or foundation sources to establish employment opportunities specifically tailored to the learning disability population. This financial support would enable the development of innovative programs that promote inclusion and independence for individuals with learning disabilities, fostering a more equitable job market and enhancing their overall quality of life.
- 14.2.6 In addition to traditional funding avenues, we suggest considering the use of a social impact bond as a means of financing these employment initiatives. Social impact bonds offer a unique approach to funding social projects by attracting private investment, with returns contingent on achieving predefined outcomes. This model has the potential to drive innovation, enhance collaboration among stakeholders, and ultimately lead to the successful implementation of sustainable employment programs for individuals with learning disabilities.

Greater collaboration with the third sector

- 14.2.7 There should be greater collaboration with the third sector for the purposes of awareness raising on learning disability issues, joint programming, resource sharing, advocacy and other meaningful partnerships.

Stakeholder conference

- 14.2.8 We recommend a continuation of the practice of disseminating the findings and insights from this report through stakeholder conferences and events. This event will serve as an opportunity for knowledge sharing, networking, and collaboration among professionals, fostering the exchange of ideas and inspiring the implementation of innovative solutions that can enhance the quality of learning disability services and lead to improved outcomes for individuals with learning disabilities.



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16. Appendix

16.1 Appendix 1

16.1.1 Stakeholders were interviewed from the following organisations/services:

- East London NHS Foundation Trust
- North East London Foundation Trust
- The Learning disability teams of the London boroughs of Hackney, Tower Hamlets and Newham
- Child and Adolescent Mental Health Services
- NHS NEL CCG
- Royal London Hospital
- Whipps Cross Hospital
- Forrest Gate college
- Three Cs (Hackney)
- Shared lives





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