Health and wellbeing needs assessment - adults with learning disability in Hackney and the City of London

City and Hackney Public Health Team

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Glossary and definitions

Term	Description
Black and Minority Ethnic (BME)	BME is a term commonly used to describe people who do not self-identify as 'White British'.
Body Mass Index (BMI)	BMI is a metric used to describe the body weight of individuals in relation to their height. The formula to calculate BMI is weight (kg)/height (m) squared
Care Quality Commission (CQC)	CQC is the independent regulator of health and adult social care in England. They monitor, inspect and regulate services to make sure they meet fundamental standards of quality and safety.
Cardiovascular disease (CVD)	CVD generally refers to conditions that involve narrowed or blocked blood vessels that can lead to a heart attack, chest pain (angina) or stroke.
City and Hackney Safeguarding Adults Board (CHSAB)	This is a multi-agency partnership which has statutory functions under the Care Act 2014. The main objective of the board is to assure itself that local safeguarding arrangements and partners act to safeguard adults at risk of abuse in the local area.
Department for Work and Pensions (DWP)	DWP is responsible for welfare, pensions and child maintenance policy. As the UK's biggest public service department it administers the State Pension and a range of working age, disability and ill health benefits to over 22 million claimants and customers. DWP is a ministerial department, supported by 13 agencies and public bodies.
Direct enhanced service (DES)	Direct enhanced services describe an additional provision which is provided for certain medical groups/procedures/population groups. The additional provision goes above what is agreed in general medical services contracts, therefore practices registered with DES are financially compensated for each additional service they deliver.
FACE Core Assessment and Outcomes Package	FACE Recording & Measurement Systems is the name of the company that produce several toolkits to assess risk and needs in health and social care, mental health, people with learning disabilities, young people, and people with substance misuse problems.
Hackney learning trust (HLT)	HLT is a department within Hackney Council's Children and Young People's service, responsible for children's centres, school/early years and adult education in the borough.

Term	Description
Health and social care information centre (HSCIC)	HSCIC is the national provider of information, data and IT systems for commissioners, analysts and clinicians in health and social care. It is now called NHS digital. It is an executive non-departmental public body.
Hospital episode statistics (HES)	HES is a data warehouse containing records of all patients admitted to NHS hospitals in England. It contains details of every hospital stay in English NHS Hospitals and English NHS commissioned activity in the independent sector.
Improving health and lives (IHAL)	Is the name of the Learning Disabilities Observatory which was established in 2010, following several inquiries into the premature deaths and health inequalities of people with learning disabilities. It is a collaboration between Public Health England, the University of Lancaster and the National development team for inclusion, but has been operated by PHE since 2013.
Indices of Multiple Deprivation (IMD)	The English Indices of Deprivation measure relative levels of deprivation in 32,844 small areas called Lower-layer Super Output Areas, in England. It measures 7 domains (Income, employment, health deprivation and disability, education skills and training, barriers to housing and services, crime and living environment) and produces a total score for each local authority. Most of the indicators used for these statistics are from 2012/13.
Ischemic heart disease (IHD) also known as coronary heart disease (CHD)	IHD (or CHD) is a condition that affects the supply of blood to the heart, due to a narrowing of coronary arteries as a result of a gradual build-up of fatty material within their walls. It is a major cause of death in the UK and worldwide.
Lower super output area (LSOA)	A small geographical area containing an average population of 1500 people, used to described neighbourhood population characteristics.
National Adult Social Care Intelligence Centre (NASCIC)	NASCIC is part of the HSCIC (now NHS digital). It aims to provide a single national resource of timely, relevant and useful information for social care services across England
National Institute of Health and Care excellence (NICE)	NICE produces evidence-based national guidance, quality standards and advice to improve health and social care.
Peripheral arterial disease (PAD)	PAD is a common condition, in which a build-up of fatty deposits in the arteries restricts blood supply to limbs.

Term	Description
Personalised independence payments (PiP)	PiP is designed to help with some of the extra costs caused by long-term ill-health or a disability for people aged 16-64. The amount received depends upon how the condition is assessed to affect an individual.
Projecting Adult Needs and Service Information (PANSI)	PANSI is a database provided by the Institute of Public Care (on license from the Department of Health) used to analyse population data. It produces estimates of the future projected number of adults age 18-64 with different care needs, to support local service planning.
Projecting older people population information (POPPI)	POPPI is a database provided by the Institute of Public Care (on license from the Department of Health) used to analyse population data. It produces estimates of the future projected number of older people (age 65+) with different care needs, to support local service planning.
Public Health England (PHE)	An executive agency of the Department of Health, responsible for supporting local government, the NHS and other people/organisations with public health knowledge, intelligence, advocacy, partnerships and providing specialist public health services.
Quality and outcomes framework (QOF)	QOF is a programme for the performance management and payment of GPs in the NHS.
Quintile	Any of five equal groups into which a set of data can be divided (representing 20%).
Self-assessment framework (SAF)	SAF aims to provide benchmarking data for local authorities and CCGs on the effectiveness of local services to tackle the needs of people with learning disabilities.
Systematized Nomenclature of Medicine (SNOMED)	A standardised list of terms used to describe patient care to facilitate the electronic recording of patients.
Transient ischemic attack (TIA)	A type of stroke, but where symptoms resolve within 24 hours.
Serious mental illness (SMI)	This is a technical term used in QOF reporting to mean bipolar disorder, schizophrenia and other psychosis.

1. Introduction - definitions, purpose and scope

This report describes the findings of a population health needs assessment of adults with learning disability in Hackney and the City, carried out in 2015/2016.

1.1 Defining learning disability

In general terms, learning disability is defined as: [1] [2] [3]

- having a reduced intellectual ability which inhibits learning of new, complex information and developing new skills
- having reduced social and adaptive functioning, leading to reduced ability to cope independently
- where onset was in childhood and has a lasting effect on development.

Box 1: Notes on terminology

'Learning difficulties' is not the same as learning disability. 'Learning difficulty' is often used in educational settings and refers to individuals who have specific problems with learning, such as dyslexia or dyscalculia. However, many people with learning disabilities prefer to use the term 'learning difficulty'.

Increasingly, international organisations and other countries use the term 'intellectual disability'– this term should be considered interchangeable with 'learning disability'.

Learning disability has a number of causes, including genetic conditions, labour complications, maternal infections during pregnancy, maternal lifestyle/behaviour, and early childhood infections (see Appendix for more detail).

Learning disability affects people in different ways, sometimes defined in terms of 'levels' of disability, as described in ***Box 2***. However, the prevalence estimates used in this report are not based on this definition – see section 3.4 for a discussion of the challenges relating to inconsistencies in classification of learning disability used in different settings.

Box 2 ICD-10 Categorisation of learning disability

Mild: ICD-10 classifies this group as having an IQ status between 50 and 69, which roughly corresponds to a child of 9-12 years. [4] This group encompasses individuals who have ability to hold conversations, communicate their needs and mostly live independently, with some assistance with complex issues. [5]

Moderate: ICD -10 criteria classifies this group as having an IQ status between 35 and 49, which roughly corresponds to a child between 6-9 years of age. [4] Socially, individuals in this category would be able to communicate with some basic language skills and would be able to carry out day-to-day tasks themselves with some support. [5]

Severe: ICD-10 criteria classifies this group to have an IQ between 20 and 34, which roughly corresponds to a child of aged between 3 and 6. [4] Individuals in this group have very basic language skills and communicate with use of words and hand gestures. Likely to have additional medical needs and require more support with day to day living. [5]

Profound: ICD-10 criteria classifies this group to have an IQ of less than 20, which roughly corresponds to a child of aged under three. [4] Individuals have significant difficulty communicating and characteristically have very limited understanding. Many people express themselves through non-verbal means, or with minimal a few words or symbols. Patients in this group also may exhibit challenging behaviour. [5]

1.2 Purpose of this needs assessment

Adults with learning disability are at increased risk of poor physical and mental health, are disproportionately affected by socio-economic disadvantage (including unemployment, poverty and social isolation) and have a significantly lower life expectancy than average. The failure of the health and care system to meet the complex needs of this population has been highlighted by a number of high profile reviews, notably the report of the Winterbourne View ‘scandal’. [6] [7]

A population health needs assessment was undertaken to review the health and wellbeing issues facing the adult learning disabled population in the City and Hackney, assess the adequacy of local services to meet these needs, and inform service planning to address any gaps identified.

The specific objectives of this needs assessment are set out below, along with the relevant chapter(s) of this report that address them.

Table 1: Objectives of this needs assessment

Needs assessment objectives:	Covered in chapter:
• Describe the prevalence of adult learning disability in Hackney and the City	6. Prevalence of adult learning disability in Hackney and the City
• Quantify the health conditions and social determinants of health affecting this population	5. National context - health inequalities in adults with learning disability 7. Health and wellbeing needs of learning disabled adults in Hackney and the City
• Summarise best practice recommendations for meeting these needs	4. National policy & evidence review
• Describe current health and related services and support available locally for adults with learning disability	8. Local services and support
• Make recommendations for commissioning and service provision, based on the evidence presented	9. Conclusions and recommendations

1.3 Scope

The data and evidence presented in this report primarily cover adults aged 18 and over who are living, or registered with a GP, in Hackney or the City of London local authority areas.

A disabled children's needs assessment being undertaken in 2016/17 will complement the findings of this adult assessment, and will cover transition services in more detail.

2. Key findings

This chapter summarises the key findings of each of the main chapters of this report, on which the conclusions and recommendations in Chapter 9 are based.

2.1 National policy and evidence review (Chapter 4)

As described above, a number of key policy documents have been published in recent years which aim to protect and promote the health and wellbeing needs of people with learning disabilities. These policies are a response to evidence of significant health inequalities, vulnerability to abuse, poor access to needed services and lack of choices available to enable independent living. In broad terms, the following themes are identified as key to meeting the needs of people with learning disabilities within the health and care system:

- independence and choice
- care closer to home
- reducing inappropriate hospital admissions and residential placements
- integration of services (including health and social care, housing and employment support)
- workforce development.

A summary of the key recommendations emerging from the rapid evidence review is provided below.

Organisation of health and care services

- All people with learning disabilities should be offered support to access mainstream services through reasonable adjustments. However, specialist services should also be considered as a complement to current services as needed.
- Healthcare staff should be regularly trained to meet the needs of people with learning disabilities.
- People with learning disabilities should be identified as early as possible to support their access to care.
- Learning disability and related health needs should be recorded routinely, and this data used to monitor, review and inform service design and planning.
- Regular health checks should be proactively offered and consideration given to how to improve uptake of population screening programmes in adults with learning disability.
- Health and healthcare information should be accessible, easy to read, and proactively disseminated to people with learning disabilities and their carers. Information must be culturally appropriate and respond to language barriers.
- Physical environments of health and care services should be made as accessible as possible for people with learning, as well as physical, disability. Accessible transport options should be made available to travel to/from appointments.

- Effort should be made to enable communication and consent. Patients should be offered extended appointments. Healthcare professionals must adhere to the Mental Capacity Act.
- Communication within and between agencies must be improved and joint working should be encouraged. A named health professional should coordinate the care of those with multiple health conditions. Primary care and acute liaison nurses should be integrated into local commissioning plans.
- People with learning disabilities should be actively involved and represented in the design of services.
- Health Action Plans should be informed by regular health checks and used to support a patient to take care of their own health. Hospital Passports can facilitate information sharing between services.
- Carers must be supported in their caring responsibilities and to engage in social and leisure activities of their own. Carers must have access to regular breaks. The health needs of carers must be understood and addressed.

Managing the health needs of adults with learning disability

- Evidence is lacking for some of the most important health needs of adults with learning disability (including respiratory and circulatory disease) and there is little published guidance on how to manage co-morbidities in this population.
- Early detection of co-morbid health conditions can be difficult in people with learning disability. Families, friends and carers play an important role in identifying and managing these health needs, and should be involved (as appropriate) in decisions about their care.
- All adults with Down’s syndrome should be assessed for dementia by the age of 30 to provide a baseline for future assessments.
- There is strong and growing evidence for the effectiveness of a range of behavioural and psychological interventions in the management of behaviour that challenges.
- Dedicated sexual health clinics for people with learning disabilities can help to address significant unmet need in this population.
- On average, adults with learning disabilities are less likely to be physically active, more likely to have a poor diet and to be obese than non-disabled adults, and should therefore be prioritised in local obesity strategies.
- Carers should be educated and supported to address the oral health needs of people with learning disability and specialist treatment should be available for residents of care homes.
- Evidence-based prevention and treatment pathways should be in place for dysphagia in people with learning disabilities.

Housing support

- Planning for future housing needs in a local area must take account of the adequacy of accommodation available for people with learning disabilities.
- Support should be offered to access housing applications and waiting lists, as well as alternative accommodation such as the private rental sector or home ownership.

- For people with learning disabilities who live with older parents or carers, future accommodation needs should be planned well in advance to avoid emergency or crisis situations.
- Information about housing and support services must be clearly communicated in an accessible, easy to read format.
- People with learning disabilities should be enabled to make informed choices regarding their accommodation. Housing options should be presented and discussed.
- Best practice guidance suggests there should be a clear separation between housing and support provision, to avoid a single organisation acting as both landlord and support provider.
- People with learning disabilities should be supported to live independently, when appropriate and in line with individual preferences. Suitable home adaptations should be available to enable independent living.
- Clinical Commissioning Groups (CCGs) may consider allowing use of Personal Health Budgets to pay towards housing costs, if this meets a health need and is agreed as part of a care and support plan.
- Housing services should be evaluated using the views of people with learning disabilities and their carers.

Employment support

- Improving access to employment for adults with learning disabilities should be made a central strategic priority for local authorities.
- Employment should be promoted as an option early in transition planning. The idea that people with learning disabilities are ‘incapable’ of employment must be challenged.
- Further education must prepare people with learning disabilities who want to work to gain employment. Educational institutions should link with employment services to facilitate this transition.
- Supported employment should be offered to aid people with learning disabilities to gain and retain paid work.
- The needs and objectives of people with learning disabilities and employers should be taken into account when planning employment options.

2.2 National context – health inequalities in adults with learning disabilities (Chapter 5)

People with learning disabilities are known to have greater heath needs compared with the general population and a greater likelihood of dying prematurely. However, access to services is often difficult and a significant amount of morbidity remains untreated, resulting in avoidable deaths.

Specifically, adults with learning disabilities:

- have a shorter life expectancy then the general population (an estimated 20 years shorter for women and 13 years for men)
- are more than twice as likely to have co-morbid health problems than other adults, in particular:

    - respiratory disease, which is a major cause of premature death
    - severe mental illness
    - early onset dementia
    - epilepsy (a common cause of preventable hospital admissions in this population)
    - diabetes, obesity and physical inactivity
    - sensory impairment
- are less likely to attend regular health checks or take up population screening programmes
- experience significant untreated morbidity due to delays/problems with diagnosis and treatment and poor response to changing needs within the health and care system
- often live in relative deprivation and can be socially isolated, due to reduced employment opportunities and inadequate living conditions.

2.3 Prevalence of adult learning disability in Hackney and the City (Chapter 6)

- Estimates suggest that 2.4% of adults in the City and Hackney population have a learning disability (ranging from 2.6% in those aged under 45, to 1.8% in those aged 85+) - this equates to 4,937 people in Hackney and 177 people in the City in 2015.
- Almost one quarter (22%) of adults with a learning disability are estimated to have a moderate or severe condition. This is more common in younger age groups.
- Overall, in line with expected population trends, the size of the local adult learning disabled population is expected to grow over the next 15 years (to 2030), by around 900 people (or 17%). Around 200 people are expected to be living locally with a moderate/severe learning disability by 2030.
- Approximately 0.4% of adults registered with a Hackney or City GP were *recorded* as having a learning disability (based on QOF register) in 2014/15. There is significant variation in the recorded prevalence of learning disability between GP practices.
- Comparing estimated prevalence with GP recorded prevalence suggests that as many as 200 adults with moderate/severe learning disability may not be known to their GP (nearly 4,200 with any learning disability – including those with mild disability).
- In line with modelled estimates, there are a greater number of men than women with learning disability known to local services (a ratio of 1.4:1 on GP records and 1.6:1 on the adult social care caseload).
- Since March 2010, the number of learning disabled adults receiving a care package from Hackney Council has decreased by almost 30%, with this fall most notable among females. One third of these clients are having their care needs met out of the borough (primariy residential care). Equivalent data for the City of London are not available.
- The greatest proportion of adults with learning disability in contact with local services are classified as British/White British/Mixed British/English (around

30%). A relatively high proportion of adults receiving a care package in Hackney identify as Jewish.

- People with a learning disability are more likely to be living in the most deprived local neighbourhoods compared with the total population (according to GP data).

2.4 Health and wellbeing needs of learning disabled adults in Hackney and the City (Chapter 7)

Common coexisting conditions

- There are significantly higher rates of SMI in adults with learning disability, with around 14% of learning disabled patients affected locally (in comparison to around 1% of the total adult patient population). Provisional national data indicates that local rates are higher than might be expected (around 9% of learning disabled patients nationally coded with SMI).
- The majority of inpatients with a learning disability in London are receiving care/treatment under the Mental Health Act (74% of patients) and most had received anti-psychotic medication within the past 28 days (81%).
- Despite adults with learning disability being at greater risk of developing dementia and at a younger age, there is significant under reporting of dementia in the local learning disabled patient population, with only 11 patients recorded in City and Hackney GP practices (7 of whom were over the age of 65). Adults with a learning disability make up an *estimated* 6.5% of the total estimated number of dementia cases in the City and Hackney.
- An estimated 90 learning disabled adults display challenging behaviour in Hackney and the City.
- Around 13% of local learning disabled GP patients have epilepsy, which compares to less than 1% of all patients in the City and Hackney, but is below the range of prevalence estimates for people with learning disability in the literature. A significant portion of all A&E attendances by adults with a learning disability are related to seizures or epilepsy.
- There is good recording of BMI in learning disabled patients known to primary care. Local learning disabled GP patients are almost twice as likely to be obese as adult patients in general, primarily in younger age groups ($\leq$44 years). ‘Underweight’ is also much more common in learning disabled adults locally than in the wider GP patient population.
- The prevalence of asthma is significantly higher amongst local learning disabled GP patients than in the total adult patient population.
- Locally, as nationally, dysphagia is likely to be significantly under-reported in the local adult learning disabled population.
- Learning disabled GP patients in Hackney and the City are twice as likely to have diabetes as people in the total patient population (age 18-34)
- Over half of learning disabled adults are estimated to have a visual impairment, although currently there is no data to quantify this locally.

- There is significant underreporting of ASD in patients with learning disability despite strong associations between the two conditions.
- Only just over half the expected number of Down's Syndrome patients are recorded as such on local GP systems, but this is likely due to coding issues rather than representing a significant unmet need.

Cancer screening

- Locally there is significantly lower uptake of cervical screening in eligible women with learning disability than in the total female patient population. Reasons cited focus on the assumed sexual inactivity of women with learning disability, but this is based on anecdotal evidence only.
- There is no reliable source of data on which to base a robust assessment of local uptake of bowel and breast cancer screening in the eligible learning disabled population.

Behaviour/lifestyle

- A slightly smaller proportion of local learning disabled GP patients are recorded as current smokers compared to the total adult patient population. However, as most patients on GP registers are thought to have a moderate/severe form of learning disability (who are less likely to be smokers), it is likely this is not capturing the higher rate of smoking reported in the literature for people with mild disability.

Carers health

- There is very little information regarding the health and wellbeing needs of people who care for adults with learning disability specifically.
- Around a quarter of all Hackney respondents to the Adult Social Care Carers' survey reported caring for someone with a learning disability. In general, carers locally (as nationally) have significant health and wellbeing needs.

Wider determinants of health

- Adults with learning disability who are in contact with social care services are unlikely to be in paid employment. In Hackney, the employment rate is significantly lower than comparable areas in London (Hackney rate 2.9%, CIPFA comparator group rate 6.2%).
- Employment and welfare benefits services in Hackney are currently unable to identify clients with a learning disability.
- Around 40% of adults with learning disability are estimated to be living with their parents. This is much more common in younger age groups. The predicted ageing of the local adult learning disabled population is likely to create additional support and housing needs over the next 15 years and beyond.

- Since 2012, the number of adults with learning disability (in contact with social care services) who are in ‘settled accommodation’ has been declining.
- Overall, almost 40% of learning disabled adults with a care package in Hackney are in residential or nursing care; almost all of these adults are placed out of borough.
- Local learning disabled adults are at significant risk of social isolation.

2.5 Local services and support (Chapter 8)

- There are several integrated services within Hackney and the City of London designed to support the health and wellbeing of adults with learning disability. Service integration mainly comprises of health and social care service elements, with fewer links observed between employment and education provision.
- There is no formal transitions service within Hackney or the City of London that caters for the health and social care needs of people moving from children’s to adults’ services. Current arrangements in Hackney are complex and can lead to delays which can affect continuity of care.
- For young people who are not expected to be eligible for adult social care services, a transitions team within the Hackney Ark supports their health and wellbeing needs.
- Data systems and reporting practices are not currently adequate to identify learning disabled adults who are accessing different elements of the local Integrated Learning Disability Service (i.e. those who may not be eligible for social care, but are getting specialist support from health teams).
- Implementation of the primary care DES for people with learning disability in Hackney and the City shows increasing numbers of patients being identified and a high level of uptake of annual health checks.
- Over 80% of Hackney learning disabled adults placed in residential care are placed out of borough.
- Apart from mainstream NHS services, other relevant health services for people with learning disability in Hackney include support via the council’s sensory team, community special dental care services, plus a specialist sexual health clinic (being funded as a 12 month pilot).
- Social housing services in Hackney and the City are universally available through the relevant teams in each area. People with a learning disability do not have specific provision under the Housing Act, but (as for all residents) if they are assessed as having a ‘priority need’ then additional support is available. It is not currently possible to identify socially rented households where people with a learning disability reside.
- A range of specialist housing provision (of varying support levels and types) is delivered through Hackney and the City of London for people who meet the eligibility criteria for adult social care services. For people who do not meet this criteria, specialist provision can be purchased on the open market.
- Hackney Community College provides specialist support for students with a learning disability, but no data on participation have been made available for analysis for the purposes of this needs assessment.

- Employment support is available to adults with a learning disability in Hackney through mainstream and specialist services.
  - Mainstream services are unable to identify or report on the number of adults with learning disability who are using their services. Disability specialist advisors are in place at all Jobcentre Plus sites, but no specific employment pathway exists for jobseekers with learning disability.
  - Specialist employment services in Hackney offer pre-employability courses and work placements for people with learning disability.
  - Awareness of specialist employment support provision within local mainstream employment services appears poor.
- It is not possible to identify/quantify the number of adults with a learning disability who are claiming welfare benefits locally through current data recording systems.

3. Methods and limitations

3.1 Introduction

This chapter aims to give a brief overview of the methods used to capture and describe the health and wellbeing needs of adults with learning disability in the City and Hackney. The chapter is structured around the key chapter headings used in this report. Some of the methodological and data limitations which may affect the results and conclusions are highlighted.

3.2 National policy and evidence review

3.2.1 National policy review

The information provided on relevant national policies described in Chapter 4 was obtained through a pragmatic literature search of key policy documents on the HM Government and NHS England websites. In addition, reports and other publications from national voluntary organisations representing people with learning disabilities were also reviewed. Where relevant, references in these reports were followed up for further information.

Websites were searched for relevant reports since 2011, the year of publication of *Valuing People.* [8]

Updates on progress against key policy recommendations are current as of September 2016.

3.2.2 Rapid evidence review

Methods

The evidence review used a multi-methods approach. First, search terms were collaboratively designed to encapsulate relevant nomenclature related to learning disabilities and health, housing, and employment. The first draft of the search terms used are in ***Box 3*** below.

Box 3: Search terms (first iteration)

Healthcare Search

("Learning disabilit*" OR "Learning difficult*" OR "Intellectual disabilit*" OR "special education* need" OR "SEN" OR "S. E. N." OR "S.E.N." OR "Mental retardation" OR "Mental Handicap*") AND ("health care*" OR "healthcare" OR "health service*" OR healthservice* OR "health support" OR "health and social care" OR "health protection" OR "health promotion" OR "wellbeing" OR "wellness" OR "medicine" OR "medical" OR "clinic*")

Employment Search

("Learning disabilit*" OR "Learning difficult*" OR "Intellectual disabilit*" OR "special education* need" OR "SEN" OR "S. E. N." OR "S.E.N." OR "Mental retardation" OR "Mental Handicap*") AND (job* OR employ* OR work* OR career* OR unemploy*)

Housing Search

("Learning disabilit*" OR "Learning difficult*" OR "Intellectual disabilit*" OR "special education* need" OR "SEN" OR "S. E. N." OR "S.E.N." OR "Mental retardation" OR "Mental Handicap*") AND (Hous* OR "Social Hous*" OR Rent* OR "Private Rent*" OR "Social* Rent*" OR Home* OR Homeless* OR "Rough sleep*" OR shelter* OR residenc*)

Next, the search terms were employed on multiple databases; NHS Evidence was primarily used for this review given its focus on health and social care literature. The search terms were then revised and simplified to fit the framework of each database.[1] Health-specific search terms were also employed to target areas where there was a paucity of evidence (for example, 'learning disabil*' and smoking). The review was limited to evidence produced since 2000. To supplement the evidence generated by the database search, a purposive search of the grey literature was also undertaken (including national policy documents).

Data Sources

As already mentioned, NHS Evidence was the primary data source used for the review. NHS Evidence sources include the British National Formulary, Clinical Knowledge Summaries, SIGN, the Cochrane Library and Royal Colleges, Social Care Online and GOV.UK.

To supplement the evidence retrieved from NHS Evidence, a purposive search of the grey literature was also undertaken, including:

- relevant guidance produced by the National Institute of Health and Care Excellence (NICE)
- government policy documents, in particular from the Department of Health

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[1] Please see https://www.nice.org.uk/about/what-we-do/evidence-services/evidence-search/how-to-search for further information on generating a search term for NHS Evidence.

- specialist learning disability organisation websites, including Mencap; other volunteer and community sector organisations that focus on specific health or social care areas relevant to learning disabilities were also included
- Public Health England's (PHE) *Improving Health and Lives* (IHAL) Learning Disabilities Observatory - recent publications and archives.

Limitations

The rapid evidence review has attempted to be as comprehensive as possible within the time and resources available. However, it is possible that some relevant research or policy papers have not been identified and, therefore, their recommendations not reflected in the results.

3.3 National context - health inequalities in adults with learning disabilities

Publications on the IHAL website were the main sources of information for Chapter 5. References contained within these publications were followed up for further detail where relevant. This information was supplemented by materials from the public Health England (PHE) Learning Disabilities Conference 2016, which are based on data from GP records in England. [9] The CIPOLD study was also used to highlight the main causes of premature death in this population. [10]

OpenAthens, National Elf Service and the Cochrane library resources were utilised to identify prevalence rates of different conditions in the general population compared with the learning disabled population.

3.4 Prevalence of adult learning disability in Hackney and the City

A number of different sources of data on local prevalence of learning disability have been used for the purposes of this needs assessment.

3.4.1 Prevalence estimates (POPPI and PANSI)

PANSI – projecting adult need and service information

POPPI – projecting older people population information

Methods

POPPI and PANSI are systems provided by the Institute of Public Care and Oxford Brookes University. The platforms provide a practical analysis of research and literature into the services and support needs of the population. For the provision of learning disability prevalence estimates, research from the Centre of Disability Research at Lancaster University (on behalf of Mencap) is used. [11]. The original paper (2004) made adjustments for ethnicity and mortality, this was updated (2008). POPPI and PANSI have applied these predicted prevalence rates to ONS population projections (2011) in order to provide local authority estimates.

The methodology underpinning the prevalence estimates used in this report is described in ***Box 4*** below:

Box 4: Methodology for producing local authority prevalence estimates for adult learning disability [11]

1. The number of children with Special Educational Needs (SEN) associated with learning disability in England was ascertained from the Department of Children, School and Families' (DCSF) spring 2008 School Census.

2. These data, adjusted for the effects of mortality, were used to estimate the number of children SEN associated with learning disability in England who would reach 18 years of age between 2009 and 2026.

3. Upper, middle and lower estimates of the percentage of these children likely to become eligible for adult social care services under current Fair Access to Care Services (FACS) eligibility criteria were then derived.

4. Information from the Information Centre for Health and Social Care and information extracted from the Sheffield, Merton, Sutton and Lambeth learning disability case registers was used to estimate the number and age profile of adults with learning disabilities who were using social care services in 2008.

5. The population of current adult service users was adjusted for the expected effects of mortality over the period 2009-2026.

6. These data were combined with estimated inflows from child services to estimate net changes in need over the period 2009-2026. For each of the three estimates of eligibility (upper, middle, lower), three scenarios to the rationing of adult social care were investigated, as follows:
    a. adult social care only available to people with critical or substantial need
    b. adult social care only available to people with critical or substantial need and 50% of people with moderate need
    c. adult social care available to people with critical, substantial or moderate need.

Limitations

Limitations of the research (by Emerson & Hatton) which underpins the prevalence estimates from POPPI and PANSI are listed below.

- The different forms and complexities of learning disability are not fully understood in the literature. This presents challenges in the classification, reporting and measurement of needs in this population and will influence the population captured in this research
- Historically, the diagnostic criteria for individuals who are thought to have a learning disability has required subjective judgement on the part of a health professional. This leads to a lack of consistency in diagnoses, documentation and reporting of the health and wellbeing of people with a disability and will influence the population captured in this research.

- There have been reports of lack of awareness and understanding of learning disability from some health professionals, particularly regarding the differences between a learning difficulty and a learning disability (see section 1.1). This contributes to the challenges of classification, reporting and measurement of need in this population.
- The stigma associated with learning disabilities may evoke a reluctance to disclose any problems to professionals, or to access services at all which will influence the population captured in this research.
- There is a decrease in the surveillance of people with a learning disability post-education (often around the age of 18) by health and social care agencies which means there is less chance of a diagnosis being made and therefore will limit the population captured in this research.
- Once individuals leave an educational setting, the disabling impact of having a learning disability can be less visible to others which will make it less likely to get a diagnosis which will affect the population captured in these estimates
- The eligibility criteria for specialist social care services may be a deterrent for some individuals who may feel they do not meet the level of need required which limits the application of those estimates as having a moderate/severe form of learning disability.

The methods used to apply prevalence estimates to the Hackney and City of London population also have limitations which include the following.

- Estimates of the life expectancy of people with learning disability have not been updated since 2010. The prevalence estimates may therefore be conservative, as they are not sensitive to recent improvements to life expectancy for people with a learning disability.
- Prevalence estimates do not account for the unique ethnic diversity of Hackney, in particular the Charedi community in the north of the borough, a traditional and self-contained community with large families. Local evidence from the Interlink Foundation (a voluntary organisation representing this community) indicates that rates of learning disability may be higher in this population, although evidence from adult social care and GP data is not conclusive (see Chapter 6). The original prevalence estimates used in the model adjusted for higher rates of learning disability observed in South Asian communities, but not other minority ethnic groups.
- POPPI and PANSI give estimated values for the *total* number of people with a learning disability, and separately for the number with a *moderate* or *severe* disability. For the purpose of this report, it has been assumed that the difference between the total number and the number with a moderate/severe disability is the number with a ‘mild’ learning disability. However, this classification is not necessarily reflective of the level of ‘need’ or ‘potential for harm’ which determines eligibility for care (which is based on different criteria).

The data presented in Chapters 6 and 7 use comparator groups to identify whether local prevalence of learning disability are higher/lower than expected. The comparator boroughs/regions are taken from CIPFA[2] classifications which take into account a range of socio-economic factors in producing groupings of ‘statistically comparable’ areas. Inevitably, as in all areas, both Hackney and the City of London have unique attributes which cannot all be accounted for through statistical classification processes. That said, CIPFA comparators are deemed to be reasonably reliable for the Hackney population, but significantly less so for the City.

3.4.2 Local service data

GP data

GP data used in this report are taken from the following sources, along with supporting bespoke datasets extracted by the Clinical Effectiveness Group (CEG) for the purpose of this needs assessment:

- primary care DES – direct enhanced service (2014/15; 2015/16)
- QOF – Quality and outcomes framework (2014/15; 2015/16)
- SAF – Self-assessment framework (2014/15; 2015/16)
- bespoke data extracts (April 1st 2015 and 2016).

Methods

Patients with a learning disability are recorded by GP practice information systems (EMIS) and can be coded either to the Quality and Outcomes Framework (QOF) learning disability register or the Direct Enhanced Services (DES) register.

Generally, those individuals on the DES register are known to other services (such as adult social care), are likely to have a confirmed diagnosis of learning disability and a more severe impairment. This register has been in existence since April 2014. The QOF register has been in existence since 2004.

For the purposes of this needs assessment, the QOF register has been used to describe the number of people known to primary care services. This is because this source is likely to be more complete (as it has been in place for longer) and is considered to be more representative of local residents at this current time. As the DES register becomes more established, this is likely to change (see limitations below).

Limitations

The number and proportion of patients recorded with a learning disability at each GP practice is likely to be affected by several factors, such as:

- geographic variation in underlying prevalence of learning disability
- proximity to local specialist learning disability services (e.g. Yad Veozer supported living scheme close to one particular GP practice)
- size of practice
- clinical special interest of GP located in the practice

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[2] CIPFA - The Chartered Institute of public Finance and Accountancy

- patient choice of practice based upon cultural factors associated with care
- coding practices (coding of learning disability on GP records can be affected by staff knowledge/understanding of learning disability and administrative practices).

Anecdotally, the QOF register is likely to contain adults who may have been coded incorrectly with a learning disability in the past, with an impairment/disability originating from a different aetiology (e.g. dementia/brain injury). It is likely that the needs of individuals on the QOF register are similar to those with a learning disability, but there is a greater chance of miscoded diagnoses on the QOF list compared with DES.

Finally, and importantly, these data are unlikely to capture 'usual residents',[3] homeless people, traveller communities and recent migrants - all of whom are less likely to be registered with a local GP. Other residents who are registered with a GP outside of Hackney or the City are also excluded.

Hackney adult social care data (data extracts from the Hackney performance team)

The main sources of data on learning disabled adults know to social care services in Hackney are listed below. Due to small numbers, the same sources cannot be used to report equivalent data for the City of London.

- SALT (Short and long term) statutory return data
- ASCOF – Adult Social Care Outcome Framework
- bespoke data analysis (extracted March 2016 by Hackney Council's performance team)

Councils with adult social services responsibilities (CASSR's) are required to submit data to the government on the number of adults receiving services from the local authority, on an annual basis to contribute to the SALT and ASCOF reports. This data is captured through the Mosaic social care database which records all social care activity within Hackney teams (and some external partners).

A bespoke data extract for this needs assessment was made using identical methods as discussed for SALT and ASCOF reports (above) by the council's adult service Performance Team.

Limitations

The Care Act (2014) determines service eligibility against a person's ability to complete specific tasks related to daily living and whether their area of need has a significant impact on their wellbeing. The past eight years have involved several legislative and organisational changes to adult social care services across England. These changes have affected service eligibility, organisational structures and payments for services for adults with learning disabilities; all of which affect the data

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[3] 'Usual residents' is a term used where there are no suitable care facilities available locally so the individual resides in another area/region, but their entitlements and social care is paid for by the City or Hackney. In these cases, it is likely the individual would be registered at a practice closer to their residential address.

available and included in this report, and present limitations in the interpretation of comparisons over time.

Data were derived from the statutory reporting of care packages funded by local authority social care; data on non-costed services provided by health professionals (e.g. occupational therapy and psychology) are not available and are therefore not represented in social care data.

Due to the nature of service use and method of data collection, the annual snapshot data used in the bespoke report may not capture clients who have more seasonal or intermittent use of services.

The lack of data from the City of London means transferability of the findings from this needs assessment to (the very small number of adult learning disabled) residents of the City may be limited.

Finally, these data are only able to describe adults who are eligible for adult social care, which is to say those assessed with a 'critical' or 'substantial' need as defined under the Care Act.

Hospital utilisation data

Information on use of hospital services by learning disabled patients was obtained from a bespoke data extract (December 2015) provided by Homerton University Hospital Foundation Trust (HUHFT).

Methods

All patients with a coding of learning disability (SNOMED code F819) [4] attending HUHFT between 1st April 2014 and 15th December 2015 were extracted from hospital records. Anonymised patient data was used to determine presence of various medical conditions and number of attendances in different departments. Information was presented for the following patients:

- all patients attending accident and emergency (A&E)
- all inpatient discharges
- all outpatient appointments.

Date of birth was not available for all datasets and so any attendances, discharges or appointments in paediatric departments were excluded for reporting purposes.

Limitations

Hackney residents, and in particular City residents, may present at hospital sites other than HUHFT - such as University College Hospital, The Royal London Hospital, St Bartholomew's Hospital and other specialist hospitals (such as Moorfields Eye Hospital). However, data from these sites were not available for this assessment. Likewise, patients residing in other boroughs may attend Homerton

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[4] SNOMED - Systematized Nomenclature of Medicine – a standardised list of terms used to describe patient care to facilitate the electronic recording of patients

hospital and be counted in the figures reported. Based on outpatient data, around 7% of attendances were residents of other local authority areas (mainly Islington residents).

The acute liaison nurse for learning disability and the epilepsy specialist nurse, following a review of patient notes, have confirmed that the number of patients coded with learning disability is likely to under-represent the actual number of learning disabled patients in contact with their services.

As alluded to earlier, these data do not present a fully accurate picture of the number of *adult* patients coded with learning disability, due to missing information on date of birth. As an approximation, all entries relating to care in a paediatric department were excluded from this analysis, although it is possible that some patients under the age of 18 will be captured in these data.

Finally, it is important to note that the absence of individual identifiers in the anonymised patient data extracted for this assessment mean that numbers maybe significantly over-estimated, if repeat attendances are common in learning disabled patients.

3.4.3 Estimates of unmet need

The assessment of unmet need in the City and Hackney is dependent upon the accuracy of prevalence estimates. As the POPPI and PANSI estimates do not include confidence intervals, the accuracy of the predictions are not clear and, therefore, the level of local unmet need could be over or under inflated.

Importantly, the number of ‘known’ learning disabled adults does not include those residents not recorded on local GP registers. This includes people registered with a GP in another borough, those not registered with a GP at all (including homeless people, travellers, recent migrants and ‘usual residents’) and those whose care needs might be being wholly met through family or friends (and therefore not known to their local GP).

In general, prevalence estimates of specific health conditions reported in the literature are not available as age-standardised rates. This is likely to lead to inaccurate *local* prevalence estimates when these rates are applied to the very young population profile of Hackney and the City. Similarly, the highly ethnically diverse, urban population of Hackney and the City may render some regional and national comparisons invalid.

3.5 Health and wellbeing needs of learning disabled adults in Hackney and the City

3.5.1 GP data

The main source of data on health needs of adults with learning disability in Hackney and the City is GP records (see also section 3.4.2). A number of limitations with using this data source for this purpose are outlined below.

- Some patients with a learning disability may have more frequent contact with their GP than patients in the general population, for example as result of the DES annual health check programme (section 8.3.1). Therefore, comparisons between learning disabled patients and the total patient population may be misleading in some cases where health issues in the latter may be not be as accurately recorded (a good example of this is body mass index, or BMI, to determine levels of overweight and obesity – see section 7.2.9).
- Small numbers mean that it can be difficult to make reliable comparisons of sub-groups of patients (for example comparison of conditions by age).
- People with severe mental illness (SMI) and learning disability may be more likely to have their care needs met outside of the borough, due to the need for specialist services reflecting the complexity of their co-existing conditions. This may result in fewer such patients being registered in City and Hackney GP practices, and so this source of data may under-represent the ‘true’ numbers known to services.
- Coding and management of depression on QOF is associated with financial incentives for GP practices. However, several of the tools used to monitor and assess patients with depression have been criticised as inappropriate for use in patients with a learning disability. This has led some observers to hypothesise that, as a result, practices are less likely to record depression in adults with a learning disability, as the incentivised outcomes are not achievable in this population. [12].

3.5.2 Adult social care data

The FACE tool collects information on how a person’s mobility is affected by their weight. This is a subjective assessment and does not distinguish between mobility being impaired by a person being underweight or overweight/obese. However, anecdotally it is most commonly excess weight that is believed the main cause (see section 7.2.9).

3.5.3 Learning Disability Census

The Learning Disability Census responds to a recommended action in *Transforming care: A national response to Winterbourne View* (see Chapter 4), by recording key information about the location and level of inpatient care for patients with learning disabilities and/or autistic spectrum disorder (including Asperger's). The census is focused on inpatients receiving treatment or care in a facility registered by the Care Quality Commission (CQC) as a 'hospital' (either NHS or private).

To appear in the census, patients must meet one of the following inclusion criteria:

- have a diagnostic category of learning disability (ICD-10 code F70-F79)
- have a diagnostic category of autistic spectrum disorder (ASD) (ICD-10 code F840, F841 or F845)
- the predominant service type of the ward where care is being provided is for learning disabilities.

Limitations

The ICD-10 codes used to identify census participants use a narrow definition of learning disability, referring only to intellectual capacity as a diagnosis.

Moreover, the dataset does not exclusively look at patients with learning disability, as the inclusion criteria also counts patients with autism who do not have a learning disability. However, there is significant crossover between these two patient groups (as discussed in section 7.2.11).

Finally, the census includes patients of all ages, not exclusively those aged 18+ and is, therefore, not comparable to other data in this report which is based on adults only.

3.5.4 Community survey

A short community questionnaire was developed with the primary aim of eliciting directly from adults with learning disability what their health and wellbeing needs are.

The survey was developed in consultation with the Integrated Learning Disability Service, POhWER advocacy group and the acute liaison nurse for learning disability. A copy of the questionnaire is included in Appendix E.

The survey was carried out with groups of adults with learning disability at several public events:

- Hackney forum for people with learning disabilities (16th March 2016)
- Yad Voezer community centre (February 2016)
- PoHWER speaking up group (March 2016)
- People First self-advocacy project (January 2016).

Among other things, the survey asked adults with learning disability about their perception of their body weight. Self-reported body size is known to be inaccurately reported and this is likely to be particularly problematic in people with learning disability. As such, these data from the community survey should be treated with some caution.

3.6 Local services and support

This report has attempted to be as comprehensive as possible in describing the full range of health, care and related services available to adults with learning disability in Hackney and the City. However, it is likely that a number of services or programmes have been omitted, particularly those delivered by the voluntary sector.

Key services and organisations were identified through collaboration with the commissioning officer for learning disabilities, the community liaison nurse for learning disability, POhWER advocacy group and other colleagues within Hackney Council the City of London and community groups (through the Integrated Learning Disability Service). Once contact was made, a meeting was requested with a named officer to collect information on the purpose, activities and capacity of the service, as well as how information on clients with a learning disability was captured. Following this meeting, a data request was submitted to each service to obtain information on the service caseload and any other data available on service users (including demographic information, indication of severity/level of need of service users).

Unless otherwise stated in the report, all data on local services relate to adults (18+) with a diagnosed learning disability.

4. National policy and evidence review

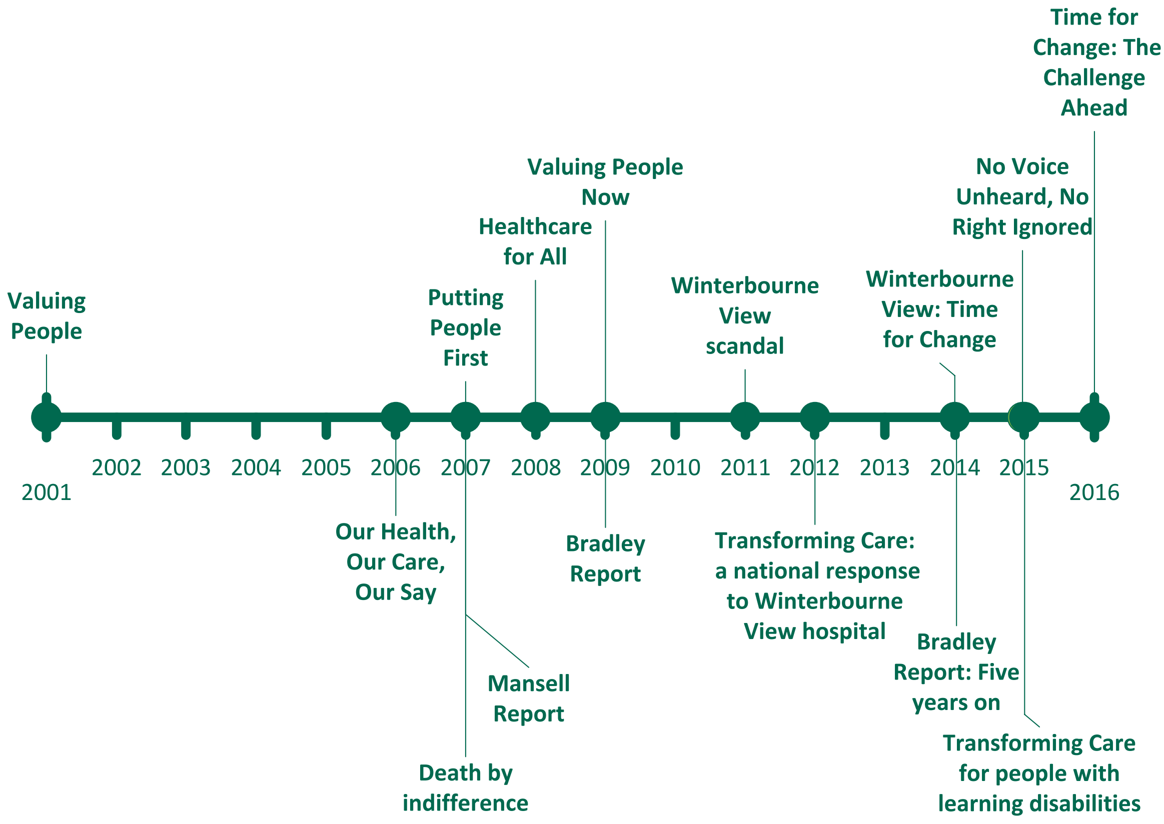
4.1 Introduction

This Chapter discusses some of the key policy drivers which aim to improve the lives of people with learning disabilities. In addition, it provides a review of evidence-based recommendations for meeting their health and related needs.

4.2 Key national policy documents

Figure 1 provides a summary of the key national policy documents published between 2001 and 2016, which impact on the lives of people with learning disabilities. The rest of this sections provides a brief description of each of these and an update on progress against recommended actions, where available.

Figure 1: Infographic on key national policy drivers for people with learning disabilities (2001 to 2016)



Source: Hackney public Health Team

4.2.1 Valuing People (2001) and Valuing People Now (2009)

In 2001, the Department of Health published the White Paper, *Valuing People: A New Strategy for Learning Disability for the 21st Century*, which set out how the Government at the time would provide new opportunities for children and adults with learning disabilities, as well as their families, to live independent lives. [13] This strategy made reference to a new Learning Disability Development Fund that amounted to £50 million per annum from April 2002, as well as an Implementation Support Fund of £2.3 million a year (for three years) to fund developments such as advocacy support and a new national information centre. The proposals within this strategy intended to:

- tackle social exclusion and achieve better life chances for people with learning disabilities
- ensure value for money from public investment in learning disability services
- reduce variation and promote consistency and equity of services across the country
- promote effective partnership working at all levels to ensure a true person-centred approach to delivering quality services
- drive up standards by encouraging an evidence-based approach to service provision and practice.

These proposals were underpinned by the following four principles:

1. **Legal and civil rights**: All public services must treat people with learning disabilities with respect and challenge discrimination. Fundamental rights were also set out in areas where people with learning disabilities may need additional support, namely rights to:
    - a decent education
    - vote
    - marry and have a family
    - express their opinions.
2. **Independence:** While taking account of differing needs, the starting presumption should be on promoting and enabling independence.
3. **Choice:** People with learning disabilities should be enabled to have a say in where they live, what work they do and who should look after them, and be given the opportunity to make important choices and express their preferences about their day-to-day lives.
4. **Inclusion:** Enabling people with learning disabilities to do “ordinary” things, make use of mainstream services and be active in their local community.

Box 5 shows the objectives taken from the *Valuing People* strategy, which were developed as part of a consultation process, and relate to maximising positive outcomes for people with learning disabilities as well as improving systems to help deliver these outcomes

Box 5: Valuing People objectives [13]

Objective 1: Maximising opportunities for disabled children

To ensure that disabled children gain maximum life chance benefits from educational opportunities, healthcare and social care, while living with their families or in other appropriate settings in the community where their assessed needs are adequately met and reviewed.

Objective 2: Transition into adult life

As young people with learning disabilities move into adulthood, to ensure continuity of care and support for the young person and their family and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment.

Objective 3: Enabling people to have more control over their own lives

To enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approach to planning the services they need

Objective 4: Supporting carers

To increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively.

Objective 5: Good health

To enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard and with additional support where necessary.

Objective 6: Housing

To enable people with learning disabilities and their families to have greater choice and control over where and how they live.

Objective 7: Fulfilling lives

To enable people with learning disabilities to lead full and purposeful lives in their communities and to develop a range of friendships, activities and relationships.

Objective 8: Moving into employment

To enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work, and to make a valued contribution to the world of work.

Objective 9: Quality

To ensure that all agencies commission and provide high quality, evidence-based and continuously improving services which promote both good outcomes and best value.

Objective 10. Workforce training and planning

To ensure that social and healthcare staff working with people with learning disabilities are appropriately skilled, trained and qualified, and to promote a better understanding of the needs of people with learning disabilities amongst the wider workforce.

Objective 11: Partnership working

To promote holistic services for people with learning disabilities through effective partnership working between all relevant local agencies in the commissioning and delivery of services.

Building on the first White Paper, *Valuing People Now: a new three-year strategy for people with learning disabilities* was published in 2009, which took a human rights based approach as described below. [14]

- **Including everyone** - ensuring that the needs of the following groups are being included:
  - people with more complex needs
  - people from Black and Minority Ethnic (BME) groups and newly arrived communities
  - people with autistic spectrum conditions
  - offenders in custody and in the community.
- **Personalisation** - ensuring that people with learning disabilities are able to make choices and have control over their lives to enable independent living. This is linked to the *Putting People First* vision for transforming social care (see 4.2.3).
- **Having a life** - improving the outcomes for people with learning disabilities, particularly in the following areas:
  - health
  - housing
  - work
  - education
  - relationship and family.
- **People as citizens** - ensure people with learning disabilities are able to participate as citizens through:
  - advocacy
  - access to transport
  - leisure services and social activities
  - being safe in the community and at home
  - access to justice and redress.
- **Making it happen** – ensuring the development of capacity and capability at local levels.

The *Valuing People Now: summary report* (published in December 2010), concluded that "*considerable progress has been made under the Valuing People Now programme across key priorities in health, housing and employment*", while recognising that more still needed to be done. [15] It considered Learning Disability Partnership Boards to have a vital role and stated there was an opportunity for them to be linked to the then proposed Health and Wellbeing Boards.

4.2.2 Our Health, Our Care, Our Say (2006)

In 2006, the Department of Health published *Our Health, Our Care, Our Say*, which helped to set the direction for reforming health and social care and outlined the following four main goals: [16]

1. health and social care services will provide better prevention services with earlier intervention
2. give people more choice and a louder voice
3. do more on tackling inequalities and improving access to community

4. more support for people with long-term needs.

This paper identified the significant health inequalities that people with learning disabilities continue to face. It made reference to around 3,000 people with learning disabilities who live as inpatients in NHS residential accommodation and the link with poorer outcomes when compared to those living in community-based settings, which offer more independence and greater inclusion. Improved outcomes were to be achieved through:

- Practice Based Commissioning
- shifting resources into prevention
- more care undertaken outside hospital and in the home
- better joining up of services at the local level
- encouraging innovation
- allowing different providers to compete for services.

4.2.3 Putting People First (2007)

Putting People First: a shared vision and commitment to the transformation of adult social care was published by the Department of Health in 2007. [17] It aimed to influence local authorities to move away from service-based options to more person-centred arrangements, to allow individuals more of a say about how they are supported. For local authorities, this meant changing commissioning practices to cater for more people taking up Personal Budgets. Service providers were also expected to make changes to ensure they are better able to tailor support to the needs of the individual.

4.2.4 Mansell report (2007)

The Department of Health published *Services for people with learning disabilities and challenging behaviour or mental health needs* in 2007, which is more commonly known as the *Mansell Report.* This report, which was an update of the Department of Health's 1993 report of the same name, aimed to assist commissioners to develop high quality services for people with learning disabilities. It acknowledged that while progress has been made, challenges still remained and saw good quality commissioning as a driving force. The focus of the recommendations of the report was to *"develop preventative strategies that avoid crises; and to make the most effective use of available funding"*.

4.2.5 Death by Indifference (2007)

Building on Mencap's "Treat me right!" campaign, the organisation published their *Death by Indifference* report in 2007, which examined the institutional discrimination experienced by people with learning disabilities within the NHS and the poor healthcare that many receive. [18] The report examined the deaths of six individuals who had learning disabilities, questioning whether their deaths were preventable and demanding an independent inquiry. It concluded that the *"failure to tackle unequal access of people with a learning disability has resulted in institutional discrimination"* and highlighted the following contributing factors:

- people with a learning disability are seen to be a low priority within the NHS
- many healthcare professionals have a poor understanding of learning disability and the needs of people affected
- many healthcare professionals do not properly consult with or involve the families and carers of people with a learning disability in decisions about their care
- many healthcare professionals do not understand the law around capacity and consent to treatment
- health professionals rely inappropriately on their own assessments of a person's quality of life
- the complaints system within NHS services is often ineffectual, time-consuming and inaccessible to people with learning disabilities and their families.

4.2.6 Healthcare for all: independent inquiry into access to healthcare for people with learning disabilities (2008)

Following Mencap's *Death by Indifference* report, Sir Jonathan Michael led an independent inquiry into healthcare for people with learning disabilities which published its report in 2008. [19] This report provided 81 recommendations to be implemented to ensure adults and children with learning disabilities receive the right level of support and treatment by the NHS.

This inquiry concluded that people with learning disabilities receive less effective care than they are entitled to receive and that there was evidence of a significant level of avoidable suffering and a high likelihood of preventable deaths occurring. The report noted that while there is a legislative framework to support people with learning disabilities, there is *"insufficient data, poor information about people with learning disabilities and shortcomings in training",* and highlighted the lack of awareness of published guidance on how to deliver effective healthcare for people with learning disabilities.

This inquiry lead to the development of the Learning Disabilities Observatory in April 2010, Improving Health and Lives, which aims to provide better information on the health and wellbeing of people with learning disabilities.

4.2.7 The Bradley Report (2009) and the Bradley Report five years on (2014)

Lord Bradley conducted an independent review of people with mental health problems or learning disabilities in the criminal justice system, which was published in 2009. [20] The purpose of this review was to:

- examine the extent to which offenders with mental health problems or learning disabilities could, in appropriate cases, be diverted from prison to other services and the barriers to such diversion
- make recommendations to government, in particular on the organisation of effect court liaison and diversion arrangements and the services needed to support them.

Eighty two recommendations were made to help ensure that offenders with mental health problems or learning disabilities "*are properly identified and assessed, appropriately sentence and helped with their rehabilitation and resettlement*."

The Bradley Commission was set up by the Centre for Mental Health, as an independent review, to examine the progress made since the publication of the Bradley Report. In 2014, *The Bradley Report five years on: an independent review of progress to date and priorities for further development* was published. [21]. This review concluded that there had been significant process towards achieving the vision of the Bradley Report, with new creative ways emerging to support people with learning disabilities across the criminal justice system (such as the street triage initiative). It also made nine recommendations, including for the Department of Health to commission a study of the prevalence of poor mental health, learning disability and other vulnerabilities within the criminal justice system (***Box 6***).

Box 6 Recommendations from the Bradley Report five years on [21]

	Recommendation
1	Assuring adherence to the Youth Justice Liaison and Diversion Model
2	Ensuring the availability of 'appropriate adults' and intermediaries
3	Developing an operating model for prison mental healthcare
4	Making the operating model for liaison and diversion an all-stage operating Model
5	The government should establish a review to identify solutions to achieving appropriate accommodation for offenders with vulnerabilities
6	Assuring efficient transfer to and from secure mental healthcare
7	The Department of Health should commission a study of the prevalence of poor mental health, learning disability and other vulnerabilities throughout the criminal justice system
8	NHS England, public Health England, Department of Health, Department of Education, Department for Communities and Local Government, Home Office and Ministry of Justice should work with health and social care research commissioning bodies to achieve a programme of research to develop the evidence base for liaison and diversion
9	A new Concordat should be developed committing all key agencies to ensuring all front line workers receive appropriate mental health awareness and regular updated training

4.2.8 Winterbourne View (2012, 2014)

In 2012, the Department of Health published *Transforming Care: a national response to Winterbourne View hospital*. [22] Winterbourne View was a specialist hospital for patients with learning disability and autism who were unable to live in the community (usually due to challenging behaviour or severe mental health problems). It was established to help patients to be treated and to gain skills to be able to live in the community safely. However, in 2011 serious events of abuse were highlighted, leading to an overhaul in the approach to the care of people with learning disabilities; mainly to shift their care to community-based services and away from inpatient services. [23] The aspiration is for individuals to have better access to services and a choice in where they live and who they live with. The aims are to provide services to allow safe transfer out of inpatient care and to provide preventative support to individuals at risk of admission. Research has found that once patients are admitted, they are likely to stay in hospital for unnecessarily long times, often far away from family, and that if they had the right support in the community they could be discharged in a fraction of the time. [24] [22] [25]

The summarised main actions from this paper, and progress to date (where this has been possible to ascertain), are described in ***Table 2***.

Table 2: Progress against main recommendations from the Winterbourne View report

Theme	Action (deadline)	Progress to date
The right care in the right place	Review all current placements and support everyone inappropriately placed in hospital to move to community based support (June 2014)	Status report from December 2013 confirm that Hackney had reviewed all inpatient cases and that users in NHS forensic placements under section, are in services that meet their needs. [26] The status report for the City of London shows that no in-patients had been identified and therefore no reviews were needed. [27]
	There should be a locally agreed joint plan in all areas to develop high quality care and support services for people with learning disabilities of all ages (April 2014)	The Inner East London Transforming Care Partnership (INEL TPC) has developed a plan, which was presented to the Hackney Health and Wellbeing Board in July 2016.
	Providing national leadership to support local change, the Local Government Association and the NHS	A two-year joint improvement programme was set up to support local

Theme	Action (deadline)	Progress to date
	Commissioning Board (now known as NHS England) will develop an improvement programme led by a senior sector manager.	partners to improve provisions for people with learning disabilities, focusing on; - support to local areas - information, learning and sharing - engagement and co-production - children and young people - finding common purpose - the workforce
Strengthening accountability	Sanctions to hold Boards to account when the quality of care is unacceptable	Since 1 April 2015, all registered providers must meet new registration requirements, which will allow the Care Quality Commission (CQC) to hold Boards to account.
Tightening the regulation and inspection of providers	Improved inspections of institutions that have learning disabled individuals as inpatients and regulations to be implemented to ensure prevention of any harm/mistreatment to the patient during their stay.	CQC has implemented new methods of inspection and has scheduled inspections until 2016
Improving quality and safety	Development of: - guidance on children in long-term residential care (2013) - core principles on a statement of ethics to reflect wider responsibilities in the health and care system (April 2013) - framework of guidance and support on commissioning workforce solutions to meet the needs of people with challenging behaviour (February 2013) - national minimum training standards and a code of conduct for healthcare support workers and adult social care workers (January 2013)	The Department of Health published a research report on *The place of residential care in the English child welfare system in June 2015*. [28] In May 2015, the National Institute for Health and Care Excellence (NICE) published guidance on prevention and interventions for children, young people and adults with a learning disability and challenging behaviour. [29] In 2013, Skills for Care and the National Development Team for Inclusion published guidance on supporting staff

Theme	Action (deadline)	Progress to date
		working with people who challenge services. [30]
	CQC to take enforcement action against providers who do not operate effective processes to ensure they have sufficient numbers of properly trained staff	Fixed penalty notices (FPN) have been issued to providers with locations operating without managers. Between November 2013 and April 2014, 590 FPNs had been issued.
Monitoring and reporting on progress	Commission an audit of current services for people with challenging behaviours	The National Audit Office produced a report on the services available for people with learning disabilities and challenging behaviours, which was published in 2015. [31]
	Develop measures and key performance indicators to support commissioners in monitoring progress, as well as a learning disability minimum data set. Also to implement a joint health and social care self-assessment framework to monitor progress of key health and social care inequalities	The Health Equalities Framework was published in 2013. This framework aims to provide a way for services to agree and measure outcomes for people with learning disabilities. [32] A Mental Health and Learning Disabilities Data Set has been available since September. This contains data about the care of children, young people and adults who are in contact with mental health, learning disabilities or autism services. The first joint Health and Social Care Learning Disability Self-Assessment Framework was published by public Health England in 2014 (based on 2013 data).
	The Learning Disability Programme Board (cross-government) to measure and regularly report on progress against the action plan	The National Learning Disability Board meet three times a year and provides progress updates.

In response to recommendations relating to providing the right care in the right place, NHS England commissioned Sir Stephen Bubb to produce a report and make recommendations for a national commissioning framework that would enable local commissioners to secure community-based support for people with learning disabilities. [6] This report (*Winterbourne View – time for change: transforming the commissioning of service for people with disabilities and/or autism*) was published in 2014 and highlighted the key recommendations shown in ***Table 3***.

Table 3: Key recommendations from Sir Stephen Bubb's report [6]

Theme	• Recommendations	• Progress to date
Strengthening Rights	Development of a Charter of Rights for people with learning disabilities and their families, which should underpin all commissioning	A Charter of Rights has yet to be published. Sir Stephen Bubb stated in 2016 that there is a need to establish a commissioner who has a statutory duty to protect the rights of all people with learning disabilities in England. The government's response to the *No Voice Unheard, No Right Ignored* consultation (see 4.2.10 below) included an early action to "build on the proposal of a (non-statutory) 'Charter of Rights'. [33]
	The Government should respond to *The Bradley Report Five Years on* to ensure better care for people with learning disabilities in the criminal justice system	NHS England has commissioned Liaison and Diversion services to ensure early identification of offenders with mental health, learning disability or substance misuses vulnerabilities – and ensure that appropriate support is provided. [34]
	People with learning disabilities and their families should be given a "right to challenge" decisions to admit or continue keeping them in inpatient care	NHS England agreed to introduce a Care and Treatment Review (CTR) for inpatients (or their families). This review process involves independent advisors examining whether the individual needs to be in hospital or whether their treatment needs could be carried out in the community. The CTR team can also make recommendations to ensure an individuals is safely discharged from hospital. [35]
	NHS England should extend the right to have a Personal Budget to more people with learning disabilities	NHS England agreed to develop a clearer model for services for people with learning disabilities and explore options to develop additional rights to a Personal Budget. [35]

Theme	• Recommendations	• Progress to date
	The Government should look at ways to protect an individual's home tenancy when they are admitted to hospital	Joint commissioning guidance has been published on supporting people with learning disabilities by building up community capacity and reducing inappropriate hospital admissions. [36] This guidance recommends commissioners to work with providers and housing associations to ensure the tenancies' of those going into hospital are protected. [37]
Forcing the pace on commissioning	The Government and NHS England should require all local commissioners to follow a mandatory commissioning framework	A framework for commissioners to develop more community services for people with learning disabilities was published in 2015. [38] Alongside the national service model, it sets out what support should be in place by March 2019, with an expectation that between 35% and 50% of inpatient provision will close, with alternative care options available in a community setting. [38]
	Community-based providers should be given a 'right to propose alternatives' to inpatient care	NHS England agreed to work with commissioners on the 'right to propose' alternatives, suggesting the possibility of developing community-based support packages for those in hospitals. [35]
Closure of inpatient institutions	The commissioning framework should be accompanied by a closure programme of inappropriate institutional inpatient facilities	In 2015, NHS England committed to a closure programme of inappropriate and outmoded inpatient facilities, which is highlighted in the commissioning framework mentioned above [38]
Building capacity in the community	To develop a national workforce "Academy" for this field	In 2014, Skills for Care and Skills for Health published joint guidance for commissioners on workforce development in relation to staff working with people who challenge. [39] The Department of Health commissioned a new training framework (published in 2016) in conjunction with Skills for Life,

Theme	Recommendations	Progress to date
		Skills for Care and Health Education England [40]
	A "Life in the community" Social Investment Fund should be established to facilitate transitions out of inpatient settings and build capacity in community-based services care.[5]	Agreement to fund a detailed feasibility study on Sir Stephen Bubb's proposals for social investment model. A working group has been set up by the Department of Health. [35] During summer 2015, six Fast-Track areas received a share of a £10 million fund and were supported to develop plans to transfer their services for people with learning disabilities.[6] It is predicted that the bed usage for each area will reduce by 50% over 3 years, helping to free up money which can be invested into community-based support, thus reducing hospital admissions. [38]
Holding people to account	Improve collection and publication of performance data, and a monitoring framework at central and local level	This is being addressed as part of the "*Transforming care for people with learning disabilities"* agenda (see 4.2.9). [35]

4.2.9 Transforming care for people with learning disabilities (2015)

In January 2015, a joint report was published by NHS England, the Local Government Association (LGA), Health Education England, Department of Health, Care Quality Commission and the Association of Directors of Adult Social Services (ADASS), entitled *Transforming care for people with learning disabilities - next steps*. [35]

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[5] 'The proposed Investment Fund, seeded with £30 million from NHS England and/or Government, could leverage £200 million from other investors to make investment more easily accessible to expand community-based services'

[6] The six areas are Greater Manchester, Lancashire; Nottinghamshire; Arden, Herefordshire and Worcestershire; Cumbria and the North East; and Hertfordshire. They were chosen due to the high number of people with learning disabilities in hospital settings. The purpose of the £10 million was to help fund transitional costs and speed up the implementation, and not to fund a new service model.

This report set out some of the early actions from Sir Stephen Bubb's report on how to accelerate transformation of care for people with learning disabilities. It reinforced previous recommendations as well introducing new actions such as "care and treatment reviews", which would allow an inpatient (or their family) the right to challenge their admission or continued placement. There was also a commitment to implement robust admission gateway processes, to ensure there is challenge to check that there is no available alternative. A clearer service model is also promised, with established performance indicators and standards, based on continued promotion of joint working across health and social care commissioners and the possibility of expanding the Better Care Fund to this area. More emphasis was also put on workforce development, with the promise of a scoping study to identify current gaps in provision.

4.2.10 No voice unheard, no right ignored (2015)

In March 2015, the Department of Health published a report following a consultation which focused on views on assessment and treatment in mental health hospitals for people with a learning disability or autism. It also examined views on adult care and support, primarily for those with a learning disability but also for adults with autism. [33] The Government's response to the consultation findings was published in November 2015. This response lays out a number of proposals, which have been grouped into three implementation phases [41]. A summary of the consultation findings and government response is presented in ***Figure 2***.

Figure 2: Infographic on the No voice unheard, no right ignored consultation themes and government response [41]

4.2.11 Time for Change: the challenge ahead (2016)

Following his report in 2014, Sir Stephen Bubb published *Time for Change: the challenge ahead* in 2016. [42] One of the key recommendations of this report was the need for a Learning Disabilities Commissioner who would be responsible for ensuring the rights of people with learning disabilities. This was in reply to the Government not committing to legislative changes following its response to *No Voice unheard, no right ignored* and draws parallels with the role of the Children's Commissioner. The other main recommendation in this report was for the Department of Health to commission an independent evaluation of the Transforming Care Programme, with an expectation for all interim and final reports to be in place by August 2016.

4.3 Evidenced-based recommendations for meeting the health and related needs of adults with a learning disability

This section summarises the results of a rapid evidence review of interventions and approaches to address the health and wellbeing needs of adults with a learning disability, including two key determinants of health – housing and employment (see section 5.4). First, recommendations for organising health and care services are addressed, followed by areas relevant to managing the health needs of adults with learning disability. Finally, recommendations relating to housing and employment support, and reducing social isolation, are discussed.

This review has identified a paucity of high quality research evidence on some of the key health and wellbeing needs of adults with learning disability. A meta-review of health and healthcare related systematic reviews found a number of clinical areas[7] where there were no eligible studies or a lack of strong evidence, including conditions that are a major cause of morbidity and premature mortality in people with learning disability (in particular, respiratory and circulatory disease). [43] There is also an absence of good quality evidence on the effective organisation of healthcare services for people with a learning disability and physical co-morbidities. [44] As a result, many of the recommendations included in this section are based on grey literature.

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[7] No reviews were identified that specifically covered the following ICD-10 Chapters: I Certain infectious diseases and parasitic diseases; III Diseases of the blood and blood forming organs and certain disorders involving the immune mechanism; IV Endocrine, nutritional and metabolic diseases (although it could be argued that interventions related to body fat could be categorised here instead of under factors influencing health status); VIII Diseases of the ear and mastoid process; IX Diseases of the circulatory system; X Diseases of the respiratory system; XII diseases of the skin and subcutaneous tissue; XIV Diseases of the genitourinary system; XV Pregnancy birth and the puerperium; XVI Certain conditions originating in the perinatal period; XVII Congenital malformations, deformations and chromosomal abnormalities; XVIII Symptoms, signs and abnormal clinical and laboratory finding not elsewhere classified; and XIX Injury, poisoning and certain other consequences of external causes.

4.3.1 Recommendations for organising health and care services to meet the needs of people with learning disability

A study of premature deaths in people with learning disabilities (***Box 7***) found that the most common reasons were delayed diagnosis or treatment, and problems identifying needs and providing appropriate care in respond to changing needs. [45]

Box 7: Confidential Inquiry into premature deaths of people with learning disability (CIPOLD) - summary [45]

The CIPOLD report concluded that delays in diagnosis/treatment and failure to identify or meet the health needs of people with learning disabilities was the result of poor access to services and failure to implement 'reasonable adjustments' as required by the Disability Discrimination Act 1995. It found that the ability of many people with learning disabilities to follow complex care pathways is significantly impaired, leading to high 'lost to follow-up' rates.

The majority of people with learning disabilities have more than one co-morbidity (an average of five in the CIPOLD study). However, there was found to be a lack of communication between different healthcare professionals looking after patients' different needs, often leading to unnecessarily complicated and sometimes conflicted care. Multiple comorbidity and polypharmacy is complex in any patient, but can be much more difficult to manage in a patient with a learning disability due to their reduced communication and cognitive functions.

This inquiry made a series of recommendations, including improved identification of learning disability on NHS systems and better use of data to improve care pathways, as well as the establishment of a national learning disability mortality review board (see : Key recommendations form the CIPOLD review for further detail).

Healthcare services should follow six criteria for meeting the needs of people with a learning disability: [46]

1. mechanisms in place to identify and flag patients with learning disabilities, and protocols that ensure pathways of care are reasonably adjusted to meet their needs
2. readily available and comprehensive information to patients with learning disabilities about treatment options, complaints procedures and appointments
3. protocols in place to provide suitable support for family carers
4. protocols in place to routinely include training on providing healthcare to patients with learning disabilities for all staff
5. protocols in place to encourage representation of people with learning disabilities and their family carers on boards and forums, including producing agendas and minutes in easy read format
6. protocols in place to regularly audit practices for patients with learning disabilities and to demonstrate findings in routine public reports.

Addressing barriers to access

People with learning disabilities should be supported to access mainstream services whenever possible. [47] Barriers to accessing health services include: [46]

- problems with understanding and communicating health needs
- lack of support to access services
- discriminatory attitudes among healthcare staff
- failure to make 'reasonable adjustments' to services so that they can be used easily and effectively by people with learning disabilities (***Box 8***).

Box 8: Reasonable adjustments

> **Reasonable adjustments** remove barriers faced by people with disabilities to ensure both disabled and non-disabled people receive the same services, as much as possible. Reasonable adjustments can encompass changes to policy or practice, changes to physical features, and the provision of extra aids or services. Reasonable adjustments are a key part of the Equality Act 2010.

People with learning disabilities should be involved in consultations about the design and commissioning of health services, in order to have their needs addressed. People with profound and multiple learning disabilities are particularly marginalised and should be supported to voice their requirements from health services. [47]

Family members and carers should be allowed to assist in accessing services, for example by helping to self-refer or to be present for appointments and interviews. [48] Families should be supported to get advice and help in securing and running self-directed services from user-led organisations, or self-help groups of other families. Independent advocates who represent the interest of people with learning disabilities – especially people with profound and multiple learning disabilities – should be appointed. [47]

Assistive technology and telecare/telehealth can support people with learning disabilities and their families in the community, and has the potential to reduce hospital admissions and contribute to faster discharge. [46] There is a need for better communication within and between agencies providing care and support for people with learning disabilities. Primary care and acute liaison nurses support learning disabled patients to access services and both roles should be considered when developing commissioning plans. [46] A named health professional can coordinate the care of those with multiple health conditions, aided by the routine use of patient- or carer-held health records and the continuing involvement of specialist healthcare staff. Use of staff who work on a short-term or one-off assessment basis is not appropriate. [45]

Accessibility and uptake of population screening programmes in adults with learning disability

A number of studies have reported low uptake of health promotion or population screening programmes among people with learning disabilities, including assessment for hearing or visual impairments, cervical smear tests, and breast self-examination and mammography. [46]

In a study of women with learning disabilities eligible for breast and cervical screening in North West England, nearly a quarter were found to not be registered with a GP. [49] This may result in some women with learning disabilities not receiving an invitation for breast and cervical screening. When women with learning disabilities do receive an invitation, poor literacy skills can mean that they do not understand the invitation. Adapted letters[8] tailored to women with learning disabilities are available but even then, some women may not understand the letter and not all Breast Screening Units will be aware that the woman has a learning disability. [50]

Women must be supported to decide whether to take up screening and must be prepared for the screening test. Staff who undertake the screening must be aware of the specific needs and experiences of women with learning disabilities. [50]

One recommended intervention encourages communication between the Breast Screening Unit, liaison nurse, local learning disability team and patients and carers. Alternatively, or additionally, patients and their carers can be given training to improve knowledge and awareness regarding breast screening. Finally, a teaching pack, check list and resource pack can be developed to teach staff working with women with learning disabilities about breast awareness, and how to prepare clients for breast screening. [50]

Recommendations for improving uptake of cervical screening in women with learning disabilities include facilitating joint working between community learning disability teams and primary care, training for primary care staff in effective communication with patients with learning disability, and use of accessible information leaflets about cervical screening. [51]

Identification of people with learning disabilities and routine data collection

The CIPOLD study clearly demonstrated the need to identify people with learning disabilities in healthcare settings and to record, implement and audit the provision of reasonable adjustments to avoid their serious disadvantage (***Box 7***). [45]. Protocols should be in place to allow people with learning disabilities to be identified as early as possible and patient data should be analysed in a way that enables their specific health needs to be understood. [48] [47]

A small study of GP practices in Edinburgh found only half of those surveyed always included a diagnosis of learning disability in relevant patients' records. [51] Participating GPs recognised that they would be unlikely to be aware of patients with milder learning disability who had not received a formal diagnosis, and acknowledged that patients in this category living at home with their families would be particularly difficult to identify. The study concluded that primary care must be supported to identify and record all patients with learning disabilities.

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[8] Letter templates are available on the Improving Health and Lives website: http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=267

A good understanding of the physical and mental health needs of the local learning disabled population must underpin the commissioning of local services, to ensure that these services have sufficient capacity and capability. [52] Routine collection and review of data that provides intelligence on the mortality of people with learning disabilities is recommended. [45] In addition, the development of coding and flagging systems in primary care that enable learning disability Read Codes to be linked to chronic conditions should be considered. [53] All health and care services should ensure that they collect appropriate information about their patients' needs. In the case of a patient with learning disabilities, it is difficult for services to prepare properly or make any necessary 'reasonable adjustments' if patients' communication and other special needs are unknown (see below). [52]

In response to Winterbourne View (see 4.2.8), a Mental Health and Learning Disabilities Dataset has been established to record consistent information on the care of people in contact with mental health and learning disabilities services.[9] [52]

Communication and consent

Communication difficulties are prevalent amongst people with learning disabilities. 'Total Communication' (see ***Box 9***) emphasises the importance of the context in which communication takes place and modifying the means of communication to the developmental level of the communication partner with learning disabilities. Understanding the unique needs of individual patients with learning disabilities can be achieved through listening to them and their carers, and using available resources such as communication aids and Hospital Passports (see ***Box 12***). There have been innovative advances in the development of methods to augment communication with people with learning disabilities, such as intensive interaction (see ***Box 10***) and 'Talking Mats' (see ***Box 11***).

Early intervention programmes have been shown to be effective in promoting the development of communication in children with autistic spectrum disorders (ASD) and learning disabilities. Involvement and training of parents and carers is a key principal in such programmes. Studies have shown that paid carers of people with learning disabilities tend to overestimate their clients' comprehension levels. Training programmes that support improved carer communication skills are needed. [54]

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[9] Please find the Mental Health and Learning Disabilities Statistics monthly reports on the NHS Digital website at http://digital.nhs.uk/mhldsmonthly

Box 9: Total Communication

'**Total Communication**' is a way of communicating with people with learning disabilities that utilises combinations of different communication methods; it is not limited to speech. Total Communication uses photos and symbols, signs and gestures, objects, electronic communication aids, body movements and facial expressions, as well as intensive interaction (see ***Box 10***).

Box 10: Intensive interaction

'**Intensive interaction**' is an approach to teaching the pre-speech fundamentals of communication to children and adults who have severe learning disabilities and/or autism and who are still at an early stage of communication development. The approach works by progressively developing enjoyable and relaxed interaction sequences between the interaction partner and the person doing the learning. These interaction sequences are repeated frequently and gradually grow in duration, complexity and sophistication.

Box 11: Talking Mats

'**Talking Mats**' is an interactive resource that uses three sets of picture communication symbols – topics, options and a visual scale – and a space on which to display them. This can either be a physical, textured mat, or a digital space, for example a tablet, smart board or computer screen for use of specially designed apps.

Regular health checks for people with learning disabilities

There is overwhelming evidence to support regular health checks for people with learning disabilities. Such programmes are more likely to be effective if they are delivered in a population-based, proactive, co-ordinated way, rather than relying on the individual patient to initiate contact. [54]

Following a formal investigation into the health inequalities experienced by people with learning disabilities, the Disability Rights Commission in 2006 recommended the introduction of annual health checks for people with learning disabilities in England and Wales as a 'reasonable adjustment' in primary healthcare services. [55]

The underlying rationale for the use of regular health checks in people with learning disabilities is that: [55]

- primary care services tend to be reactive, responding to problems raised by patients
- people with learning disabilities may be unaware of the medical implications of symptoms they experience, have difficulty communicating their symptoms, or may be less likely to report them to medical staff

- carers may not always attribute the manifestations of clinical symptoms to physical or mental illness
- health checks provide a way to detect, treat and prevent new health conditions in this population.

It has also been argued that regular health checks can help to provide baseline information against which changes in health status can be monitored. This is of particular relevance in situations where there is a high turnover of paid carers providing support to a learning disabled patient or client, given the difficulties that the patient may have in identifying and communicating longer term changes in their health status. The introduction of health checks for people with learning disabilities typically leads to the detection of unmet, unrecognised and potentially treatable health conditions, and the implementation of targeted actions to address health needs.

Given the specific difficulties faced by people with learning disabilities (e.g. identifying and communicating symptoms of ill health, negotiating access within complex health systems), targeted health checks constitute an effective and important adjustment to the operation of primary healthcare services, as required by the Disability Discrimination Acts 1995 and 2005, the Equality Act 2010 and, more generally, in relation to international obligations under the UN Convention on the Rights of Persons with Disabilities. [55]

Health Action Plan and Hospital Passport

All patients with a learning disability should have access to a Health Action Plan, informed by the outcome of regular health checks.

Regular health checks for people with learning disabilities). A Health Action Plan should be integrated into person-centred care and support plans and co-produced by the patient, healthcare professional and carer where appropriate. Plans may include appointments, diagnoses, test results, as well as current health needs and the actions that will be taken to address those needs. [56]

Where appropriate, Hospital Passports should be offered to help health services make reasonable adjustments for patients with a learning disability (see ***Box 12***). [36]

Box 12: Hospital Passport

The aim of the **Hospital Passport** is to assist people with learning disabilities to provide hospital staff with important information about them and their health when they are admitted to hospital. The Hospital Passport can be completed and kept at home in case of an emergency admission or deterioration in the individual's health, or can be completed prior to a planned admission when it may also be used to aid assessment and planning. Hospital Passports can facilitate information sharing between services by providing hospital staff with valuable information about the patient, which can help with planning and managing their care and reduce the likelihood of encountering situations which could trigger behaviour that challenges.

Effective communication also underpins any assessment of capacity to consent, but nurses and other healthcare professionals do not always fully understand the laws around capacity. Many people with learning disabilities do have capacity to consent, but inappropriate assumptions are often made in this regard, which directly impact on the person's autonomy and agency. [25]

Primary care should make reasonable adjustments to enable people with learning disabilities to communicate and consent, including longer appointments and accessible letters and information. [46] Easy to read materials can help patients to make informed decisions about their healthcare. Most people with learning disabilities accessing secondary or specialist care will be referred via their GP, and by the time they attend their first appointment may not remember why they are there. Therefore, it is important that consent and choice are addressed during the first contact with the service, using an appropriate easy read leaflet about the service and what treatment entails. [48]

The way in which individuals with learning disabilities express pain or discomfort should be also documented, and support workers trained to use this information and react appropriately. The 'Disability Distress Assessment Tool' can assist staff in assessing pain when patients cannot communicate verbally. [46]

Autonomy and choice

One way in which people with learning disabilities can be given more choice and autonomy over the health and care services they receive is through Personal Health Budgets, delivered either as a notional budget, a third party budget or a direct payment. Personal health budgets have the potential to engage groups not traditionally well served by health services and enable people to take more control of their lives. [46] See ***Box 13*** for further information.

Box 13: Personal Health Budgets

Personal Health Budgets are one way to give people with long-term health conditions and disabilities more choice and control over the money spent on meeting their health and wellbeing needs. A personal health budget is an amount of money to support a person's identified needs, which is planned and agreed between the individual (or their representative) and the organisation paying for their care.

Personal Health Budgets work in a similar way to the Personal Budgets that many people are already using to manage and pay for their social care.

Since April 2014, adults receiving NHS Continuing Healthcare (NHS-funded long-term health and personal care provided outside hospital) are eligible for a Personal Health Budget.

Training for healthcare professionals and staff working with people with learning disabilities

Illness and disease in people with learning disability is often misdiagnosed or undiagnosed, due to poor awareness of relevant health needs amongst healthcare staff. It has been argued that widespread ignorance results in institutional discrimination, and people with learning disabilities being misunderstood and misinterpreted. In addition, carers' needs are often inadequately met; many healthcare professionals do not properly consult and involve them, and their opinions and assessments are frequently ignored. Disability liaison nurses are crucial in supporting and educating staff around the needs of people with learning disability. [25]

GPs and other primary care staff receive little or no training in working with people with learning disabilities during undergraduate or postgraduate vocational studies; and the small number of people with learning disabilities on their lists at any one time means it is difficult for them to gain experience once in practice. Many GPs may therefore be unaware of the different pattern of health needs experienced by people with learning disabilities. To address this, GP contracts should include an enhanced service for people with learning disabilities. The enhanced service specification should include a requirement for staff to complete training on the health needs of people with learning disabilities and the best ways of working with carers and support workers; a flexible approach to appointments should also be included in the specification. [54]

A comprehensive approach would adapt all induction programmes for healthcare staff to include an introduction to the needs of people with learning disabilities. This introduction would focus on standards for practice, what supports are available for staff working with people with learning disabilities, disability equality training, and the local discrimination policy. [54]

One-stop learning disability health clinic

A recent learning disability needs assessment in Scotland recommended the establishment of a 'one-stop' health clinic for people with learning disabilities. [54] Such a clinic would comprise a group of primary care professionals with a particular interest in developing expertise in working with people with learning disabilities on a single site. This might include doctors, nurse practitioners, audiologists, opticians and therapists who could provide additional assessment, investigation, treatment and monitoring for physical health needs at a level beyond that appropriately managed within the enhanced GP service provided by all or most practices.

Physical environments and transportation

There are often inappropriate facilities for families and carers in hospital settings who can also sometimes be expected to provide physical nursing care to the patient. Hospital signage and site maps may be confusing for patients with learning disability and cluttered clinical environments can hinder accessibility. However, physical environments can be thoughtfully modified by decluttering, using appropriate signage and using colour codes, ensuring that lighting is not too bright, and that noise is minimised. [25]

People with learning disabilities should also have access to reasonably adjusted local amenities and transport facilities that enable them to participate fully in programmes and services and build / maintain social networks. [46]

Transition from children's to adults' services

NICE offers recommendations to guide the transition from children's to adults' services for young people using health or social care services. ***Box 14*** provides a summary of overarching principles - for further recommendations and guidance, please see NICE guideline NG43.

Box 14: Overarching principles to guide transition from children's to adult's services for young people using health or social care services [57]

- Involve young people and their carers in service design, delivery and evaluation related to transition.
- Ensure transition support is developmentally appropriate.
- Use person-centred approaches.
- Health and social care service managers in children's and adults' services should work together in an integrated way to ensure a smooth and gradual transition for young people.
- Service managers in both adults' and children's services, across health, social care and education, should proactively identify and plan for young people in their locality with transition support needs.
- Every service involved in supporting a young person should take responsibility for sharing safeguarding information with other organisations, in line with local information‑sharing and confidentiality policies.
- Check that the young person is registered with a GP.
- Consider ensuring the young person has a named GP.

Carers

Family members or carers should be advised about their right to access a formal carer's assessment of their own needs (including their physical and mental health) and short breaks and other respite care. When providing support to family members or carers (including siblings), the impact of living with or caring for a person with a learning disability and behaviour that challenges should be recognised and information provided on how to access family advocacy, family support and information groups or formal disability-specific support groups. [29]

Early interventions – when carers first take on caring responsibilities – might include advice and equipment to assist with lifting and moving, or assistive technology which supports service users to maximise their independence, as well as enabling carers to continue to work and to engage in social and leisure activities. In addition, any carer who is experiencing depression or anxiety disorder, whether as a result of their caring or not, should be supported to access treatment from local services set up under the Improving Access to Psychological Therapies (IAPT) programme. [58]

Commissioners of health and social care services should make provision for a range of short break or respite services. No family or other carers should be denied regular short breaks from their caring responsibilities. [47] Carers tend to prefer direct payments that allow them to organise their own breaks. [58]

4.3.2 Recommendations for managing co-morbid health conditions in people with learning disability

Mental health

People with learning disabilities and mental health problems should be enabled to access mainstream mental health services where possible, with support from specialist learning disability services where needed. [46] [48]

Protocols should be in place to allow people with learning disabilities to be identified as early as possible when accessing mental health services so that appropriate support can be provided. [48] There is a general need to promote greater awareness of psychiatric disorders associated with learning disabilities, including practical guides and information for carers. [54]

Mental health services for people with learning disabilities should be commissioned in partnership with the local authority learning disability team and specialist mental health services. [59] Mental health service providers should consider, in advance, what adjustments people with learning disabilities need in order to access their services. Reasonable adjustments include removing physical barriers to access, as well as making alterations to service delivery, policy, procedure and staff training to ensure that services work equally well for people with learning disabilities. [59] The *Green Light Toolkit* can be used to audit mental health services to make them more effective for people with learning disabilities. [60]

Psychodynamic models of psychotherapy have been found to be effective forms of treatment for people with learning disabilities and additional mental disorders. [54]

There is strong and growing evidence for the effectiveness of a range of behavioural and psychological interventions in the management of aggressive behaviour in people with learning disabilities, particularly group interventions. Psychological interventions have also been found to be effective in the treatment of self-injurious behaviour, as well as sleep disorders and bereavement, in people with learning disability. A recent Cochrane Review of pharmacological interventions for self-injurious behaviour was unable to draw any firm conclusions about the benefits or safety of medications in this population due to data limitations. [61]

Anti-epileptic drugs and drugs used as treatments for mental illness can interact, and drugs used for mental illness can also affect seizure control. Management of such patients therefore requires carefully co-ordinated care, led by a designated health professional. [54]

Dementia

There are advantages to detecting the onset of dementia as early as possible in people with learning disabilities, as for the general population. This allows access to cognitive-enhancing drugs for which there is some evidence of effectiveness, and also to a range of other biological, psychological, social and developmental approaches designed to improve quality of life and to support carers. [54]

It can be particularly difficult to diagnose dementia in people with a learning disability, which can make early detection problematic in this population. A person with a learning disability will already have some differences in their thinking, reasoning, language or behaviour, and their ability to manage daily living. It is a change or deterioration in these – rather than a single assessment – that may suggest dementia. This means carers, friends and family play an important part in helping to identify early signs of dementia, such as changes in behaviour or personality and loss of day-to-day abilities. They should be supported to raise any concerns promptly with their GP or learning disability team. It is important not to assume that a person with a learning disability has dementia simply because they fall into a high-risk group or because they are getting older. Equally, it is important that symptoms of dementia are not missed because they are mistakenly seen as part of the learning disability. [62]

When communicating about dementia with someone with a learning disability, information about the diagnosis is best broken down into small chunks and tailored to their ability to understand the past, present and future, as well as to their individual communication needs. [62]

Given the higher risk of dementia in this patient group (see Chapter 5), it is recommended that every adult with Down’s syndrome is assessed for dementia by the time they reach the age of 30, to provide a record or ‘baseline’ with which future assessments can be compared. As well as this baseline assessment, an adult with Down’s syndrome should routinely be offered an annual health check with their GP. Assessment for someone with Down’s syndrome is best carried out by a multidisciplinary team that includes a GP, psychiatrist, community learning disability nurse, occupational therapist and clinical psychologist. Each of these professionals, with the exception of the GP, should be a specialist in learning disabilities. The learning disability service may work closely with the local memory clinic (where people are routinely assessed for suspected dementia) for advice on diagnosis or management. [62]

Behaviour that challenges

NICE has published specific guidance on challenging behaviour and learning disabilities. A summary of the recommendations from this guideline is provided in ***Box 15*** below.

There is strong and growing evidence for the effectiveness of a range of behavioural and psychological interventions in the management of aggressive behaviour.

There can be high turnover of staff in a team that supports people with behaviour that challenges due to the demands of the role; staff require adequate training to enable them to provide the necessary support. [63]

Box 15: NICE recommendations for challenging behaviour and learning disabilities

- Consider personalised interventions that are based on behavioural principles and a functional assessment of behaviour, tailored to the range of settings in which they spend time.
- Consider individual psychological interventions for adults with an anger management problem. These interventions should be based on cognitive-behavioural principles and delivered individually or in groups over 15–20 hours.
- Do not offer sensory interventions such as Snoezelen rooms (therapeutic environments delivering high levels of stimuli) before carrying out a functional assessment to establish the person's sensory profile. Bear in mind that the sensory profile may change.
- Consider developing and maintaining a structured plan of daytime activity (as part of the curriculum if the person is at school) that reflects the person's interests and capacity.
- Consider medication, or optimise existing medication, for coexisting mental or physical health problems identified as a factor in the development and maintenance of behaviour that challenges.
- Consider antipsychotic medication to manage behaviour that challenges only if psychological or other interventions alone do not produce change within an agreed time, or if treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour, or the risk to the person or others is very severe. Only offer antipsychotic medication in combination with psychological or other interventions.

[29]

Epilepsy

Epilepsy and mental ill health often co-exist in people with learning disabilities. However, it can be difficult to diagnose epilepsy in people with learning disabilities, and so care should be taken to obtain a full clinical history. Confusion may arise between stereotypic or other behaviours and seizure activity.

People with learning disability and epilepsy, and their family and/or carers where appropriate, should be supported to take an active part in developing a personalised care plan, taking into account any co-morbidities. Healthcare professionals should be aware of the higher risks of mortality for children, young people and adults with learning disabilities and epilepsy and discuss these with the patient, their families and/or carers. Particular attention should be paid to the possibility of adverse cognitive and behavioural effects of anti-epileptic drugs. [64]

In addition to following mainstream guidance for epileptic patients, NICE also recommends risk assessments for people with epilepsy and a learning disability that include: bathing and showering, preparing food, using electrical equipment, managing prolonged or serial seizures, the impact of epilepsy in social settings, sudden unexpected death in epilepsy (SUDEP), and the suitability of independent living, where the rights of the individual are balanced with the role of the carer. [64]

Anti-epileptic drugs and drugs used as treatments for mental illness can interact, and drugs used for mental illness can also affect seizure control. Management of such patients therefore requires carefully co-ordinated care, led by a designated health professional. [54]

Dysphagia

Dysphagia (or difficulty swallowing) is a relatively common condition in people with learning disabilities. All those who support people with learning disabilities should have training in recognising and managing swallowing difficulties. Medication reviews of patients with dysphagia should take into account swallowing difficulties, as the person may be unable to swallow tablets or other medication or supplements. [56]

Organisations providing healthcare for people with learning disabilities and dysphagia should have a lead clinician (preferably a speech and language therapist) with overall responsibility for dysphagia services. Care and support from specially trained practitioners should also be available. Sufficient preventative services for people with learning disabilities at high risk of respiratory illness be should commissioned, including ready availability of speech and language therapists or other suitably qualified practitioners able to undertake swallowing assessments, aggressive treatment of gastro-oesophageal reflux, clear clinical pathways for gastrostomy insertion and frequent reviews of patients waiting for a gastrostomy procedure. [46]

Oral Health

It is recommended that all children, young people and adults with learning disabilities should visit the dentist twice a year. Support staff working with people with learning disabilities should be offered training on the importance of oral health and how to help someone clean their teeth. All those who support people with learning disabilities should be alert to changes in behaviour such as loss of appetite, unwillingness to participate in activities, sleeplessness, irritability or self-harm, and should find out if mouth or tooth pain is a possible cause of these changes. [56]

NICE has produced specific recommendations for the care of oral health in adults in care homes, as outlined in ***Box 16***.

Access to off-site dental services may be difficult for many residents, not just those with mobility issues. Community dental services, including special care dentistry teams, can provide dental treatment to residents who have complex oral health needs and/or moderate to severe learning disability. [65] Community dental services can be available in hospitals, specialist health centres and mobile clinics as well as home visits or visits in nursing and care homes.

Box 16: NICE recommendations for the oral healthcare of adults in care homes [65]

For the oral healthcare of adults in care homes, NICE recommends that:

- care homes ensure policies set out plans and actions to promote and protect residents' oral health
- care staff assess the oral health of all residents and include mouth care in personal care plans
- managers ensure that residents are provided with daily support to meet their mouth care needs and preferences, as set out in their personal care plan after their assessment
- care home managers ensure that staff have the knowledge and skills to support in the care of residents' oral health
- Health and Wellbeing Boards ensure local oral health services address the needs of people in care homes
- oral health promotion services develop and provide care homes with oral health education materials, support and training to meet the oral health needs of all residents, especially those with complex needs
- dental practitioners provide residents in care homes with routine or specialist care and treatment.

Obesity, healthy eating and physical activity

The major focus of interventions to reduce cardiovascular disease risk factors in this population should be on increasing exercise and reducing body weight. [66] Given the high prevalence of overweight and obesity in adults with learning disabilities (see Chapter 5) they should be considered a priority group in obesity strategies.

People with learning disabilities and their carers should be involved in the planning, commissioning and monitoring of both specialist and mainstream behaviour change interventions, to ensure that their social, cultural, environmental and individual needs are taken into account.

Regular health checks for people with learning disabilities (see 4.3.1) should include consideration of factors relevant to nutritional health - including body weight, weight change, bowel health, oral health, specific medical conditions, difficulties with eating and drinking, and medication reviews. Health Action Plans (see 4.3.1) should also include information on the patients' nutritional health. The monitoring of healthy eating and physical activity measures in Health Action Plans should be included within service specifications [56, 53].

Specialist Services

Weight management specifically, and healthy lifestyles in general, should be considered in the commissioning of services to meet the health needs of people with learning disabilities, their families, and their carers. Relevant guidance should inform practice.[10]

A life-course approach to supporting people with learning disabilities to maintain a healthy weight should be adopted - ensuring that appropriate holistic support is available around physical activity, healthy eating, weight management, emotional wellbeing, and resilience, for services users of all ages. A commitment to embed good nutrition and physical activity in all relevant settings should be an aspiration. Healthy food options should be provided at every meal. Making Every Contact Count principles should be employed (***Box 17***). [53].

Box 17: Making Every Contact Count [67]

Making Every Contact Count is an approach focused on continuous health improvement through the contacts an organisation or service has with individuals. Making Every Contact Count involves:

- systematically promoting the benefits of healthy living across the organisation
- asking individuals about their lifestyle and changes they may wish to make, when there is an appropriate opportunity to do so
- responding appropriately to the lifestyle issue/s once raised
- taking the appropriate action to either give information, signpost or refer individuals to the support they need.

For adults who live in supported accommodation, provision should be made for staff to be able to supervise and implement daily exercise and weight reduction programmes for residents. [66] Commissioners should ensure that nutritional standards are included in their service specifications when commissioning catering and other services in residential, day care or domiciliary settings for people with learning disability. All providers should adopt, implement and monitor nutritional standards in these settings. [56]

Courses in nutrition and health and basic cookery should be available for people with learning disabilities, and should be accessible for family, friends and other carers

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[10] For example, the appropriate sections of the CQC 'Guidance about compliance; Essential Standards of Quality and Safety'.

where appropriate. Special courses should be made available for those people with learning disabilities who are parents or who wish to become parents. [56]

Referral to tier 3 clinical obesity services should be considered if the patient has specialist support needs that cannot be adequately managed in a tier 2 lifestyle weight management service. [68]

Mainstream services

Local weight management, physical activity, healthy eating and dietetic services should be reviewed to assess how well they are meeting the needs of people with learning disabilities. [53] All mainstream health promotion programmes should be inclusive for people with learning disabilities. This could involve ensuring that existing healthy eating campaigns specifically consider the communication needs of people with learning disabilities, or that tailored interventions on nutrition and physical activity are developed for this population. [52]

Learning disabled adults should be supported to accesses a range of relevant services such as slimming clubs, exercise referral, activity classes, weight management clinics at GP surgeries and hospitals, and dieticians. They should also be supported to access local Health Trainer services, where these exist. [53]

GP practice staff should be proactive in identifying and working with patients with learning disabilities to coordinate, monitor and manage their nutritional health. Nutritional guidelines, in an accessible, easy-to-read format, should be available to people with learning disabilities and their families and carers. [56] To aid service planning and development, data extraction queries could include cross-referencing of patients with a learning disability who are overweight/obese at consortia and practice level. [53]

Motivation and compliance

Motivation and capacity to achieve and maintain a healthy lifestyle is allied to improving a client's knowledge and understanding of what this entails. Not feeling competent has been identified as a barrier for people with learning disabilities to engage in physical activity: not knowing how, not having anyone to show you how, not having anyone to exercise with, and finding equipment hard to use, have all been shown to be barriers to exercise. [69]

A qualitative study involving people with learning disabilities, their carers and support staff identified the importance of creating a social environment where physical activity is 'normalised' by systematically incorporating exercise into daily activities. Providing transportation to where activities take place is key. Fitness programmes based on social learning and behaviour change have been successful in engaging people with learning disabilities to participate in physical activity. Prior to individuals taking action, they need their concerns and perceived barriers addressed, they need to feel that the benefits will outweigh any negative aspects, and they need to be taught specific skills and coping strategies. Individuals beginning to take action require both tangible and emotional reinforcement and rewards. [69]

Motivation to comply with lifestyle changes also increases when carers and participants identify with the programme and its values. [70] Behavioural interventions, along with education, are key to success; the use of self-control techniques and self-monitoring of food intake, mindfulness programmes and relapse prevention strategies are of particular relevance. [70] NICE recommends that all health, education and social care staff should be trained in assessing and managing overweight and obesity in people with learning disabilities. [68]

Musculoskeletal care

Postural care is a way of preserving and re-establishing body shape for people with movement difficulties. In meeting this need, there is a requirement for people to have access to services, equipment and training to support the long term management of their body shape. [46]

To minimise the possibility of low bone density, people with learning disabilities should be as mobile as possible, spend time outside in the sunshine safely, and have adequate vitamin D and calcium intake. Anyone with a learning disability who has little regular exposure to summer sunshine should be considered for vitamin D supplementation. [56]

Smoking

On average, people with learning disabilities are less likely to smoke than the general population. As described in Chapter 4, those with milder disability and/or living independently are more likely to smoke (and also drink alcohol), which highlights the importance of providing accessible health promotion messages to these individuals, for example through regular health checks in primary care (see section 4.3.1). [54]

A small-scale pilot of a smoking education course for people with learning disabilities in Australia was found to have positive results. Some participants either quit smoking or cut down significantly, with many expressing a desire to stop smoking at the completion of the course, and demonstrating increased awareness and concern about the effects of smoking on their health. [71]

Sexual health

Sexual health is a particularly neglected area in the management of the health needs of people with learning disabilities. This has affected take up of cervical screening. There is limited information available about the sexual experiences of people with learning disabilities, however it is clear that a proportion of women with learning disabilities will have experienced consenting and/or nonconsenting sexual relationships and, consequently, women with learning disabilities cannot be assumed to be at negligible risk of cervical cancer. [46]

Sexual health should feature in all person-centred planning and reviews, and teenagers and adults with learning disabilities should have access to appropriate information about sex, sexuality and relationships. A nominated staff member should be available to respond to someone with learning disabilities who wants to know about or discuss personal matters. Relationships and sex education initiatives in schools and day centres for people with learning disabilities should include information and education on appropriate and inappropriate behaviours, and promote self-protection. [72]

Sexuality and relationships should feature in all training courses for professionals who are involved in caring for people with learning disabilities. Carers should have additional support available to help them cope with the developing sexuality of the person in their care. [72]

Awareness of sexual health services is likely to be low amongst people with learning disabilities unless services are actively promoted in a targeted way. As with other health and care services, extended or repeat appointments can be useful, depending on the needs of the individual. [73]

A sexual health needs assessment conducted in the Royal Borough of Kingston-upon-Thames recommended a dedicated, monthly sexual health clinic aimed at people with learning disabilities. [74]

4.3.3 Recommendations for housing support

Meeting the housing needs of people with learning disabilities

Mencap estimates that the most common housing arrangements for people with a learning disability are living with family and friends, in a registered care home or in supported accommodation (see Chapter 5). However, most people with learning disabilities want to live independently: 43% of those Mencap surveyed wanted to live alone, while 30% want to share a home with friends. [75] Ordinary housing, with small numbers of occupants, is preferable to large-scale residential accommodation for people with learning disabilities. [76]

Local authority housing plans must address the need for suitable accommodation for people with learning disabilities, including provision for independent living wherever possible. The first step is to establish a voluntary register of the number of people with a learning disability in the borough, the types and severity of learning disability experienced, and where people with a learning disability currently live. [75]

Housing allocation policies should ensure that the following residents with learning disability are prioritised: [63]

- victims of hate crime
- those with care and support needs
- those who live with parents aged 70 or older.

When people with learning disability move into their own homes, their involvement in reviewing the quality and outcomes of their services or support arrangements is paramount. Individuals and their families provide a valuable source of information about the service they receive. Tenants need to be clear about what they are expecting to receive, the standards that this should be delivered to, and how to best ‘evaluate’ their housing and support service or arrangements. Local authorities can use feedback from tenants as part of the evidence they will gather in order to ensure they are meeting their statutory responsibilities and that individual needs are being met. [77]

Mencap reports that three quarters (76%) of local authorities have had difficulty arranging housing for adults with ‘profound and multiple learning disabilities’ (PMLD). This compares to 29% stating difficulties arranging housing for people with a mild learning disability. Meeting the housing needs of people with PMLD means ensuring they have the right physical environment. This may include wheelchair-accessibility, equipment such as a hoist and/or sufficient space to enable support needs to be met. [63]

People with behaviour that challenges have specific housing needs, requiring accommodation with extra space and 24-hour support. It is very important that their housing and support is carefully designed and that they have ‘capable environments’ that respond to their needs. A well-managed environment that reduces possible triggers will reduce the potential for people to display behaviour that challenges. [63]

Planning for future housing needs

To meet demand arising from the projected growth in the learning disabled population, Mencap estimates that over the next 15 years England and Wales will require 19,860 new registered care home places, 14,122 supported accommodation places, 10,766 general needs tenancies with local authorities and housing associations, and 2,967 private tenancies. [75] In planning for future housing need, local authorities should review the adequacy and mix of existing housing and support options for people with learning disabilities, with particular consideration given to whether current provision offers real choices for residents. Strategies for future housing need should be developed in partnership with other relevant agencies (including the private rented sector) and should involve service users and their carers. [63] [77] There should be particular consideration given to whether current provision is adequate to offer real choice for people with learning disabilities. In particular, local authorities must plan strategically for housing people with PMLD in the future, as these individuals often require expensive packages of care alongside their housing arrangements.

Parents and carers (particularly those above the age of 70) of adults with learning disabilities should have a plan in place for future care and accommodation needs, in preparation for the time when they are no longer able to provide caring support. Local authorities should facilitate this planning process - providing information, advocacy and advice services - to prevent or reduce the risk of people with learning disabilities approaching the Council in housing crisis. [78, 63]

Promoting independence and choice through housing support

Mencap recommends that local authorities take a leading role in promoting independence through appropriate housing and support services. [63]

People with learning disabilities and their carers should be supported to make genuine, independent housing choices. Local authorities should be aware of the difficulties some carers face when the person in their care leaves home. Carers may feel that their home is the most suitable environment and that they provide the best care. Extensive information about alternative housing options should be offered to carers and, where possible, service users should be able to try out facilities prior to a final decision being made. Evidence of successful moves by other service-users should be shared with clients considering a move. [79]

The Joseph Rowntree Foundation has published best practice guidance for providing appropriate housing support to people with learning disabilities, as summarised in ***Box 18***.

Box 18: Joseph Rowntree Foundation best practice guidance for housing support for people with learning disabilities [80]

- Set local eligibility criteria for accessing housing support and funding.
- Ensure that all parties involved in the provision of housing and support fully understand the rights and responsibilities of tenancies.
- Ensure that people with learning disabilities are supported to access housing applications and waiting lists, and are made aware of and supported to access alternative accommodation, e.g. private rented accommodation.
- The most appropriate support should be provided. Ensure a clear separation between housing and support in local provisions, so that organisations do not act as landlord and support provider.
- Be aware of what aspects of tenants' lives may be under the control of other individuals, and whether it would be possible to shift the balance of choice to the client. Clients should be supported to make their own informed choices.
- Assess the physical, social and financial risks to which individuals may be exposed.
- Support clients to be in control of their own finances. Ensure tenants are receiving all the financial benefits to which they are entitled. Support tenants to live within their financial means, to understand where money is sourced from, and how it is spent.

People with a learning disability who have a mental health condition or whose behaviour challenges should be offered a choice of housing, including small-scale supported living to enable them to live as independently as possible (rather than in 'institutional' settings). This includes those people leaving specialist hospitals after long inpatient spells. Housing options may include 'mainstream' accommodation provided by a housing association, private landlord, family or shared ownership scheme; suitable opportunities for home ownership or ensuring security of tenure should also be explored. It should not be assumed that individuals want to live with others; the choice of the individual should be respected. [36]

For PMLD and other adults with high support needs, existing property may need to be adapted to meet the individual's needs, for instance by installing safety equipment or assistive technology. Use of a Disabled Facilities Grant (DFG) might be needed to do this and the rules over DFG usage need to be interpreted with appropriate breadth and paying full attention to the guidance, i.e. it is not just for adaptations to accommodate physical disability and the needs of the family should be considered also. CCGs could consider allowing people with a personal health budget to use some of their budget to pay for or ‘top up’ housing costs, if this meets a health need and is agreed as part of the individual’s care and support plan. [36]

Many people with learning disabilities may not ask about housing options, as they may not be aware that any alternatives are available to them. They may remain in unsuitable housing unless they are presented with options and supported to articulate their need and choice. The user voice is essential in determining how services might be developed in order that their needs are adequately met. [76]

4.3.4 Recommendations for employment support

Chapter 5 (section 5.4.4) and Chapter 7 (section 7.9.2) describe the low employment rates and barriers to employment faced by adults with a learning disability.

Supported employment and Individual Placement and Support (IPS) are the most effective solutions for supporting people with learning disabilities into paid jobs.[11] IPS consists of intensive individual support, job search and placement, and in-work support for employee and employer. Evidence shows that support providers who use established best practice across job identification, job matching, job gaining and employment support achieve better outcomes for individuals and value for money. [60]

The National Development Team for Inclusion (NDTI) have developed a resource for health and social care commissioners to deliver cost-effective employment support with positive outcomes for adults with learning disability. ***Box 19*** outlines the key NDTI recommendations.

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[11] The British Association for Supported Employment provides further information on supported employment. Please see http://base-uk.org/information-commissioners/what-supported-employment

Box 19: NDTI recommendations for employment support for people with learning disabilities [60]

NDTI recommends that:

- Employment outcomes for people with learning disabilities should be a Council priority and reported to the Health & Wellbeing Board. The employment strategy should be led by a committed and informed leader and championed at a senior level. The strategy should have commitment from employment support services and employers across sectors should be engaged.
- Employment should be clearly defined in terms of salary, number of hours worked, and other minimum standards for 'successful' employment status. The definition should include enough information to track outcomes such as wages and hours and should be shared and understood by all stakeholders. Maintaining and retaining employment should be viewed as of equal importance to gaining employment.
- As a central strategic outcome, the employment strategy should be owned by key players and include best practice and national policy. The strategy should include the transition to adulthood, be linked with economic regeneration and implemented as a measurable, deliverable plan.
- Knowledgeable leadership must be in place that works with all stakeholders and providers to develop systems and markets to deliver employment objectives. Providers should have a clear understanding of best practice and be monitored to ensure fidelity to best practice.
- Data is recorded and collated to analyse performance outcomes of employment support services. Outcomes should be used to inform the development, monitoring and review of services. Data should also include customer satisfaction and individual stories.

Employment should be promoted and supported as an option early in transition planning, which should involve specialist employment agencies. People with learning disabilities should have access to individually tailored and flexible work experience, with on-the-job personal support when needed. Transition workers should be provided as a single point of information and support. Consistent and high quality vocational training should be provided in school and colleges. The idea that people with learning disabilities are 'incapable' of employment needs to be challenged. [81]

Collaborative working between students, parents, education staff and employers is recommended. [82] Specific advice for family carers has been published by the Foundation for People with Learning Disabilities to help them support those they care for to find meaningful employment (see ***Box 20***).

Box 20: Foundation for People with Learning Disabilities employment support recommendations [83]

The Foundation for People with Learning disabilities offers the following employment advice to family carers:

- Engage the person with learning disabilities in discussing what they enjoy doing, what they are good at and whether they would like to work.
- Seek out work experience and apprenticeships.
- When considering further education, ask the academic institution what is being done to lead to employment and how many students entered paid work in the previous year. If currently in further education, ask what work options and plans have been discussed.
- Challenge any suggestions that the family member is not ready or mature enough to work or would be a risk under health and safety rules.
- Ask your school contact or social worker about a direct payment for them to employ a personal assistant to support them with a Saturday job and work experience. If your family member has a Personal Budget, use this to employ a job coach to support a work placement or job.
- Find out if there is an employment sub-group on the local Learning Disability Partnership Board.
- Ask for a referral to the local employment support provider. Ask how many people with moderate to complex needs have gained employment in the last year.
- Contact a local small business group for access to employers.
- Find out who the Disability Employment Advisor is at the Jobcentre.
- Consider self-employment or setting up a small business.

One further education institution for people with learning disabilities the UK has been successful in securing 68% of graduating students with work-based placements. They currently run an employment studies programme and, as part of this programme, they utilise links with other services to support students, including Job Centre Plus, Social Services, Connexions and Supported Employment Agencies. They also employ an employment officer to support the students in accessing employment opportunities and offer one-to-one travel training, so that students can access the workplace independently. In addition to this, the organisation runs what they refer to as the MORE project, *Meaningful Opportunities Realistic Employment*, which also assists students to find employment, prepare for leaving education and participate in employment opportunities. [82]

Best practice in supported employment advocates giving individuals control of their vocational destinies through self-determination, facilitated by person centred planning and a career-based approach. This means employment specialists acting as facilitators rather than experts. Other features of best practice include: [84]

- taking account of employers' as well as individuals' needs

- using intentional strategies to enhance social integration
- supporting self-employment
- follow-up support
- ensuring people with severe disabilities can access supported employment.

Box 21: Supported internships [85]

Supported internships are one-year, structured study programmes based primarily in a workplace, equipping young people with the skills they need for work. All young people aged 16-24 in education with a Learning Difficulty Assessment who want to move into employment can follow the supported internship as their study programme.

Box 22: Project Search [86] [87]

Project Search is a business-led, supported internship programme where participants learn relevant marketable skills while immersed in the business over an academic year, aiming to secure employment with the business at the end of the programme. A pilot evaluation of 11 UK sites found that that around one in three interns gained full-time or part-time employment; but the authors expressed concern about the cost of the programme (£10,500 per participant per year). A later evaluation of 17 active UK sites found 36% in full-time employment (defined as more than 16 hours per week) and a further 11% in part-time employment.

4.3.5 Recommendations for reducing social isolation

Partly linked to their housing circumstances and reduce employment opportunities, people with learning disabilities are among the most socially excluded in society, often having poor social networks and a lack of connectedness to their local community (see Chapter 5).

A recent review of interventions to improve social networks and social participation in adults with learning disabilities found that effective components included: [88]

- person-centred planning
- supported learning programmes
- semi-structured group sessions (including exercises that incorporate learning objectives and taught social skills).

Deliberate approaches to developing social relationships may not always be the most effective method of enhancing the social participation and networks of individuals with learning difficulties. Pre-existing relationships should not be jeopardised when looking to form new ones, and approaches which embrace naturally occurring opportunities to enhance social networks may be more effective. [88]

5. National context - health inequalities in adults with learning disabilities

5.1 Introduction

This chapter describes the key health and wellbeing needs of adults with a learning disability. It examines the impact of the wider determinants of health and outlines the health inequalities experienced by this population, based on national data and research, while outlining a number of key mental health and physical health conditions that are often faced by people with learning disabilities.

The care of people with learning disabilities has undergone major change since the Winterbourne View scandal, but significant health inequalities remain.

5.2 Mortality, causes of death and contributory factors

While life expectancy is improving, particularly for people with Down's syndrome and those with mild impairments, overall people with learning disabilities have a shorter life expectancy then the general population. [89] Mortality rates for people with moderate to severe learning disabilities are three times higher when compared to the general population, in particular amongst young adults, women and people with Down's syndrome. [89] [90]

The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) undertaken in 2011 reported that females with learning disabilities on average die 20 years earlier than the general population and males on average 13 years earlier. One in five deaths (22%) in people with learning disabilities are in those aged under 50. While this may be due to medical problems associated with a learning disability, it may also be the result of avoidable factors which could have been prevented with better access to healthcare. [91]

Table 4 provides summarised data on the common immediate causes of death for people with learning disabilities, comparing the top 10 causes with those in people without a learning disability. This table shows that respiratory disease is the leading immediate cause of death for people with learning disabilities, accounting for over half of deaths compared with just over a quarter of deaths in people without a learning disability. Circulatory diseases (including heart disease and stroke) are the second most common immediate cause of death in people with learning disabilities. [92] [93] Cancer is a much less immediate cause of death in people with learning disabilities than in those without such a disability.

Another study into how people with learning disabilities die highlighted two main causes of premature death: lung problems (caused by solids or liquids going down the wrong way) and epilepsy or convulsions. [92]

Table 4 Top ten causes of death: people with any condition associated with learning disabilities compared to those without (% with condition as immediate cause) [92]

	Any condition associated with learning disabilities		**No condition associated with learning disabilities**	
1	Respiratory diseases	3,866 (52%)	Circulatory diseases	681,126 (28.9%)
2	Circulatory diseases	898 (12.1%)	Respiratory diseases	602,880 (25.6%)
3	Infectious and parasitic diseases	459 (6.2%)	Cancers and other growths	518,150 (22%)
4	Nervous system diseases	393 (5.3%)	Other signs and symptoms	163,301 (6.9%)
5	Other signs and symptoms	332 (4.5%)	Infectious and parasitic diseases	103,472 (4.4%)
6	Congenital and chromosomal conditions	301 (4%)	Digestive system diseases	94,485 (4%)
7	Cancers and other growths	284 (3.8%)	Injury and poisoning	63,809 (2.7%)
8	Genito-urinary diseases	202 (2.7%)	Genito-urinary diseases	47,733 (2%)
9	Injury and poisoning	197 (2.6%)	Nervous system diseases	30,676 (1.3%)
10	Digestive system diseases	191 (2.6%	Mental and behavioural disorders	23,167 (1%)

The CIPOLD study reviewed the patterns of care received by people with learning disabilities prior to their premature death and explored possible contributory factors. The study found that the most common reasons for premature death were:

- delays or problems with diagnosis or treatment
- problems identifying needs and providing appropriate care in response to changing needs.

These delays and problems were found to be largely due to poor access to services and failure to implement ‘reasonable adjustments’ as required by the Equality Act 2010. Poor care of learning disabled and other vulnerable patients in the NHS has also been highlighted in various reports by Mencap, including *Treat me right*, *Death by indifference* and the *Six lives* report (see Chapter 4). [94] [95] [96]

The CIPOLD study also reported that the ability of many people with learning disabilities to follow complex care pathways is significantly impaired (due to poor communication aptitude and reduced cognitive function), leading to high ‘lost to follow-up’ rates in health and care services. Continuity of care is a significant problem for these patients.

The majority of people with learning disabilities have more than one long-term co-morbid condition - an average of five in the CIPOLD study. There was found to be a lack of communication between different healthcare professionals looking after patients' different needs, often leading to unnecessarily complicated and sometimes conflicted care. Multiple comorbidity and polypharmacy is complex in any patient, but can be much more difficult to manage in a patient with a learning disability, due to their reduced communication and cognitive functions as described above.

Healthcare staff were generally found to be poorly trained in the care of learning disabled patients and there was overall very poor understanding of, and adherence to, the Mental Capacity Act 2005 and Independent Mental Capacity Advocate (IMCA). This often led to inadequate management and sub-optimal care. In some cases, local hospital policies were not followed, leading to deterioration in care. Poor record keeping by healthcare staff meant that potential problems were often not picked up early enough and communications between care professionals did not routinely mention the diagnosis of learning disability, which resulted in inappropriate discharge arrangements. Inadequate staff training was blamed for an inability to pick up relevant signs, fewer investigations undertaken than needed and a reluctance by staff to ask for help.

Another common theme highlighted in the CIPOLD study was poor communication with the families of patients with learning disabilities and a failure to fully take their views and wishes into account. This often led to delayed or incorrect diagnosis. Families frequently found the complaints system to be poor and ineffective.

This study also found that, at the time of death, a high proportion of people with learning disabilities lived in residential care homes (64%), most with 24-hour paid carer support. For one in five (20%) of those examined in the review, safeguarding concerns had previously been raised; for a further 8% safeguarding concerns were raised retrospectively as part of the CIPOLD review and had not been reported or investigated previously. [91]

5.3 Health conditions affecting people with a learning disability

As mentioned in Chapter 4, following an independent inquiry into access to healthcare for people with learning disabilities, the *Improving Health and Lives: Learning Disabilities Observatory* was established in 2010.[12] The Observatory gathers information to help provide a better understanding of the health and wellbeing needs of people with learning disabilities and has published a number of reports which have been used throughout this chapter. For example, ***Table 5***, which provides a list of the major health problems in this population, is taken from a report which aimed to explore the data needed to inform health planning to meet the needs of people with learning disabilities. ***Table 6***, taken from another source, provides a similar overview of health needs, but with some important differences (e.g. while

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[12] https://www.improvinghealthandlives.org.uk/

cancer is a significant health problem for people with learning disability, it is less common than in the general population). ***Table 6*** also alludes to the fact that, while people with learning disability may have more healthcare consultations on average, they are less likely to experience continuity of care.

Table 5: Major health problems for people with learning disabilities

Health	Illnesses	
General Health Status	Respiratory disease	Constipation
Diet	Heart disease	Endocrine disorders
Exercise	Epilepsy	Cancer
Obesity and underweight	Sensory impairments	Injuries, accidents and falls
Substance use	Oral health	Osteoporosis
Sexual health	Dysphagia	Physical impairments
	Diabetes	Mental illness
	Gasto-oesophageal reflux disease (GORD)	Dementia

Source: IHAL (2010) NHS Data Gaps [97]

Table 6: Summary of health related patterns of people with learning disabilities [98]

More	Less
Epilepsy	Ischaemic heart disease
Severe Mental illness	Cancer
Dementia	Continuity of care
Hypothyroidism	
Heart failure	
Consultations	

Various studies have examined the prevalence of specific health conditions affecting people with learning disabilities. While estimates vary, certain health problems are consistently found to be more common than average in this population as described above. [89] ***Table 7*** shows the prevalence of a selection of chronic disease experienced by people with learning disabilities compared to rates in different 'control groups'. The data is from a study published in 2016, which concluded that people with an intellectual disability generally have higher levels of chronic disease when compared to the general population. [99]

The remainder of this section discussed the major health needs of adults with learning disability in further detail.

Table 7: Prevalence of chronic diseases in people with an intellectual disability compared to the general population

Disease	% Intellectual disability	% Controls
Epilepsy	18.5%	0.7%
Severe mental illness	8.6%	1%
- Schizophrenia	6.8%	0.7%
- Affective disorder	2.5%	0.4%
Ischaemic Heart Disease	1.7%	2.7%
Heart failure	0.8%	0.4%
Stroke and transient ischaemic attack	1.8%	1.1%
Atrial fibrillation	0.8%	1%
Hypertension	10.7%	12.1%
Peripheral vascular disease	0.4%	0.5%
Chronic kidney disease	3.2%	2.1%
Diabetes	6.9%	4.4%
Hypothyroidism	7.9%	3.1%
Asthma	8.2%	6.6%
Chronic obstructive pulmonary disease (COPD)	1.1%	1.4%
Cancer	1.6%	2.4%
Osteoporosis	1.7%	1%
Rheumatoid arthritis	0.5%	0.6%
Dementia	1.1%	0.2%
Depression	17.7%	17.6%
Anxiety (ever)	16.3%	14.6%

Source: [99]

5.3.1 Mental Health

People with a learning disability are at higher risk of developing mental health problems and poorer outcomes have been reported in this group. [99]

It is important to note that the number of learning disabled individuals with mental health problems may be under-reported due to poor access to healthcare, atypical presentations and poor communication. [100]

Specific causes of learning disability are linked to increased risk of particular mental health problems, examples of which are listed in ***Table 8*** below.

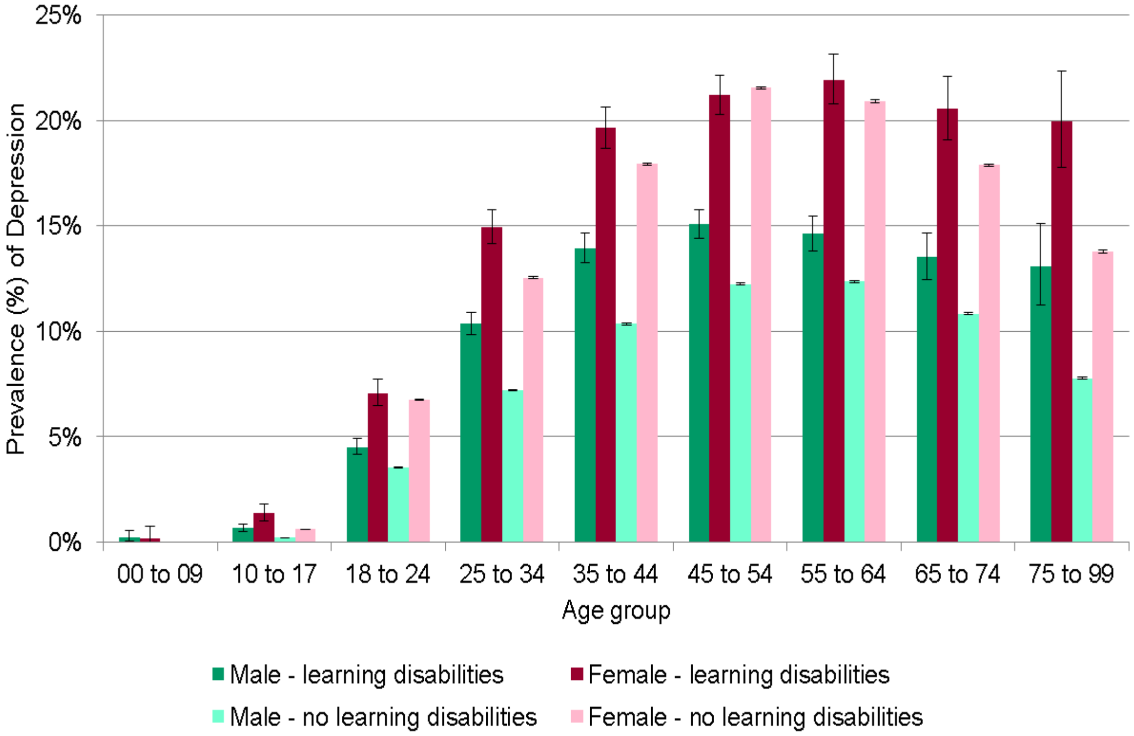
Table 8: Learning disability subgroups with an increased risk of particular mental health conditions

Learning disability sub group	Increased risk
Downs Syndrome	Dementia (specifically Alzheimer's disease)
Prader Willi Syndrome	Affective psychotic illness
22qdel syndrome	Schizophrenia
William's syndrome	Specific anxiety disorders
Fragile-X syndrome	Generalised anxiety disorder
Autistic spectrum conditions	Anxiety and mood disorders

Source: PHE learning disability conference, 2016 [98]

Estimates of the prevalence of depression in people with learning disabilities vary, [89] but ***Figure 3*** suggests that there is a higher prevalence amongst the learning disabled population in most age groups (for men and women) compared to those without such a disability.

Figure 3: Recorded prevalence of depression by age and gender (based on English GP records)

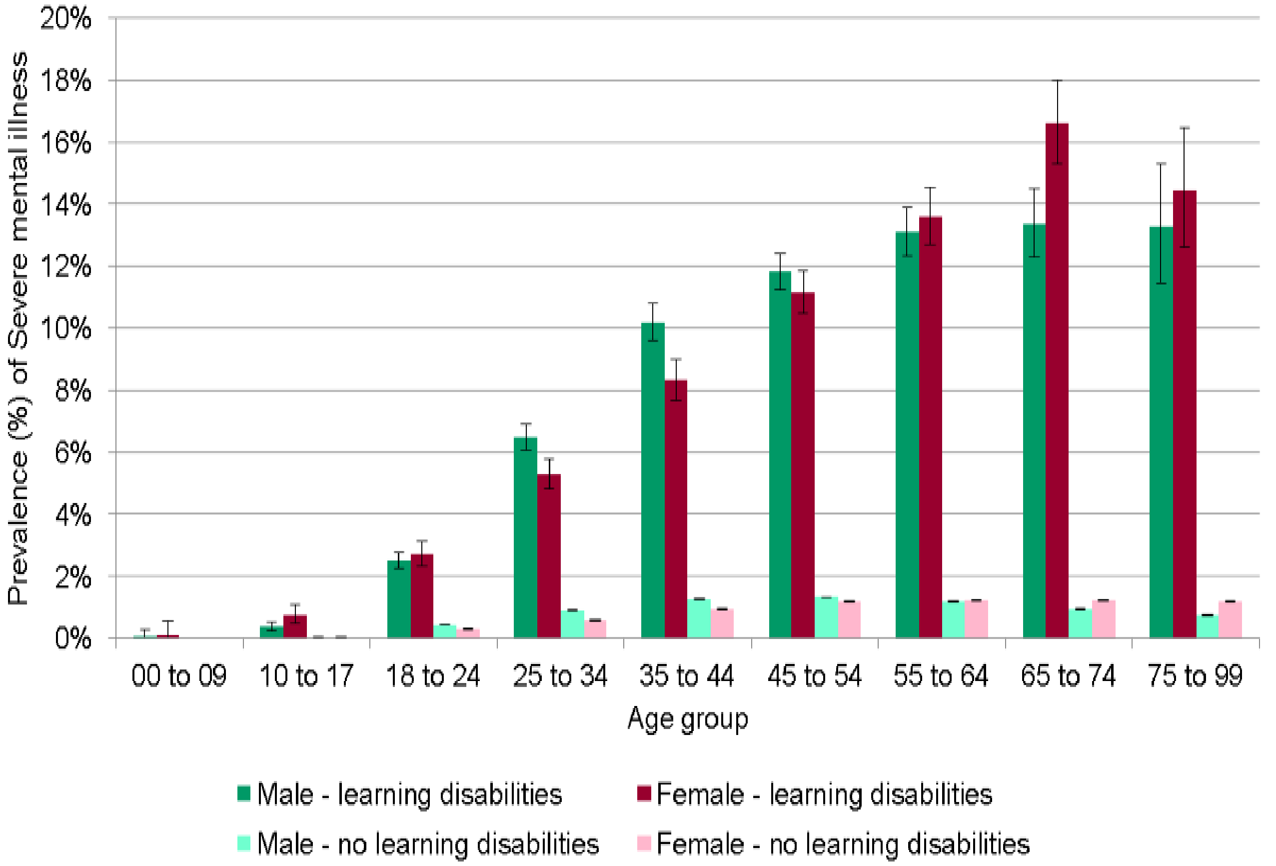


Source: PHE learning disability conference, 2016 [98]

Based on this same data source, ***Figure 4*** reveals a much higher prevalence of severe mental illness (SMI) amongst people with learning disabilities than other patients, and that recorded prevalence increases markedly with age. The Carey et al study suggests 8.6% of adult learning disabled patients have a SMI, compared to 1% of all adult patients. [99]

Evidence suggests that the prevalence of schizophrenia in the learning disabled population is three times higher than in the general population. [89] [101]

Figure 4: Recorded prevalence of severe mental illness by age and gender (based on English GP records)



Source: [98]

5.3.2 Dementia

Dementia covers a range of different progressive memory loss conditions as illustrated in ***Box 23***. There are different causes and types of dementia, of which Alzheimer's is the most common. [102]

Box 23: Types of dementia [103]

Type of dementia	Estimated proportion of all cases of dementia	Physical cause	Symptoms other than memory loss
Alzheimer's disease	62%	Damaged tissue building up in the brain	May include difficulty communicating or learning new things as well as changes in mood, judgement and personality.
Vascular dementia	17%	A series of small strokes	May come on more quickly than Alzheimer's disease. Symptoms may include changes in mood, hallucinations, physical impairment.
Mixed dementia	10%	A combination of more than one type of dementia	Vary according to the types of dementia present.
Dementia with Lewy bodies	4%	'Lewy bodies': tiny deposits of protein in nerve cells	Shares symptoms with Alzheimer's disease and Parkinson's dementia (see above and below). May also include problems with alertness and attention, and hallucinations.
Frontotemporal dementia	2%	Death of nerve cells in the frontal and/or temporal lobes of the brain.	Vary depending on which parts of the brain are damaged. May include behaviour change or language difficulties.
Parkinson's dementia	2%	Parkinson's disease	May include cognitive difficulties, emotional difficulties, hallucinations.
Other	3%	Vary	Vary

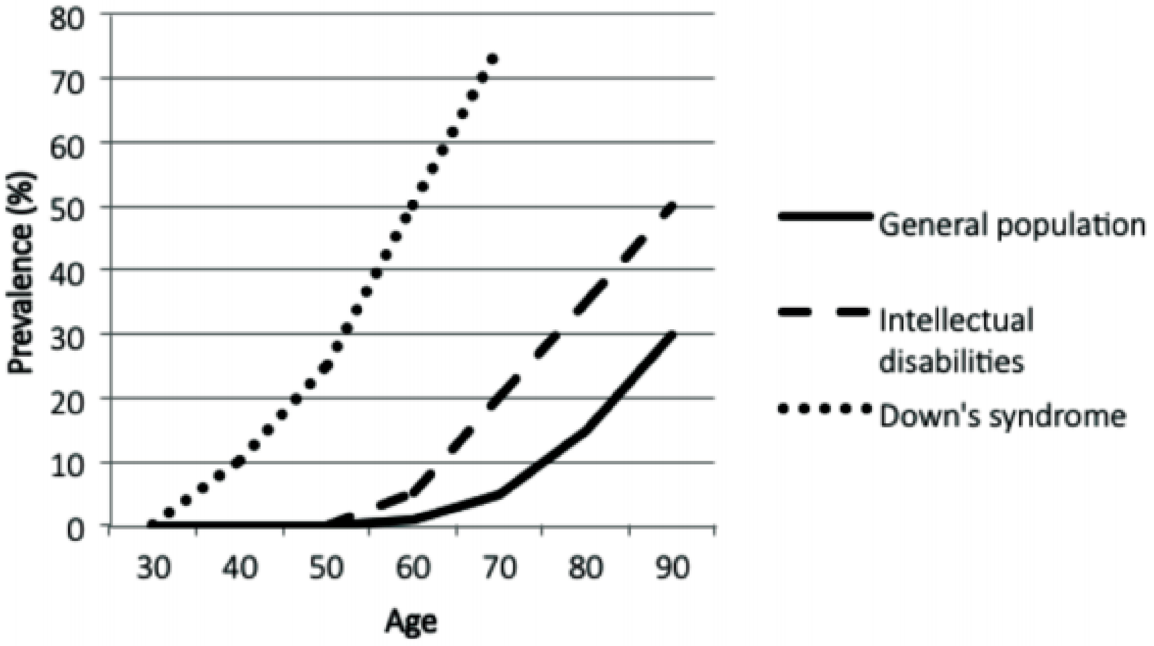
People with learning disabilities are at greater risk of developing dementia across all age groups, especially if they are diagnosed with Down's syndrome (***Figure 5***). Dementia prevalence is most commonly reported exclusively for the over 65 population. National age-standardised prevalence estimates indicate that around 20% of learning disabled and 7.1% of the non-disabled 65+ population has dementia. [104] [105]

Early onset dementia is classified as a diagnosis of the condition before the age of 65, and is more common amongst people with learning disability. Early onset dementia is a phenomena which is particularly linked to people with Down's syndrome, who experience an increased risk of Alzheimer's disease at an early age (age 30+).

Amongst people with Down's syndrome, the estimated prevalence of dementia in those under 40 years of age is 10-15%, compared to 0.9% of under 40s in the general population. [105]

These trends in early onset dementia are presented in ***Figure 5***.[13] The average age of diagnosis of dementia in Down's patients is estimated at 55 years. [106]

Figure 5: Estimated trends of dementia prevalence by age



Source: The British Psychological society, 2015 [106]

5.3.3 Behaviour that challenges

Behaviour that challenges is defined as signs of aggression, self-injury, stereotypic behaviour, self-injury, disruptive or destructive acts, or withdrawn behaviour (it is also linked to arson and sexual misconduct), leading to increased risk of contact with the criminal justice system. [107]

The number of people presenting to services with 'challenging behaviour' is important to describe for commissioners, service professionals and service users, to be aware of the need for specialist support and/or reasonable adjustments in day-to-day care. A report on reasonable adjustments for people with learning disability is available through PHE's IHAL website. [108]

There are some difficulties in quantifying 'challenging behaviour' in practice, however: first, because of the potentially stigmatising proxy measures used to determine such behaviour (including 'incidents' such as hurting others, self-harm and destructive

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[13] The British Psychological Society have advised caution on the exact prevalence rates presented in ***Figure 5***, but there is overall acceptance of the general trends observed at population level.

behaviour); and second, because of the important role of environmental factors and the actions of others in the presentation of this type of behaviour.

Challenging behaviour is not a diagnosis and is likely to be underpinned by multiple factors, especially in adults with learning disability.

One third of patients with learning disabilities show challenging behaviour at some point in their lives. [100]

5.3.4 Epilepsy

The prevalence of epilepsy in learning disabled adults is significantly higher than in the general population. For people with a learning disability, prevalence estimates range between 16% and 26%. [99] [109] [110] Provisional data from PHE indicates a crude epilepsy prevalence rate of around 16% in learning disabled GP patients in London. This compared with approximately 1% in the general population. [110] [111] [112]

Epilepsy prevalence tends to be higher in younger adults with learning disabilities and declines with age, which may be due to the increased risk of early mortality associated with epilepsy in people with learning disabilities. [110]

Epilepsy patients with learning disabilities have more frequent seizures on average, and these seizures tend to be more severe and resistant to antiepileptic medication. [113] It has been documented that epilepsy is one of the commonest reasons for preventable hospital admissions in individual with learning disabilities. [114]

Certain antiepileptic drugs can also exacerbate behavioural and psychological problems. [110] [113] Clinical studies of adults with learning disability have identified higher rates of behaviour and psychological problems in those who also have epilepsy, compared with those without epilepsy. [111] [113]

While a higher percentage of patients with learning disabilities have a seizure diary[14] (***Figure 6***), they are much less likely to remain seizure free over a 12 month period compared with patients without a learning disability (***Figure 7***). This suggests that seizure control in people with learning disabilities is more challenging and could warrant further investigation to determine whether current tools are suitably implemented for this group of patients.

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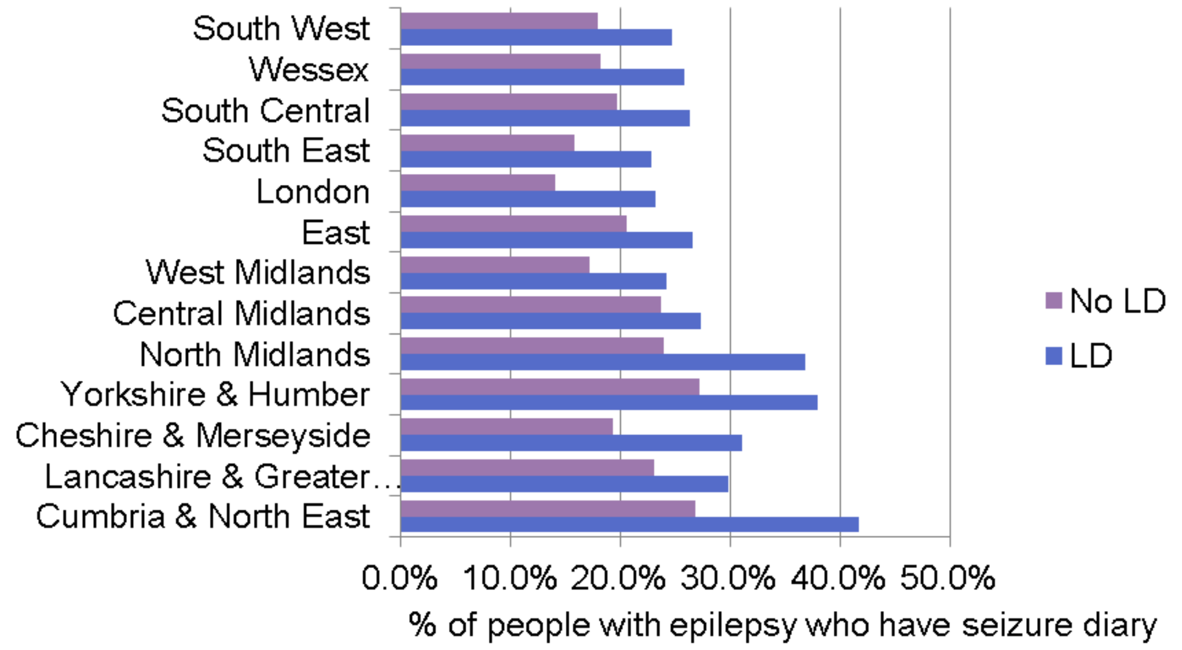
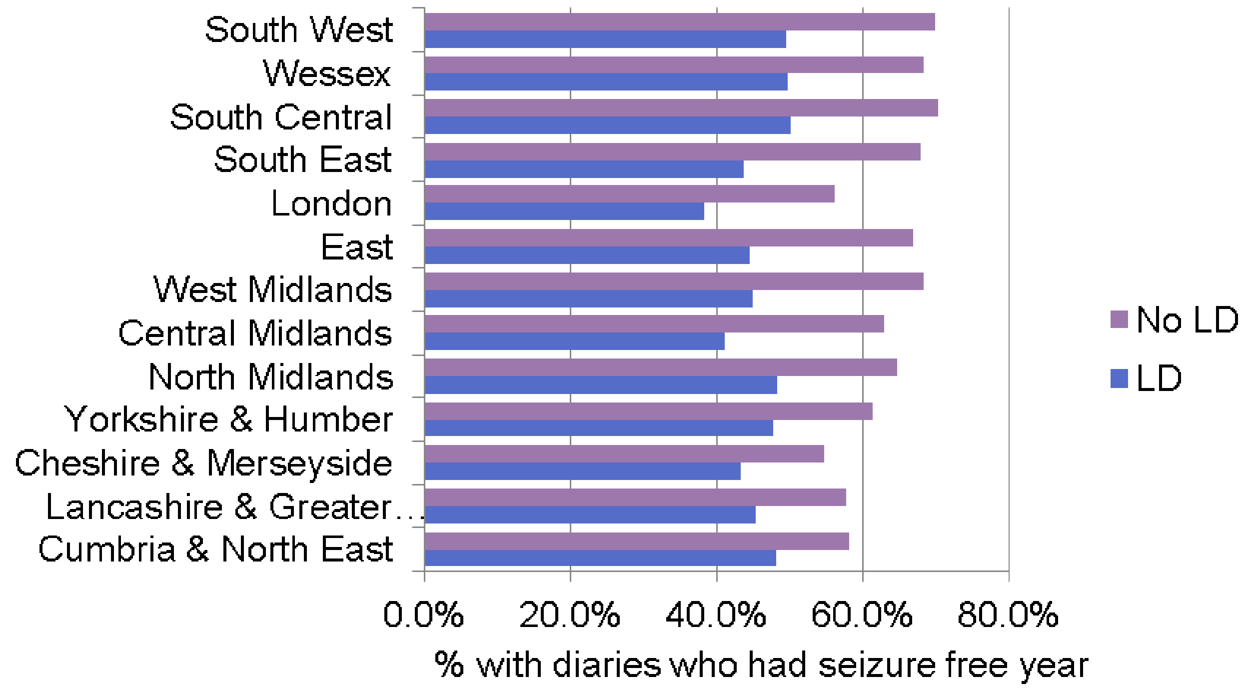
[14] The NHS recommends patients with epilepsy keep a diary to record details on their seizures, including information such as what happened before, during and after the seizure. This information can be shared with health professionals.

Figure 6: Percentage of people with epilepsy who have seizure diary (based on English GP records)



Source: PHE learning disability conference 2016 [98]

Figure 7: Percentage of epileptic patients with diaries who had seizure free year (based on English GP records)



Source: PHE learning disability conference 2016 [98]

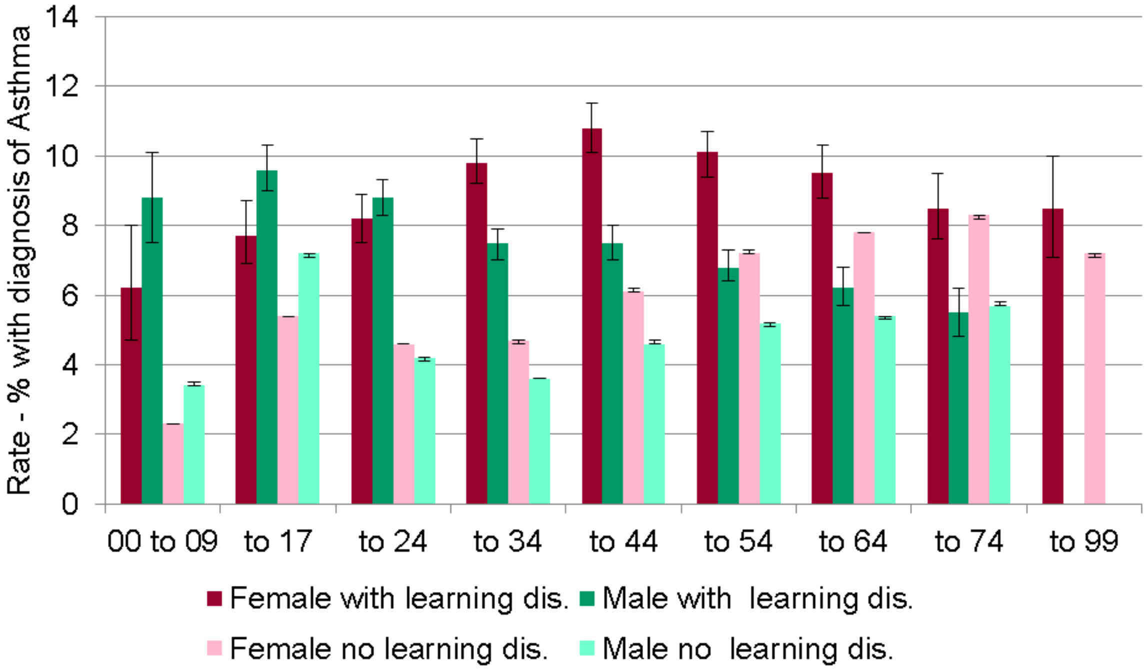
5.3.5 Respiratory disease

Respiratory disease is any condition that affects the lungs and causes difficulty in breathing. It is the most common cause of premature death in people with learning disabilities (***Table 4***, page 71). Approximately 50% of people with learning disabilities have had some form of breathing problems, compared to 15% of the general population. [89]

Pneumonia (infection of the lower respiratory tract) is one of the most common types of respiratory disease in people with a learning disability, most likely due to food aspiration due to swallowing difficulties (see section 5.3.6). [114] [91]

Figure 8 shows that recorded asthma is more common in people with learning disabilities, especially at younger ages. As in the non-disabled patient population, males with a learning disability have a higher prevalence than females in younger age groups; the reverse is true for older age groups (i.e. recorded asthma prevalence is higher in females than males).

Figure 8: Recorded prevalence of asthma by age and gender (based on English GP records)



Source: PHE learning disability conference 2016 [98]

Prevalence of COPD is very similar in the local adult learning disabled GP patient population and the non-disabled patient population (1.9% and 1.4%, respectively). [99]

5.3.6 Dysphagia and gastrointestinal problems

Dysphagia refers to difficulty or discomfort in swallowing, as a symptom of disease. It is associated with poor feeding and impacts on quality of life. Patients with dysphagia can develop coughing/choking and an increased risk of aspiration pneumonia caused by food/saliva being accidentally inhaled into the lungs. [115]

National estimates of dysphagia in different disease/condition groups are presented in ***Table 9.***

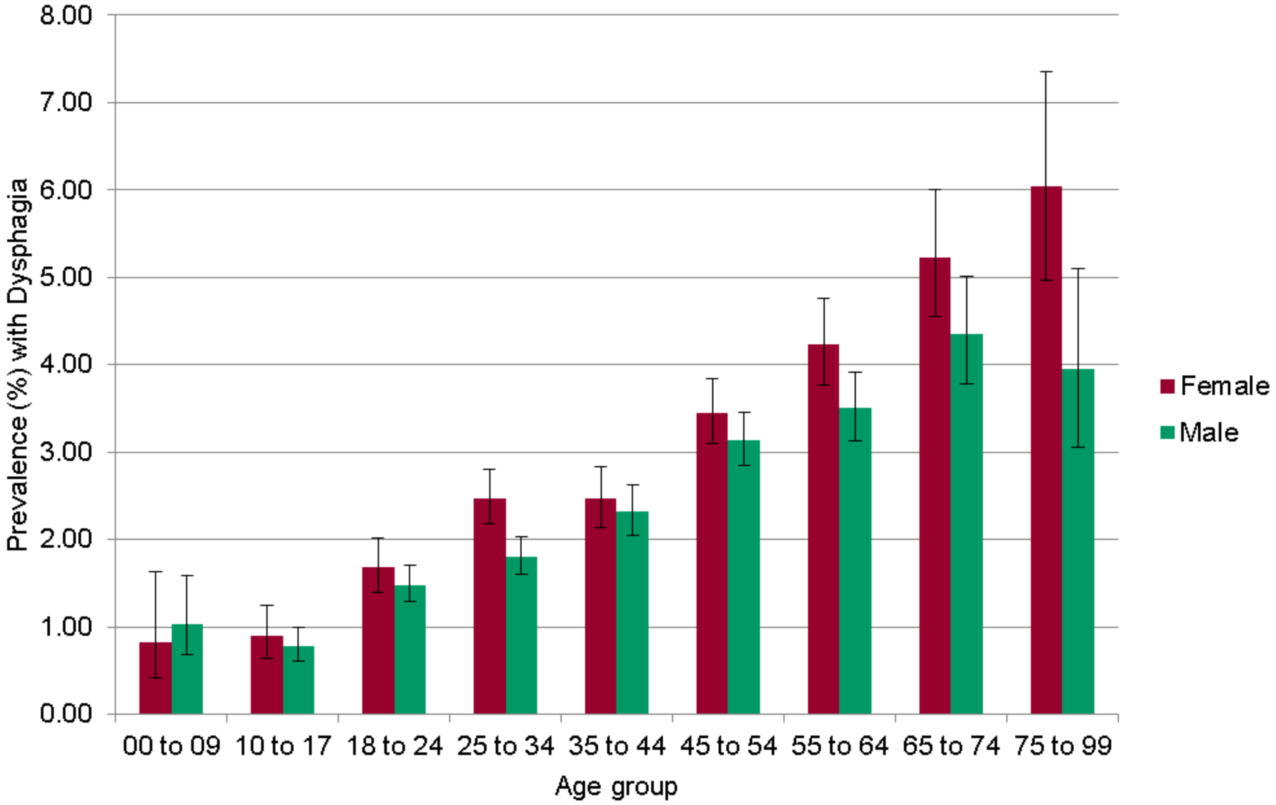
Table 9: Summary of literature on prevalence of dysphagia in disease/condition groups [116]

Client group	Research	Reference
Adults with learning disability	5.27% of adults with a learning disability living in the community were referred for advice regarding dysphagia	Chadwick 2003;2009
Dementia	68% of those with dementia in homes for older people have dysphagia	Steele 1997
Nursing home residents	Between 50 and 75% of nursing home residents have dysphagia	O'Loughlin & Shanley 1998

The Joint Health and Social Care Self-Assessment Framework 2014 reported a median rate of 2.4% of people with learning disabilities known to have dysphagia. [117] Similarly, provisional national data from another source indicates a recorded dysphagia prevalence of 2.5% in GP patients with a learning disability (all ages), although the authors highlight under-reporting in this population and cite a prevalence of 8.1% from the literature. [98] [118]. Another study estimates that one in ten people with learning disabilities have dysphagia, but again suggest this is an under-estimate, due to under recognition by staff and carers. [119]

Figure 9 shows that recorded dysphagia increases with age in the learning disabled patient population, for males and females (but is higher amongst women at all ages).

Figure 9: Recorded prevalence of dysphagia in patients with learning disability in England (based on English GP records)



Source: PHE learning disability conference 2016 [98]

Chronic constipation is very common in individuals with learning disabilities, with as many as 69% affected at any one time, compared with an estimated prevalence of 8.2% in the general population. [120] [121] The higher prevalence in people with learning disabilities is linked to a combination of poor diet and reduced physical activity (see section 5.3.16), secondary to medical problems such as hypothyroidism or an adverse effect of medication. Constipation has a significant impact on the quality of life of people with learning disability. However, identification of constipation is often delayed in this population due to unspecific symptoms such as distress, behavioural changes and urinary incontinence; such delay leads to unnecessary hospital admissions with abdominal pain and impaction. [114]

Gastro-oesophageal reflux disease (GORD) is a common condition where acid from the stomach leaks up into the oesophagus. Long-term, untreated, GORD is a risk factor for developing ulcers and oesophageal cancer. The prevalence GORD in people with learning disabilities is thought to be around 10-15%, and is likely to be even higher in individuals with certain conditions such as Down's syndrome and also linked to adverse effects of medication. [114] Prevalence estimates for people with severe learning disabilities living in institutions are as high as 50%. [114] Diagnosis may be difficult as heartburn (the most common symptom) is commonly not reported by people with learning disabilities.

5.3.7 Cardiovascular Disease

Cardiovascular disease (CVD) collectively describes conditions that are caused by reduced function of the heart and major blood vessels. CVD is a leading cause of death in people with learning disabilities (see ***Table 4*** on page 71). This is likely to be due to multiple reasons, including 'lifestyle' factors (see section 5.3.10 and 5.3.16), as well as co-existing cardiac malformation, which is very common in Down's Syndrome patients and in some other genetic conditions that can cause learning disability. [122]

Table 10 shows the prevalence of CVD health conditions for people with learning disabilities compared with 'controls'.

Table 10: Recorded national prevalence of CVD health conditions for people with learning disabilities [99]

Disease/condition	Recorded prevalence for people with learning disabilities	Recorded prevalence for controls
Stroke and TIA	1.8%	1.1%
Heart failure	0.8%	0.4%
Ischemic heart disease (IHD)	1.7%	2.7%
Peripheral vascular disease (PAD)	0.4%	0.5%

5.3.8 Diabetes

Diabetes is one of the most common endocrine disorders and involves poor blood sugar control leading to a large amount of damage to the body, including the eyes, nerves, blood vessels and heart. People with poorly controlled blood sugars are also more susceptible to infections.

Studies show that there is a higher prevalence of diabetes in people with learning disabilities compared to the general population (11% compared to 6%) and this is true across most age groups (***Figure 10*** and ***Figure 11***). [114]

This higher prevalence is linked to obesity, poor diet, sedentary lifestyles and restricted access to exercise or daily activities in people with learning disabilities. [123] Diabetic management is poor in these patients and they are more likely to attend A&E for diabetic emergencies than other groups. [114]

Figure 10: Recorded prevalence of type 1 diabetes (based on English GP records) [98]

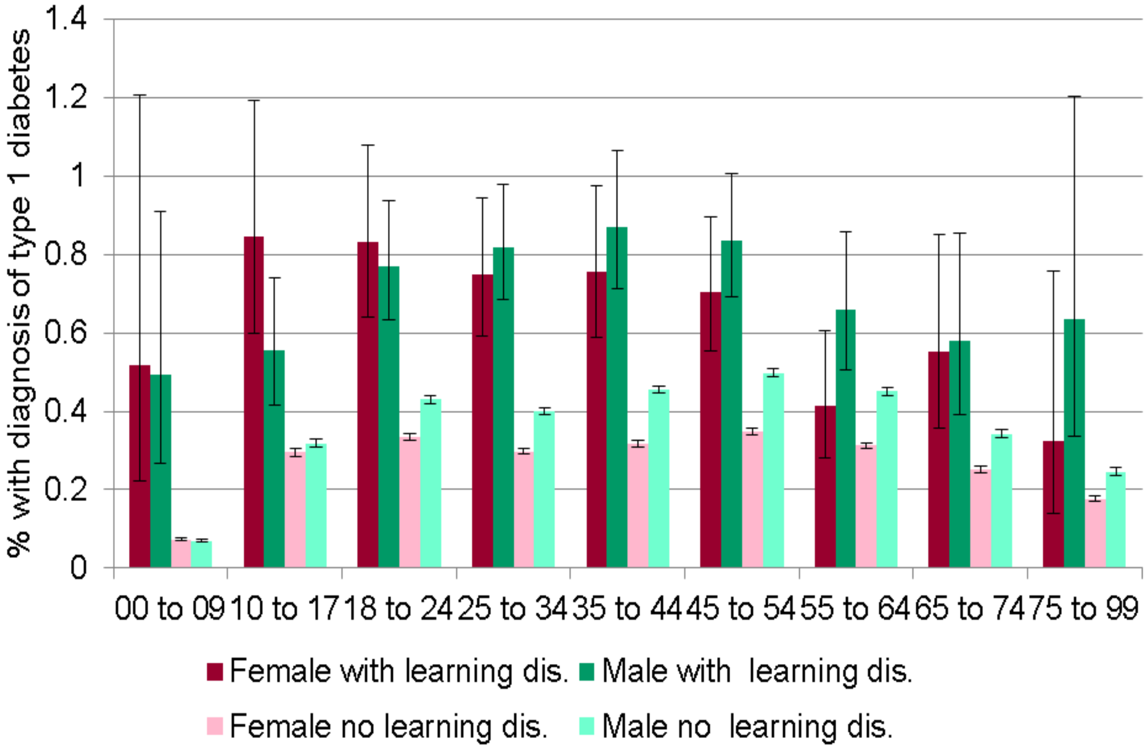
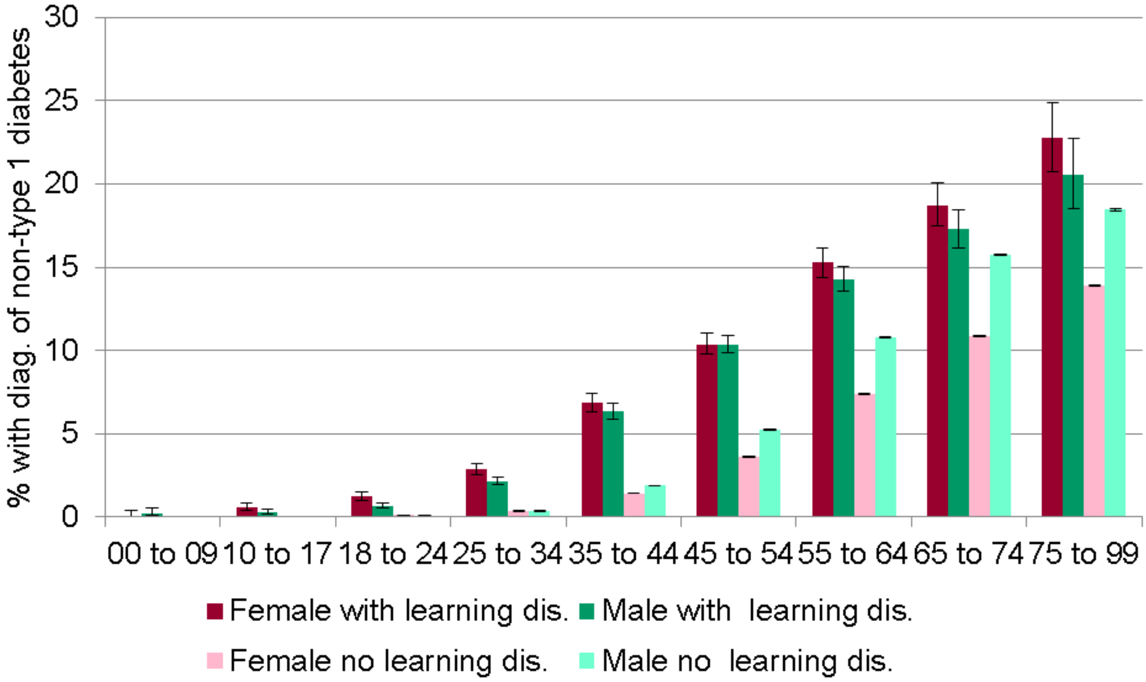


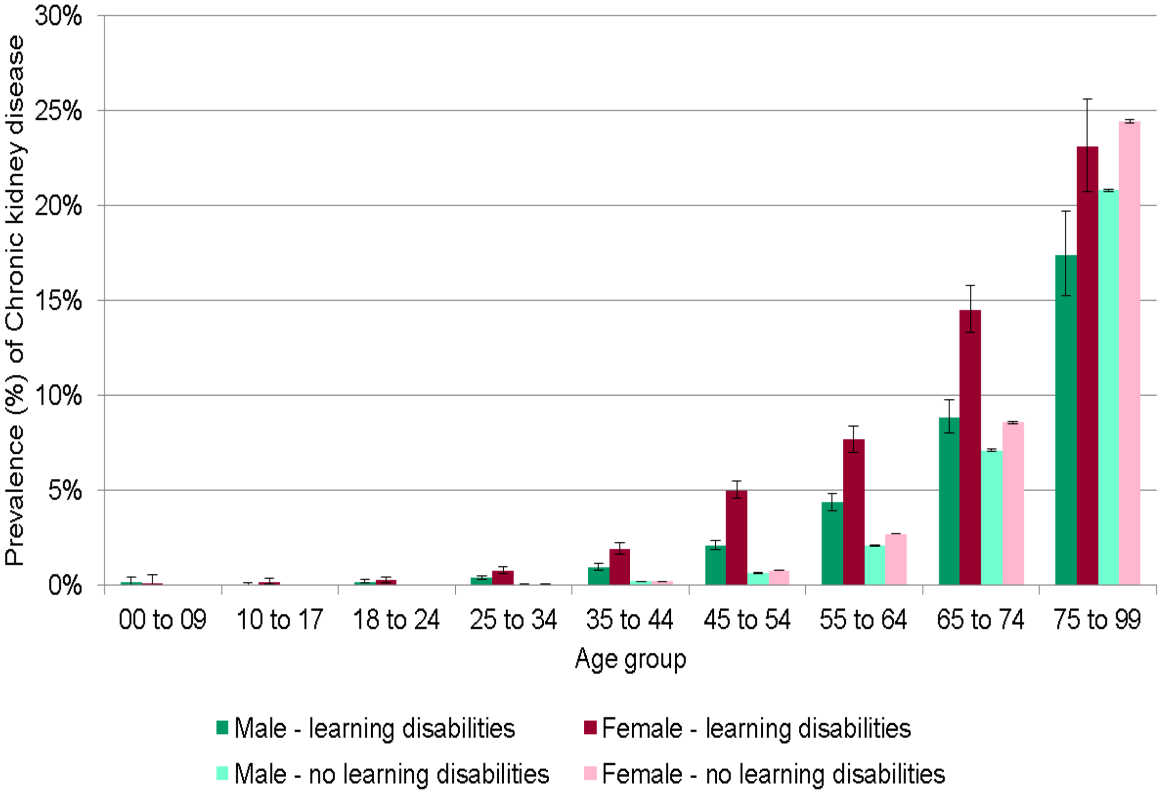
Figure 11: Recorded prevalence of non-type 1 diabetes (based on English GP records) [98]



5.3.9 Chronic kidney disease

As indicated in ***Figure 12***, chronic kidney disease is more commonly recorded in people with learning disabilities at all ages, with the exception of the over 75 age group. The difference between males and females is also more pronounced in people with learning disabilities compared to those without.

Figure 12: Recorded prevalence of chronic kidney disease by age and gender (based on English GP records) [98]



5.3.10 Obesity and underweight

Obesity increases the risk of a range of physical conditions (including cardiovascular disease, type 2 diabetes and some cancers), and is associated with poor mental health. [124] The prevalence of obesity in the adult population in England is 25.6%. [125]

Adults with learning disabilities are more likely than the general population to be obese and, to a lesser degree, underweight than a 'healthy weight' (based on BMI measurement).[15] [89] Estimates suggest that the prevalence of obesity in people with a learning disability (all ages) is between 20 and 50%. [126] [127] Other research has shown that obesity is more prevalent in women and in individuals with a 'less-severe' form of learning disability, as well as amongst people with Down's and Prader-Willi genetic conditions. [128]

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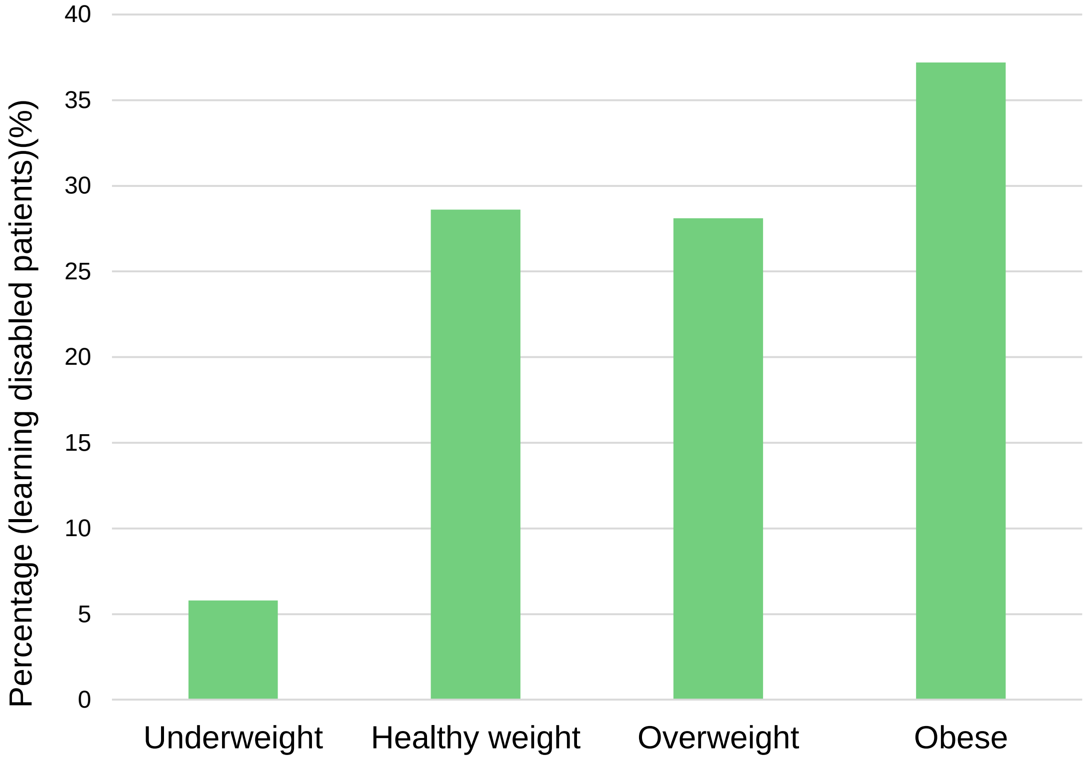
[15] Body Mass Index: weight in kilogrammes divided by height in metres squared
Classifications: underweight <18.5, healthy weight 18.5-24.9, overweight 25-29.9, Obese 30+

Figure 13 presents prevalence estimates for underweight, healthy weight, overweight and obesity in a national sample of GP patients.

Figure 13: Prevalence of underweight, healthy weight, overweight and obesity in people with learning disabilities (based on English GP records) [98]



5.3.11 Cancer and cancer screening

Evidence suggests that some types of genetic causes of learning disability increase the risk of cancer. For example, Down's syndrome patients are more likely to develop leukaemia. [129] However, overall cancer incidence is lower than average in people with learning disabilities, which is thought to be due to lower life expectancy amongst this group. As life expectancy for people with learning disabilities increases, these patterns may change over time. [89] [92]

UK cancer screening programmes for adults include:

- cervical cancer - a 3 yearly test in females aged 25-49, and then 5 yearly for ages 50-64
- breast cancer - 3 yearly screening in women aged 50-70
- bowel cancer - 2 yearly screening for all adults aged 60-74.

Adults with learning disabilities are on average 45% less likely to have undergone any cancer screening compared to adults with no learning disabilities. [130]

5.3.12 Thyroid disorders

Individuals with Down's syndrome are more likely to have thyroid disorders, such as congenital hypothyroidism, than the general population. Recorded prevalence of recorded hypothyroidism increases with age in patients with Down's syndrome, from 9-19% in children to 22% in adults. [89] The estimated prevalence of hypothyroidism in the general population is 1-2%, although some healthcare professionals suggest the rate is higher. [131]

5.3.13 Sensory impairment

Visual impairment is relatively common in individuals with learning disabilities, due to an impaired developmental pathway, and is most common in those with severe forms of disability. Poor vision plays a significant role in communication, education and independence, which exacerbates the impact and manifestation of learning disabilities.

Recording of visual impairment is often poor in individuals with learning disabilities (with no national monitoring), which makes it difficult to establish the true prevalence. A recent report estimated the prevalence of visual impairment to be roughly 19% in the UK learning disabled population and the prevalence of blindness to be approximately 5%. [132] The combined UK population prevalence of blindness and visual impairment is 3%. [133]

5.3.14 Autistic spectrum disorders (ASD)

Autism and learning disability are conditions commonly associated with each other. Prevalence estimates based on the work of Baird et al 2006 indicate that 55% of people with autism also have an IQ below 70 (an indicator of learning disability). Research in the learning disabled population estimates that around 10% of adult GP patients with learning disability also have an ASD. [99]

It is important to note that the different rate of ASD across the genders has been questioned as to whether it is a true phenomenon, or whether it reflects significant under-detection or under-reporting of cases amongst girls and women. [134]

5.3.15 Osteoporosis

Osteoporosis is defined as reduced bone density, leading to fragility and high risk of injury. Osteoporosis is strongly linked to age, but older learning disabled adults are at a higher risk of developing osteoporosis than the wider older population. This is due to a multitude of factors, including limited weight bearing exercise, side effects of medications (e.g. antipsychotics), poor dietary intake and low vitamin D levels due to reduced outdoor activity. [89] [114]

5.3.16 Behaviour and lifestyle

Physical activity

Regular exercise is essential for overall health, it can reduce the risk of CVD, diabetes, colon and breast cancer, depression, fractures and help control weight. [135] Four in five learning disabled adults (80%) do less than the recommended amount of physical activity,[16] compared with 53-64% of the general population. [89]

Adults with learning disabilities are more likely to have a physical or limiting disability that prevents them from being more active, as well as more restrictive living conditions and daily routines. For example, they are more likely to be socially isolated and less likely to be in employment (see section 5.4).

Smoking, alcohol and other substance misuse

When compared to the general population, people with learning disabilities who are known to services (and therefore likely to have higher support needs), are less likely to smoke or drink on average. [122] However, smoking rates are higher amongst those not known to services (who may have milder disability) [136] and in adolescents with mild learning disabilities (compared to adolescents with no learning disabilities). [137]

While alcohol intake is lower in learning disabled adults in general, those who do drink alcohol are predominantly male and have milder learning disabilities. [89]

Evidence use of other substances (including illegal drugs) is lacking in this population

5.3.17 Oral health

The oral health of people with learning disabilities has improved in the last 25 years, but associated health inequalities still exist, with one in three learning disabled adults having unhealthy gums or teeth. [89]

A study carried out in Sheffield in 2011 found that poor access to services was one of the main causes of poor oral health amongst adults with learning disabilities. [138] Living alone with no support, and being unable to travel to get to appointments, were important contributory factors, as was inadequate communication between the dental team and patient. Fear and patient anxiety about dental treatment and lack of parental compliance with treatment and basic preventative care, along with dietary factors (i.e. frequent consumption of sugar), also play a part. [139]

5.3.18 Sexual health

There is very little information available on the sexual health of learning disabled adults, suggesting a lack of research in this area. [122] Adults with learning disabilities

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[16] The NHS provides guidelines on the amount of physical activity individuals should undertake, which varies based on age - see http://www.nhs.uk/Livewell/fitness/Pages/physical-activity-guidelines-for-adults.aspx

often have poor sex education, and sexual health is often not considered to be ‘relevant’ compared with other health needs. [140]

5.3.19 Injury, falls and accidents

There is a higher rate of accidents and injury in people with learning disabilities, linked to poor mobility, medication side effects, physical disability, and sight and hearing impairments. [89] [92] [114]

A prospective cohort study, published in 2010, reported that epilepsy was a significant risk factor in injuries and falls in people with learning disabilities (people with autism were less likely to get injured, due to being less inclined to interact with their environment). The study also concluded that the higher rate of injury in people with learning disabilities may relate to the dependency of carers for things like the use of safety equipment and not being knowing how to such equipment themselves. [141]

5.3.20 Carers health needs

Based on Census 2011 figures, it is estimated that there are 6.5 million unpaid carers in the UK and the peak age for caring is 50 to 64 years. [142] However, the number of carers over the age of 64 is increasing. [142] Those caring for 50 hours or more are twice as likely to be in bad health as non-carers. [143] A study into the health and wellbeing of unpaid carers reported that carers leave little time to focus on their own health; 20% considered themselves to have a mental health condition and 58% do not get support to manage their own health and wellbeing. [144]

In general, carers are often physically, financially and emotionally burdened, with the impacts increasing as they grow older. They are more likely to be socially isolated, which also results in poor physical and mental wellbeing. Carers often neglect their own health, partly because they do not see their own needs as a priority and also due to time constraints. [145] [146]

A UK survey of 3,400 carers showed that their health is affected in the following ways: [147]

- anxiety or stress (91%),
- depression (53%)
- injury such as back pain (36%)
- the deterioration of an existing condition (26%).

Financial burdens were also confirmed as a major concern, with carers often having to balance work with their caring responsibilities, regularly having to give up full-time employment to meet their caring obligations. Moreover, the individuals they care for often have needs that can be expensive, leading to a further financial drain. There is also evidence that indicates that carers frequently report feeling excluded by clinicians and other healthcare workers, rather than as experts in the needs of the person they care for. [147] [148] [149]

Mencap's *'Breaking Point'* report highlighted the fact that eight out of 10 carers of individuals with severe or profound learning disabilities felt that they could not carry on due to the strain of caring. [145] There is no evidence to suggest that this picture has changed significantly since then. [146] In fact, recent reductions in the number of day centres and short break schemes, in the context of reduced local authority funding from central government, suggest that the pressure on carers may be increasing due to poorer access to respite options. As the learning disabled population ages, and has to rely on older family carers, these pressures are likely to be ever more keenly felt in terms of health and wellbeing impacts.

5.4 Social and environmental risk factors for health

Any person's health and wellbeing is influenced by a wide range of individual, social and environmental factors - at the local, national and global level. ***Figure 14*** provides a simplified representation of these complex relationships.

Figure 14: Dahlgren and Whitehead model of the wider determinants of health [150]

The relatively poorer health outcomes of people with learning disabilities are linked to high risk of exposure to many health harming influences, including: [101]

- specific genetic and biological causes of learning disabilities
- personal health risks and behaviours
- communication difficulties and reduced health 'literacy'
- deficiencies in access to high quality healthcare provision
- greater prevalence of many of the 'social determinants' of health (such as deprivation, social isolation, poorer educational and employment outcomes, and inappropriate housing).

5.4.1 Deprivation

The link between high levels of deprivation and poorer health outcomes is well established, but further research is needed to truly understand the effects of deprivation on people with learning disabilities. [151]

A report published by the Centre for Disability Research indicated that people with learning disabilities, who live in private households, are more likely to live in deprived areas. [152] Another study, conducted between 2012 and 2013, looked at the relationship between area deprivation and contact with intellectual disabilities psychiatry in Glasgow and Clyde. The study found that 52% of patients in contact with this service lived in the most deprived decile (based on the Scottish Index of Multiple Deprivation) and over 90% were from one of the five lowest deciles.[17] [153]

Another study reported an association between lower household socio-economic position and increased rates of identification of intellectual and developmental disabilities. [154]

5.4.2 Housing

The Marmot report on social determinants of health highlights the link between quality of housing and health outcomes. [151] While there have been improvements recently in the housing situation for people with learning disabilities (such as a move away from segregated institutions) there are still many barriers that may prevent them living independently.

Mencap commissioned a report into the housing situation for people with learning disabilities, which showed that the majority want to live independently.[18] [155] This same report showed that the main types of accommodation for people with learning disabilities were ‘with family and friends’, ‘in a registered care home’ or ‘in supported accommodation’; a smaller proportion lived in local authority housing or in the private rented sector (***Figure 15***).

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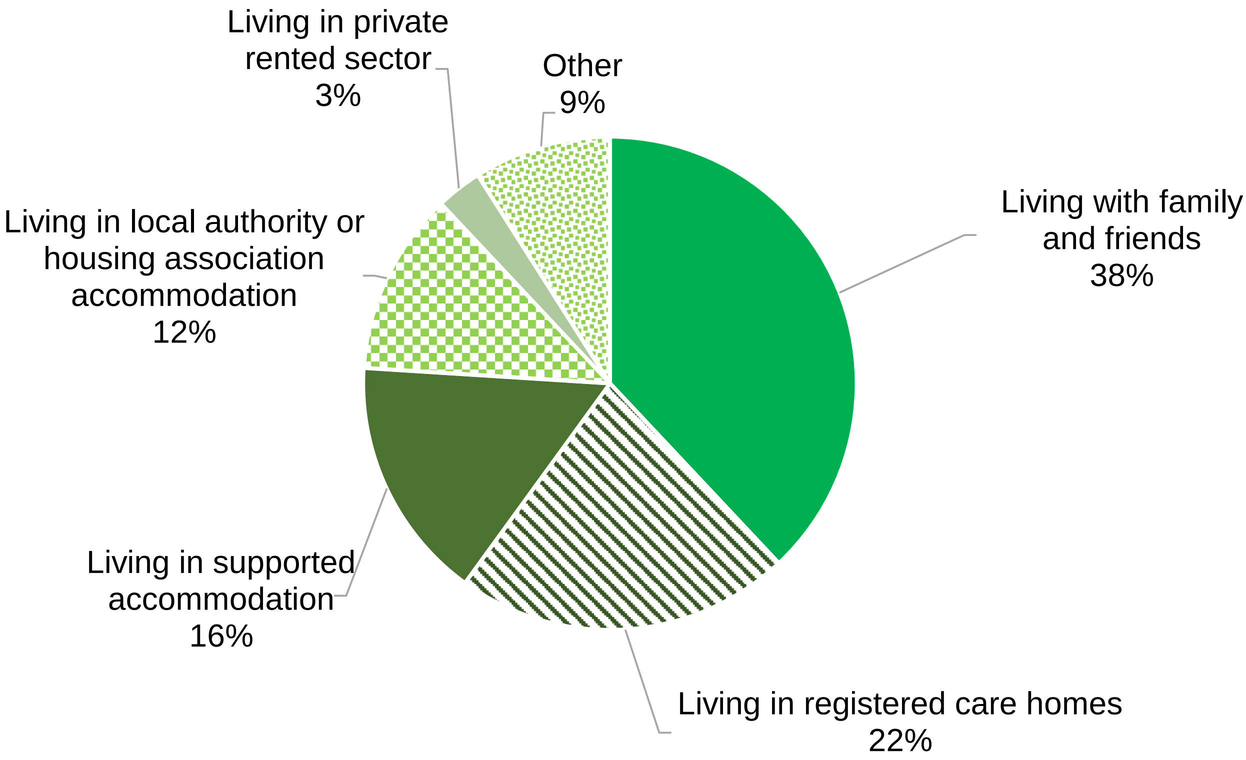
[17] A decile represents 10% of the population. The most deprived decile is the most deprived 10% of the population; the five most deprived deciles are the most deprived 50% of the population

[18] The report stated that 40% of people with a learning disability wanted to live by themselves, with a further 30% wanting to share a home with friends

Figure 15: Where people with a learning disability known to social services live [155]



Mencap's report also found that almost 20% of people with a learning disability (known to local authorities) live in homes that need improving, and almost 6% were on a waiting list for housing with support. The report also showed that increasing demands on housing, in addition to budget cuts, has made it increasingly difficult for local authorities to find adequate accommodation for people with learning disabilities. With the size of the learning disabled population expected to increase and as life expectancy continues to rise, the level of demand for housing related support services is likely to increase.

Findings of a qualitative study show that families seeking accommodation for an adult child with a learning disability can find the process stressful and frustrating. [156] Some families reported being prevented from planning ahead due to the lack of suitable accommodation.

5.4.3 Education and transitional support

The transition period between leaving school and moving into adult life can be both rewarding and challenging at the same time. For young people with learning disabilities, the challenges they face can have a negative impact on their health and wellbeing.

Some reports have indicated that the transition from children's services to adult services can be problematic and may result in unmet needs for people with learning disabilities. [122] Carers have fed back concerns over the lack of coordination between services. A study into the transition of teenagers with learning disabilities found weaknesses in a number of areas, such as poor communication and a need for earlier and more coordinated planning, which led to lower levels of satisfaction amongst carers. [157]

5.4.4 Employment

The Marmot review also highlighted the importance of fair employment opportunities in helping to reduce health inequalities and improve health and well-being for all. [151]

Only 6% of adults with learning disabilities were known to be in paid employment in England in 2014/15. [158] However, this is likely to be an underestimate due to poor data recording of learning disabilities by employers. [159] Approximately 65% of people with learning disabilities say they want to work. [160]

There was a 22% increase in the number of people with learning disabilities in paid employment in England between 2008 and 2013. [159] However, most adults with learning disabilities who are in employment (approximately 70%) work fewer than 16 hours per week. [159]

5.4.5 Social isolation, community participation and experience of crime

Lack of social contact can be detrimental to a person’s health and well-being, leading to physical, mental and cognitive dysfunction and, therefore, poorer quality of life. [161]

People with learning disabilities are particularly vulnerable to social isolation due to their reduced mental and physical ability, poorer access to employment and restricted living conditions. One study found that while many people with learning disability want to participate in their community, in this case through voting in elections, practical difficulties (e.g. difficulties in registering to vote) or explicit exclusion (e.g. being turned away from a polling station because of their disability) meant they were unable to do so. [162]

In the context of reducing local authority budgets, there is a risk that the options available for people with learning disabilities to participate in activities outside their home will become more and more limited. [161]

There is also evidence to suggest that people with learning disabilities are more likely to be exposed to violent crime and hate crime than non-disabled people. [163] [122]

6. Prevalence of adult learning disability in Hackney and the City

6.1 Introduction

This chapter provides estimates of the prevalence of learning disability in adults in Hackney and the City of London, and compares these to the number of adults with a learning disability known to (or using) local services. It also contains a description of inequalities in learning disability prevalence across different population groups and localities within the local area.

6.2 Population estimates (2015)

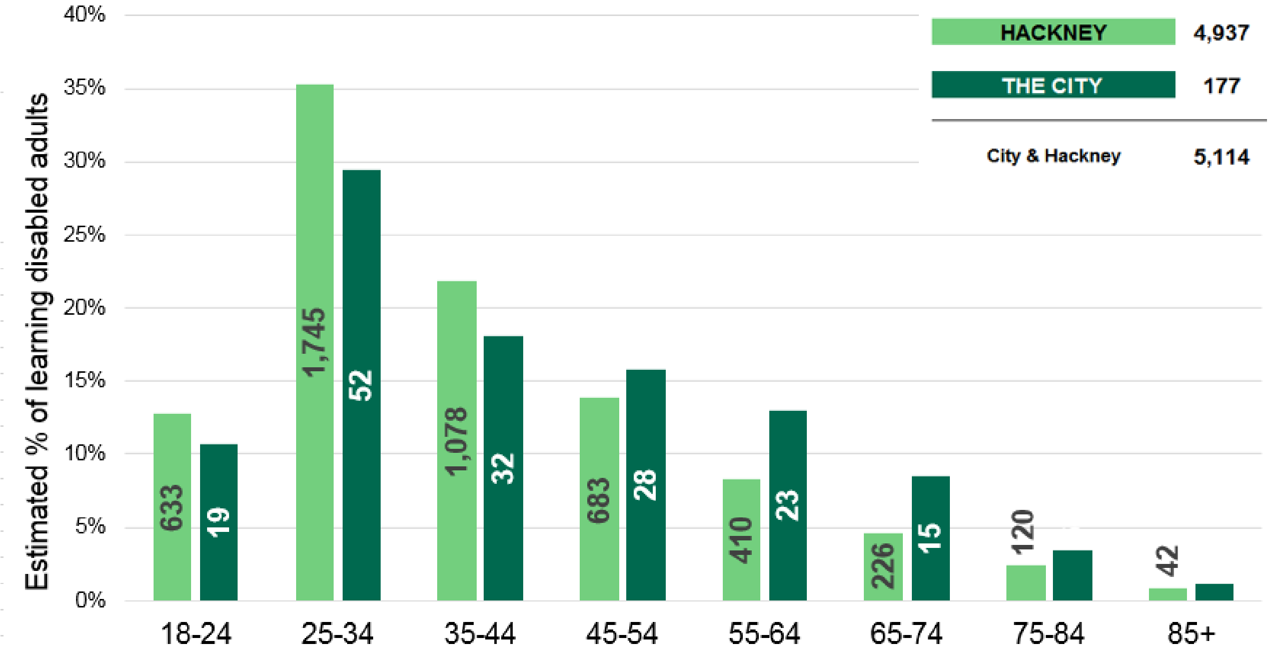
Section 3.4.1 describes the sources used to derive estimates of adult learning disability prevalence in Hackney and the City.

These estimates suggest that there were 5,114 adults (age 18 and over) with a learning disability living in the City and Hackney in 2015, a prevalence rate of 2.4% (***Figure 16***). This is broken down into 4,937 in Hackney and 177 in the City of London. By age group, the prevalence of learning disability is estimated to vary from 2.6% in the under 44 year old population, to 1.8% in those over the age of 85.

In absolute terms, the largest number of people affected by learning disability are estimated to be in the 25-34 year age group. This is due to the relatively young Hackney population as well as the higher prevalence of learning disability in younger people. There is a slightly older age distribution amongst learning disabled adults in the City compared with Hackney, which reflects the older age profile and longer average life expectancy in the City compared to Hackney [164].

A more detailed discussion of prevalence estimates by age group and gender is covered in section **6.5.1** of this chapter.

Figure 16: Estimated prevalence of adult learning disability in the City and Hackney, by age [165] [166]



6.2.1 Projections 2015 to 2030

The POPPI and PANSI tools predict significant increases in the number of older people with learning disabilities as well as a greater number of young people requiring support.

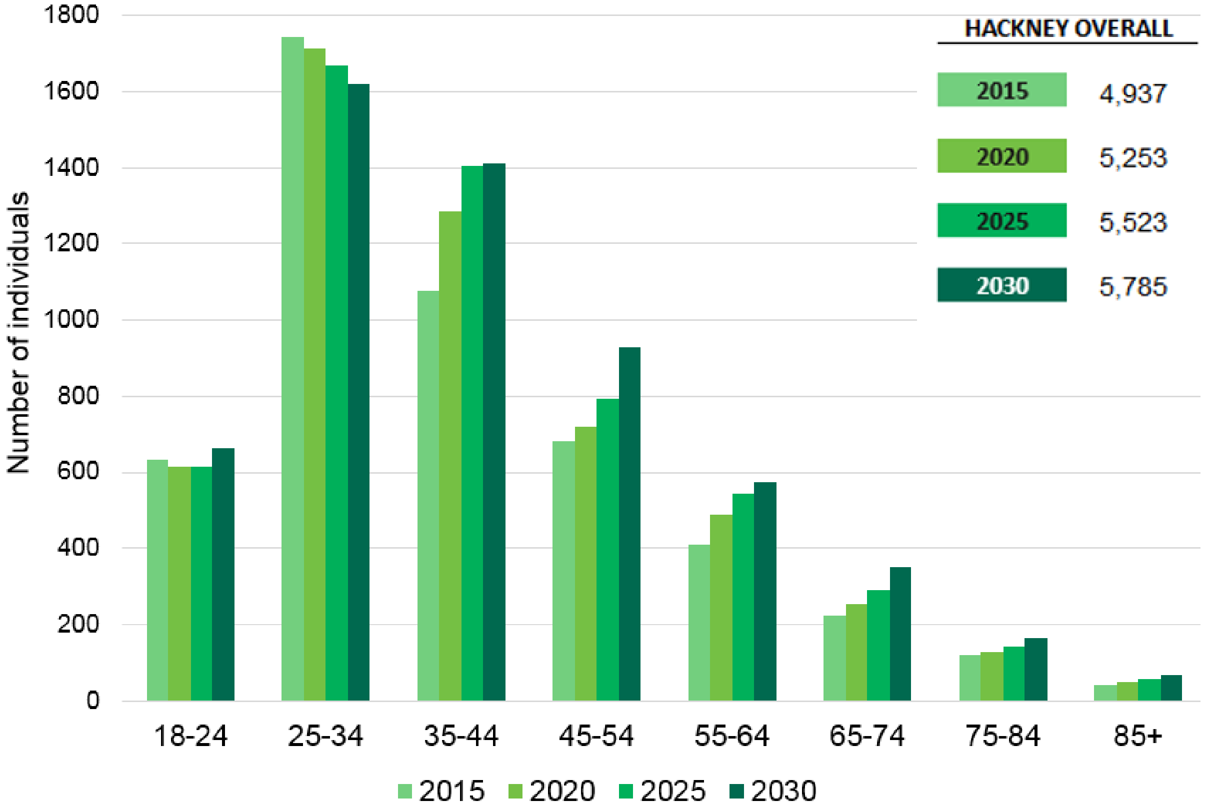
When projected local population growth is applied to adult learning disability prevalence estimates, a different pattern of growth is shown in the learning disabled population across different age groups, as shown in ***Figure 17*** and ***Figure 18*** below. The projected estimates are conservative as they do not account for recent improvements in life expectancy amongst people with a learning disability [167].

In Hackney, overall the number of adults with a learning disability is expected to increase by 316 in the next five years and by 848 in the next 15 years (an increase of 6% and 17%, respectively). The majority of this growth in absolute terms is expected in the 35-54 year age group (***Figure 17***).

Over the same period 2015 to 2030 in Hackney, it is predicted that:

- there will be an increase in the *total* number of people with a learning disability across all age groups, except the 25-34 year range, which is predicted to see a 7% decline
- the largest *proportional* increases will be seen in the older age groups, in particular the 55-64 year group (40% increase) and 65-74 year group (55%); this increase is linked to the increasing average age of the learning disabled population [168].

Figure 17: Estimated number of adults with learning disability in Hackney 2015 to 2030, by age group [165] [166]



In the City, overall the number of adults with a learning disability is expected to increase by 21 in the next five years and by 47 in the next 15 years (an increase of 12% and 27%, respectively). ***Figure 18*** also shows that:

- unlike Hackney, the 25-34 year age group is estimated to see a slight increase in numbers in the City as opposed to a decline (likely due to migration of younger adults into the area)
- similar to Hackney, the greatest *proportional* growth is estimated to occur in the older age groups (55+) in the City (15% growth in the next 5 years and 45% in the next 15 years).

Figure 18: Estimated number of individuals with learning disability in the City of London 2015 to 2030, by age group [165] [166]

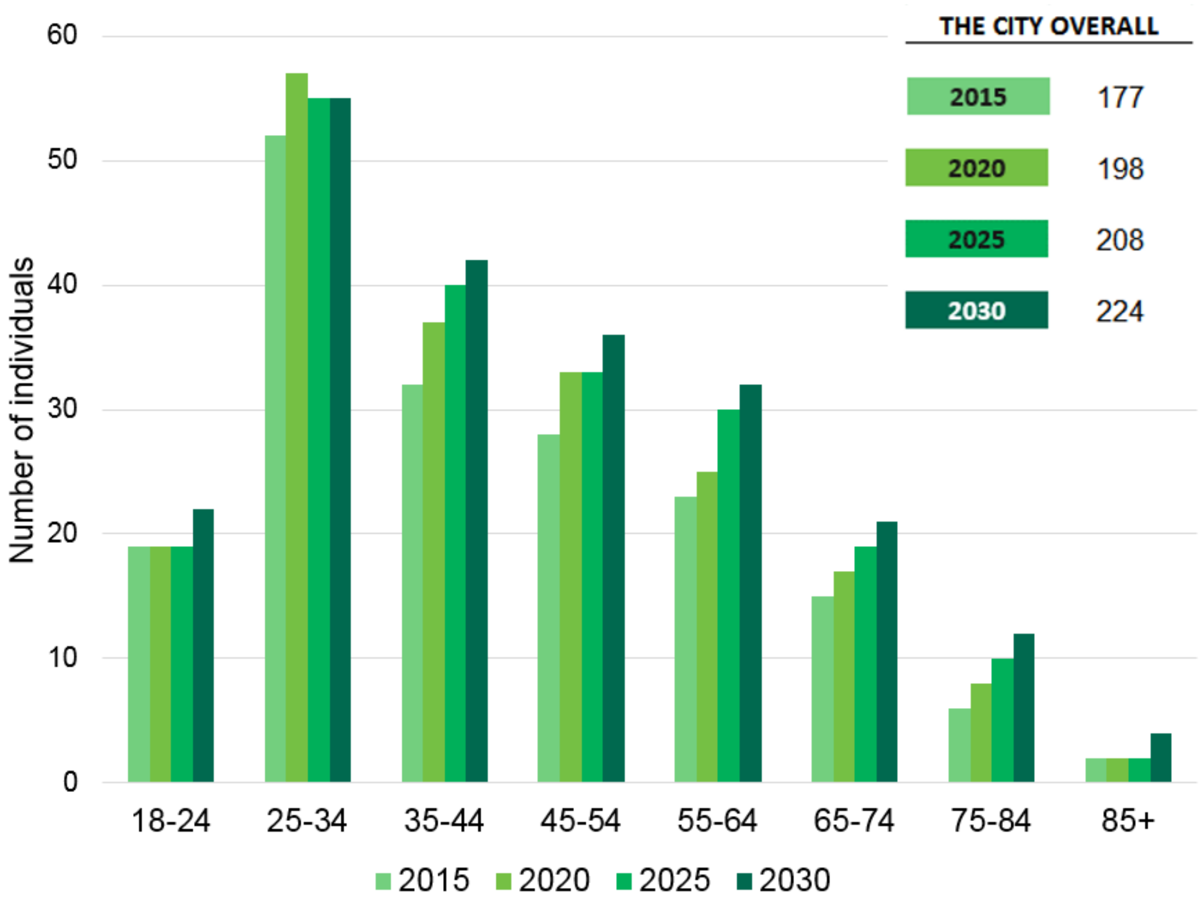


Table 11 below combines these projections for City and Hackney to show the total predicted increase in the adult learning disabled population across the two authority areas over this 15 year period.

Table 11: The estimated number of individuals with learning disability in the City and Hackney 2015 to 2030

City & Hackney learning disabled adult population	
Year	**Number**
2015	5,114
2020	5,451
2025	5,731
2030	6,008

Source: [165] [166]
Note: Numbers in Figure 17 and Figure 18 may not add up to exact totals in Table due to rounding.

Mencap estimates that over the next 15 years England and Wales will require 19,860 new registered care home places, 14,122 supported accommodation places, 10,766 general needs tenancies with local authorities and housing associations, and 2,967 private tenancies for people with learning disabilities [169]. Locally, there is no specific housing strategy for people with learning disability to enable a comparison Hackney's progress towards providing suitable housing for this growing population.

6.2.2 Severity of learning disability

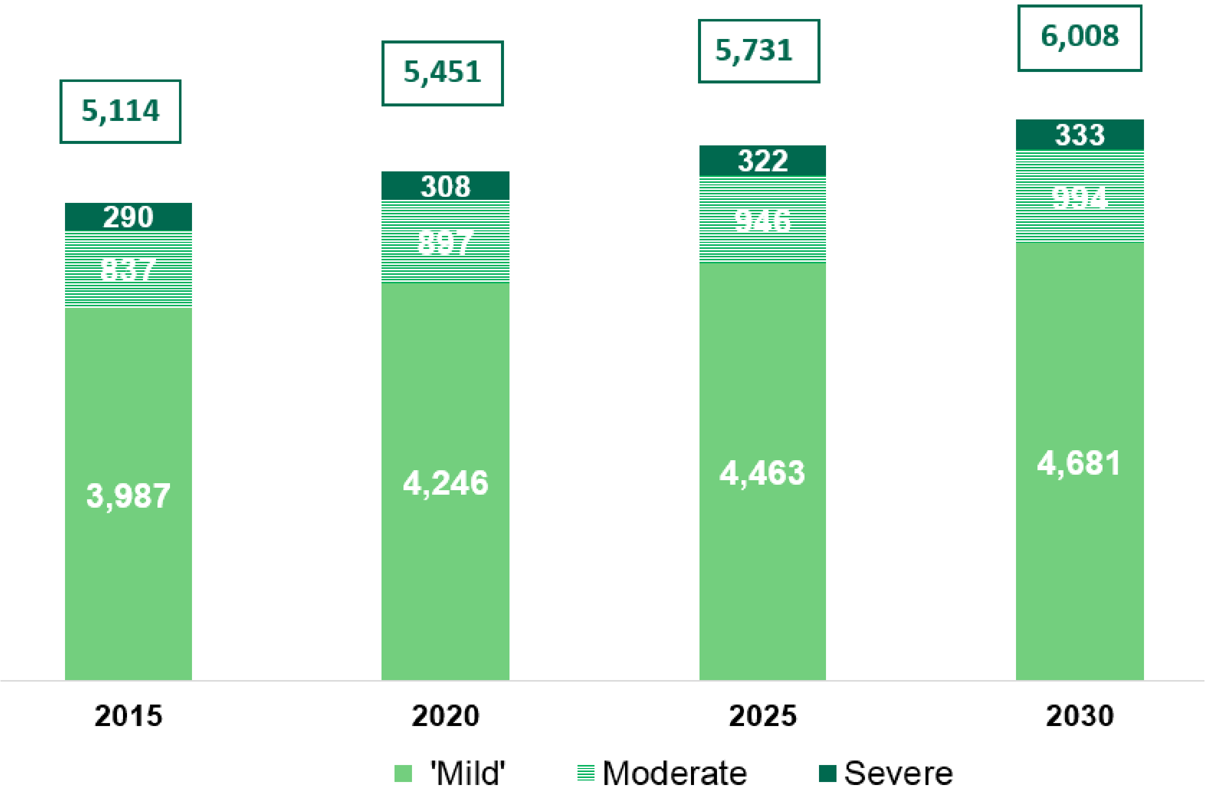
This section describes the modelled prevalence of adult learning disability by severity, as estimated by POPPI and PANSI. POPPI and PANSI provide estimates of the total number of people with a learning disability and separate estimates of the number with a moderate or severe learning disability. For the purposes of this needs assessment, when the number of moderate/severe cases are deducted from the total estimated population, the remaining cases are assumed to be 'mild' learning disability.

Prevalence by severity of condition is reported here as a potential indicator of the level of demand for health and social care services. However, using severity as an indicator of local service demand is problematic, because the terminology of 'moderate' or 'severe' cases of learning disability (used in POPPI and PANSI estimates) does not directly correspond to the criteria used in the care system to determine service eligibility. Specifically, the mild, moderate and severe classification of learning disability used here does not quantify the impact of a person's learning disability on their activities of daily living and, therefore, may not be reflective of the level of service 'need' or 'potential for harm' that determines eligibility for social care support.

With these caveats in mind, it is estimated that, in 2015, 22% of the local adult learning disabled population had a moderate or severe condition. The proportion of people with a moderate/severe form of learning disability is estimated to decline with age (see section 6.5.1**)**.

The overall proportion of learning disabled adults with a moderate or severe condition is projected to remain constant over the next 15 years, which equates to an additional 200 people in the City and Hackney by 2030 (***Figure 19*** below).

Figure 19: Projected number of adults with a learning disability in the City and Hackney 2015 to 2030 by severity of condition [165] [166]



6.3 Adults with a learning disability who are known to local services

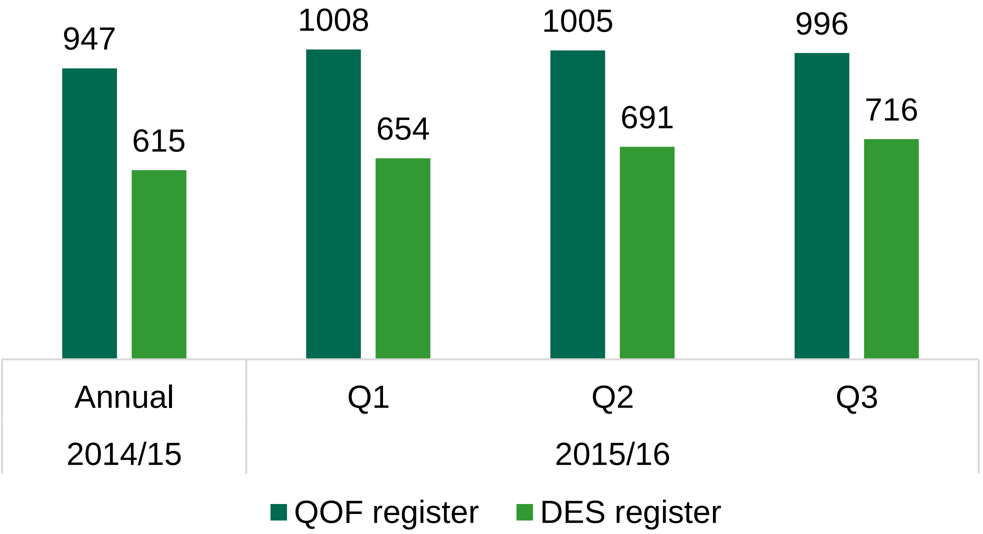
Local services included in this chapter are general practice, Hackney Council adult social care and Homerton University Hospital Foundation Trust (HUHFT). It is important to note that the learning disability 'caseload' of each of these services as recorded in this section is influenced by coding and data capture accuracy/completeness, service eligibility criteria, as well as underlying prevalence.

6.3.1 Prevalence recorded in general practice

There are two different sources of data on recorded prevalence of learning disability in general practice – the QOF learning disability register and the DES learning disability register. For the purposes of this report, the QOF register is used as the main source of data, as it is more established and therefore currently more 'complete' than the DES register (which was established in April 2014). However, over time, it is likely that the DES register will be the more reliable source for capturing recorded prevalence (see Chapter 2 for more detail). Currently, the size of the DES register is around 60% of the size of the QOF register in City and Hackney (although it is has not been possible to ascertain whether patients on the former are a subset of those on the latter).

The figures presented in this section refer primarily to patients registered in the 2014/15 financial year, as this is the latest full year of data available at the time of writing. It is worth noting in ***Figure 20*** below that the number of adults on the DES register steadily increased during 2015/16, suggesting improvements in the monitoring and identification of patients with a learning disability through this route.

Figure 20: Number of adult GP patients registered with learning disability during the reporting year [170]



City and Hackney GP patient records reveal a total of 947 individuals (aged 18 or over) recorded on the QOF learning disability register and 615 on the DES learning disability register in 2014/15. The QOF learning disability register represents 0.43% of the 18+ patient population in the City and Hackney, and the DES register represents 0.27%.

Published national and regional prevalence rates derived from the QOF register include patients of all ages and are, therefore, not comparable to these local adult recorded prevalence figures. In ***Figure 21***, data is presented on the basis of the 'all age' QOF learning disability register for comparative purposes. This provides a reasonable approximation to comparing adult recorded prevalence, as the QOF register was only extended to include 14-17 year olds in April 2014 and so the proportion of under 18s on the register is very low (86% of patients on the local City & Hackney QOF register are aged 18 or over). ***Figure 21*** shows that, based on the 'all age' QOF learning disability registers, Hackney has a higher rate of recorded learning disability than most of its statistical neighbours (CIPFA comparator)[19]. For the City of London, the rates of learning disability are significantly lower than all other London areas, although due to the unique population structure of the City it is difficult to ascertain whether this is comparable to other areas.

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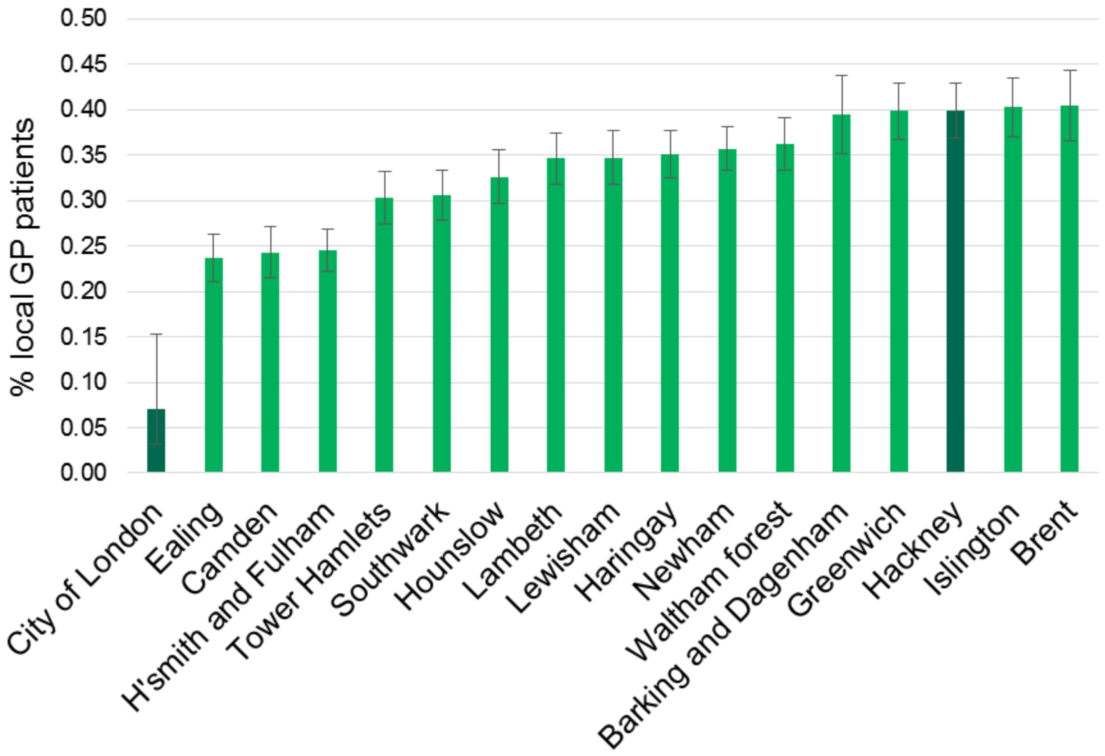
[19] A selection of statistically comparable local authorities in London, based on a range of socio-economic indicators. More information available from The Chartered Institute of public Finance and Accountancy

Figure 21: Proportion of GP patients (all ages) with a QOF coding relating to a learning disability in 2014/15 [12]

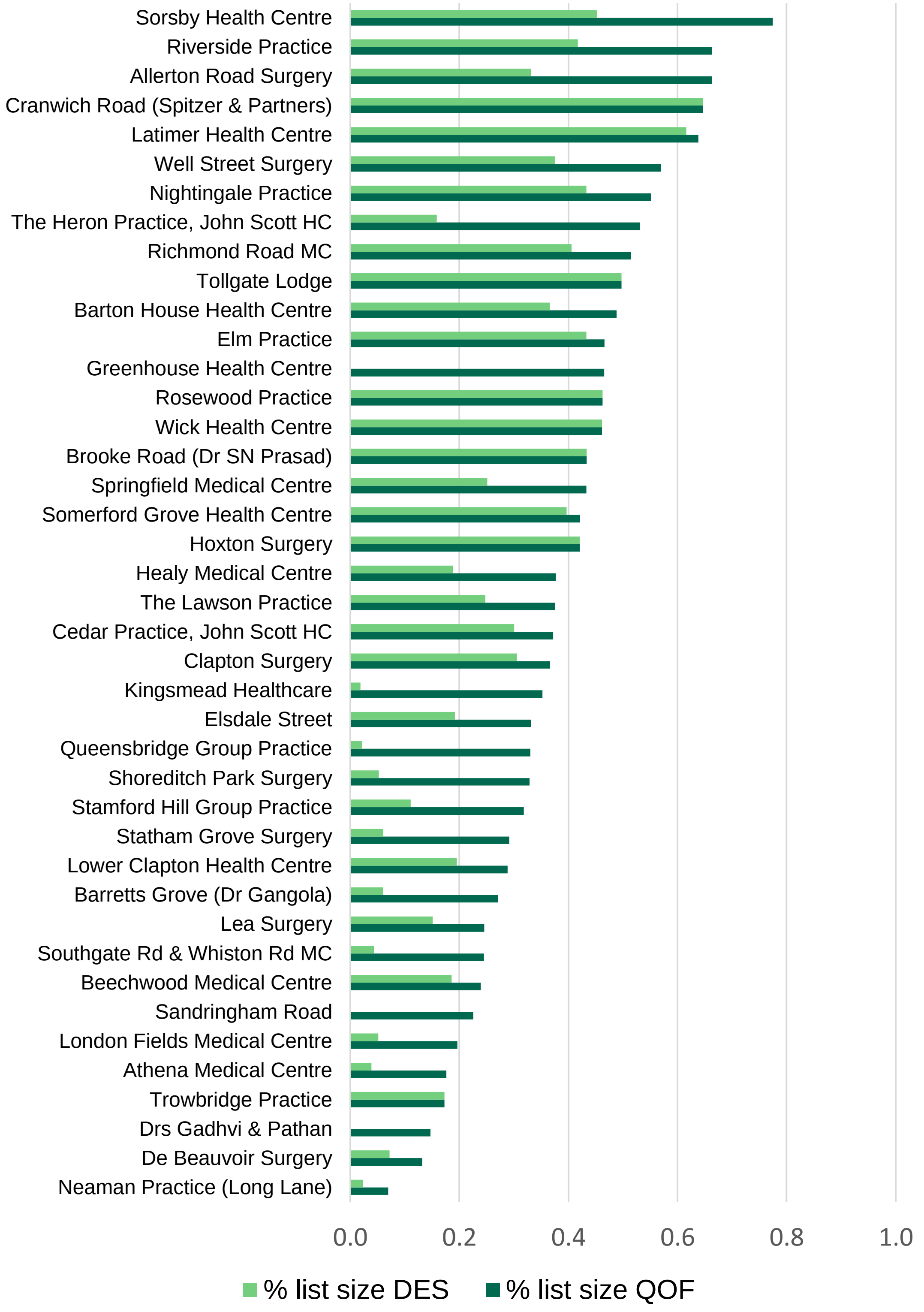


When local data is analysed at GP practice level it becomes clear that there is significant variation in recorded learning disability prevalence across Hackney and the City. There may be several factors contributing to this, as discussed in the Chapter 2.

In summary, this practice level analysis shows that:

- every practice in the borough has patients recorded as having a learning disability on the QOF register, although not all practices have patients on the DES register
- the proportion of adult patients per practice with a learning disability according to the QOF register ranges from 0.07% (the Neaman Practice in the City) to 0.77% (Sorsby Health Centre near Hackney Marshes in the east of the borough).

Figure 22: Proportion of adult GP patients registered with learning disability in 2014/15, by practice (CEG 2015) [170]



6.3.2 Adults with a learning disability receiving a care package (Hackney)

Box 24: Notes on the data presented in this section

The data in this section refers only to clients accessing social care services through the London Borough of Hackney. The data includes those who receive support from the local Integrated Learning Disability Service (ILDS), as well as learning disabled adults receiving support from other mental health and adult social care teams in Hackney Council.

Both City and Hackney residents are eligible to use health care services provided by the ILDS team in Hackney, although at present health service data is not captured in a way that is meaningful for service description.

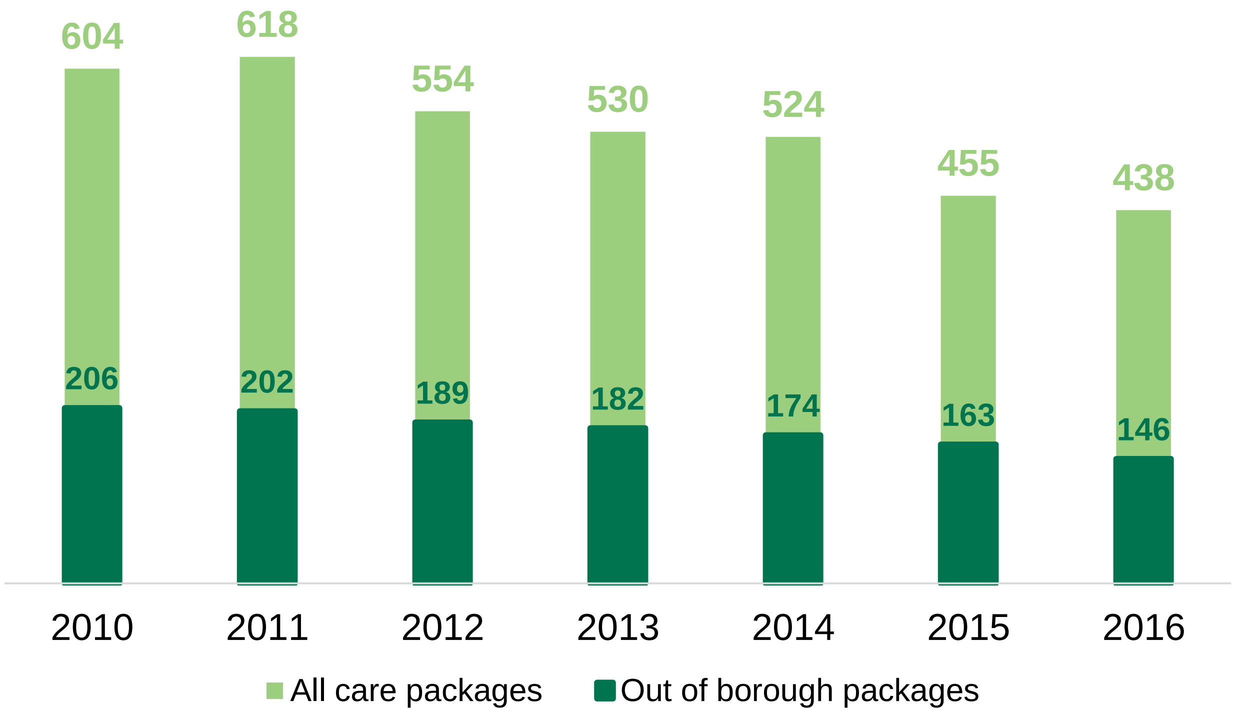
Low numbers of clients in the City of London mean that we cannot report this data without potentially identifying individuals.

Figure 23 shows that the number of adults with a learning disability receiving a care package in Hackney in March 2016 was 438 - 269 male, 169 female. Of these, a third were having their care needs met through services out of the borough.

There are a number of reasons why clients may receive care outside their 'home' borough; a common reason is the lack of suitable specialist facilities in the local area to meet the most complex health and care needs. Out of borough care is often not an ideal arrangement, however, as it can lead to service users being separated from family and social networks. In addition, the local authority incurs a greater cost for out of borough placements, as a result of the increased staff time and travel costs associated with client assessments.

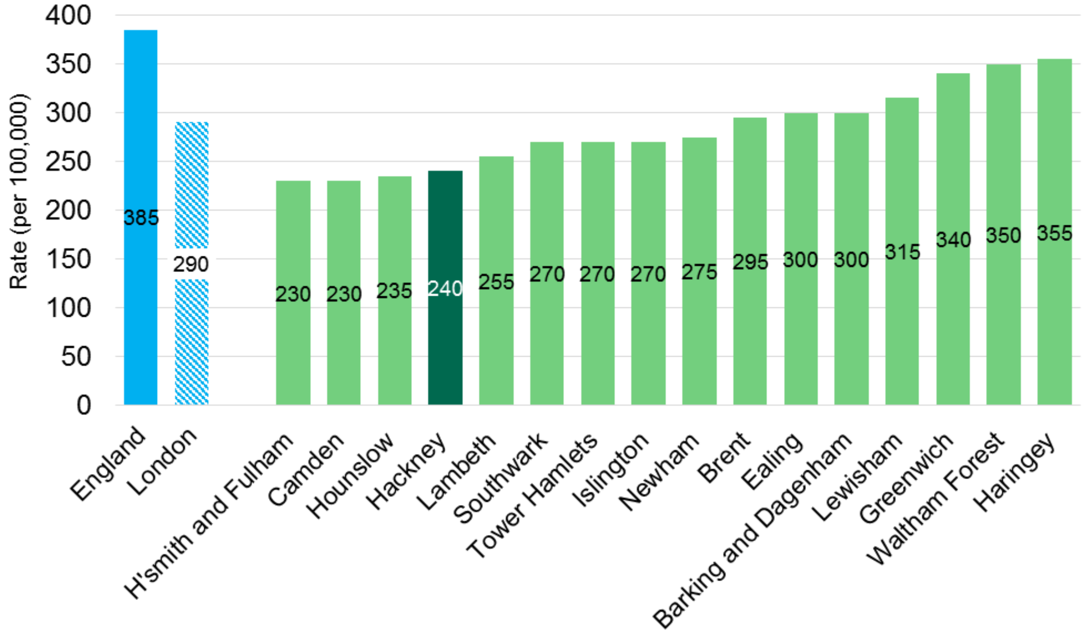
Since March 2010, the number of adults receiving a care package has decreased by almost 30%, for all clients (again, see ***Figure 23***). This is despite the fact that learning disabled residents are a relatively stable population, as they tend to have fewer opportunities to move out of the area due to limited employment and housing options, and the fact that they are often being cared for by family living locally (see Section 7.9).

Figure 23: Number of adults (18+) with a learning disability receiving a care package funded by the London borough of Hackney on 31st March 2016 [171]



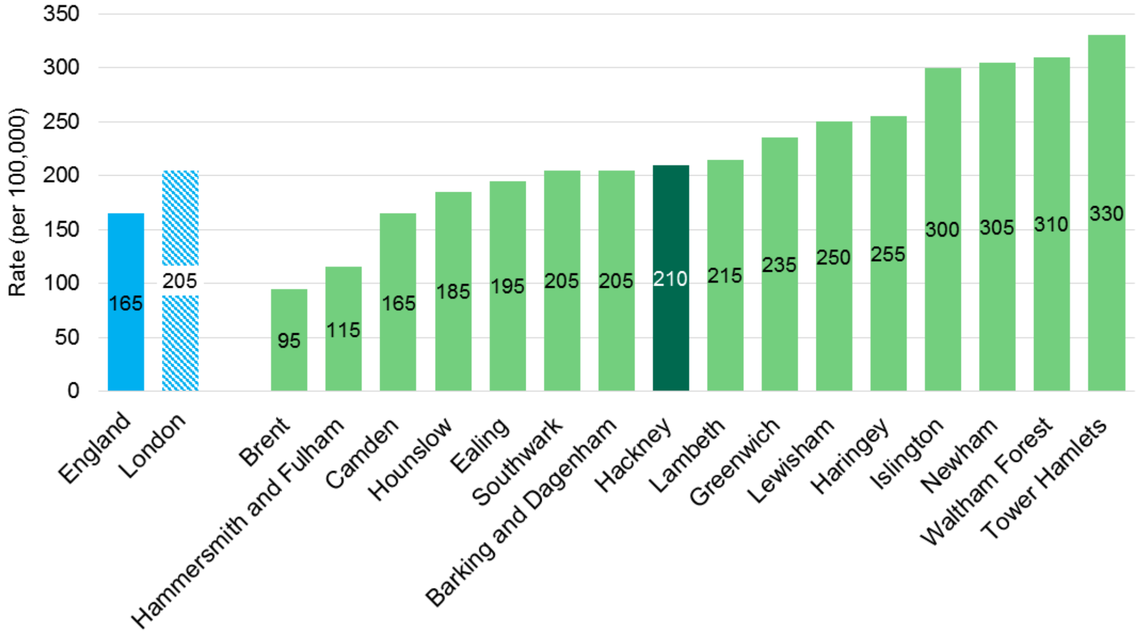
Compared to many similar local authorities, London and England, receipt of long-term social care support by learning disabled adults is relatively low in Hackney, especially among 18-64 year olds (Figure 24 and Figure 25).

Figure 24: Clients (aged 18-64) with a learning disability receiving long term social care support by local authority (rate per 100,000 people in the population)



Source: SALT LTS001a Tables 1a and 1b, 2015 Mid-Year Population Estimates from the Office for National Statistics
Note: Definition of Long Term Support includes people in receipt of any of the following; Home care; Day care; Meals; Direct payments; Professional support; Other – transport; Residential care; Nursing care. Numbers rounded to the nearest 5.

Figure 25: Clients (aged 65+) with a learning disability receiving long term social care support by local authority (rate per 100,000 people in the population)



Source: SALT LTS001a Tables 1a and 1b, 2015 Mid-Year Population Estimates from the Office for National Statistics
Note: Definition of Long Term Support includes people in receipt of any of the following; Home care; Day care; Meals; Direct payments; Professional support; Other – transport; Residential care; Nursing care. Numbers rounded to the nearest 5.

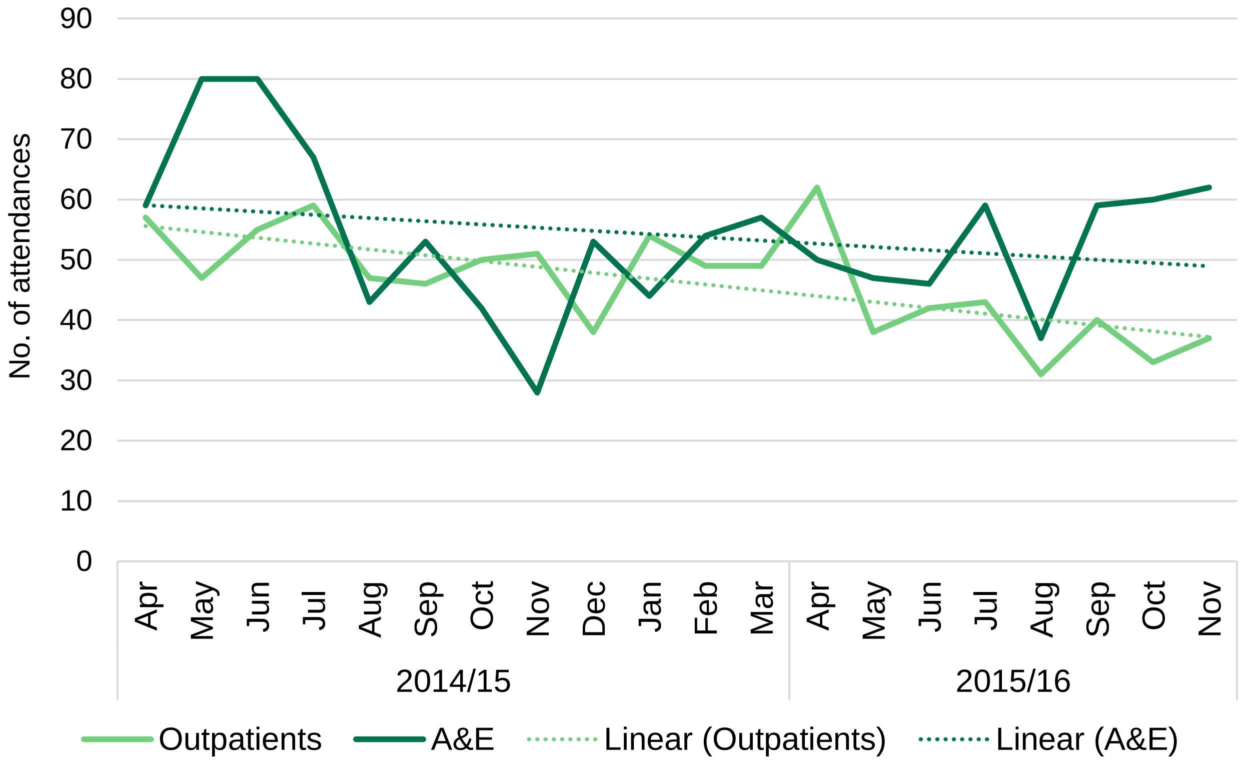
6.3.3 Homerton University Hospital Data

The data reported in this section relates to presentations of adults (18+) coded with learning disability at HUHFT (SNOMED code F819). [20]

In 2014/15, there were 660 Homerton A&E attendances and 602 outpatient attendances in adults coded with a learning disability. Over time, the average number of attendances at Homerton clinics by learning disabled adults shows a slight decline between April 2014 and November 2015 (***Figure 26***).

Of all A&E attendances (in patients of any age), 0.6% were in people coded as learning disabled (HES, 2015). However, some of these will be repeat attendances and, therefore, this figure does not represent the proportion of *patients* attending A&E who have a recorded learning disability [172].

Figure 26: Number of patients with a learning disability coding attending Homerton A&E and Outpatient clinics April 2014 – Nov 2015 [172]



6.4 Unmet need

By comparing numbers on the GP register, and numbers receiving a care package, to prevalence estimates from POPPI and PANSI, we are able to identify potential unmet health and social care needs amongst adults with a learning disability in the local area. When interpreting the data in this section, it should be noted that various limitations affecting disclosure, identification and coding of learning disability may

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[20] SNOMED: Systematized Nomenclature of Medicine – a standardised list of terms used to describe patient care to facilitate the electronic recording of patients

affect the comparability of estimated versus recorded prevalence (see Chapter 3). With these caveats in mind, the figures reported here can only provide broad estimates of unmet need.

Prevalence estimates predict that 2.4% of the adult population has a learning disability, however only 0.43% of City and Hackney adult patients are recorded as such by their GP on the QOF register.

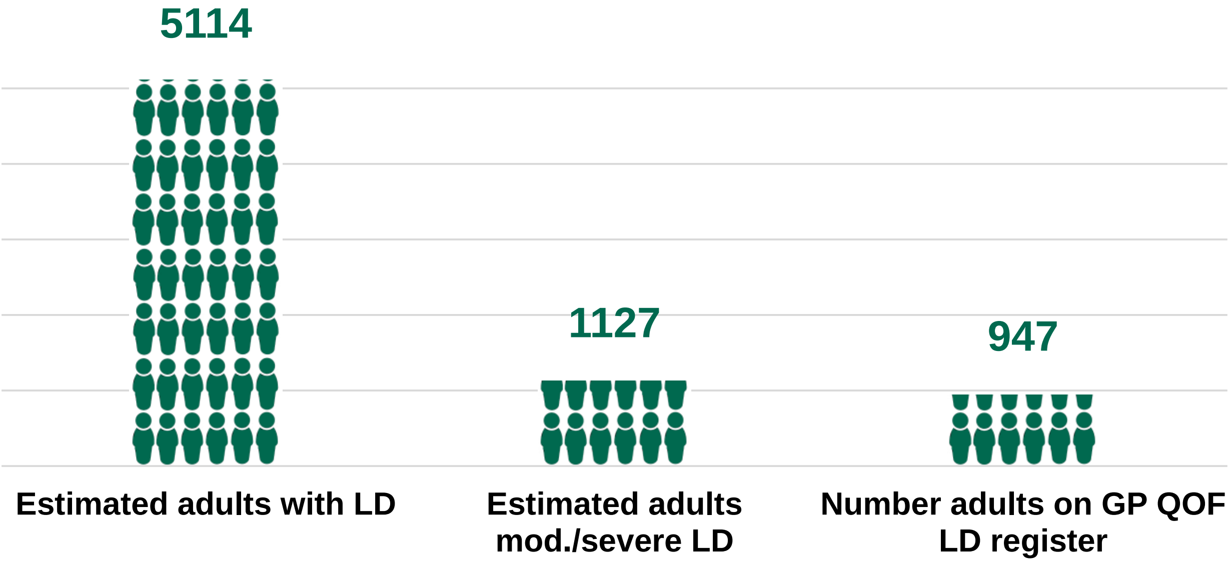
In terms of numbers, there are an estimated 5,114 adults with a learning disability in the City and Hackney, of which 1,127 might be expected to be ‘known to services’ due to the severity of their condition (either moderate or severe). In 2014/15, 947 adults were known to local GP services as having a learning disability according to the QOF register (see ***Figure 27***). The number of adults on the GP QOF register represents 84% of the predicted number of moderate/severe cases (and 19% of all cases) of learning disability in the City and Hackney (note values have been rounded). This suggests that almost 200 adults with a moderate/severe learning disability may not be known to their GP (nearly 4,200 patients with any learning disability).

In terms of adult social care, 438 adults with a learning disability were receiving a care package in Hackney (31st March 2016). This equates to around 40% of the number of adults estimated to have a moderate/severe learning disability and living in the borough.

This analysis suggests that a large number of adults with a learning disability living in Hackney and the City may not be accessing the health and care services they need to help address the significant health inequalities observed in this population (Chapter 7).

Of those patients known to have a learning disability (QOF), 525 adults received an annual health check in 2014/15. This equates to around 60% of patients with a recorded learning disability being assessed using the local health check tool.

Figure 27: Estimated and recorded number of adults with learning disability in the City and Hackney 2015



Source: [173]; [165] [166]

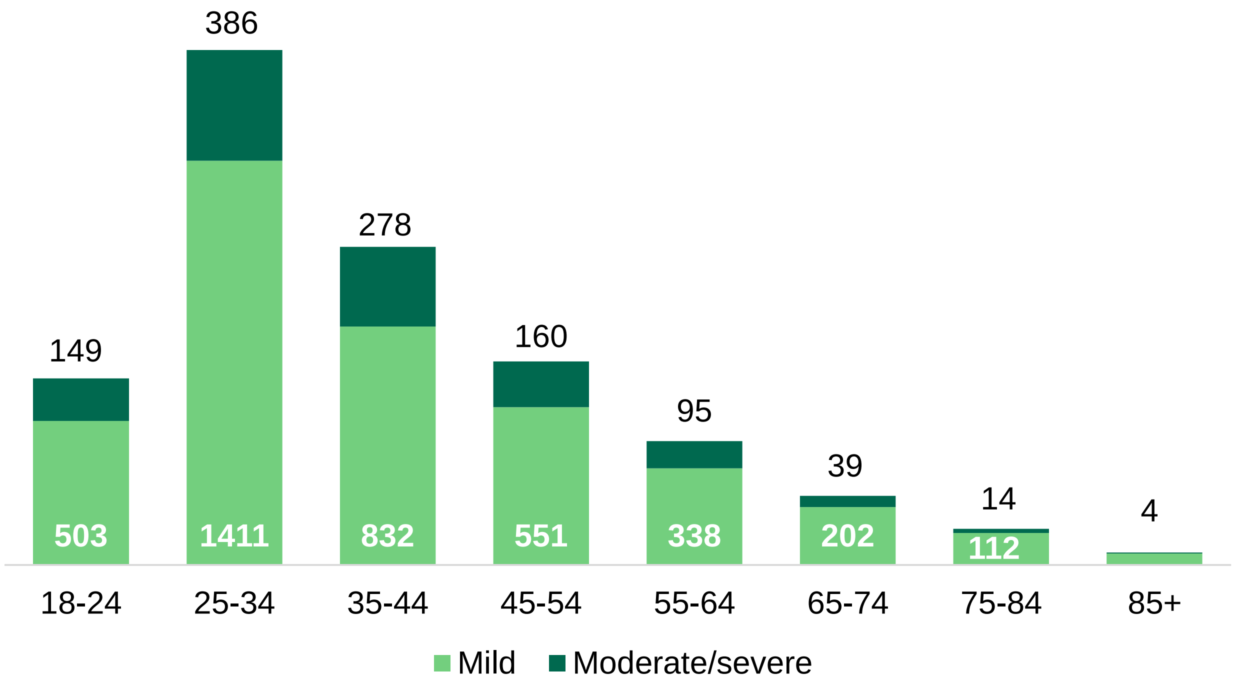
6.5 Inequalities

This section explores the inequalities in learning disability prevalence between different socio-demographic groups in the local population. Due to the relatively small numbers of learning disabled people known to local services, a more detailed comparative analysis than that presented here is not possible.

6.5.1 Age and gender

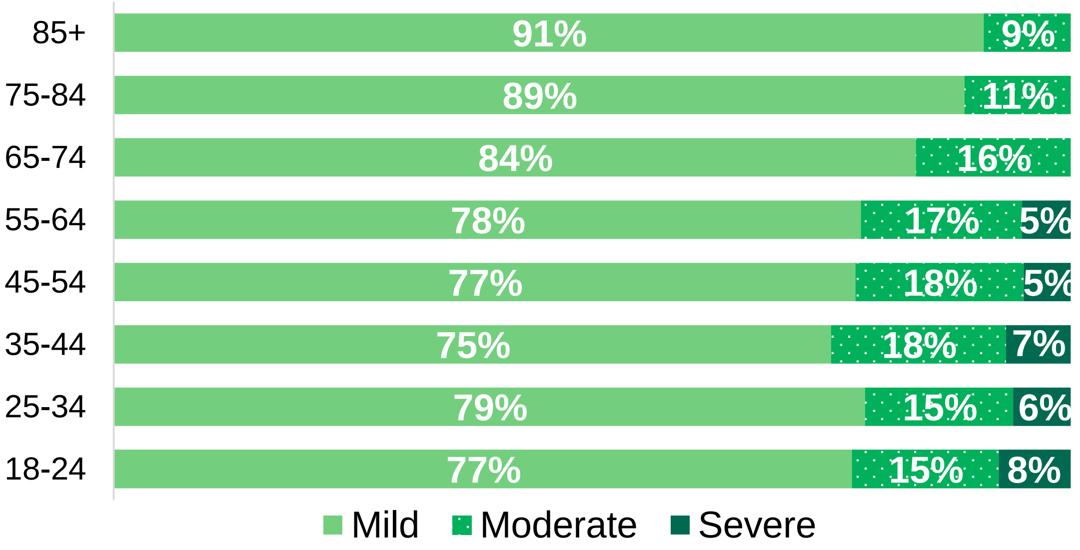
Given the strong links between age and learning disability, overall estimated prevalence by age group has been covered previously (section **6.2**). Focusing on those most likely to be in touch with services, estimates suggest that prevalence of moderate or severe disability is higher in younger than older adults (***Figure 28*** and ***Figure 29***). More than 70% of adults estimated to have a moderate/severe disability fall in to the 18 to 44 year age range.

Figure 28: Estimated number of adults with learning disability in the City and Hackney, by age and severity of condition (2015)



Source: [165] [166]

Figure 29: Percentage of learning disabled adults in different severity categories, by age group



Source: [165] [166]

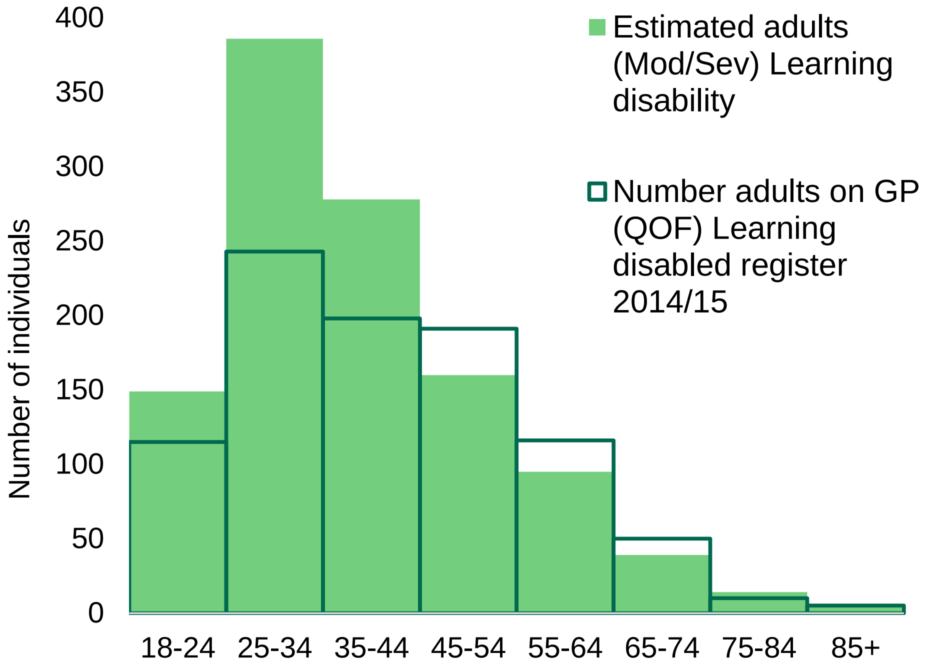
The literature indicates a higher prevalence of learning disability in men than women. Overall, prevalence estimates show a ratio of 2:1 male to female, although certain conditions are more common in (or exclusive to) the different genders. This overall gender difference is also reflected in local service data – for every adult female on the QOF learning disability register, there are 1.4 men. This difference is slightly more pronounced in those receiving adult social care packages funded by Hackney Council, where the learning disabled caseload shows a ratio of 1.6 men for every female client.

From ***Figure 30*** below, we can see that the age distribution of patients on the QOF register in Hackney and the City broadly follows the estimated prevalence of moderate/severe learning disability, although it is clear that many cases are not identified on local GP records. As reported in section 6.4 the number of adults on the QOF register represents 84% of the estimated number of all adults with a moderate/severe learning disability (18% of all cases of learning disability).

The greatest difference between estimated and recorded prevalence of adult learning disability appears to be in the younger age groups (18-44 years), where the majority of under recording is apparent. In these age groups, estimates suggest there are around 160 individuals with a moderate/severe form of learning disability who may not be known to their local GP. This finding is important for local service planning.

The number of learning disabled adults aged 45+ on GP records appears to be slightly higher than modelled estimates of the number of adults with a moderate/severe disability in this age range (again, see ***Figure 30***). This finding should be treated with some caution given the use of modelled estimates as well as limitations in GP data related to coding issues and patient turnover (including deaths in older learning disabled patients)".

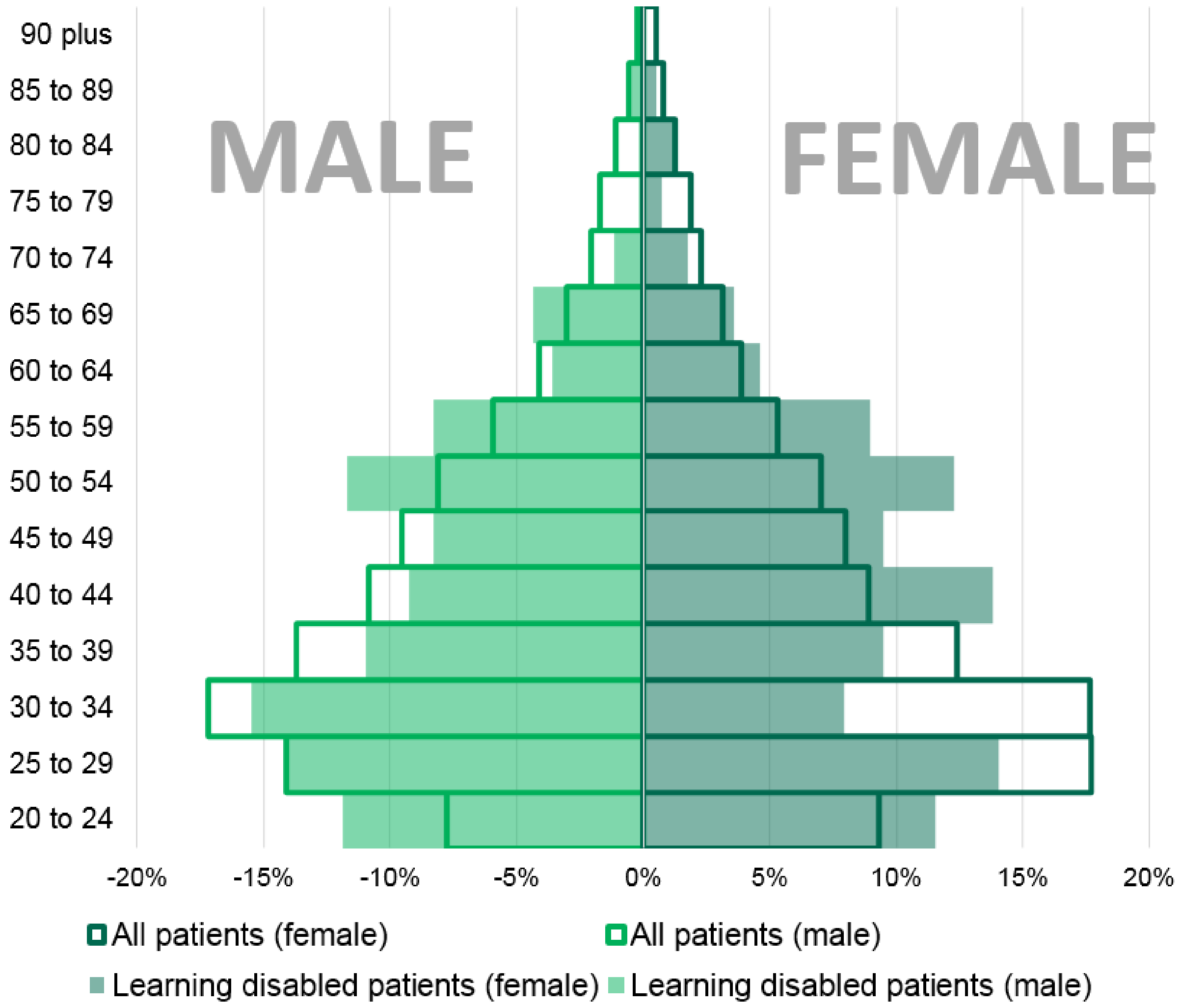
Figure 30: City and Hackney GP patients with a moderate/severe learning disability (QOF) compared with local prevalence estimates, by age (2015)



Source: [173] [165] [166]

Figure 31 shows how the age distribution of the QOF learning disabled population compares with the total GP patient population. The distribution shows a greater *proportion* of learning disabled patients falling into the 50-60 year age group compared to the total patient population. This may be reflecting the limitations of prevalence estimates which have not accounted for recent improvements in the life expectancy of people with learning disability (further discussion Chapter 2).

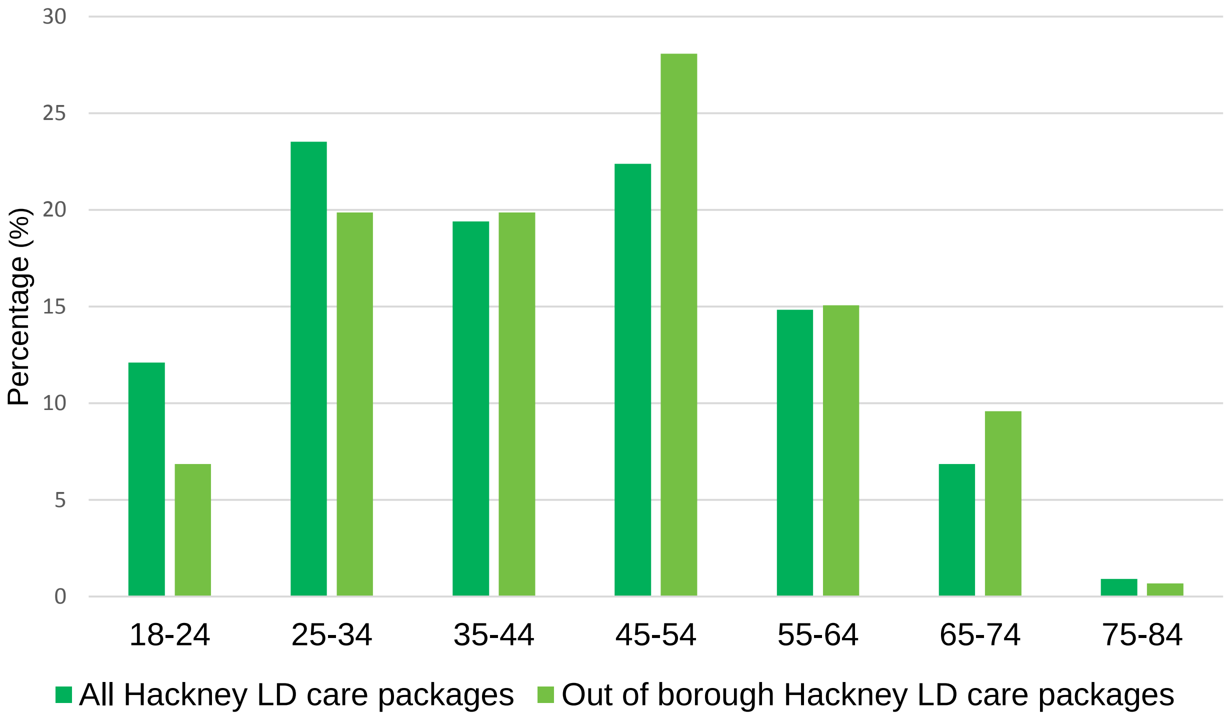
Figure 31: Age and gender distribution of GP patients on the QOF learning disability register in City and Hackney (2014/15) compared with the total patient population



Source: [173]

Figure 32 shows the age distribution of adults receiving care packages funded by Hackney Council. Unlike those receiving care within Hackney, the greatest proportion of adults receiving care out of borough fall into the 45-54 year age group. This potentially indicates a lack of suitable care facilities locally for ‘middle-aged’ adults with learning disability.

Figure 32: Adults with learning disability receiving adult care packages in Hackney 2016

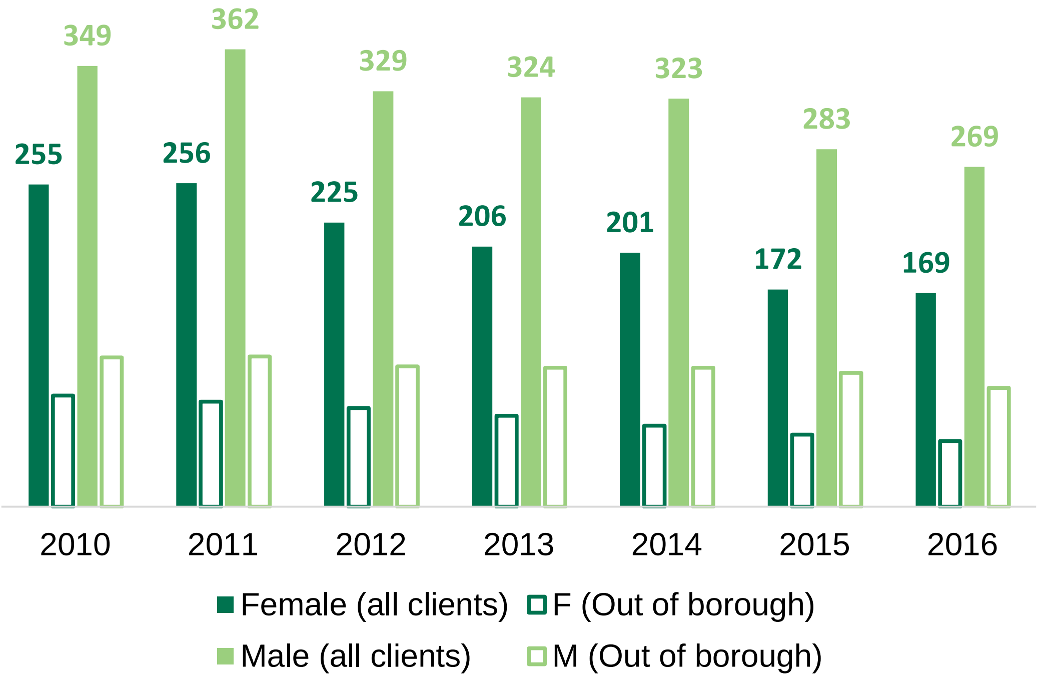


Source: [171]

As discussed in **section 6.3.2**, overall there has been around a 30% decline in the number of learning disabled adults receiving a care package from Hackney Council between 2010 and 2016. Over this period, the largest proportional decrease in numbers are seen in the younger age groups (18 to 54 years), including a 48% fall in the number of 18-24 year olds receiving support. This is reflected in those receiving care both in and out of borough. Part of this change in service use can be attributed to change in adult eligibility criteria and expansion of transition services to encompass people aged up to 24 years of age**.**

From a gender perspective, there has been a larger proportionate reduction in the number of learning disabled women receiving care packages (by 34% between 2010 and 2016) than for men (23%) (***Figure 33***). The ratio of males to females receiving a care package has increased from 1.4:1 in 2010 to 1.6:1 in 2016. This gender difference is particularly stark in relation to the number out of borough care packages, where there has been a 41% decrease over this period amongst women compared to 20% for men. It is likely that this gender difference reflects the change to eligibility criteria for accessing adult social care (available to those with a critical or substantial need), which would infer that females may have less substantial care needs than males. However, these patterns may also highlight potential inequalities in access to appropriate care/support for women with a learning disability in Hackney.

Figure 33: Number of adults with a learning disability receiving a social care package through Hackney Council



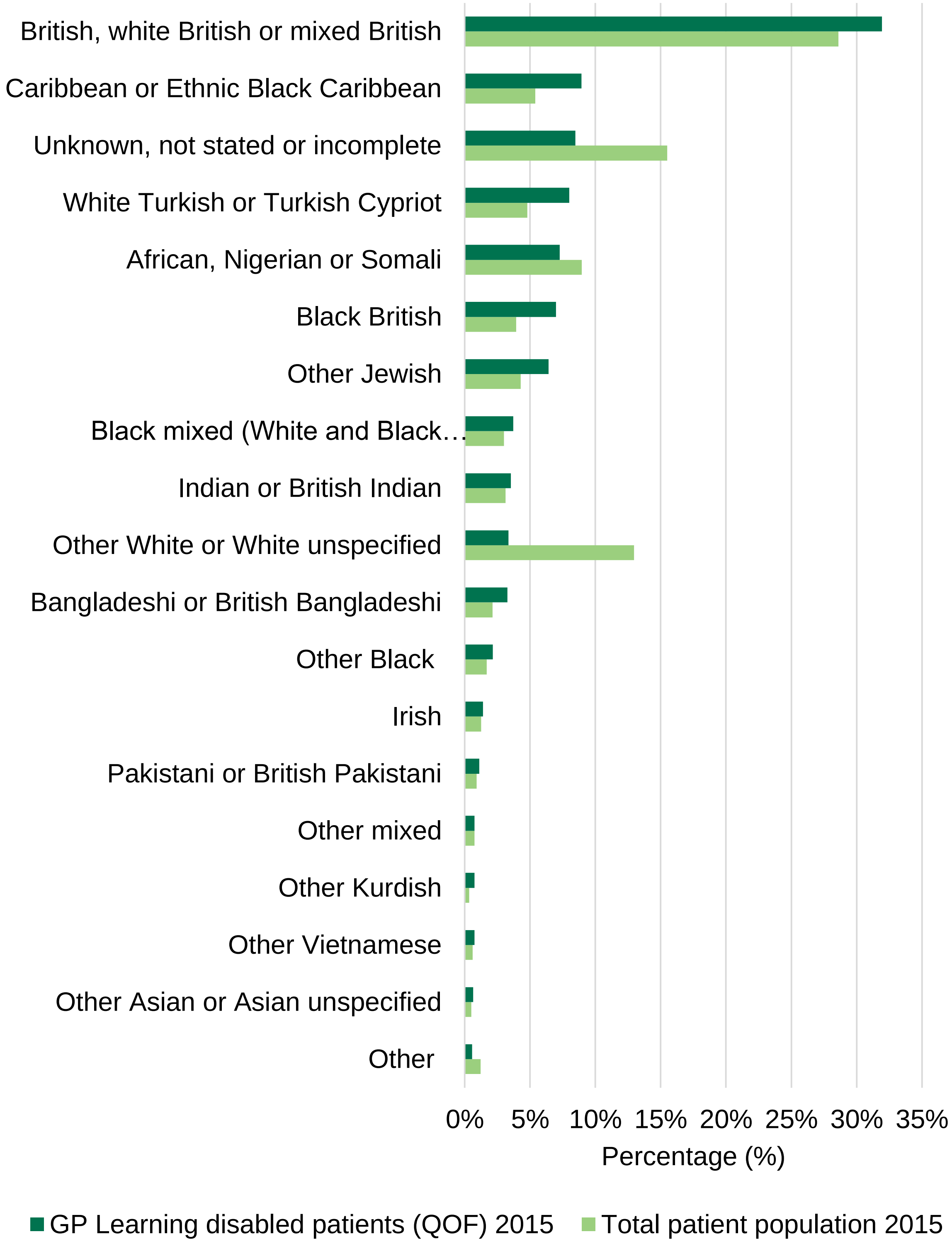
Source: [171]

6.5.2 Ethnicity

The data presented below describe the ethnic profile of learning disabled individuals known to local services, based on detailed ethnicity codes used by GPs and Hackney Council (which unfortunately are not comparable). Some ethnic groups have been combined for analysis purposes due to small numbers.

Figure 34 shows the largest percentage of learning disabled GP patients in the City and Hackney to be in the 'British, white British or mixed British' category. A slightly higher percentage of QOF registered learning disabled patients fall into this category than the general GP patient population. Other ethnic groups that are over-represented in the learning disabled patient population include 'Caribbean', 'White Turkish or Turkish Cypriot', 'Black British' and 'other - Jewish'. The main ethnic group that is *under*-represented on the QOF registered learning disability register is 'Other White or White Unspecified'. It is possible that this category includes a mix of ethnic groups which are relatively common locally, including Orthodox Jewish and Eastern Europeans. A final point of note is the much lower percentage of 'unknown' ethnicity recorded for learning disabled patients compared to the GP registered population as a whole.

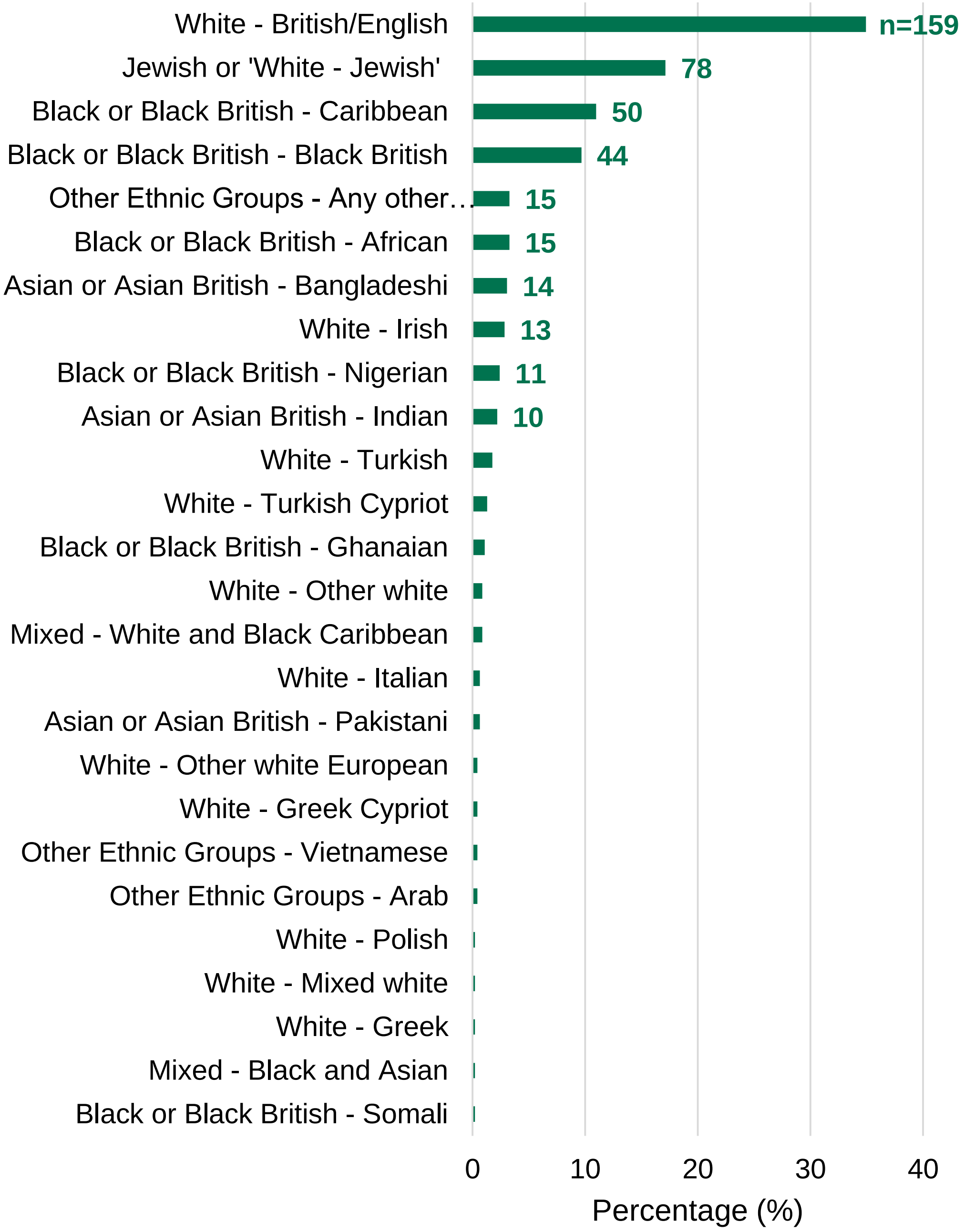
Figure 34: Detailed ethnic profile of QOF learning disability register patients (all ages) compared to all patients registered with a GP in City and Hackney



Source: [173]

For adults (18+) receiving a care package funded by Hackney Council (both in and out of borough), detailed ethnicity information shows the greatest proportion fall into the ‘White British/White English’ category. This is followed by those identifying as ‘Jewish or White-Jewish’ and then two categories of ‘Black or Black British’.

Figure 35: Number (and percentage) of adults with learning disability receiving a care package from Hackney Council 2016, by detailed ethnic group

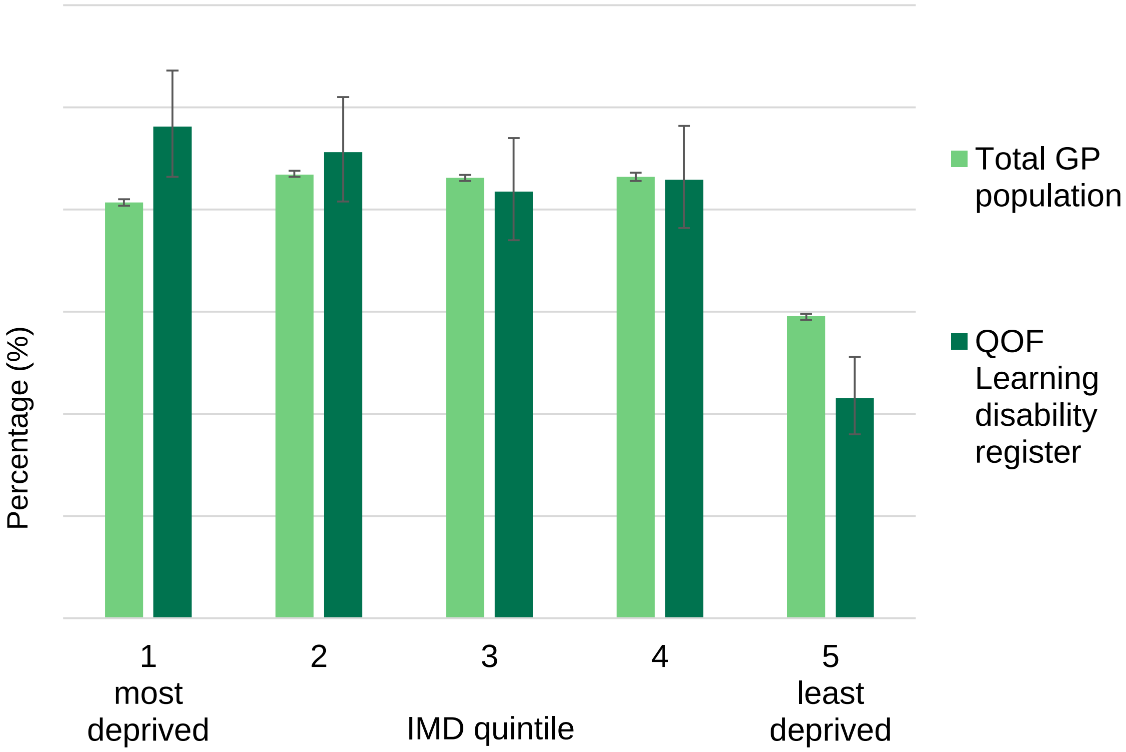


Source: [171]

6.5.3 Deprivation

A higher proportion of patients (all ages) on the QOF learning disability register live in deprived neighbourhoods than is true of the general GP registered population in City and Hackney (***Figure 36***). This is also described in national reports into the health of people with learning disabilities in England [168]. Learning disabled patients are significantly *more likely* to be living in the *most deprived* area 'quintile' and significantly *less likely* to be living in the *least deprived* (or most affluent) quintile. [21] A number of different factors may contribute to this (as discussed in Chapter 4) for example smoking and malnutrition which are linked to deprivation as well as pregnancy and early years risk factors for learning disability. [174] [175] [176].

Figure 36: Proportion of QOF learning disability register patients (all ages) in each deprivation quintile compared to all patients registered with a GP in City and Hackney (CEG 2015).



Source: [173]

6.5.4 Location within Hackney and the City

The map in ***Figure 37*** below shows that a higher prevalence of recorded learning disability is observed amongst adults in the north west of Hackney (0.77% of all patients compared with 0.4% on average across City and Hackney). This area of relatively high recorded prevalence is also a locality with high levels of relative deprivation (see section 6.5.3) and contains a high preponderance of

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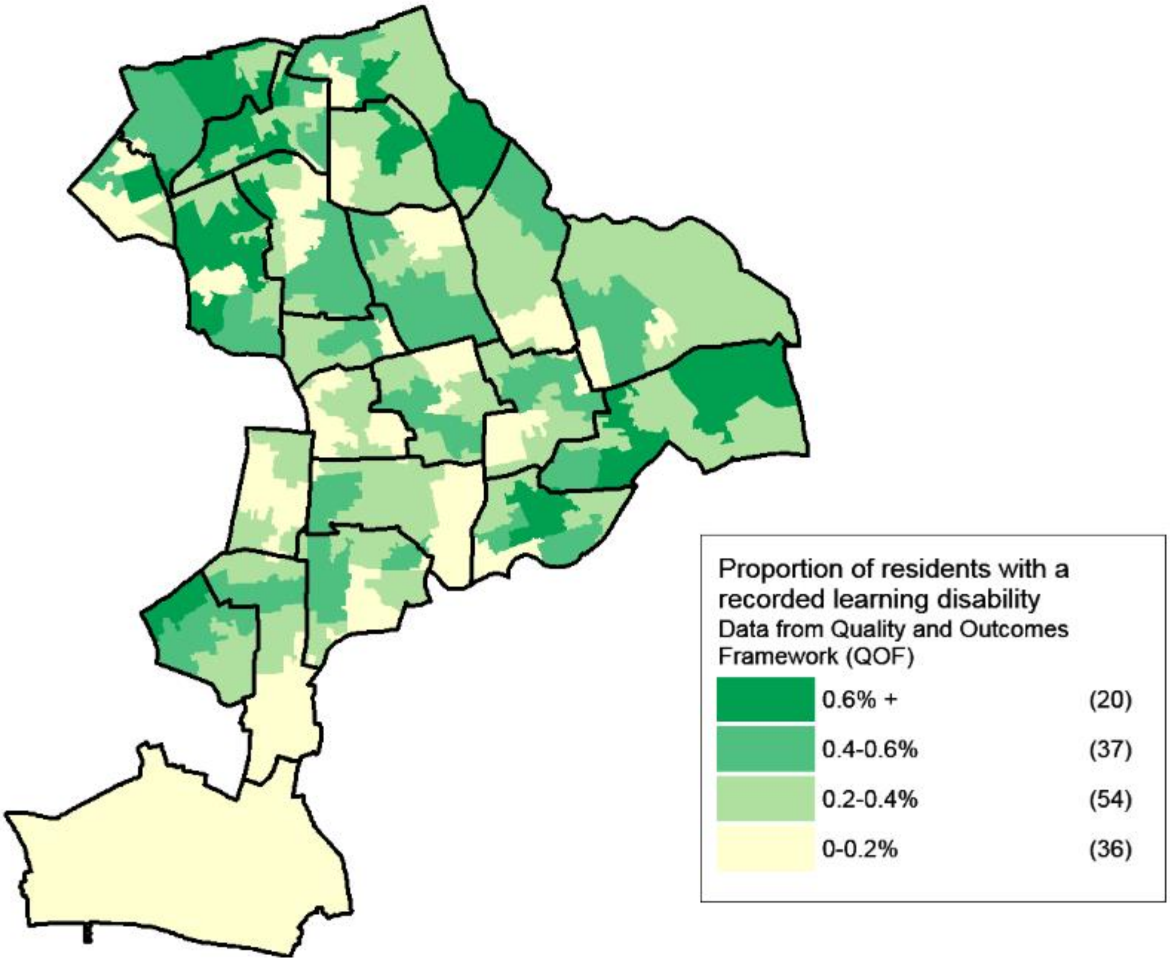
[21] Quintile – any of five equal groups into which the population is divided according to the IMD scale of most and least deprived in England

Charedi/Orthodox Jewish households. There are also relatively high rates of recorded learning disability towards the south east of Hackney near the Homerton hospital, which is close to a number of supported living accommodations.

The reasons for the observed geographical patterns cannot be fully understood by these data, but may reflect a higher underlying local prevalence of learning disability or different recording practices by GPs located in these areas (as discussed in Chapter 2 of this report).

Figure 37: Geographic patterns in learning disability prevalence (QOF register – all ages) in City and Hackney 2015



Source: [173] [164]

7. Health and wellbeing needs of learning disabled adults in Hackney and the City

7.1 Introduction

Chapter 5 provides an overview of the key health & wellbeing needs of adults with learning disability in England and the UK. This chapter presents local data and evidence of these needs (where available) amongst affected adults living in Hackney and the City. The majority of local evidence of need is taken from GP records of patients registered at practices in the local area (cross sectional data extract April 2015), specifically those on the QOF learning disability register. Other sources are also used where relevant, including hospital, community and survey data. Where local data are not available, London-wide evidence is reported were possible.

7.2 Common coexisting conditions

7.2.1 Mental Health

As described in Chapter 5, people with a learning disability are at increased risk of developing mental health problems, but under-reporting of such conditions is a particular problem in this population.

Severe mental illness (SMI)

Local GP data shows significantly higher rates of recorded serious mental illness (SMI) [22] in the learning disabled population than the overall patient population (***Figure 38***). For adult patients with a learning disability, 13.6% (n=134) were recorded to have SMI, compared to 1.3% in the total GP adult patient population.

National data shows a rate of 8.6% of adult learning disabled GP patients with SMI, compared to 1% of all adult patients (see Chapter 5). This indicates that the prevalence of SMI is greater in the City and Hackney than compared to nationally reported figures.

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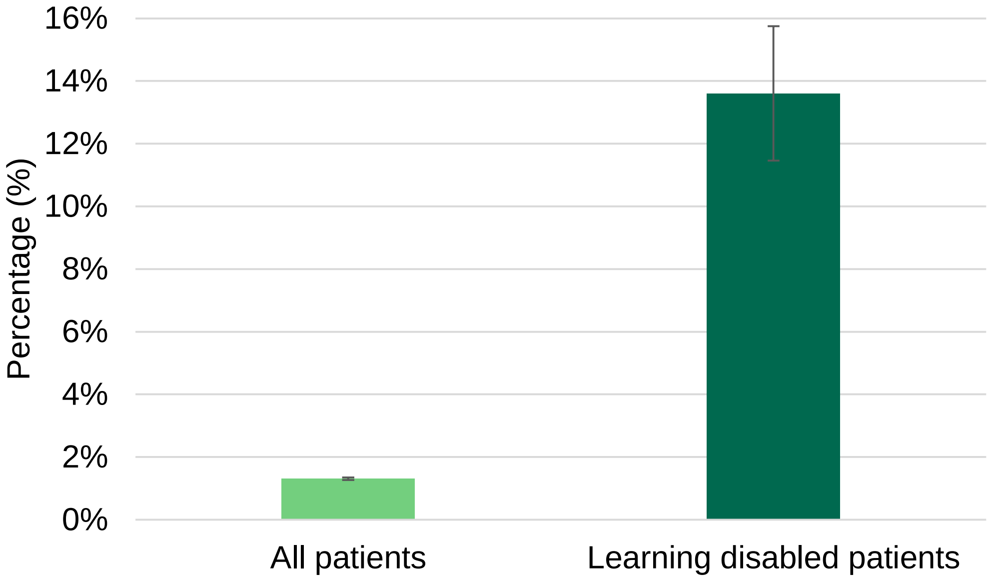
[22] The term ‘Severe Mental Illness’ (SMI) does not cover all severe and enduring mental illnesses. It is a specific term used in the Quality and Outcomes Framework (QOF) to mean bipolar disorder, schizophrenia and other psychosis. GPs have guidelines for recording data on people with SMI, and so we have much more local data about people with SMI than we do about people with other severe and enduring mental illnesses. (Mental health JSNA update 2016)

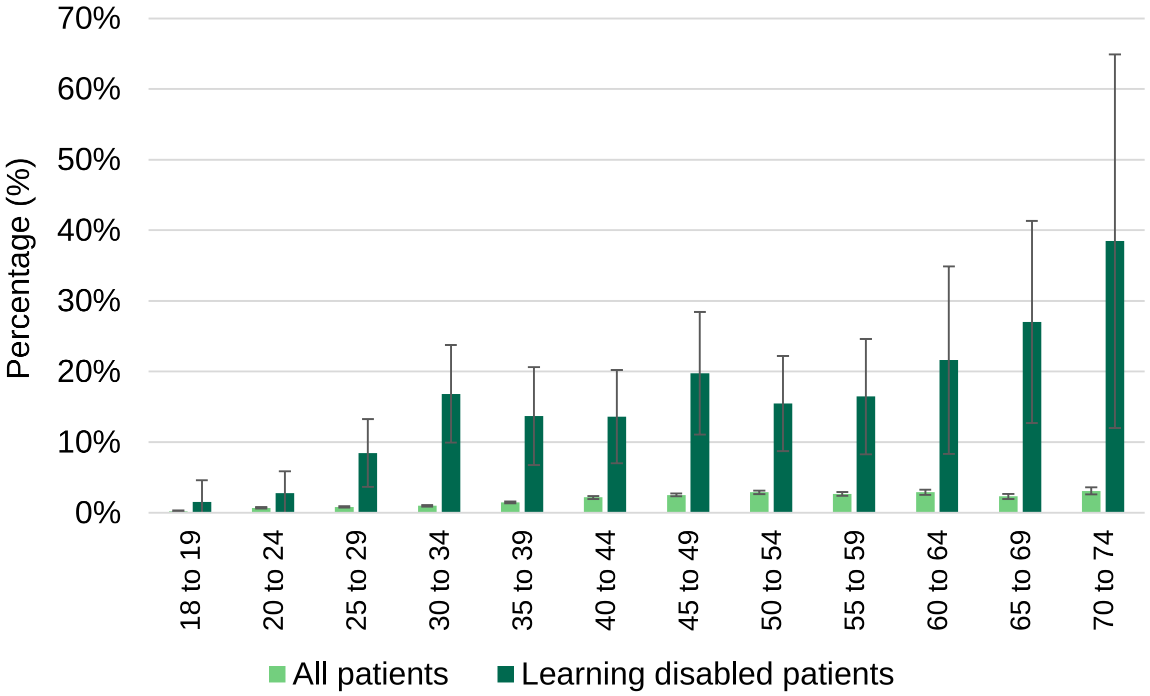
Figure 38: Prevalence of recorded SMI in adults (age 18+) with learning disabilities in City and Hackney (GP practice records)



Source: [177] [178]
Note: Black bars on figure are 95% confidence intervals. This is a statistical indicator of how closely the reported figures are likely to reflect the 'true' or underlying pattern.

The age distribution of local SMI patients with a learning disability follows a broadly similar pattern to that described in the latest research from national representative samples. However, due to the small numbers involved, no reliable conclusions can be drawn on how SMI prevalence varies by age in the local learning disabled adult population (as indicated by the wide confidence intervals in ***Figure 39***), except to say that diagnosed SMI appears to be lower at younger ages.

Figure 39: Prevalence of recorded SMI in adults (18+) with learning disabilities in City and Hackney (GP practice records), by age

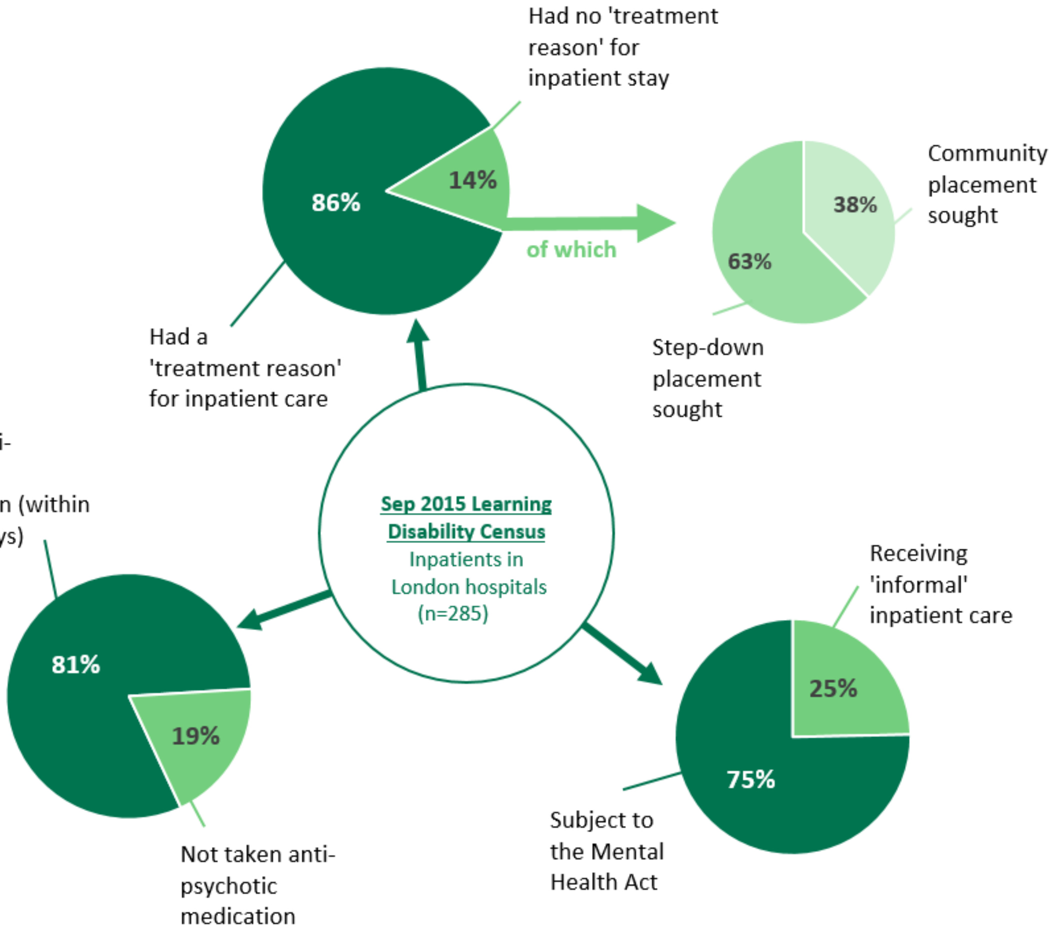


Source: [177]
Note: Age groups 75+ excluded due to small number of patients affecting display of data

Data from the Learning Disability Census provides further information relevant to SMI in people with learning disabilities. The Census collects information on inpatients (all ages) with a learning disability, challenging behaviour and/or autistic spectrum disorder. It captures a sample of inpatients receiving treatment/care in a facility registered by the CQC as a 'hospital' (either NHS or private). London level regional data are presented below.

In London in 2015, 25% of inpatients were receiving care on an informal basis whilst 75% were residents under the Mental Health Act. In addition, 81% of inpatients had received anti-psychotic medication within the last 28 days (***Figure 40***).

Figure 40: Results of the London region Learning Disability Census



Source: [179]
Notes to Figure 40:
'Subject to the Mental Health Act' refers to patients held under the legislation of The Mental Health Act 1983 (amended 2007)
'Informal inpatient care' refers to patients receiving standard NHS care
'Step down placement sought' refers to a local step-down placement to an inpatient psychiatric unit in preparation for community resettlement
'Community placement sought' refers to a new community placement actively being sought as previous placement no longer viable
'Taken anti-psychotic medication' refers to a patient receiving anti-psychotic medication within 28 days prior to census day

Depression

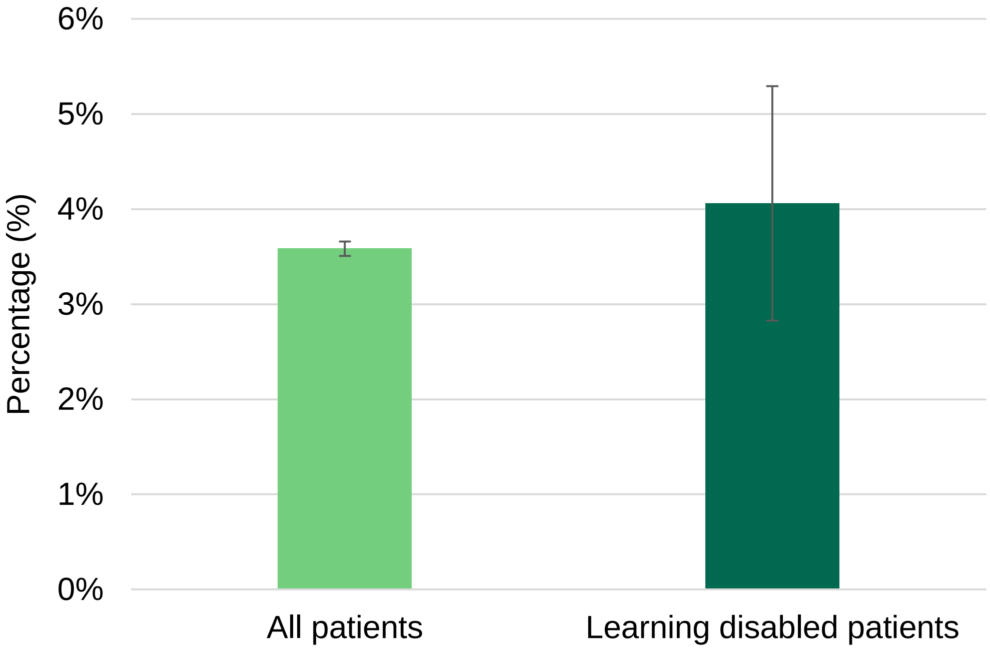
The figures reported below are based on GP recorded depression prevalence. However, it is important to note that for learning disabled patients in particular, the QOF recording system on which these estimates are based is likely to significantly under-report true prevalence of depression (this is discussed further in Chapter 2).

In 2015, 4.1% of adults with a learning disability and 3.6% of the total adult patient population were coded with depression on GP registers (***Figure 41***). The difference in crude prevalence of depression between all patients and those with a learning disability is not statistically significant.

National data shows the rate of depression 'ever recorded' on the QOF register to be around 18% amongst both learning disabled and non-disabled adult patients (see Chapter 5). Local data presented here are based on coding of 'current depression'[23] and are not comparable with these national QOF prevalence estimates.

Data from the Homerton University Hospital show that of the patients with a learning disability attending A&E in 2015, 3.1% of all attendances (with a reason recorded) were related to depression and/or anxiety. A figure displaying a more complete breakdown of this data is available in Appendix C).

Figure 41: Prevalence of recorded depression in adult patients with learning disabilities in City and Hackney GP practices



Source: [177]

7.2.2 Dementia

A detailed description of dementia prevalence in Hackney and the City is available in the *Mental Health JSNA 2016*.

As discussed in Chapter 5 research suggests an increased risk of dementia in adults with learning disability and a greater risk of earlier onset (defined as under 65 years of age). Looking at the adult *all* age prevalence of dementia in learning disabled local patients, the data show just under 1% to be recorded with the disease. This compares with 0.3% of the total adult patient population.

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[23] 'Current depression' is defined as the most recent recording within the past 5 years.

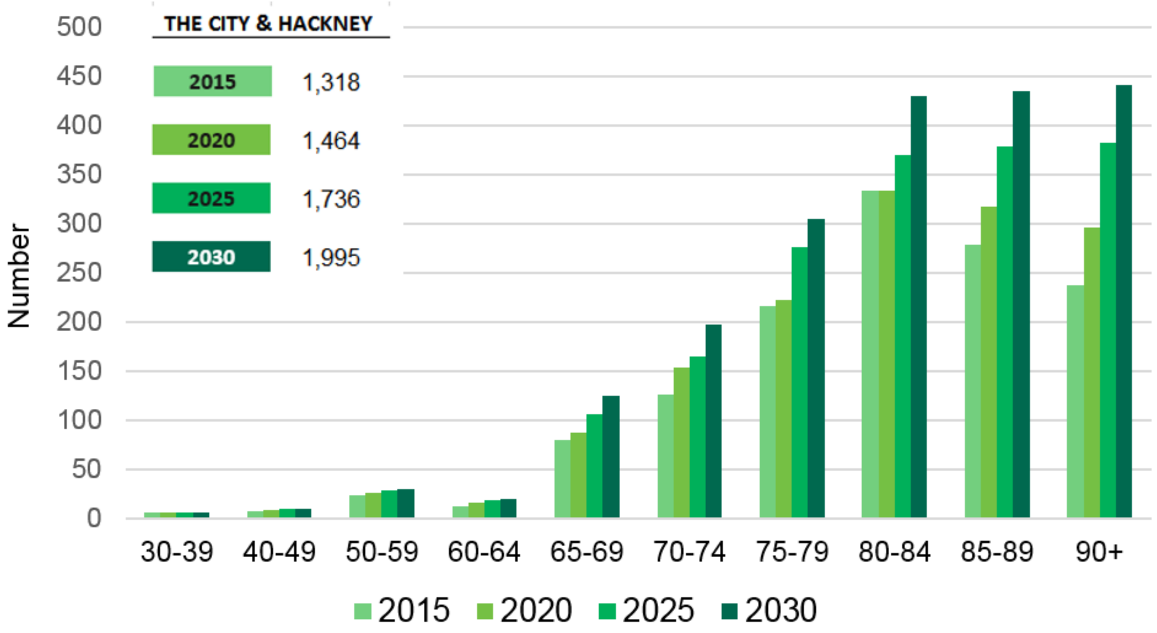
Due to the significant association between advance age and dementia prevalence, reporting of dementia is most commonly presented exclusively for the over 65 population. National age-standardised prevalence estimates indicate that around 20% of learning disabled and 7.1% of the non-disabled 65+ population has dementia (Chapter 5). Application of these rates to the estimated number of learning disabled adults over 65+ living in Hackney and the City (see Chapter 6) equates to around 80 learning disabled adults living with dementia locally. This implies that 6.5% of the expected number of adults age 65+ with dementia have a learning disability.

Local GP data shows 11% of all adults (65+) with a learning disability are recorded with dementia (n=7) (***Figure 43***). This compares to 4% of the total patient population (65+) recorded with the condition.

As already mentioned, prevalence estimates indicate around 20% of older learning disabled adults (aged 65+) in City and Hackney have dementia (n=82). This suggests that, locally, only 9% of cases of dementia in learning disabled adults aged 65+ are currently captured on local GP records.

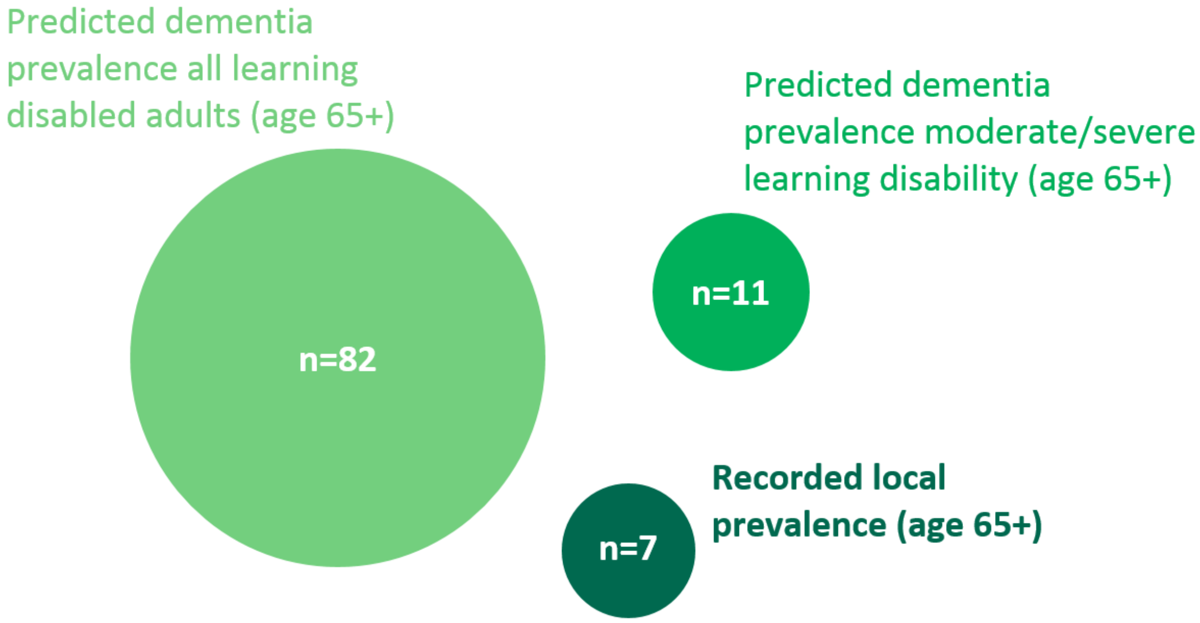
Until national data is published and verified (due July 2016), we are unable to determine how local under-reporting compares with the national average.

Figure 42: Estimated number of all adults with dementia in the City and Hackney, 2015, by age.



Source: [165] [166]

Figure 43: Predicted and recorded prevalence of dementia in learning disabled patients aged 65+



Source: [165] [166]; [177]; [180]; [181]

As nationally (see Chapter 5), the vast majority of adult GP patients recorded with dementia in Hackney and the City are over 65 (95% of all those diagnosed). In the local learning disabled population, fewer than five patients diagnosed with dementia (in April 2015) were under 65. Patients with recorded learning disability and dementia in the City and Hackney range from 45 to 89 years of age.

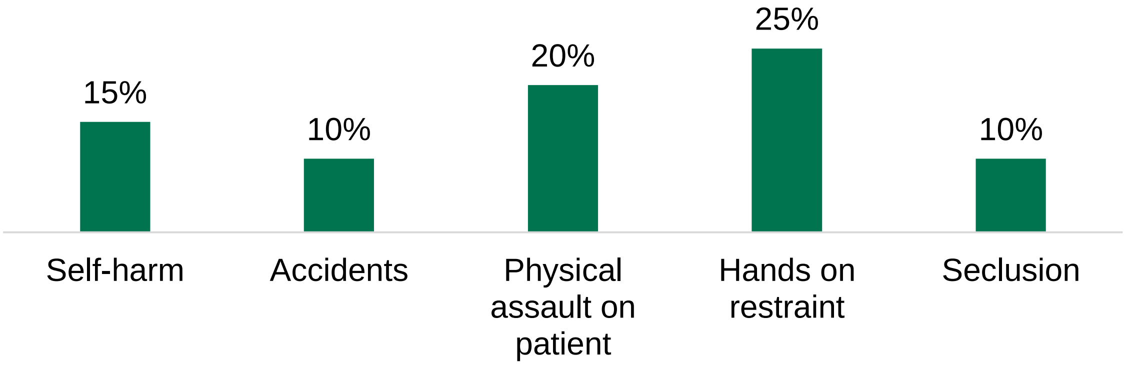
7.2.3 Behaviour that challenges

Prevalence estimates suggest that around 90 learning disabled adults displayed challenging behaviour in Hackney and the City in 2015 [165] [166].

Data from Homerton hospital show that 2.4% of A&E attendances in patients with a learning disability were related to self-harm (again, data is from 2015).

Forty-five percent of inpatients in London (as measured through the Learning Disability Census) report having experienced any 'incident' within the past 3 months – the most common being 'hands on restraint' followed by 'physical assault' (***Figure 44).*** The types of incident are not directly reflective of challenging behaviour, although there is likely an overlap of cases.

Figure 44: Patients experiencing various incidents within the past 3 months

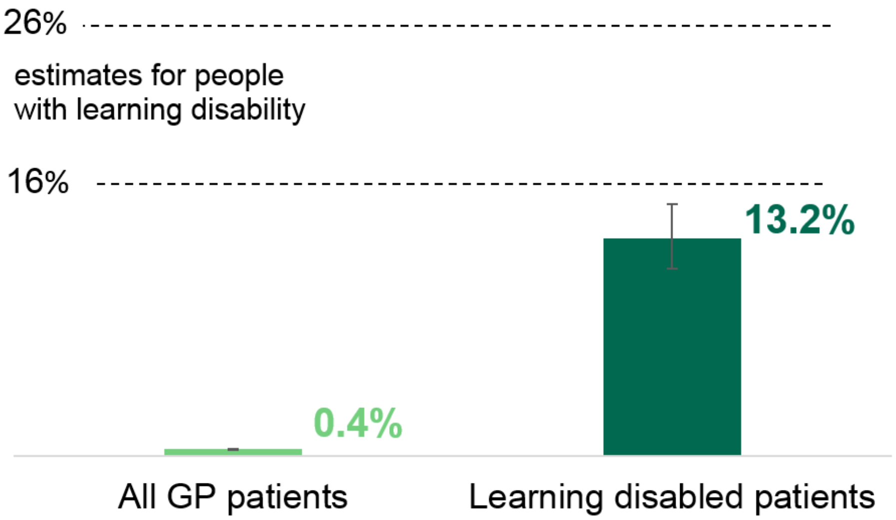


Source: [179]
Note: Categorical variables are captured from the ***Mental health services dataset*** *descriptions (UID M505020; M507915)*

7.2.4 Epilepsy

According to local GP data, 0.4% of all adult patients in Hackney and the City are coded as having epilepsy, compared with 13.2% of adults with a learning disability. This difference is clearly significant, although recorded prevalence rates in learning disabled patients are lower than that predicted by the literature (***Figure 45***)

Figure 45: Proportion of GP patients (all ages) with epilepsy in Hackney and the City



Source: [177]

Data from Homerton hospital gives an indication of the level of need in relation to epilepsy-related attendances and admissions (2014/15), for example:

- the neurology department's outpatient epilepsy clinic provided 611 appointments to 106 people with learning disabilities (of all ages) in 2015; in total, people with learning disabilities made up 17% of all neurology appointments in that year. Although the epilepsy specialist nurse has advised

a high chance of patients with learning disability not being coded accurately based on a review of case notes.
- 8% (n=15) of inpatient discharges from Homerton hospital (attributed to people with learning disability) had an admission label related to epilepsy; for discharges exclusively from general medicine departments, 27% (n=22) of discharges were epilepsy-related
- for attendances at Homerton A&E by adults with learning disability, 13% of all attendances with reason recorded (n=37) were seizure-related; in one third of these seizures, epilepsy was listed as a related cause.

7.2.5 Respiratory conditions

Respiratory conditions are a major cause of death in people with learning disabilities. This section describes the prevalence of a range of respiratory conditions in learning disabled adults in Hackney and the City, based on currently available data. Further discussion on this topic is available in Chapter 5. Data from Homerton hospital shows that 9% of learning disabled inpatients (all ages) discharged in 2014/15 were coded with a respiratory condition as a primary diagnosis (includes discharges from all inpatient wards excluding paediatrics).

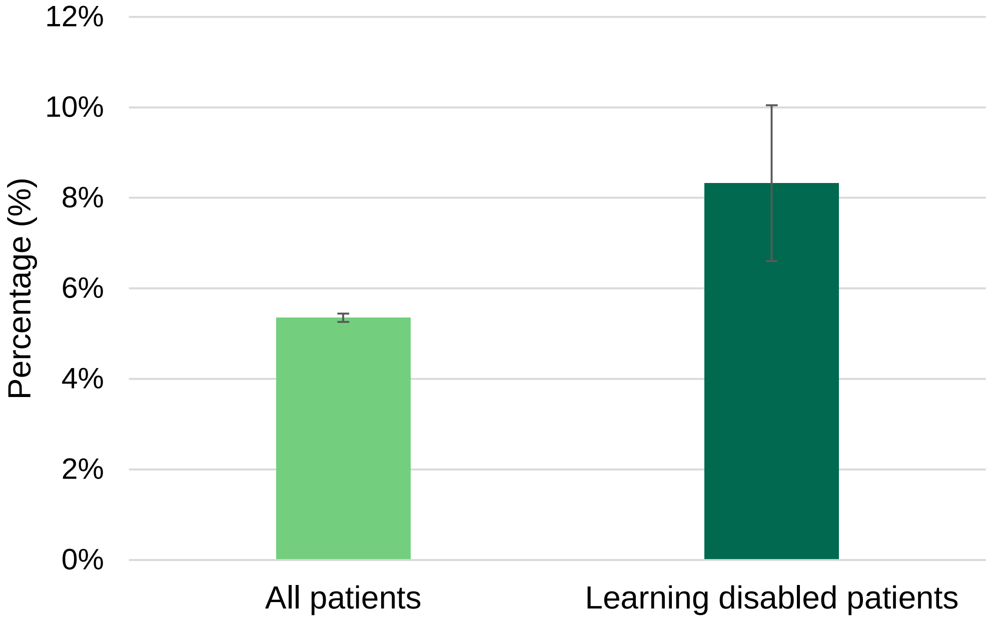
COPD

Prevalence of COPD is very similar in the local adult learning disabled GP patient population and the non-disabled patient population (1.9% and 1.4%, respectively).

Asthma

Local and national data shows that asthma is more common in patients with a learning disability than those without. Local GP records show that 8.3% of learning disabled adult patients have asthma, compared to 5.4% of the total adult patient population (***Figure 46****)*. This is in line with provisional national data from PHE.

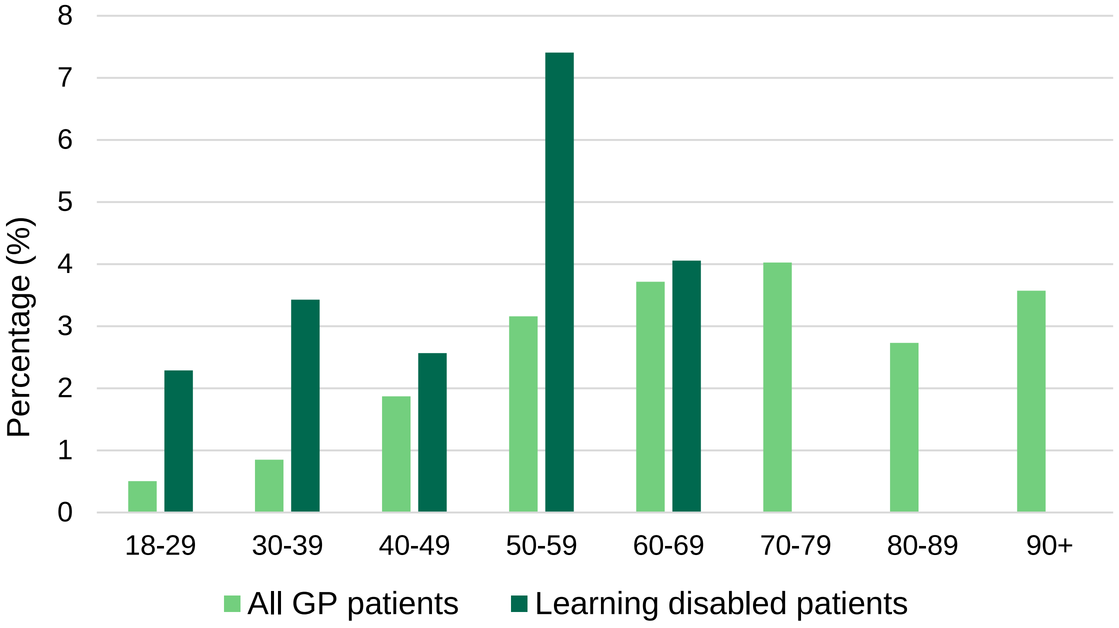
Figure 46: Prevalence of asthma in adult patients in Hackney and the City (GP practice data)



Source: [177]

Figure 47 shows a notably different age distribution in the local prevalence of asthma in learning disabled patients compared to the total adult patient population, with a very high peak in recorded prevalence in the 50-59 year age group. Provisional national data shows a different age distribution, as discussed in Chapter 5.

Figure 47: Prevalence of asthma in adult patients in the City and Hackney



Source: [177]

Pneumonia

Data from Homerton hospital shows that 6% of learning disabled inpatients (all ages) discharged in 2014/15 were coded with pneumonia as a primary diagnosis (includes discharges from all inpatient wards excluding paediatrics).

7.2.6 Dysphagia

In the 2015 annual Self-Assessment Framework (SAF) report for the City and Hackney, 2% of patients receiving an annual health check for their learning disability (age 14+) had a record of dysphagia [170]. It is important to note that this is likely to reflect significant under-reporting in this population – national estimates suggest a prevalence of 8% (see Chapter 5).

For the adults in contact with the Integrated Learning Disability Service, 35 people were seen by the speech and language team in relation to their dysphagia (2015/16). We do not have an accurate denominator to reflect percentage of those affected by the condition.

7.2.7 Cardiovascular disease (CVD)

Due to small numbers, an analysis of specific CVD conditions (e.g. coronary heart disease, stroke and peripheral artery disease or PAD) in adults with learning disabilities, as recorded on City and Hackney GP records is, not meaningful. As described in Chapter 5 national estimates suggest higher prevalence of some CVD conditions in adult patients with learning disability compared to those without.

Applying these national rates locally suggests that 18 adult learning disabled patients in Hackney and the City may be affected by stroke/TIA[24], 17 may have IHD[25] and four have PAD (***Table 10***). However, care should be taken when interpreting these estimates, as discussed in Chapter 3.

Table 12: Recorded national prevalence of CVD health conditions with application to local patient population [178]

Disease/condition	**Recorded prevalence (Carey et al, 2016)**	**Prevalence rates applied to local GP learning disabled patient population**
Stroke and TIA	1.8%	18
Ischemic heart disease (IHD)	1.7%	17
Peripheral vascular disease (PAD)	0.4%	4

Hypertension is one of a number of conditions that significantly increase the risk of CVD, along with obesity (see 7.2.9) and diabetes (see 7.2.8), amongst others. ***Figure 48*** reveals a higher local rate of hypertension in adults with learning disabilities (14.1%) than in the total GP patient population (12.1%), although this difference is not statistically significant. Local GP recorded hypertension prevalence in learning disabled adults is higher than national estimates (10.7%), although as elsewhere these figures are not directly comparable.

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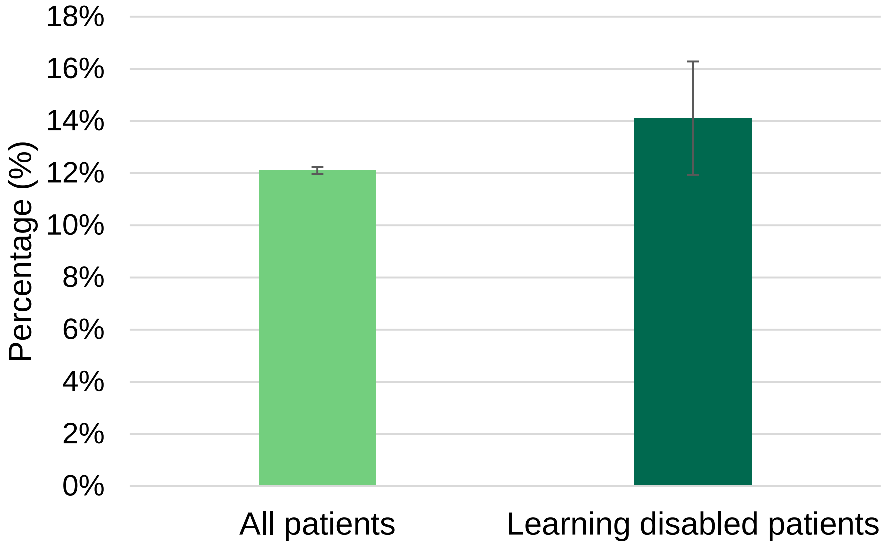
[24] TIA – trans ischemic attack

[25] IHD – ischemic heart disease

Figure 48: Local prevalence of hypertension in the adult City and Hackney GP patient population

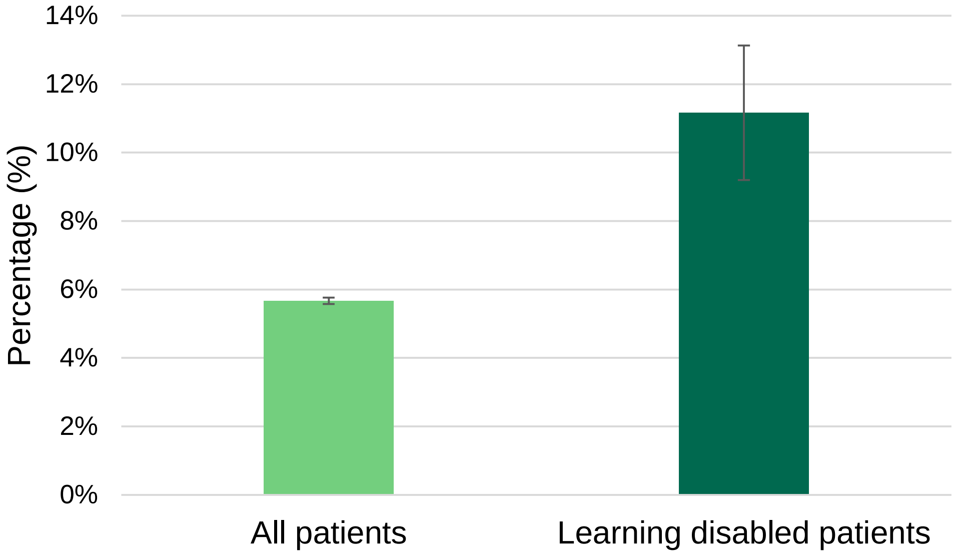


Source: [177]

7.2.8 Diabetes

This section describes overall prevalence of diabetes in the learning disabled population. It is not currently possible to present local data for prevalence of Type 1 and Type 2 diabetes separately for 2015 but prevalence of all diabetes was *11.2% compared with 5.7% in the total patient population).* In 2016, the prevalence of type II diabetes alone was 11.4% (5.4% in total patient population).

Figure 49: Local prevalence of diabetes (all types) in the adult (18+) City and Hackney GP patient population



Source: [177]

7.2.9 Obesity and underweight / Body weight

The following BMI data is taken from a more recent snapshot of patient records from April 2016 (as opposed to 2015 used elsewhere).

Figure 50 shows that adult patients with a learning disability in the City and Hackney are significantly less likely to be a 'healthy' weight (based on a Body Mass Index, or BMI, score of 18.5-24.9)[26] than the total patient population. There are no significant differences between the total and learning disabled patient population in terms of prevalence of 'overweight' (BMI 25-29.9). A significantly higher proportion of learning disabled patients are either 'underweight' (BMI <18.4) or 'obese' (BMI >30), with the greatest differences observed in the 'obese' classification, as revealed below.

Ninety-three percent of learning disabled adult patients in the City and Hackney have a BMI measure recorded in GP records. For the total patient population that figure is around 88%, and a provisional national sample of learning disabled GP patients (all ages) shows 58% have a BMI recorded. This indicates that local recording of BMI in learning disabled patients may be better than nationally observed rates.

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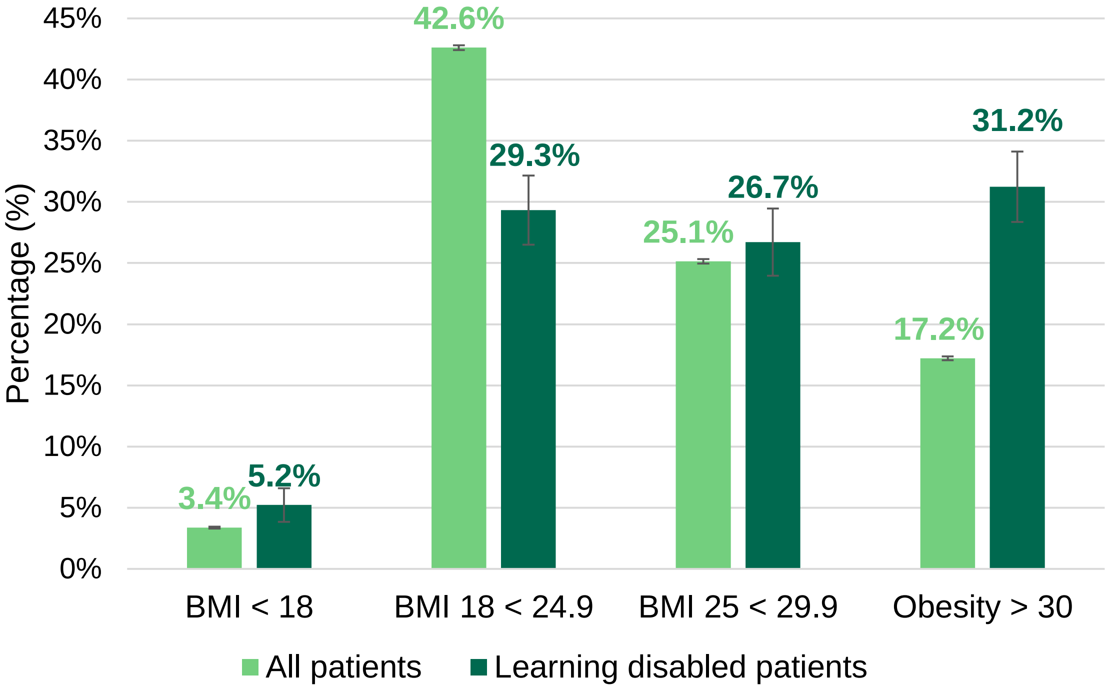
[26] BMI is calculated by: $\frac{\text{Weight (kg)}}{\text{Height (m)}^2}$

Obesity

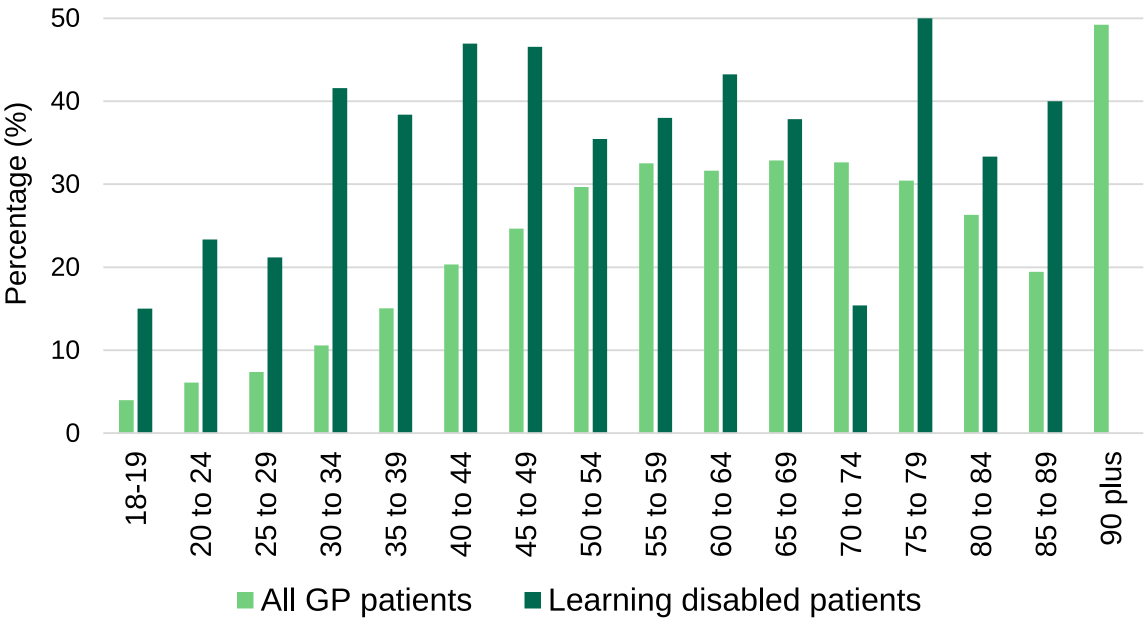
Local GP data shows that 31.8% of learning disabled adult patients are recorded as obese, compared to 17.2% of all GP patients (***Figure 50***). This is broadly in line with provisional national estimates (see Chapter 5). The age distribution of obese learning disabled patients broadly reflects patterns reported in the literature, with particularly high rates in the younger (18-49) age groups (***Figure 51***).

Figure 50: Body mass index (BMI) of all patients and learning disabled patients in Hackney and the City (GP data)



Source: [177]
Notes: BMI<18.5 = underweight; 18.5-24.9 = 'healthy' weight; 25-29.9 = overweight; 30+ = obese

Figure 51: Prevalence of obesity (BMI≥30) in Hackney and the City, by age (GP data)



Source: [177]

Note: Prevalence rates in older age groups are particularly unreliable given the very small numbers involved

Out of a total of 36 learning disabled adults in Hackney who responded to the local needs assessment survey, eight self-reported themselves to be ‘overweight’ and none identified as ‘obese’. However, as discussed in the Chapter 2 of this report, self-reported body weight is not a very reliable measure, especially in people with a learning disability.

Further local data for Hackney on the social care needs related to overweight and obesity in adults with learning disabilities is available via information collected though the FACE assessment tool,[27] which asks about the extent to which a client’s weight affects their mobility. Of the 185 adults with a learning disability who have been assessed locally since 2015, 21% are described as having a body weight which impacts their mobility in some way (***Figure 52***). A limitation with this data is that this question does not offer any insight into whether it is *excess* weight or *under*weight that is affecting a person’s mobility. However, anecdotally the inference is that it is excess weight that people are referring to in this question.

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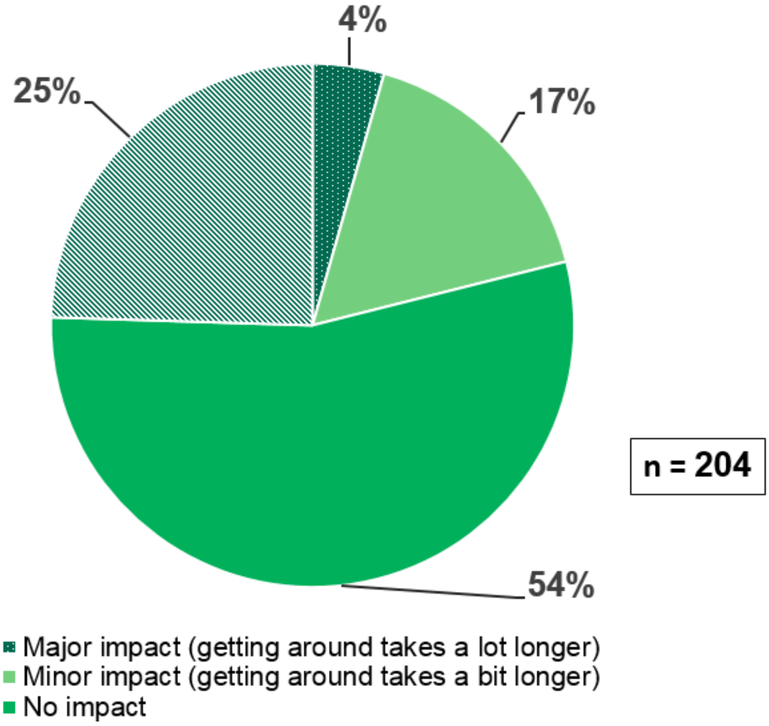
[27] The FACE Care Act Toolkit for Adult Social Care is a system designed to collect service user information with a view to informing a client’s care needs. The software is designed to work within the requirements of the Care Act 2014 and provide a provisional resource allocation for the data submitted for service users.

Figure 52: Response to FACE® community care assessment question 'to what extent does your weight affect your mobility?' for learning disabled clients who have had an assessment through Hackney Council



Source: [171]

Underweight

The Integrated Learning Disability Service in Hackney advise that the majority of their clients known to be underweight are those with profound and multiple learning disabilities. This is often in association with dysphagia and related nutritional deficits from problems with choking hazards when eating (section 7.2.6).

GP data shows around 5% of learning disabled patients are recorded with a BMI under 18.5 (categorised as 'underweight'), which compares to around 3% of the total patient population (small yet significant difference) (***Figure 50***). The number of recorded underweight learning disabled patients equates to 18% of the predicted number of 'severe' learning disabled adults in the City and Hackney (5% of the predicted moderate *or* severe learning disabled adults).

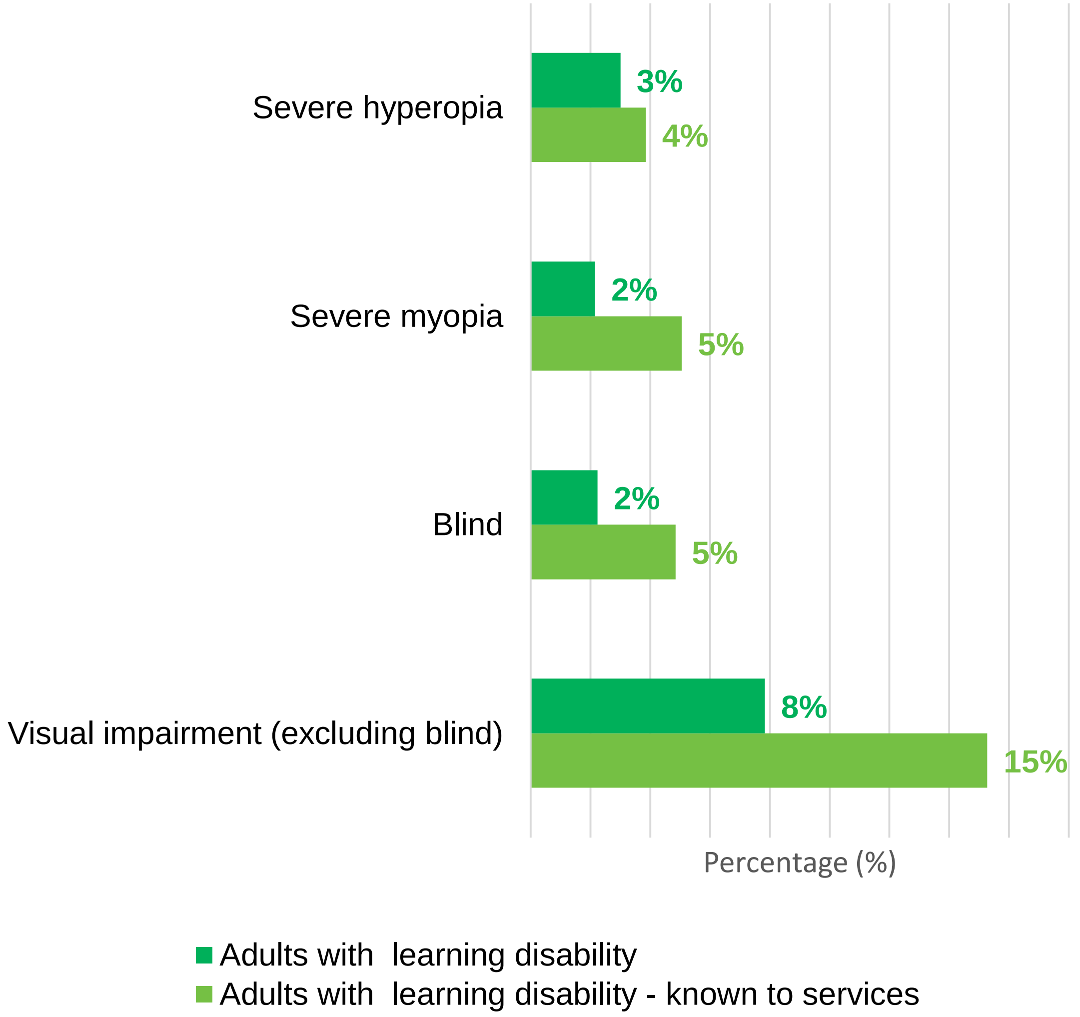
7.2.10 Visual impairment

Visual impairment is more common in individuals with a learning disability due to the nature of their developmental pathway. As described in Chapter 5, recording of visual impairment is often poor in people with learning disability, despite the significant impact on a person's communication, education and independence.

Local GP data indicates that 1.1% of all patients with a learning disability are also recorded as 'registered blind'. The *estimated* prevalence in this group is around 5%

in people known to services and 2% in all adults with a learning disability ***Figure 53***). This highlights potential under-recording of blindness in patients with learning disability locally.

Figure 53: Estimated prevalence of visual impairments in adults (age 20+) with a learning disability



Source: [132]

Table 13 shows the estimated prevalence of different types of visual impairment amongst adults with learning disabilities ‘known to services’, along with the predicted number of adults in Hackney and the City affected if these estimates are applied to the local learning disabled population.

Table 13: Estimated prevalence of visual impairment (in people 'known to services') applied to the local learning disabled patient population

Visual impairment	Predicted prevalence (20-49 years)	Predicted prevalence (50+ years)	Predicted number of local learning disabled patients (age 20+) with visual impairment
Refractive error	59%	64%	556
Visual impairment (excluding blind)	12%	18%	130
Blind	5%	5%	46
Severe myopia	5%	5%	46
Severe hyperopia	4%	4%	35

Source: [132] [177] [165] [166]
Notes to Table 13:
Refractive error refers to the amount of myopia, hyperopia or astigmatism which can results in blurred or distorted vision
Severe myopia is commonly known as short-sightedness
Severe hyperopia is commonly known as farsightedness

As of 31 March 2014 (the latest data available), Hackney Council's sensory team (see Chapter 0 for service description) had a caseload that included around 20 adults with a learning disability. The majority of these clients were recorded as being blind or severely sight impaired. Clients with learning disability formed around 10% of the sensory team's caseload in 2014.

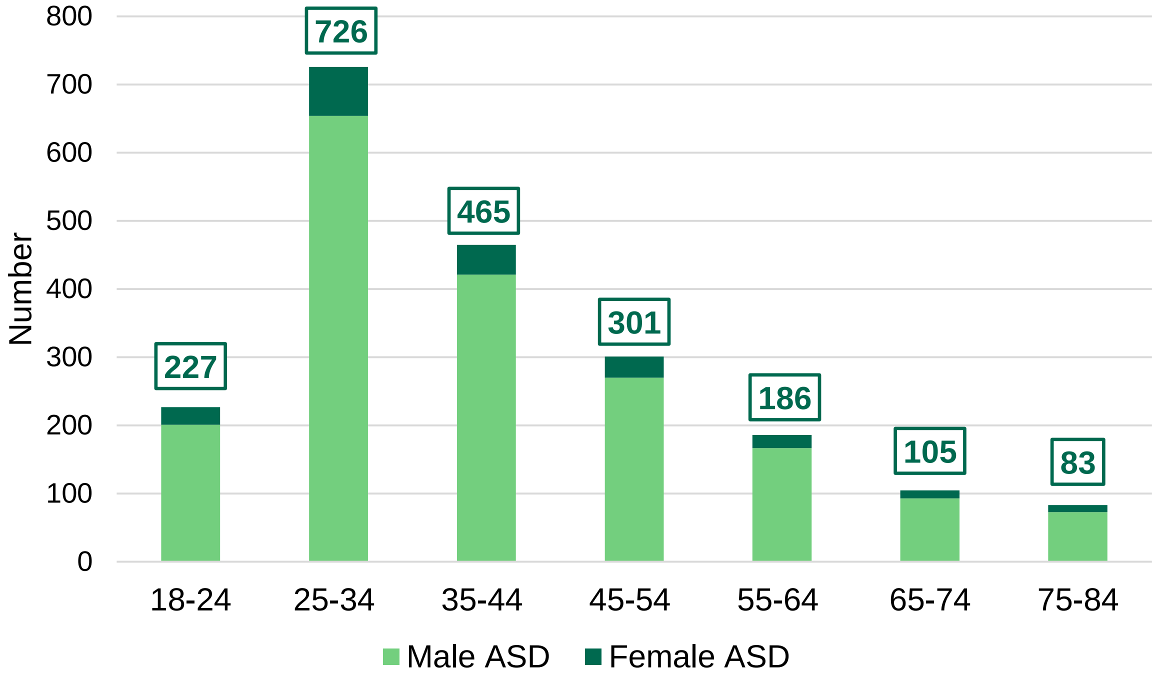
The total number of people receiving support from the Hackney sensory team has remained pretty consistent between 2011 and 2014 (around 1050 people). However the number of clients with a learning disability appears to have increased, from less than 5 in 2011 to around 20 in 2014. From discussion with the senior sensory team occupational therapist, this is likely due to improved recording of learning disability amongst these clients, rather than a marked increase in the number of learning disabled clients accessing the service.

7.2.11 Autistic spectrum disorders (ASD)

Autism and learning disability are conditions commonly associated with each other (see Chapter 5).

The *estimated* number of people with ASD (with/without learning disability) living in Hackney and the City is just over 2,000, the majority (90%) of whom are male. ASD is most prevalent in the 25-34 age group (***Figure 54***).

Figure 54: Predicted age distribution and number of people with ASD in the City and Hackney

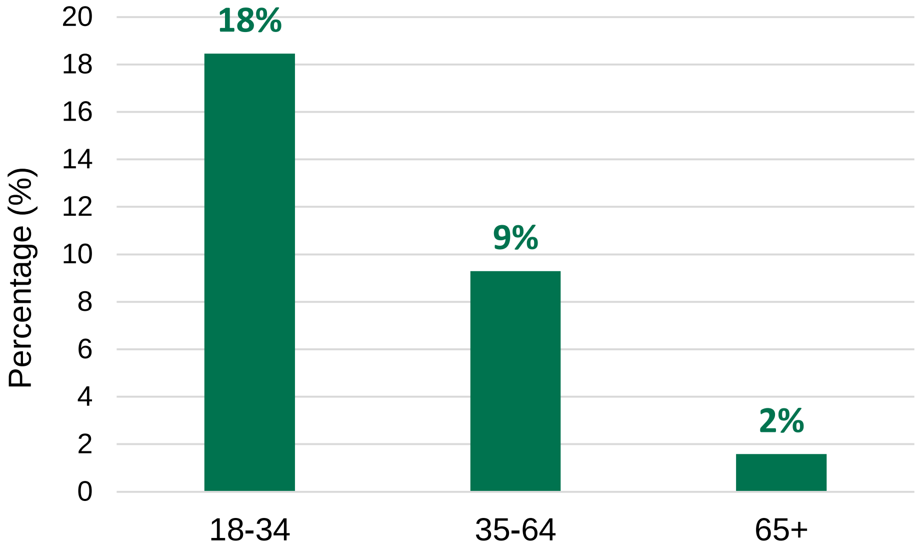


Source: [165] [166]

The number of adult GP patients in Hackney and the City recorded to have both a learning disability and autism was 120 people in 2014/15 and 133 in 2015/16. This represents around 13% of all adult learning disabled GP patients, although prevalence varies by age, as shown in ***Figure 55*** below.

While this needs assessment is focused on adults (age 18+), it is important to highlight here that recorded prevalence of learning disability with autism is significantly higher in younger age groups, at 26% for patients aged 14-17 and 30% for those age 13 or under. This finding is significant as both learning disability and ASD are lifelong conditions, therefore as the younger cohorts age the recorded prevalence is likely to increase. It also implies significant underreporting of ASD in older adults.

Figure 55: Recorded prevalence of local GP patients with learning disability and ASD.

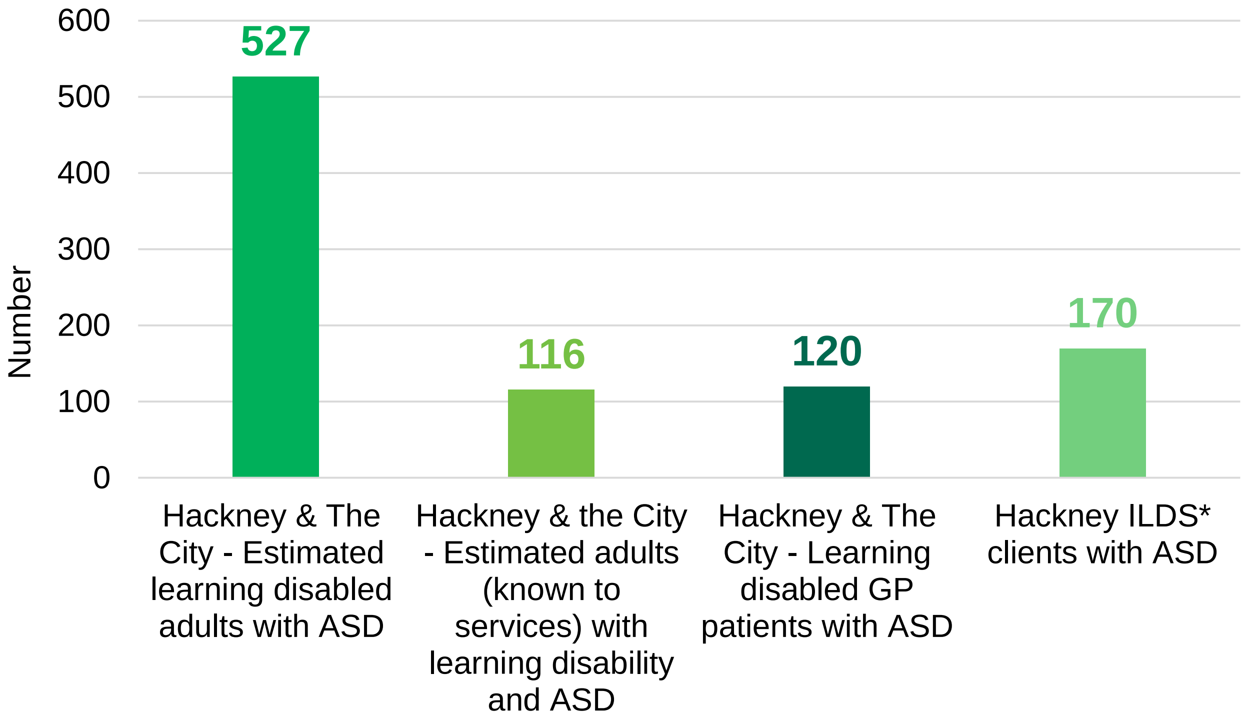


Source: [170]

The Integrated Learning Disability Service within Hackney Council had a total caseload of 170 clients with a learning disability plus ASD in 2015/16.

Potential unmet need is identified by comparing the estimated number of individuals to the locally recorded patients/clients in contact with services. Local GP data appears to reflect the estimated prevalence of ASD in adults with a moderate/severe form of learning disability (i.e. assumed to be known to services). When looking at all learning disabled adults, just 22% of the estimated number with both conditions are known to services (***Figure 56***).

Figure 56: Estimated prevalence and recorded cases of ASD and learning disability



Source: [178] [177] [182]
** ILDS – Integrated Learning Disability Service, Hackney (no data from the City is included or available)*
Note: a rate of 10.3% in adult patients with learning disability was applied

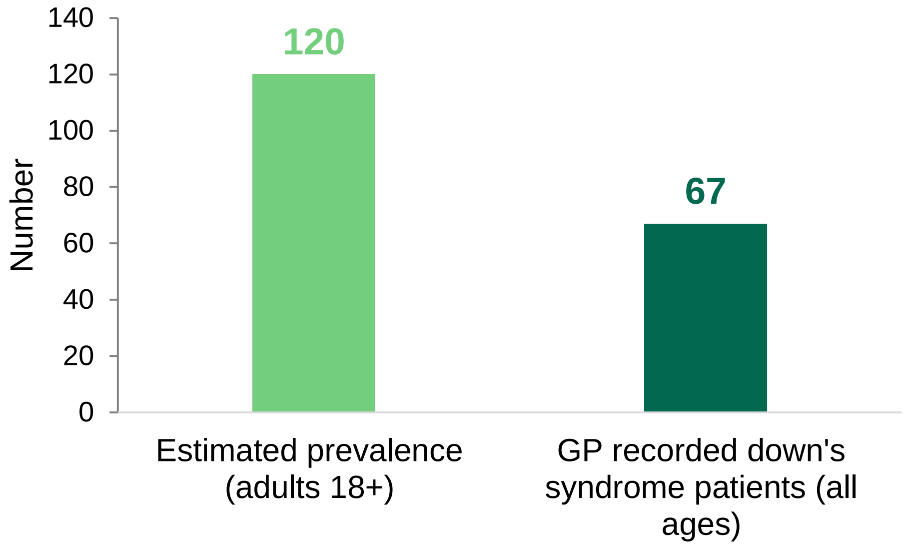
7.2.12 Down's syndrome

An estimated 120 adults were living with Down's syndrome in Hackney and the City in 2015 (116 in Hackney and 4 in The City) [165] [166]. This number equates to 10% of the predicted number of adults with a moderate/severe form of learning disability, and 2.3% of all adults with a learning disability.

In April 2015, 67 GP patients (of all ages) were recorded to have Down's syndrome locally. This is only just over half the number expected from prevalence estimates (***Figure 57***). This discrepancy between predicted and recorded number of people with Down's syndrome is likely due to patient coding (QOF, DES and Down's syndrome coding), although with existing data we are unable to verify this. Estimates suggest that the largest number of people with Down's syndrome is expected in the 25-34 year age group (***Figure 58***), but it is not possible to make comparisons with the age distribution of patients *recorded* with Down's locally due to very small numbers.

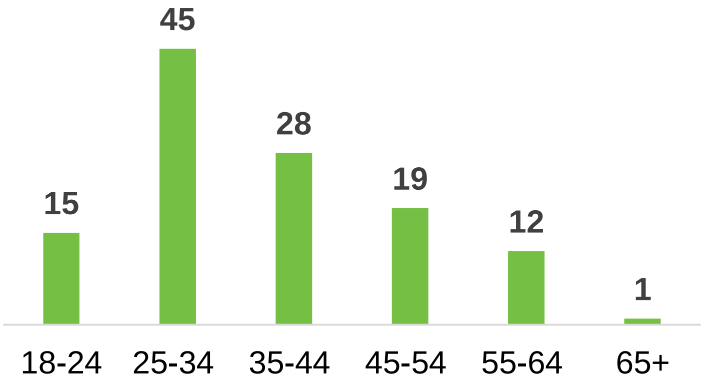
The number of adults with Down's syndrome living in Hackney and the City is predicted to grow by 16% (or 19 people) between 2015 and 2030 (***Figure 59***).

Figure 57: Estimated number of adults with Down's syndrome in Hackney and the City and Hackney, 2015



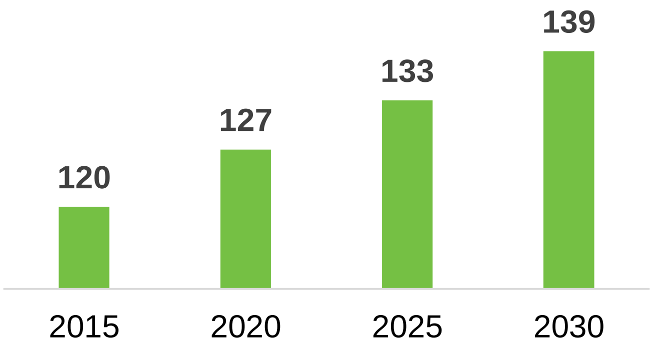
Source: [177] [165] [166]

Figure 58: Estimated number of adults with Down's syndrome in the City and Hackney, 2015



Source: [165] [166]

Figure 59: Estimated number of adults with Downs syndrome, projected to 2030.



Source: [165] [166]

7.3 Cancer screening

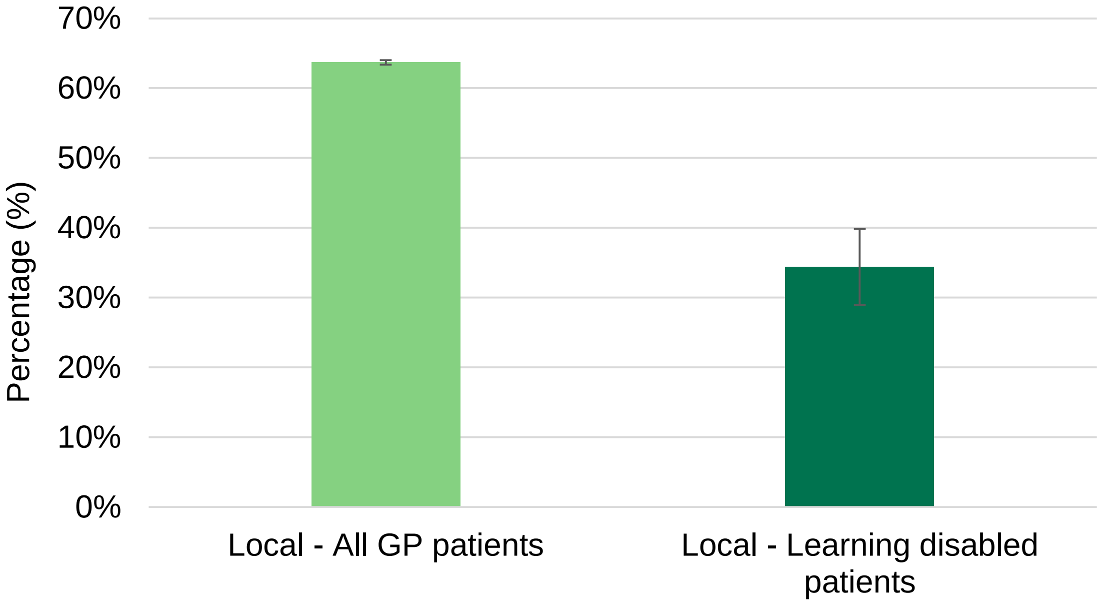
The focus of this section refers to the uptake (in the eligible population) of bowel cancer, breast and cervical screening programmes.

7.3.1 Cervical screening

Figure 60 shows that uptake of cervical cancer amongst eligible patients with learning disabilities in City and Hackney is significantly below the average. Local cervical screening data (2014/15) indicates an uptake of 34% in female learning disabled patients within the past three or five years (depending on their age eligibility). This compares to an uptake of 64% in the total eligible population based on the same data source, or 68% when compared with official PHE statistics (PHOF, 2016).

The local learning disability liaison nurse has clarified that this is a concern for some GP’s in the area, although the extent of this problem locally is not known.

Figure 60: Local uptake of cervical cancer screening in eligible adult GP patient population



Source: [177]

7.3.2 Bowel cancer screening

There is no reliable source of data on local coverage of bowel cancer screening to allow for a robust comparison between the learning disabled and total eligible patient population. National data suggests uptake is similar in the eligible learning disabled and non-disabled populations (see Chapter 5).

7.3.3 Breast screening

As for bowel cancer, there is no reliable source of data on which to compare local coverage of breast cancer screening in the learning disabled population with the total eligible patient population. National data suggests uptake is lower in eligible learning disabled patients compared with non-disabled patients (see Chapter 5).

7.4 Behaviour and lifestyle

7.4.1 Smoking

Local GP data shows that 15.4% of all patients with a recorded learning disability are recorded as current smokers,[28] in comparison to almost 18% of the total patient population (please note that these figures relate to the total, all age, patient population and is not restricted to adults).

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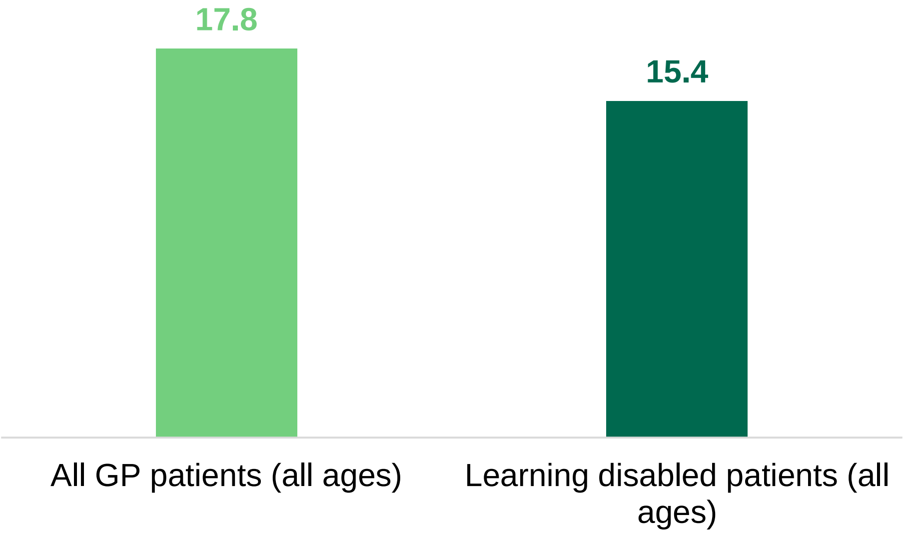
[28] Smoking status is defined at the most recent positive status reported within a 5 year time period

As reported in Chapter 5, smoking prevalence varies in the learning disabled population according to age (higher in younger age groups) and severity of disability (higher in adults with ‘mild’ disability). As it might be expected that patients with a more severe disability would be known to their GP, this could explain the relatively lower average smoking prevalence recorded in this population.

Figure 61: Proportion of City and Hackney patients (all ages) identified as ‘current smokers’



Source: [177]

7.4.2 Physical activity

As discussed in Chapter 5, adults with learning disability are often less physically active than the rest of the population. At present, there are no routine representative samples (locally or nationally) that accurately capture the activity patterns of adults with learning disability. Within Council-funded (GLL) leisure centres in Hackney, there are around 234 members (all ages) who have a self-reported learning disability (around 0.6% of all Hackney GLL members).

The recent community learning disability questionnaire showed around 50% of respondents reporting doing some exercise in the past week (n=19), however the majority of these did less than the recommended 150 minutes of moderate intensity exercise per week[29] (***Figure 62***).

As discussed in Chapter 5, in addition to formal exercise, lower rates of employment and social engagement (see 7.9.2 and 7.9.3) suggest that adults with learning disability are at a greater risk of being physically inactive in their day-to-day lives than the general population.

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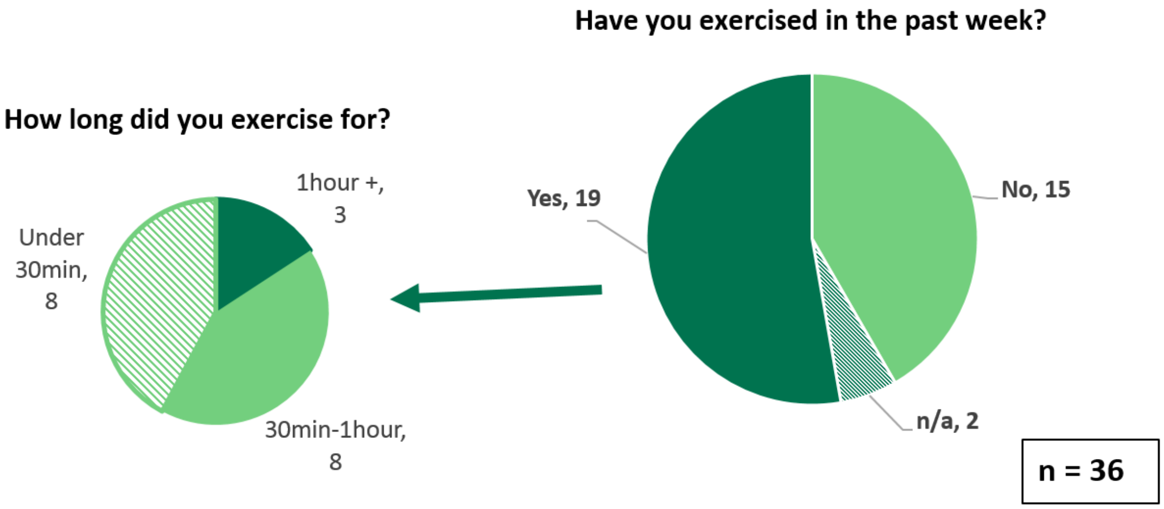
[29] UK physical activity guidelines

Figure 62: Response to community learning disability questionnaire

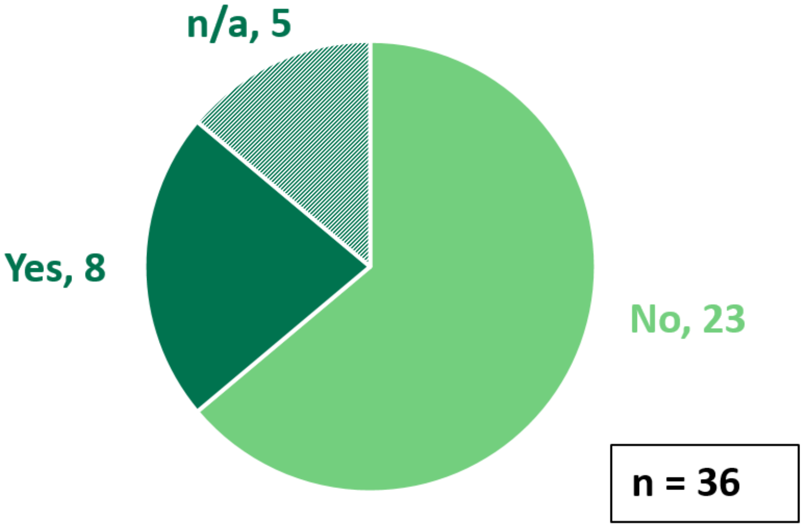


Source: [183]

7.4.3 Nutrition

A community learning disability questionnaire was posed to adults at the Hackney Learning Disability Forum in March 2016, where the majority of participants highlighted that they did not eat the recommended minimum of 5 fruit and vegetables per day (***Figure 63***).

Figure 63: Response community learning disability questionnaire; 'Have you eaten at least 5 portions of fruit and vegetable every day for the past week?'



Source: [183]

7.5 Oral health

There is no local data available to describe the oral health needs of adults with learning disability. Chapter 5 describes national evidence on the relatively poor oral health of this group.

7.6 Sexual health

As discussed in Chapter 5, there is a lack of evidence on the sexual health needs of adults with learning disability. At the time of writing, local data is not accessible for this cohort.

7.7 Safeguarding

In 2014/15, 96 safeguarding concerns were raised with the City and Hackney safeguarding adults board (CHSAB – see Chapter 0) on behalf of clients with a learning disability. After initial assessments, 41 official safeguarding investigations were completed; of these 50% were fully or partially substantiated claims.[30]

Of all safeguarding concerns raised to CHSAB in relation to adults with learning disabilities, the most frequently reported type of abuse fall into the ‘physical’ category, with the least likely form of abuse to be reported as ‘institutional’ abuse.

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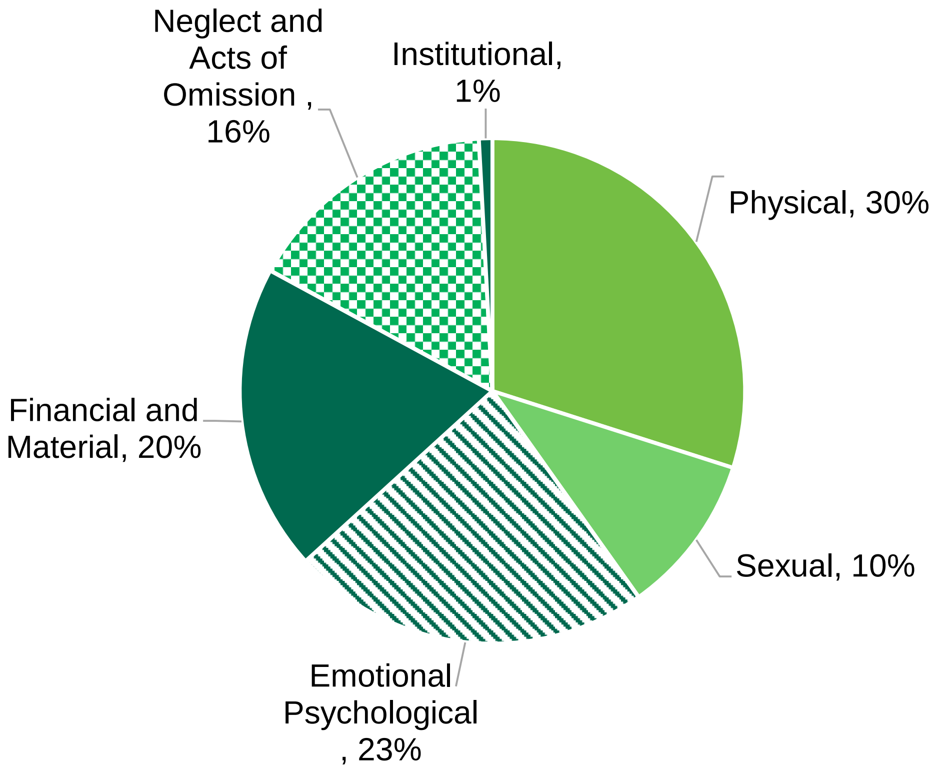
[30] Fully or partially substantiated concerns (n=21), inconclusive concerns (n=12), no substantiated (n=suppressed), investigated ceased (n=suppressed)

Figure 64: Safeguarding concerns by abuse type for Hackney residents



Source: [171]
Note: This figure is based on the 96 concerns raised in relation to adults with learning disability (2014-15), with a total of 117 different types of abuse recorded

7.8 Carers health needs

Capturing the health and wellbeing needs of carers of adults with a learning disability poses several methodological challenges, due to the way people identify as a 'carer' and the way services are able to capture this group of individuals.

The Personal Social Services Survey of Adult Carers sends questionnaires to a sample of registered carers in the local area, with around 300 surveys completed for Hackney in 2015.[31] In this sample, 24% of all carers identified as looking after an adult with a learning disability. Of all carers in Hackney, 2% reported personally having a learning disability or difficulty themselves (***Table 14***).

Table 14 to ***Table 20*** show responses to this survey for all carers (separate data for those caring for someone with a learning disability are not available). Half of carers reported having a health condition. In addition, around 20% of the 2015 Hackney carer sample reported experiencing social isolation and neglecting their own needs; and most said they don't spend enough time doing things they value or have enough

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[31] Data for the City of London is not presented here due to the low sample size of this population limiting the generalisability of results.

control over their own lives. Most Hackney carers are not in paid employment. More than one third (37%) said they do not work because of their caring responsibilities.

The majority of carers responded that they do not receive (enough) support in their caring role and a third said they have not received any information about available support in the past 12 months. One quarter had some concerns about their personal safety ***Table 17***.

Table 14: Response from Hackney carer's survey: health and wellbeing [184]

Do you have any of the following?	Response (%)	Did someone help you to complete this questionnaire?	Response (%)
A physical impairment or disability	17%	Yes	18%
Sight or hearing loss	11%	No	82%
A mental health problem or illness	7%	No response	8%
A learning disability or difficulty	2%		
A long standing illness	23%		
Other	17%		
None of the above	51%		

Note: figures may not sum due to rounding

Table 15: Response from Hackney carer's survey: health and wellbeing [184]

Which of the following statements best describes how you spend your time?	Response (%)	Which of the following statements best describes how much control you have over your daily life?	Response (%)
I'm able to spend my time as I want, doing things I value or enjoy	21%	I have as much control over my daily life as I want	28%
I do some of the things I value or enjoy with my time but not enough	61%	I have some control over my daily life but not enough	57%
I don't do anything I value or enjoy with my time	18%	I have no control over my daily life	14%
No response	4%	No response	5%

Note: figures may not sum due to rounding

Table 16: Response from Hackney carer’s survey: health and wellbeing [184]

Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well – which statement best describes your present situation?	Response (%)	Thinking about how much social contact you’ve had with people you like, which of the following statements best describes your social situation?	Response (%)
I look after myself	44%	I have as much social contact as I want with people I like	35%
Sometimes I can’t look after myself well enough	35%	I have some social contact with people but not enough	47%
I feel I am neglecting myself	21%	I have little social contact with people and feel socially isolated	18%
No response	5%	No response	7%

Note: figures may not sum due to rounding

Table 17: Response from Hackney carer’s survey: health and wellbeing [184]

Thinking about your personal safety, which of the statements best describes your present situation?	Response (%)	Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?	Response (%)
I have no worries about my personal safety	70%	I feel I have encouragement and support	36%
I have some worries about my personal safety	26%	I feel I have some encouragement and support but not enough	48%
I am extremely worried about my personal safety	3%	I feel I have no encouragement and support	16%
No response	5%	No response	8%

Note: figures may not sum due to rounding

Table 18: Response from Hackney carer's survey: health and wellbeing [184]

In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits?	Response (%)		In the last 12 months, how helpful has the information and advice you have received been?	Response (%)
I have not tried to find information or advice in the last 12 months	31%		I have not received any information or advice in the last 12 months	36%
Very easy to find	15%		Very helpful	20%
Fairly easy to find	25%		Quite helpful	32%
Fairly difficult to find	17%		Quite unhelpful	8%
Very difficult to find	12%		Very unhelpful	4%
No response	7%		No response	8%

Note: figures may not sum due to rounding

Table 19: Response from Hackney carer's survey: health and wellbeing [184]

In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be in discussions about the support or services provided to the person you care for?	Response (%)
There have been no discussions that I am aware of, in the last 12 months	34%
I always felt involved or consulted	21%
I usually felt involved or consulted	20%
I sometimes felt involved or consulted	18%
I never felt involved or consulted	6%
No response	7%

Note: figures may not sum due to rounding

Table 20: Response from Hackney carer's survey: health and wellbeing [184]

In addition to your caring role, please tell us which of the following also applies to you?	Response (%)	Thinking about combining paid work and caring, which of the following statements best describes your current situation?	Response (%)
Retired	26%	I am in paid employment and I feel supported by my employer	12%
Employed full-time	11%	I am in paid employment but I don't feel supported by my employer	7%
Employed part-time (working 30 hrs or less)	13%	I do not need any support from my employer to combine work and caring	6%
Self-employed full-time	2%	I am not in paid employment because of my caring responsibilities	37%
Self-employed part-time	3%	I am not in paid employment for other reasons	17%
Not in paid work	30%	I am self-employed or retired	20%
Doing voluntary work	12%	No response	6%
Other	17%		

Note: figures may not sum due to rounding

In order to determine the health needs of carers who care specifically for adults with learning disabilities, a member of City and Hackney's public health team visited Hackney Carers Centre in order to survey participants at a weekly meeting group. While the purpose of the visit was to discuss the needs of carers, the five participants frequently redirected the discussion towards the functional needs of the people they were caring for (as opposed to their own needs). The sample size and methods of this 'survey' are not statistically robust, but the information collected does provide some useful local context. Particular issues were raised in relation to the suitability of the PiP (Personalised Independence Payments – see 8.6) application process and ability of staff performing the assessments to identify the needs of adults with learning disability. Another common discussion point referred to the inconsistency and lack of clear information on the transition process from children's to adult's social care services for young people with learning disability (see also section 8.2.5).

7.9 Wider determinants of health

7.9.1 Education and transition

There are currently no reliable data available on young people with a learning disability transitioning from children's to adult services (transitionary age group is 16-25 years). This is discussed further in Chapter 8 and will be an area addressed in the Disabled Children's Need Assessment being conducted in late 2016.

7.9.2 Employment and welfare provision

A recurring theme in feedback from service users, advocates, carers and those responding to a local survey about the health needs of adults with a learning disability, is the lack of employment opportunities for adults with a learning disability.

Of the learning disabled adults in contact with social services in Hackney, 2.9% were in paid employment at the end of 2015[32]. These rates are amongst the lowest for comparable areas in London and nationally, where average employment rates are 6.2% and 6.0% respectively (CIPFA comparison group;[33] [185]).

Across England and comparable areas in London, there has been a decline in the proportion of learning disabled adults in paid employment in recent years, although as shown in ***Figure 65*** the decline for Hackney shows a steeper reduction since 2012/13.

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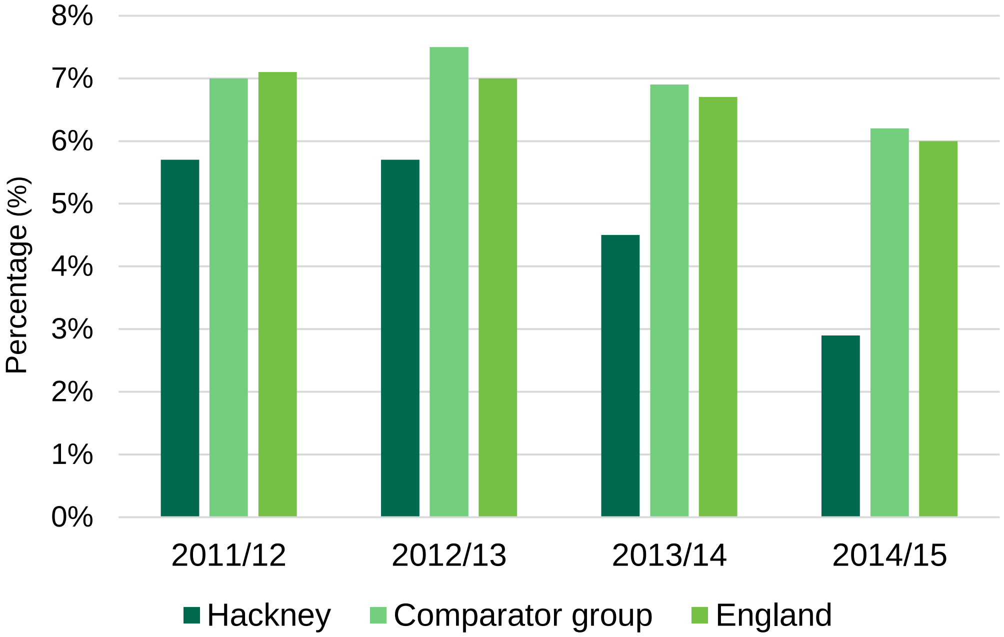
[32] Adult social care outcome framework. Indicator L1: The number of working age (18-64) learning disabled clients known to CASSRs during 1 April 2013 to 31 March 2014, by service type and gender and by employment status gathered or confirmed during the financial year

[33] The chartered institute of public finance and accountancy (CIPFA)

Figure 65: ACOF comparator report for measure 1E; Number of working age (18-64) learning disabled clients in paid employment (known to CASSRs[34]) during 1 April to 31 March



Source: [185]

In a recent local survey of adults with learning disabilities, a minority were found to be in paid work (six out of 36) (***Figure 66***). Of those not in any employment (paid or unpaid), more than half said they would like to work.

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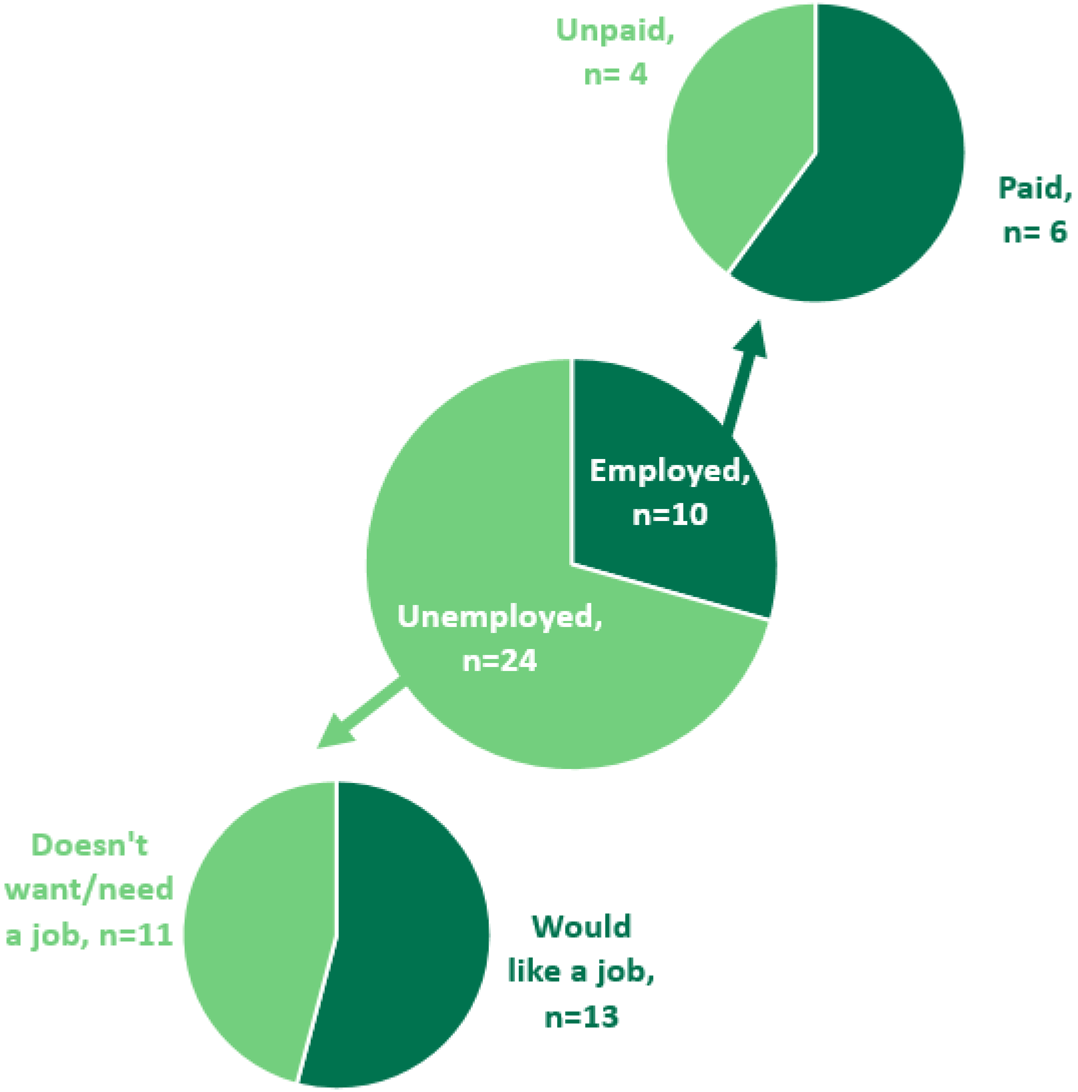
[34] CASSR - Councils with adults social services responsibilities

Figure 66: Response to community learning disability questionnaire on employment status



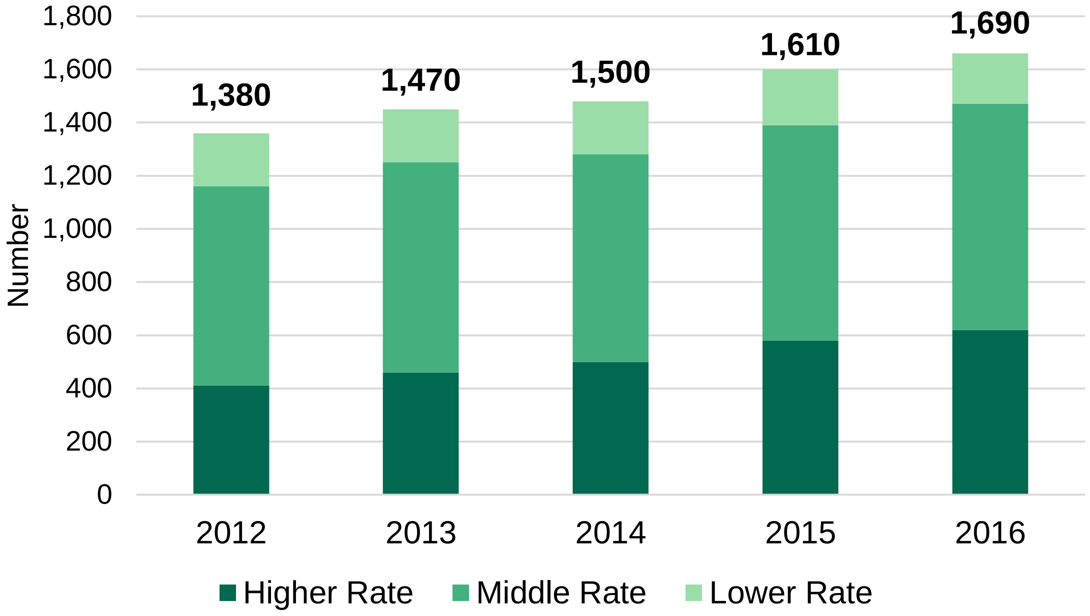
Source: [183]
Note: 2 participants' data not included due to no response

Jobcentre Plus services are unable to identify clients with learning disability from their routine data capturing, therefore we are unable to report on the number of affected adults in contact with them. There is currently no data sharing process between specialist disability advisors from JobCentre Plus and the Integrated Learning Disability Service, which may prevent clients from accessing additional employment support they may be entitled to.

The number of welfare claimants is also a potentially useful indicator of levels of employment and unemployment, but it is not possible to identify claimants with a learning disability through routine data capture. The term 'learning difficulties' is used for reporting by the Department for Work and Pensions (DWP). The term 'difficulties' or 'disability' encompass very different types of condition and cannot be reliably used to project learning disabled adults from this group. However, in looking at a snapshot of adults receiving disability living allowance (DLA) in Hackney who have a 'learning difficulty' there are 1,690 adults in Hackney in 2016 (***Figure 67)***. This represents around 15% of all DLA recipients.

Access to benefits and support is a regular and present theme of discussion with local community organisations who work with adults with learning disability (POhWER, People first and the Hackney forum). This is discussed further in Chapter 8.

Figure 67: Number of adults with 'learning difficulties' receiving disability living allowance in Hackney.



Source: [186]

7.9.3 Living circumstances and social wellbeing

The percentage of adults with a learning disability[35] known to be either living in their own home or with family (termed 'settled accommodation') is around 70% in Hackney. This is similar to the average in Hackney's CIPFA comparison group, but slightly lower than the national average (73.3%). Due to the small number of adults with learning disability in contact with services in the City of London, we are unable to report on data from this area (ASCOF, 2016).

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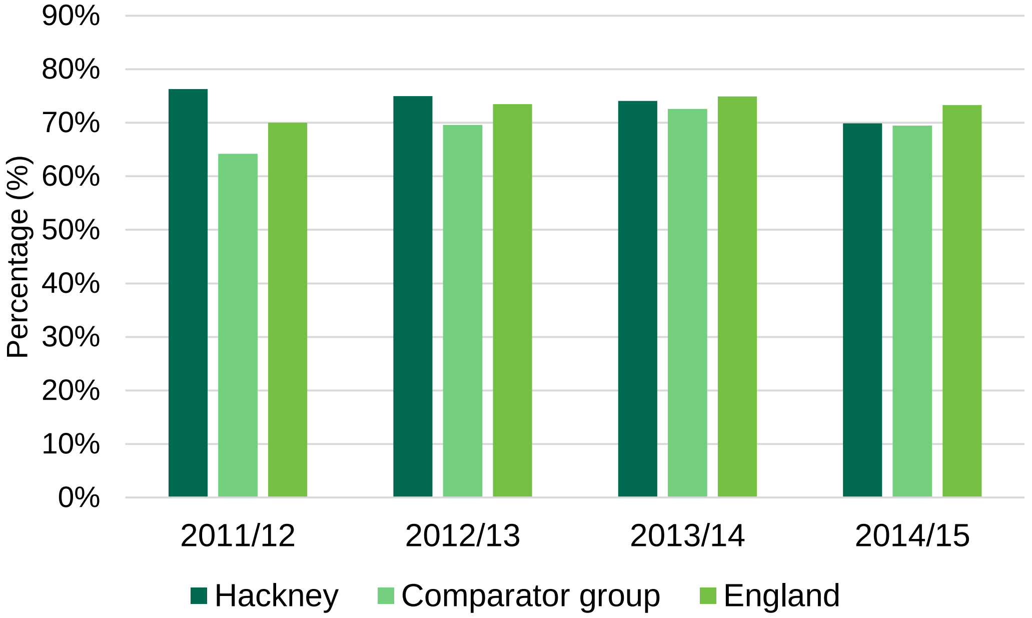
[35]

Adult social care outcomes framework. Indicator L2: The number of working age (18-64) learning disabled clients known to CASSRs (councils with adult social services responsibilities) during 1 April 2013 to 31 March 2014, by gender and by accommodation status gathered or confirmed during the financial year.

Figure 68: ASCOF comparator report for measure 1G; Number of working age (18-64) learning disabled clients (known to CASSRs[36]) living in settled accommodation at their last review



Source: [185]
Note: Settled accommodation used when people are either living in their own home (have a tenancy) or with family

Figure 69 shows that currently an estimated 40% of adults with a moderate or severe learning disability in City and Hackney live with their parents. This rate, applied to the predicted number of moderate/severely learning disabled adults living locally, equates to 452 people.

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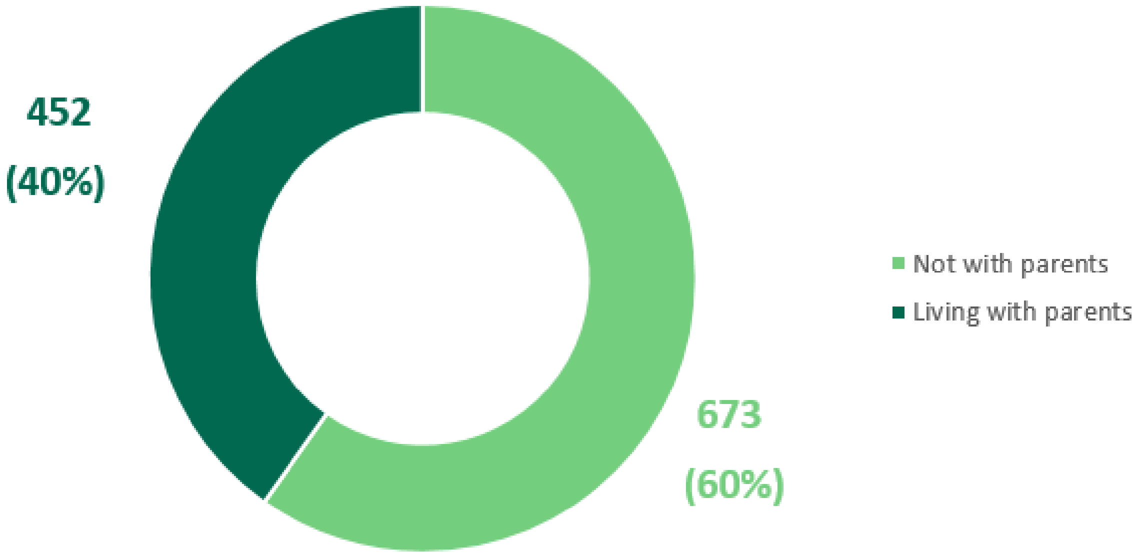
[36] CASSR - Councils with adults social services responsibilities

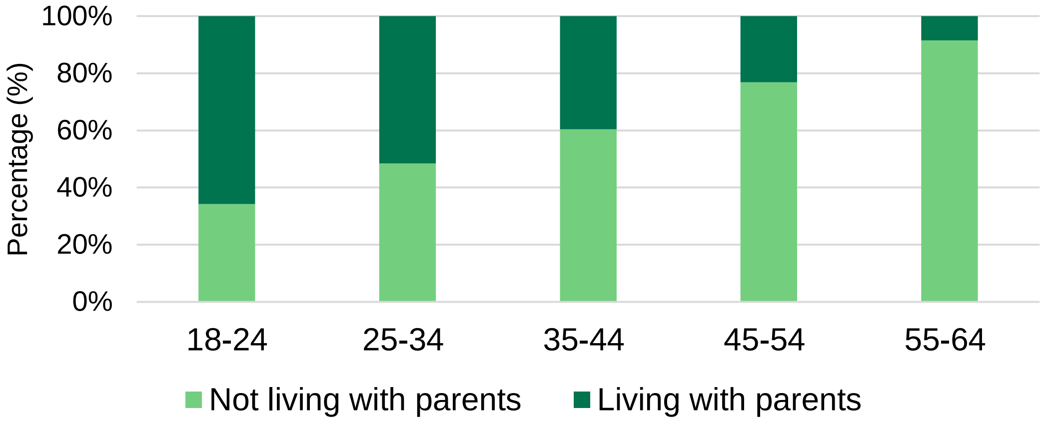
Figure 69: Estimated number of adults with a moderate/severe learning disability in the City and Hackney, by living situation (2015)



Source: [165] [166]

There is a negative linear relationship between age and the estimated proportion of adults who live with their parent(s), as shown in ***Figure 70*** below. Two-thirds (66%) of 18-24 year old adults with moderate/severe learning disability are predicted to be living with parents, compared with 8.5% of those aged 55-64.

Figure 70: Estimated percentage of adults with a moderate/severe learning disability who live with their parent(s) in the City and Hackney (2015), by age group

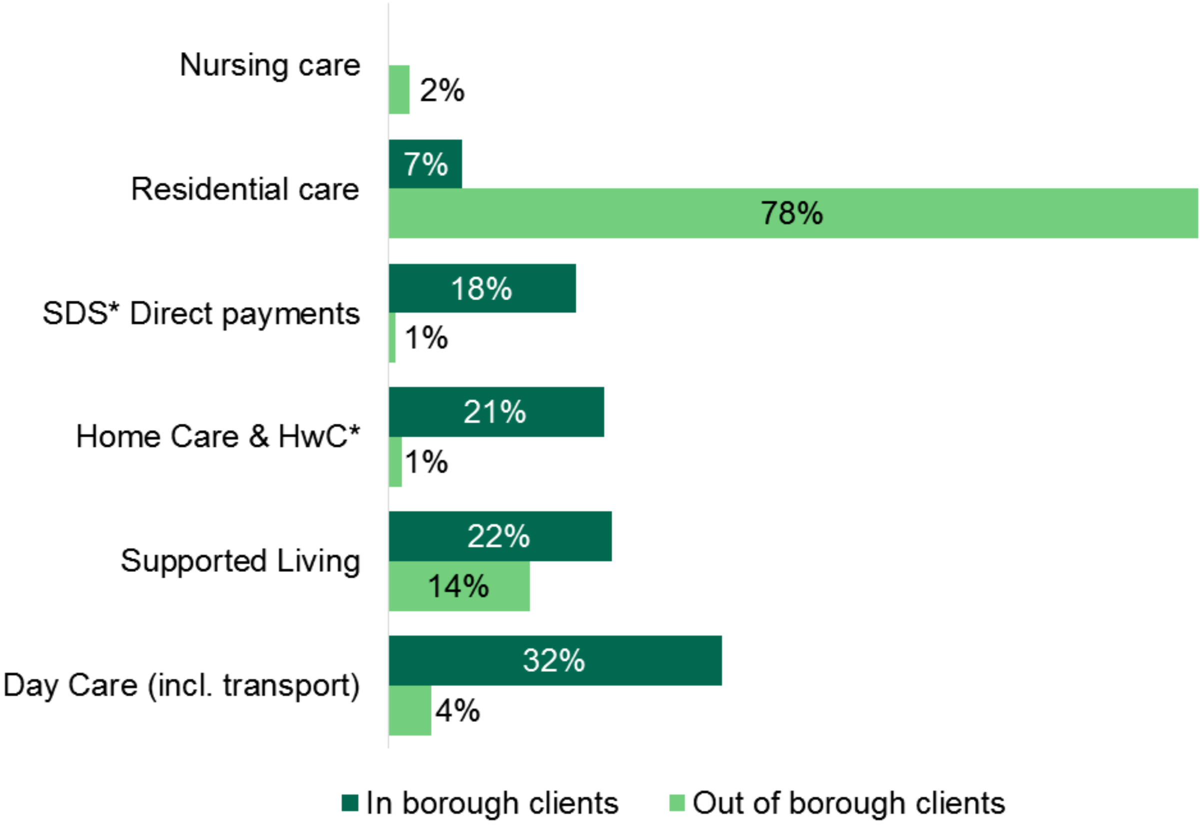


Source: [165] [166]

Prevalence estimates predict an ageing of the local learning disabled adult population (see Chapter 6), which could pose a significant challenge for social care services in coming years. Ageing adults with a learning disability who are accustomed to family support are likely to require formal support in adapting to new environments when ageing parents become unable to meet their needs. This is an important indicator of future demand that should be taken into account as part of future service planning.

As mentioned in Chapter 6, around two thirds of Hackney's learning disabled social care users are receiving services within the borough. The largest number of these clients receive day care services, followed by supported living and home care/housing with care (***Figure 71***). For clients placed out of borough, the vast majority are in residential care. In total, around a third of all service users were receiving residential or nursing care as of March 2016 - mostly this is provided out of borough.

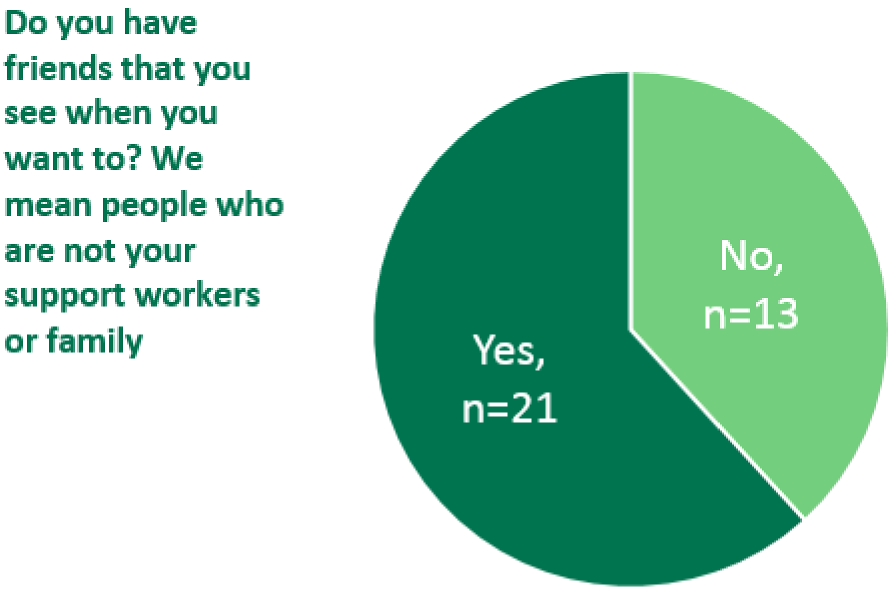
Figure 71: Percentage of learning disabled clients with a care package, by type of service (March 2016)



Source: Hackney performance team (data extract March 2016)
Note: Excludes data from the City
**SDS – self-directed support*
**HWC - Housing with care*

Linked to their living circumstances, as well as low levels of employment, adults with learning disabilities are at greater risk of social isolation than the rest of the population (Chapter 5). A community learning disability questionnaire in Hackney found that around a third of respondents reported that they did not have a network of friends (***Figure 72***).

Figure 72: Response to community learning disability questionnaire



Source: [183]
Note: 2 participants' data not included due to no response

8. Local services and support

8.1 Introduction

This chapter aims to give an overview of key services available to learning disabled adults (and their families) living in Hackney and the City of London, based on consultation with local stakeholders (including service commissioners, providers and advocacy groups). The chapter does not include an exhaustive list of all services available to residents of the City and Hackney with a learning disability, but highlights the most commonly referenced organisations locally as described in ***Figure 73***.

Where possible, service caseload has been described, and gaps in services are highlighted.

Given the prevalence of learning disability and co-morbid mental health conditions (see Chapters 5 and 7), many adults with learning disability may also come into contact with specialist mental health services. Relevant services are described within the Mental health and substance misuse chapter of City and Hackney's Health and Wellbeing Profile.

8.1.1 A note on services for City of London residents

Social care and housing services are arranged and provided for residents of the City of London separately to residents of Hackney. Due to the low numbers of adults with learning disability known to services in the City, social care and housing services are commonly spot-purchased on an individual basis. As such, these services are not generally described in detail in this chapter, although where possible relevant support has been highlighted.

Figure 73: Overview of services available to adults with a learning disability in the City and Hackney, with age group eligibility

Category	Service name	Eligibility age
Multidisciplinary	C&H Integrated Learning Disability Service	18+
	'Looking after me' group	18+
	Hackney ARK	5-19
	One Hackney	18+
Health	Direct enhanced service (DES)	14+
	Hackney sensory team	18+
	Right Choice Clinic (sexual health)	18+
	Community and special care dentistry	all ages
Housing	Floating support service	18+
	Targeted preventative service	18+
Education	Hackney community college	16-25
	Hackney ARK transitions service	14-19
Employment	Job centre plus	16+
	Ways into work	16+
	Hackney One Team	16-25
	Real opportunities project	18+
Advocacy	PoHwer	
	People First	
	VoiceAbility	

8.2 Integrated (multi-disciplinary) services

The services described in this section include those with evidence of integrated multi-disciplinary team working, or those that have structures in place which cross service boundaries with other disciplines.

8.2.1 City & Hackney Integrated Learning Disability Service (ILDS)

The ILDS is based in Hackney Council and aims to:

- provide one point of entry to specialist health and social care services for learning disabled adults
- facilitate access to appropriate services for an individual's health and social care needs
- encourage access to mainstream services where suitable.

Note: Only the health elements of this service are available to eligible City residents (see ***Table 21***).

The team accepts referrals from health professionals, voluntary sector organisations, family members and self-referrals. The eligibility pathway is available in Appendix H section 11.8. The team works with people who:

- are age 18+
- have a confirmed diagnosis of a learning disability (according to The British Psychological Society definition in Appendix G, section 11.7). [3]
- meet the residential and GP practice requirements set out in ***Table 21***.

Table 21: ILDS services available to clients/patients based upon resident and GP practice status

Residing borough	GP practice	Eligible to be assessed for (and receive) specialist health care services through the ILDS	Eligible to be assessed for (and receive) social care services through the ILDS
Hackney	Within City & Hackney	Yes	Yes
City of London	Within City & Hackney	Yes	No (managed through residing borough)
Hackney	**Not** within City & Hackney	No (managed through borough with which GP practice is based)	Yes
City of London	**Not** within City & Hackney	*Technically* Yes - although caveats*	No (managed through residing borough)
Non-resident of the City or Hackney	Within City & Hackney	Yes	No (managed through residing borough)

Source: ILDS service practice development manager
**Access to specialist health care teams within ILDS depends on the nature of the condition, treatment required, and reasons that specialist healthcare cannot be accessed locally. It also depends upon the budget available*

Box 25: Definition of learning disability from The Mental Health Act 2007

"'Learning disability' means a state of arrested or incomplete development of the mind which includes significant impairment of intelligence and social functioning"

Chapter 12, Part 1, Chapter 1, Section 2 (4)

The ILDS offers a range of specialist *health* services to any adult meeting the criteria above who is not able/appropriate to access mainstream health services, including:

- psychiatry
- speech and language therapy
- physiotherapy
- occupational therapy
- psychology
- community nursing
- acute liaison nurse (described in more detail in ***Box 26*** below).

Box 26: Homerton hospital acute liaison nurse

The acute liaison nurse at the Homerton hospital encapsulates many roles, with some key areas identified as:

- an advocate for people with learning disabilities
- collaborating between services, sectors and individuals
- communicating and ensuring information flow between healthcare environments, professional groups, health staff and carers
- educating others about the key points of working with adults with learning disability including the use of the Mental Capacity Act and safeguarding
- mediating and removing barriers inhibiting the effective communication between hospital staff and people with learning disabilities
- facilitating the implementation of reasonable adjustments to hospital environment and processes.

The ILDS also manages access to funding for *social care* services, with eligibility defined in the Care Act, 2014 (see links/additional information below). In Hackney, clients are assessed using the Basic Information Contact Assessment (BICA) to indicate whether a person has a current 'need' as defined by the Care Act. BICA is part of the FACE recording and measurement system.

People eligible for adult social care have access to the following services through ILDS:

- social work
- assertive outreach
- Hackney 'Shared Lives' service (formerly Hackney Adult Placement Scheme)
- home care.

The total number of adults currently in contact with the ILDS is difficult to determine, as the social care team and health service team use different systems to capture service user data. However, a snapshot of ILDS client data extracted in April 2016 showed there to be 438 people receiving a social care package and 477 adults listed on the health service caseload.

Links/additional information:

Hackney local offer - Integrated Learning Disability Service

The Care Act 2014 – EasyRead version

The Care Act 2014 was passed in the House of Lords in May 2013, with the aim of modernising adult social care laws in England. The key section which refers to a person's eligibility for care is summarised in Appendix D: The Care Act 2014.

8.2.2 Adults with complex needs

For adults with more complex needs, there are various housing and care options available depending on the level of assistance required. All services listed below can be accessed either as part of a care package for people who are eligible for adult social care or they can be purchased on the open market for those who do not meet the eligibility criteria. For residents of the City (who are eligible for adult social care), these services are spot purchased on a case by case basis due to the low number of resident service users with a learning disability.

For adult social care clients in Hackney, the majority receive day care services. There is a shortage of residential and long-stay care facilities in central London, which is reflected in the fact that the majority of people who receive their care out of the borough are receiving residential care services (Chapter 7).

Day care

Adult day care is a planned programme of activities designed to promote well-being through social and health-related activities and services. Day care is mainly for people who are accommodated within their family home, rather than those living in supported living units (see below). It is often used as respite for carers. Two centres provide day care for people with learning disability in Hackney:

- Trowbridge centre – provides services for older people and people with learning disabilities
- Church Walk – provides services for people with autism (who may/may not have a learning disability).

In March 2016, 100 Hackney adults with learning disability were receiving day care as part of a care package (23%), 94 of whom were living in Hackney.

Future planning for Hackney involves the development of a larger site in Oswald Street to encompass day care services (including learning disabled services) although the service specifications are still in development.

For the City of London, community day services are provided by the Tower Project which is based in Tower Hamlets.

Housing with care and supported living

Both housing with care and supported living schemes normally mean that an individual has their own tenancy agreement. Generally, both types are located in a large block of apartments, with small units for individuals along with shared space areas often for dining/activities. Local sites/facilities include Century Court and Limetree Court in Hackney.

The difference between these two types of housing are that housing with care is generally for older adults, while supported living schemes aim to support people to become more independent (and therefore tend to be for younger adults).

Of the 438 learning disabled adults with a Hackney care package in March 2016, 146 (33%) were receiving housing with care or supported living – 124 of whom were living in Hackney.

Residential home placements

Residential placements are provided for people with care needs that cannot be supported within a community setting. Some individuals may be placed in this care facility under 'Continuing healthcare' arrangements (where an individual's health needs exceed their social care needs and the NHS takes over that person's package of care). Under this arrangement the service user does not have a tenancy.

In March 2016, 135 Hackney adults with learning disability were receiving residential care as part of a care package, 114 (84%) of whom were placed out of the borough.

Nursing home placements

Nursing home care is provided for those with a health care need. Some individuals may be placed in this type of care facility under 'continuing care arrangements' (where an individual's health needs exceed their social care needs and the NHS takes over responsibility and payment for their care).

Fewer than five Hackney adults with a learning disability were receiving care in a nursing home as part of a care package in March 2016.

Transforming Care Partnership (TCP)

The inner north east London Transforming Care Partnership (TCP) has set out a plan to reduce inpatient bed usage by 20% by 2019 for people with a learning disability and people with an Autistic Spectrum Disorder who have challenging behaviour. The three core components of this improved model of care are as follows:

1. prevention and community support that minimises risk of inappropriate admission
2. focused and high quality assessment, treatment and care while in hospital
3. effective and timely discharge supported by a plan that minimises the likelihood of readmissions.

As of March 2016, the size of the inpatient cohort across the sector was 28. This represents a relatively low number of people using inpatient provision compared with the national target. However, with a growing population there is an acknowledged need to build capacity to provide appropriate local housing options.

The TCP Plan also aims to increase uptake of Personal Budgets in this cohort (prioritising people coming out of hospital), improve transition pathways, develop the local workforce, increase funding for respite care, and support the development of local advocacy and peer support to meet the needs of people with challenging behaviour.

8.2.3 ‘Looking after me’ group

Through the ILDS, the ‘Looking after me’ group promotes a person-centred holistic approach to health and wellbeing via social interaction, health education and fun group exercise. This is a pilot project comprising a10 week course, which involves an education, social and physical activity element in each session. The pilot has been successfully delivered to 12 participants with a full evaluation underway. Early results suggest that all of the participants enjoyed the groups, feeling happy to be part of their community and wanting more opportunities to be ‘busy’ and involved.

Following this successful pilot, funding has been secured to run another course in 2016.

8.2.4 Hackney Ark

The Hackney Ark is a centre for children and young people with disability and special educational needs (SEN). It is funded by the Homerton University Hospital and it brings together services from across the fields of health, education and social care to work with young people aged 19 or under.

Young people require a referral to access this service. The range of services available through the Hackney Ark include:

- Educational Psychology Service (EPS), which includes a parent advice service
- Inclusion and Specialist Support, which includes specialist teaching as well as visual and hearing services
- speech and language therapy
- Portage, which is a home visiting service
- transport solutions to facilitate attendance at school and leisure activities.

The Ark also run a small ‘Transitions Health Outreach’ service that works with young people age 14-19 with a disability, who would not normally qualify for social care and do not have dedicated support from professional services such as social workers.

The service works with young people to:

- identify barriers to health & wellbeing
- address health inequalities faced by people with learning disabilities
- provide support with access to further education
- develop independence
- reduce social isolation
- provide support to plan for the future.

The service also ensures that GP surgeries know about young people with learning disabilities and that they are recorded on the DES register. A referral is required to access this team.

Links/additional information:

Disabled children's service

Transition health outreach team

Hackney local offer - ARK transition

8.2.5 Services to support young people moving from children's to adult services

The National Institute of Health and Care Excellence (NICE) describes 'transition' as *"a purposeful and planned process of supporting young people to move from children's to adults' services"* and has produced guidance on what a full transitions service should look like. [107]

The City do not have a formal transitions service, although there is a transitions forum which meets regularly to discuss all transition cases.

There is currently no formal transitions service within Hackney, although there are several groups which have been established to discuss cases and monitor the transition process, including the following.

- **Transition Monitoring Group** (re-established in mid-2016) - meet monthly to discuss the transition of all young people (age 16-25) known to the Disabled Children's Service (DCS) (this includes children with a statement/EHCP, 'looked after children' and those eligible for 'continuing healthcare' provision). This is attended by DCS, adult social care teams, the Ark transitions service and other relevant stakeholders.
- **Preparation for Adulthood Operational Group** (established for 5+ years) – this group meets monthly to discuss and develop transitions pathways. It is attended by a wide range of stakeholders (including representatives from parents/carers organisations, children's social care teams, the Department for Work and Pensions, Hackney Community College and Hackney Ark).

There is a specific pathway in place for people in the Orthodox Jewish community, which is based around a partnership between Kisharon (local community centre for people in the Orthodox Jewish community with learning disabilities) and the Hackney College. This pathway is being reviewed in 2016.

There is also a specific panel and protocol for the transition of young people who are under 'continuing healthcare' arrangements - this is the Joint Complex Care Panel (monthly meeting). When service users turn 17, the children's community nursing team (CCNT) refer them to the ILDS and each case is discussed at the panel.

The transition process in Hackney from children and young peoples' (CYP) services to the adult ILDS can be complicated and has some identifiable gaps. The text below aims to describe this current process.

1. Children who are known to the DCS (who are also in receipt of a care package) are identified to the adult ILDS at age 14 through the use of an 'initial alert form'.

No action is taken by the ILDS at this stage; the process is designed to highlight potential caseload, not to assess need.

2. At age 16, the DCS complete a '5&6' assessment for all young people receiving a care package. This assessment is then sent to the ILDS for the team to determine whether the young person is eligible for adult social care or if there are specialist health needs that require support into adulthood. The ILDS do not make contact with the young person (or their family) until they turn 18.
3. During the time between receiving the '5&6' assessment and the young person turning 18, the needs of the individual may have changed, so the ILDS team process all transitionary cases in a similar manner to routine referrals to.
4. When clients turn 18, all computerised records of the interactions with the CYP team are 'locked down', meaning only the CYP team can view them. The ILDS can only access information on interactions going forwards from this point (which, in turn, cannot be viewed by the CYP team), unless an individual request has been made for additional information. This affects the continuity of care available to clients and can lead to lengthy delays in obtaining relevant information to inform appropriate service provision.

8.2.6 One Hackney and the City

One Hackney and the City was designed to meet the needs of vulnerable (mainly older) adults with high support needs. It provided integrated health and social care to support people to continue living as independently as possible in the community. The service works closely with GPs to identify vulnerable adults (not exclusively those with a learning disability) who may benefit from this type of support. The service worked with clients who fall into one of the following criteria:

- multiple long-term conditions, or on the Frail Home Visiting list
- significant inappropriate use of primary or secondary health services
- housebound, or limited ability to access community services
- socially isolated or not able to engage with community services due to health conditions or lack of support
- existing services are unable to meet identified needs.

The service provided access to:

- housing assessments
- facilitation of necessary adaptations/repairs needed to housing
- social activities
- accessible transport
- benefits and professional advice
- carer support.

Following an evaluation in 2016, the One Hackney and the City service has been terminated and is being replaced with new integrated care arrangements for vulnerable residents.

8.3 Health services

This section describes the health care services available specifically for adults with a learning disability in the City and Hackney (with the exception of the Sensory Team, which comes under social care provision and covers Hackney only).

Universal provision, such as routine primary and secondary care services, are not covered in this section. It is important to highlight that despite mainstream services having a legal obligation to provide ‘reasonable-adjustments’ for people with learning disabilities, this does not always occur. The use of ‘reasonable-adjustments’ within health services is not something that is captured in routine monitoring, so is something we are unable to quantify within this report.

A description of mainstream primary care and secondary care learning disabled patient caseloads is provided in Chapter 6.

8.3.1 Direct Enhanced Service (DES) annual health checks

All GP practices in the City and Hackney are subscribed to the DES for patients with learning disability. This enhanced service is designed to:

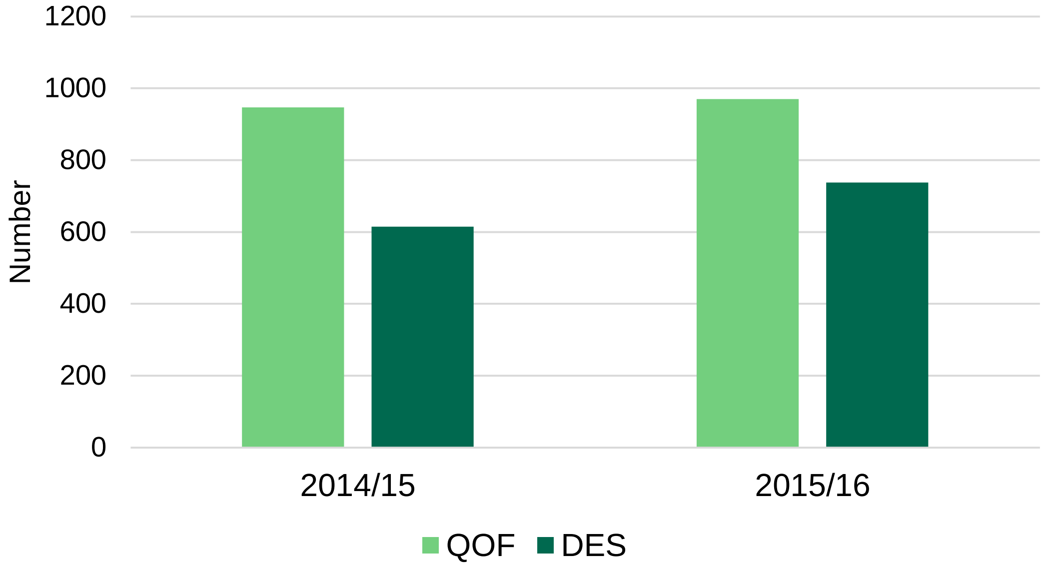
- encourage practices to identify all patients aged 14 and over with learning disabilities
- maintain a learning disabilities register
- offer these patients an annual health check, which includes producing a Health Action Plan.

The DES has been implemented in the City and in Hackney since 2014; previously the Quality and Outcomes Framework (QOF) register was the main method of capturing the details of patients with a learning disability (see Section 3.4.2). As ***Figure 74*** shows, there were 970 adult patients on the QOF register in 2015/16 and 738 on the DES register. The uptake of annual health checks for people on the DES register was 73% as of April 2016, compared to 85% as of April 2015.

Links/additional information:

General Medical Services DES directions 2016, Pages 7-9

Figure 74: Number of patients recorded with learning disabilities on QOF and DES registers



Source: CEG, 2016

8.3.2 Sensory team

The Sensory Team is a small service within Hackney Council made up of occupational therapists and social workers. The team offers advice and suitable adaptions to living space or equipment to people with a sensory (e.g. sight or hearing) impairment who are eligible for adult social care.

There are currently around 20 individuals with a learning disability using this service, which is accessible by referral.

Links/additional information:

Hackney local offer - sensory team

8.3.3 Sexual health - Right Choice Clinic (pilot project)

The Right Choice Clinic is a pilot project being funded for a 12 month period through Hackney Council's public health grants programme (the Healthier Hackney Fund). Right Choice Clinic is a sexual health service specifically aimed at people with learning disabilities in Hackney, due to be launched on 21st September 2016

This venture is a collaboration between Homerton Sexual Health Services and the Family Planning Association (FPA). The FPA have a range of experience in helping to establish sexual health clinics for people with learning disabilities, including supporting the public health team in Kingston-upon-Thames to set up the original clinic called Connect Kingston.

The Right Choice Clinic will be an appointment only service run from the Ivy Centre at St Leonards Hospital and aims to ensure that people with learning disabilities:

- have access to good quality, accessible, non-judgemental information about sex, sexual health and relationships
- have adequate time with Right Choice Clinic staff to feel safe and informed
- are looked after by trained professionals
- are positively represented in publicity images
- have the right to a private individual consultation if they wish
- have information explained to them in a way they can understand
- receive a friendly, accepting welcome into the service premises
- have the right and the opportunity to complain if they are not happy.

8.3.4 Community and Special Care Dental Service (CDS)

The Community and Special Care Dental Service (CDS) for Hackney is run by Barts Health. CDS exists to improve the oral health of people who have a physical, sensory, intellectual, mental, medical, emotional or social impairment or disability - or a combination of these. A referral is required to access this service. Provision is designed for those who have difficulty accessing mainstream services.

At present, this service is unable to easily identify learning disabled patients on its caseload. In 2013/14, a total of 1,158 appointments for domiciliary services were offered by CDS. Using a special needs complexity score, the patients seen were graded as 6% moderate, 63% severe and 31% extreme complexity.

Links/additional information:

City and Hackney community dental service

8.4 Housing support

There is significant pressure on the housing market in Hackney (as in the rest of London), with many people unable to access suitable affordable accommodation. For adults who have a learning disability and who are either not eligible for adult social care or who may not have a formal diagnosis, the provision of social housing is legislated as for the rest of the population through the Housing Act (1996 and 2004).

The local approach to housing in Hackney for people with learning disability who are known to services is captured within several local strategy documents. These include the Housing Strategy 2010-15 (2016-18 strategy due to be published soon) and the Supported Housing Commissioning Strategy 2013-18.

For the City of London, as in Hackney, provision for vulnerable adults (including people with learning disability) is encapsulated within wider housing strategies.

8.4.1 Social housing

In general, people can apply/bid for social housing through a choice based lettings platform which is referred to as ‘Hackney Choice’ in Hackney and ‘Home Connections’ in the City. Through these schemes, applicants are prioritised based on their housing need. For adults termed as ‘vulnerable’, the Housing Act 1996 dictates that they should be given priority over others in this process. Having a learning disability does not automatically define a person as ‘vulnerable’ under the Housing Act, and there are several other priority groups who also fall into this category (see ***Box 27*** below).

Box 27: Definition of people with a priority need’ under the Housing Act 1996

> *Housing Act, 1996 ch.52*
>
> *Section 189: Priority need for accommodation*
>
> The following have a priority need for accommodation :
>
> (a) a pregnant woman or a person with whom she resides or might reasonably be expected to reside
>
> (b) a person with whom dependent children reside or might reasonably be expected to reside
>
> (c) a person who is vulnerable as a result of old age, mental illness or handicap or physical disability or other special reason, or with whom such a person resides or might reasonably be expected to reside
>
> (d) a person who is homeless or threatened with homelessness as a result of an emergency such as flood, fire or other disaster.

Source: *www.legislation.gov.uk/ukpga/1996/52/section/189*

Individuals with a learning disability are not easily identified through the local housing register in Hackney or the City.

In a snapshot of current Hackney Housing tenants extracted in July 2016, a total of 72 households (0.2%) included a person (all ages) with a (self-declared) learning *difficulty*. However, these data are unlikely to be a reliable reflection of the actual number of learning disabled tenants housed by this provider.

Links/additional information:

https://www.hackney.gov.uk/housing-strategy

http://www.hackney.gov.uk/supported-living-people

http://www.hackney.gov.uk/hackneychoice

http://www.homeconnections.org.uk/

8.4.2 Floating support services

Floating support services provide housing-related support for vulnerable adults to help them manage their accommodation, sustain stable tenancies/home owner agreements and live independently and inclusively in the community. Floating support in Hackney is available for any person aged 16+ who has a learning disability. However, anecdotally only people with mild learning disability, or lower needs, would be suitable for the level of support provided. Services are delivered in relation to an individuals' level of need, with continued support available for up to a year.

The main service delivery areas involve:

- one to one support, either in the home or on the premises of the referring agency
- crisis resolution, involving short term interventions in areas such as homelessness, multiple debt and benefits payments
- advisory sessions on accessing services from external agencies (including education, training and employment support, as well as health and care services).

Link/additional information:

http://www.shp.org.uk/hackneysupport

8.4.3 Targeted Preventative Service (TPS)

TPS is commissioned by Hackney Council and encapsulates a range of services under one contract, with the primary purpose of delivering good quality, safe, efficient and personalised housing-related support to vulnerable people. The specific aims are to promote independence, health and wellbeing and provide support which:

- enables people to continue to live safely in their own homes in the community, regardless of tenure, helping vulnerable people avoid or delay the need for care packages or residential care
- prevents homelessness and helps people access and maintain suitable housing
- reduces social isolation and promotes social inclusion
- supports 'step-down' form higher support supported living services by ensuring resettlement
- reduces unplanned move on/ evictions.

The current service consists of two main components: floating support and volunteering and befriending. Adults with learning disabilities can be eligible for both service components (see ***Table 22)***.

Table 22: Eligibility to service components of the TPS

Floating Support	**Volunteering and Befriending**
People who live in the boundaries of London Borough of Hackney	
16 years or above	Age 18 plus
People who have a level of need, but not at the Fair Access to Care critical or substantial levels.	
At risk of losing of their housing or inability to maintain current housing situation which places their independence at risk	People who need a service following reablement, enablement or recovery
An individual or a family containing children under 16 at risk of losing their ability to live independently in the community for one or more of the following reasons: - stepping from higher supported living services - at risk of needing a care package or residential care or requiring follow-up to a Reablement Package - frailty caused by age - a mental health condition - a learning learning disability - a physical disability - substance misuse - long term health need	People who are vulnerable because of factors including, but not limited to: - service users who have stepped down from higher supported living services - severe social isolation - experience of crisis - frailty caused by age - moderate mental health needs - learning or physical disability - long term health needs

Source: TPS service specification

8.5 Education

The Hackney Learning Trust (HLT) sits within the council’s Children and Young People’s Service and is responsible for children’s centres, schools, early years provision and adult education.

Links/additional information:

Hackney Learning Trust

8.5.1 Hackney Community College

Hackney Community College has around 8,000 students, aged 14 to over 80 years old. They offer both accredited and non-accredited courses through various pathways, including a specialist service for people age 16-25 with a learning disability. However, no data have been made available for this needs assessment on the number of students enrolled at the college with a learning disability.

The college also runs mainstream adult courses throughout the academic year, for which there are no entry criteria although there is a fee.

Links/additional information:

Hackney community college support

8.6 Employment and welfare support

Mainstream provision of employment and welfare support is available to adults with learning disability in the local area. However, it is not possible to identify how many adults with learning disability are using these services.

Specialist provision is also available locally to adults who have a learning disability.

8.6.1 Mainstream provision

Jobcentre Plus

Jobcentre Plus aims to help people of working age find employment. Jobcentre Plus provides resources to enable job-searchers to find work, through Jobpoints (touch-screen computer terminals), Jobseeker Direct (telephone service) and the Jobcentre Plus website. They offer information about training opportunities for people who have been long-term unemployed, and administer claims for benefits such as Income Support, Incapacity Benefit, and Jobseeker's Allowance.

The scope of Jobcentre Plus' role includes working with local employers and advocacy groups to create opportunities for employment. A specialist disability employment advisor (DEA) operates at each Jobcentre Plus site, of which there are three in Hackney and one in the City of London (this role is described in more detail in the link below).

Learning disability is not routinely captured on client management systems and so it is not possible to quantify the number of learning disabled clients who are receiving support from Jobcentre Plus locally. Moreover, there is currently no process for sharing data between DEAs and the local ILDS. As such, many learning disabled adults may be being prevented from receiving the additional employment support to which they are entitled.

Links/additional information:

Jobcentre Plus Hackney

Jobcentre Plus City of London

Disability employment advisor role

Ways into Work

Ways into Work (WiW) is a recruitment service run by Hackney Council, for all residents who are unemployed or working less than 16 hours per week and would like to work. WiW is designed as a single point of contact for supporting workless residents into jobs, apprenticeships and training.

Links/additional information:

Hackney Ways into Work service

Welfare and benefits support

Social security benefits of particular relevance to adults with learning disability are described in ***Table 23***.

Access to benefits and support is a common theme of concern amongst local community organisations who work with adults with learning disability (see section 8.7). In particular, the Personal Independence Payment (PiP), which is replacing Disability Living Allowance (DLA), has been criticised as not appropriate/accessible for people with learning disabilities. Critics claim that the assessors who are involved in the PiP 'work suitability assessments' are not adequately trained to identify difficulties experienced by adults with learning disabilities (i.e. prompting behaviour and actions that the client may not have thought to perform in day to day life). Other reported problems with the transition to PiP involve clients being sent letters about the change that are not in accessible format (EasyRead) with unrealistic timescales within which to reply (with a threat of benefits being cut off with immediate effect).

Links/additional information:

Benefits in the UK 2016

Table 23: Description of relevant welfare benefits [187]

Benefit name	Description	Eligibility	Additional information
Disability living allowance (DLA)	*A tax-free benefit for disabled people who need help with mobility or care costs*	*Involves a work capability assessment*	*Discontinued. In the process of being replaced by PiP*
Job seekers allowance (JSA)	A benefit for people who are unemployed or working fewer than 16 hours per week	For adults who are actively seeking work	
Personal independence payment (PiP)	Helps with some of the extra costs caused by long-term ill-health or a disability	For people aged 16-64 Involves a work capability assessment	The rate depends on the way the condition affects you, which is assessed through a formal process.
Employment and support allowance (ESA)	A benefit for people who are unable to work due to illness or disability - clients are not expected to perform any work-related activity whilst receiving this payment	Involves a work capability assessment	Two types of ESA (which affects amount entitled to: contribution based ESA – for those who have paid enough National Insurance Income-related ESA – for those on low incomes (received in addition to any contribution-based ESA entitled to)

8.6.2 Specialist learning disability provision

Hackney One Team (previously Hackney Recruitment Partnership)

The Hackney One Team is a supported employment agency specialising in placing people with learning disabilities and people with substance misuse problems into paid employment. The service helps with job searches, applications, writing CVs and preparation for interviews, as well as providing one-to-one job coaching at the workplace.

The service is available to young people aged 16+ with learning disabilities or autism as part of the Preparation for Adulthood (formerly Transition) Work Experience programme, and adults 18+ with learning disabilities/autism.

A service description written for the benefit of this needs assessment has highlighted the following challenges:

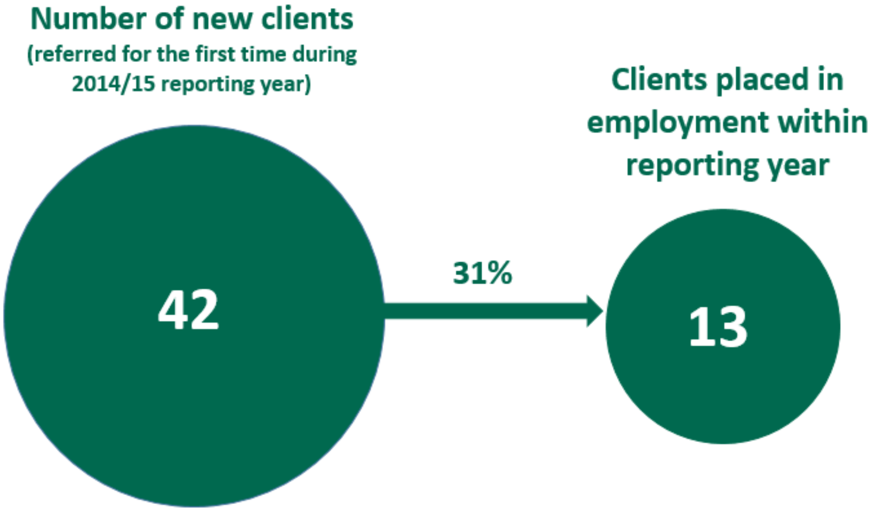
- service challenges
  - lack of continuity between children's & adult services
  - shortage of skilled job coaches
- access/client challenges
  - access can be denied or problematic for vulnerable people who may have a unconfirmed learning disability diagnosis.

The end of reporting year snapshot shows a caseload of 80 individuals with a learning disability using the service in 2014/15, and 99 individuals in 2015/16. During 2014/15, 31% of new clients referred to the team were placed into employment within the same year ***(Figure 75***).

Links/additional information:

Hackney One Team - Local offer

Figure 75: Number of people referred to the Hackney One team, 2014/15



Real Opportunities Project

The Real Opportunities Project for people with learning disabilities and/or autism is a 'pre-employment' service in Hackney, which aims to raise aspirations and offer real opportunities for those who may otherwise be excluded from the labour market. The service promotes wellbeing, confidence and life skills and provides work experience for eligible local people.

This is a two year project, which commenced in 2016 and is funded by the European Social Fund. Two local partner organisations are leading this project:

- *Peter Bedford Housing Association* will be helping people discover how the internet can be used to look for jobs. They will also be helping people learn to speak up with confidence, make friends, socialise and improve their maths and English skills. They will be offering opportunities to volunteer at the Peter Bedford shop in Islington.
- *Volunteering Matters* have expertise in matching employers from all sectors with volunteers in the community. They will play an important role in placing and supporting local people with learning disabilities and/or autism into employment.

Links/additional information:

Real Opportunities Project

8.7 Advocacy groups

Advocacy services offer assistance and support to help vulnerable people make and be involved in decisions about the care they receive. An advocate should be independent of health or social care services, and support the individual to make choices, whilst not giving their personal opinions or those of the organisation. The type of areas where advocacy is often used are:

- to help access information and services
- to help clients be involved in decisions about their lives
- to defend and promote an individual's rights and responsibilities
- to speak out about issues that matter to them.

An independent advocate could be anyone who is not a family member or friend. There are several groups offering generic advocacy services in Hackney, but this chapter describes those which focus specifically on working with adults who have a learning disability. For the City, a generic advocacy service accessible via adult social care is described.

8.7.1 POhWER

POhWER are an organisation commissioned by Hackney Council to offer a self-advocacy and empowerment group for learning disabled adults in Hackney. The organisation currently provides an empowerment project in Hackney, called the 'speaking up group', organises quarterly meetings of the Hackney Forum for people with learning disabilities and arranges an annual event for all adults with learning disabilities and their families (the 'Big do'). For a description of the full range of POhWER activities in Hackney see ***Box 28***.

Links/additional information:

POhWER

Box 28: Activities and involvement of POhWER for adults with learning disability in Hackney

- ‘Speaking up group’ – this currently involves 10 regular participants with a learning disability, who discuss various topics relating to health and wellbeing. Their feedback often contributes to local service planning.
- Forum planning group – this currently involves 10 regular participants with a learning disability who contribute to the design of the quarterly Hackney forum meetings
- POhWER represents service users at meetings of the local Learning Disability Partnership Board (see section 8.8 below)
- A regular newsletter is sent to service users and providers (around 60 service users and relevant service providers), normally every quarter
- The ‘Big Do’ – an annual social and information sharing event for service users and their families
- Support for members of the ‘speaking up group’ to attend national and regional policy events and participate in research relating to people with a learning disability

8.7.2 Hackney People First

Hackney People First aim to provide a space for user-led self-advocacy for adults with a learning disability in Hackney. As of January 2016, there were 32 registered members, with an average attendance of around six people at weekly meetings and 14 at larger monthly gatherings.

Hackney People First have recently been awarded funding to run a ‘Better Together Project’ (through the Council’s Healthier Hackney fund), which aims to support individuals to make healthier choices.

Link/additional information:

Hackney People First

8.7.3 VoiceAbility

VoiceAbility provides a free, independent and confidential advocacy service to all adults aged over 18 in the City of London with a social care need. This service requires a referral from authorised staff in the City’s social care team.

8.8 Learning Disability Partnership Board

The Learning Disability Partnership Board is designed to be a platform for local users of learning disabilities’ services to discuss services and strategy in relation to the rights, level of choice, independence, and inclusion of adults with learning disability. At the time of writing this report, the local board is currently attended by the Head of Service of the ILDS, strategic commissioners and POhWER advocacy group.

The terms of reference relating to the partnership board are included in Appendix F of this report.

8.9 City and Hackney Safeguarding Adults Board

City and Hackney Safeguarding Adults Board (CHSAB) oversees adult safeguarding arrangements in Hackney Council, the City of London, the East London Foundation Trust, Homerton University Hospital and Barts Health NHS Trust.

As described in Chapter 7, there were 96 safeguarding concerns raised with CHSAB in 2014/15 on behalf of clients with a learning disability.

Link/additional information:

City & Hackney safeguarding adults board

8.10 Carer support

The City & Hackney Carers' Centre provides support and advice for all people who provide 'informal' care for others in the borough (not just those caring for people with a learning disability). They provide expert advice on employment, welfare and benefits, training and social support. They are also commissioned to provide carers' assessments for the City of London Corporation.

Other services that the Centre provides in Hackney include:

- Hackney carer's card, which gives access to discounts on local services
- Hackney carer's emergency care scheme
- respite care (on a daily/weekly basis)
- Homeshare day care scheme, whereby volunteers provide daily respite within an individuals' own home.

Links/additional information:

City & Hackney Carers Centre

8.11 Transport

The 'access to transport' scheme is a collaborative community engagement project between Transport for London, the Metropolitan Police Safer Transport Team, the Stagecoach Bus Company and POhWER. Access to the programme is managed by POhWER advocacy group. They offer people with a physical disability, learning disability and/or additional needs the opportunity to travel on a bus staffed by actors. The bus travels a route around the local area and service users get to see different scenarios acted out and how they can be dealt with – this could include passengers arguing, passengers sitting to close to someone, someone being drunk or aggressive etc. They also offer a short session on crossing the roads and ‘stranger danger’.

Links/additional information:

POhWER

8.12 Community activities

Community activities for people with learning disabilities are often subject to short term funding arrangements and, therefore, it is difficult to provide a comprehensive description of all activities available at any one time. The iCare online platform provides access to a broad range of community activities on offer in Hackney. However, as highlighted by local advocacy groups, computer literacy may be a challenge for many people with learning disability and, therefore, access to this service may be more appropriately targeted at parents/carers.

8.12.1 St Mary’s secret garden

St Mary’s Secret Garden offer an accessible open community garden where people with support needs can get hands on experience of gardening. The programme aims to address social isolation and support people to develop skills and acquire qualifications. The type of initiatives delivered through the garden include:

- therapeutic wellbeing placements for adults with learning disabilities, adults on the autistic spectrum, adults with mental health issues, older people and adults with sensory impairments
- therapeutic wellbeing placements for people referred by the One Hackney initiative – mainly older adults with complex needs including Alzheimer’s and dementia
- accredited training in horticulture and practical gardening for people with learning disabilities and mental health issues, as well as the wider local community
- volunteer gardening opportunities and supporting individuals with disabilities in their gardening tasks
- other opportunities for people with disabilities and health issues depending on successful funding applications
- hand raised plants and produce sales - so participants can see the success and value of their work.

Links/additional information:

St Mary's secret garden website

Hackney iCare

9. Conclusions and recommendations

9.1 Conclusions

This report has described the prevalence of learning disability among adults in Hackney and the City of London and the main health needs of those affected. It provides an overview of local service provision, in the context of national policy and best practice evidence to meet the often complex needs of adults with learning disability.

The number of adults with learning disability living in Hackney and the City of London is expected to grow by 17% over the next fifteen years, to a total population of just over 6,000 by 2030. Almost a quarter of these adults are estimated to have a moderate or severe disability and, therefore, potentially complex care and support needs.

Adults with learning disability have significantly shorter life expectancy than average and respiratory disease is a common cause of premature death. The findings of this needs assessment confirm that locally, as nationally, this group of adults are at increased risk of multiple physical and mental health problems when compared to the general population, and may not be accessing all of the services they need.

Severe mental illness is particularly prevalent in the local learning disabled population, people with learning disabilities are at significantly increased risk of dementia (and at an earlier age), and they are also much more likely to experience a range of physical health problems (including epilepsy, dysphagia, asthma, obesity and diabetes). They are much *less* likely to eat a healthy diet or to be physically active (at least in part due to lower employment rates and fewer opportunities for social activities), and there is evidence of poor uptake of population screening programmes by adult learning disabled adults locally.

Many health problems are under-reported and therefore remain under-treated in this population (or are diagnosed late), either because symptoms are difficult to distinguish from the learning disability itself or due to poor understanding of learning disability among many healthcare professionals. Communication problems also play a central role.

City and Hackney Integrated Learning Disability Service (ILDS) provides support to local adults with a diagnosed disability. The numbers receiving a care package through ILDS have been falling in recent years (by 30% since March 2010) and only account for around half the estimated number of adults with a moderate/severe disability living locally. Overall, around a third of these clients are placed out of borough; almost all (over 80%) of those receiving residential care are out of borough. Males are more likely to be receiving a care package than females and there has been a larger proportional decline in the number of females receiving a care package in recent years. A relatively large number of adults receiving a care package in

Hackney identify as Jewish, compared with the representation of this group in the wider Hackney population.

Most of the estimated number of adults with learning disability who might be expected to be known to local services are on the GP QOF register (and most of these are receiving regular health checks), but there is significant variation in recorded learning disability prevalence in the adult patient population across local GP practices. An estimated 200 adults with moderate/severe learning disability may not be known to their GP. It is likely that many more adults with milder forms of disability (as many as 4,000 people) are not receiving the care and support that may help them to live longer, healthier lives.

Adults with a GP-recorded learning disability are more likely than the general population to be living in the most deprived neighbourhoods of Hackney. As nationally, the primary social needs of adults with a learning disability locally are improved access to employment opportunities (employment rates are particularly low in Hackney and the City of London) and independent living options (an estimated two in five learning disabled adults are living with their parents). This population is, therefore, at significantly increased risk of social isolation compared with non-disabled adults. Carers of adults with learning disability are also often socially isolated, may feel unsupported in their caring role and commonly have health conditions of their own to manage.

9.2 Recommendations

This needs assessment points to a number of recommendations to improve health outcomes and reduce inequalities in the adult learning disabled population of Hackney and the City of London, as described below.

9.2.1 Designing inclusive services

- All local health and wellbeing strategies and related plans should consider the needs of the adult learning disabled population, in particular where specific health needs have been identified in this report. Evidence-based guidelines for specific conditions (as described in Chapter 4 of this report) should be adhered to.
- People with learning disabilities, and their carers where appropriate, should be actively involved and represented in the design and review of mainstream and specialist services – to ensure that services are flexible to meet their needs.
- Where needed, dedicated services for adults with learning disabilities should be commissioned or provided – this may include sexual health clinics (building on the learning from the current local pilot), dental services and/or weight management support.

9.2.2 Delivering health and care services

- There is a need for a much more effective approach to transition in Hackney, to ensure continuity of care and avoid delays in transferring eligible people from the care of children's to adult services.
- Sufficient community support should be available to prevent the need for out of borough and residential placements where possible and appropriate.
- Implementation of the inner north east London TCP Plan should be prioritised to better meet the needs of learning disabled people with behaviour that challenges.
- Optimal use should be made of the learning disability liaison nurse role at Homerton hospital to continue to raise awareness of learning disability among health and care professionals, in order to support improved identification/diagnosis and provide a better understanding of relevant health and wellbeing needs. Regular training of health and care staff is required to meet the needs of this patient group – including raising awareness of employment and housing support needs.
- The offer and uptake of annual health checks of learning disabled patients in primary care should be maximised across all GP practices, and Health Action Plans regularly reviewed. Opportunities for shared learning should be sought - for example through local GP, practice nurse and practice manager forums.
- Families, friends and carers of people with learning disabilities should receive appropriate support to facilitate identification of health problems (particularly those that can be masked by learning disabilities, such as dementia and epilepsy) and be involved in decisions about the patient's care.
- All relevant service information (including population screening programmes) should be communicated in an accessible, easy to read format, and specialist support should be available to aid informed decision-making by adults with learning disability wherever possible. Extended appointments should be offered where needed.
- Attention should be paid to ensuring that the needs of adults with learning disability and their carers within Hackney's many different cultural groups (including the Orthodox Jewish community) are being met.

9.2.3 Data sharing

- Systems should be improved within the ILDS to enable more effective sharing of information between the health and social care teams - to optimise coordination of care and support to better meet service user needs. This recommendation applies to data sharing between local authority children's and adult services to improve transition planning.
- Data sharing should also be improved between different organisations that care for/support adults with a learning disability - including primary and secondary health care, ILDS, education, employment and housing services - while at the same time ensuring that robust information governance procedures are in place. Hospital Passports could facilitate improved data sharing.

9.2.4 Supporting carers

- It is essential that the information and support available to carers is adequate and timely, including in relation to the transition process from children's to adult services for those with a care package.
- Adequate local opportunities should be available for carers to engage in social and leisure activities of their own, with regular access to caring breaks available.
- To ensure that local support services are appropriate to the needs of carers of adults with a learning disability, a review of carers' health and wellbeing needs should be undertaken.

9.2.5 Housing, employment and reducing social isolation

- Local authority housing plans should take account of the housing needs of the local learning disabled population, recognising the future need for independent housing options for the growing number of affected adults living with ageing parents. Future housing needs of those living with older parent carers should be planned well in advance to avoid emergency or crisis situations.
- Support to live independently should be provided wherever this is appropriate and in line with individual preferences.
- Consideration should be given to allowing use of Personal Health Budgets to pay towards housing costs, if this meets a health need and is agreed as part of a care and support plan.
- Supported employment options should be available to all learning disabled adults to help them gain and retain paid work, taking into account both the needs of the employee and employer. There is a need for a larger local pool of job coaches/advisors trained to work with adults with learning disability, and greater awareness of specialist provision within mainstream employment services.
- Employment should be promoted as an option early in transition planning.
- Adequate support should be available to help adults with learning disability navigate the benefits system, to ensure they are claiming all support to which they are entitled.
- Consideration should be given to reducing social isolation in adults with learning disability more generally, by making sure they are not excluded from community activities and are supported to access these activities where needed - this may include providing appropriate transport options.

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11. APPENDICES

11.1 Appendix A: Causes of learning disability

There are various different causes of learning disability, some of the most common of which are described below.

Genetic causes

- *Down's syndrome* involves genetic mutation of chromosome 21. Incidence worldwide is 1:1000. [188] Routinely screened during antenatal period. Characteristic features include learning disabilities, facial dysmorphic features, congenital heart defects, and lower life expectancy. Risk of mutation increases with maternal age (1 in 2000 at age 20, 1 in 270 at age 35, 1 in 50 at age 45).
- *Fragile X* is caused by a genetic anomaly of the FRM1 gene. Incidence is 1:3600 male, 1:6000 female. [189] Characteristic features include varying degrees of intellectual disability, facial dysmorphic, poor coordination and balance. Behavioural symptoms include repetitive movements, social avoidance and hyperactivity.
- *Williams syndrome* is caused by random mutation of chromosome 7. Leads to poor development of complex thought process, good speech development and able to communicate needs. Incidence is 1:7500. [190]
- *Rett Syndrome* is a neurodevelopmental disorder which only affects females. It is caused by a random mutation in the MECP2 gene which is essential for brain development. [191] Affected children usually have normal growth and development initially which then regresses and slows down; they often exhibit poor motor and speech skills, breathing difficulties, learning disabilities and seizures. The degree of disability and the age of onset varies individually. Prevalence of Rett Syndrome is 1:10000 females. [192]

There many other random genetic mutations which in total contribute to a small percentage of all learning disabilities.

Labour complications

Low birth weight or babies born smaller than the average for gestational age (i.e. under the 10th centile for that age group). SGA babies can be classified into pathological and non-pathological. Non-pathological SGA babies are usually small due to inherited height (small parents) and are not at a higher risk for developing learning disabilities; pathological causes are either due to inborn genetic problems (discussed above) and largely due to poor placental function. Poor placental function means that the baby does not get adequate oxygen and nutrients and this affects development. Placental function may be caused by various factors such as smoking in pregnancy and maternal disease (such as high blood pressure, diabetes, kidney disease). [193]

Prematurity or babies born before 37 weeks gestation. Prematurity, independent of birth weight, is linked with a higher incidence of learning disability due to various reasons. [194]

Birth asphyxia or lack of oxygen to baby during prolonged difficult labour leading to brain dysfunction e.g. cerebral palsy. [195]

Maternal infections during pregnancy

Infections during pregnancy can be vertically transmitted from the mother to the baby and affect foetal development. There are several infections which are most likely to cause harm, collectively known as the ‘TORCH’ (toxoplasmosis, rubella, Cytomegalovirus, Herpes Simplex Virus). [196]

- *Toxoplasmosis* is contracted via cats and food contamination. Causes damage to foetal development during early pregnancy leading to long term consequences such as eye disease, hearing loss, seizures and learning disabilities.
- *Rubella* is routinely screened for in pregnancy when its consequences can be dangerous. It causes severe developmental problems during early stage of pregnancy leading to whole body disease as well are neurological complications.
- *Cytomegalovirus* is one of the most common congenital transmitted infections. It causes most harm during the first three months of pregnancy by disrupting normal development leading to growth restriction, brain damage, loss of hearing and eye disease.
- *Herpes Simplex Virus* is a common sexually transmitted infection, which can live asymptomatically on the skin. It does not cause problems in pregnancy unless the infection is acquired and active during pregnancy, where it then leads to growth restriction and premature birth. If active during labour only it can cause meningitis and encephalitis in new-borns, therefore leading to long-term neurological consequences.

Other infections such as measles, syphilis and chicken pox during pregnancy can also cause neurological damage and learning disabilities. [196]

Maternal lifestyle during pregnancy

- *Foetal-alcohol syndrome* covers a range of presentations linked to excessive alcohol consumption during early pregnancy. It causes disruption of brain development and leads to long-term neurological problems. More severe symptoms of FAS can include physical dysmorphic features and heat problems similarly to Downs’s syndrome children. [197]

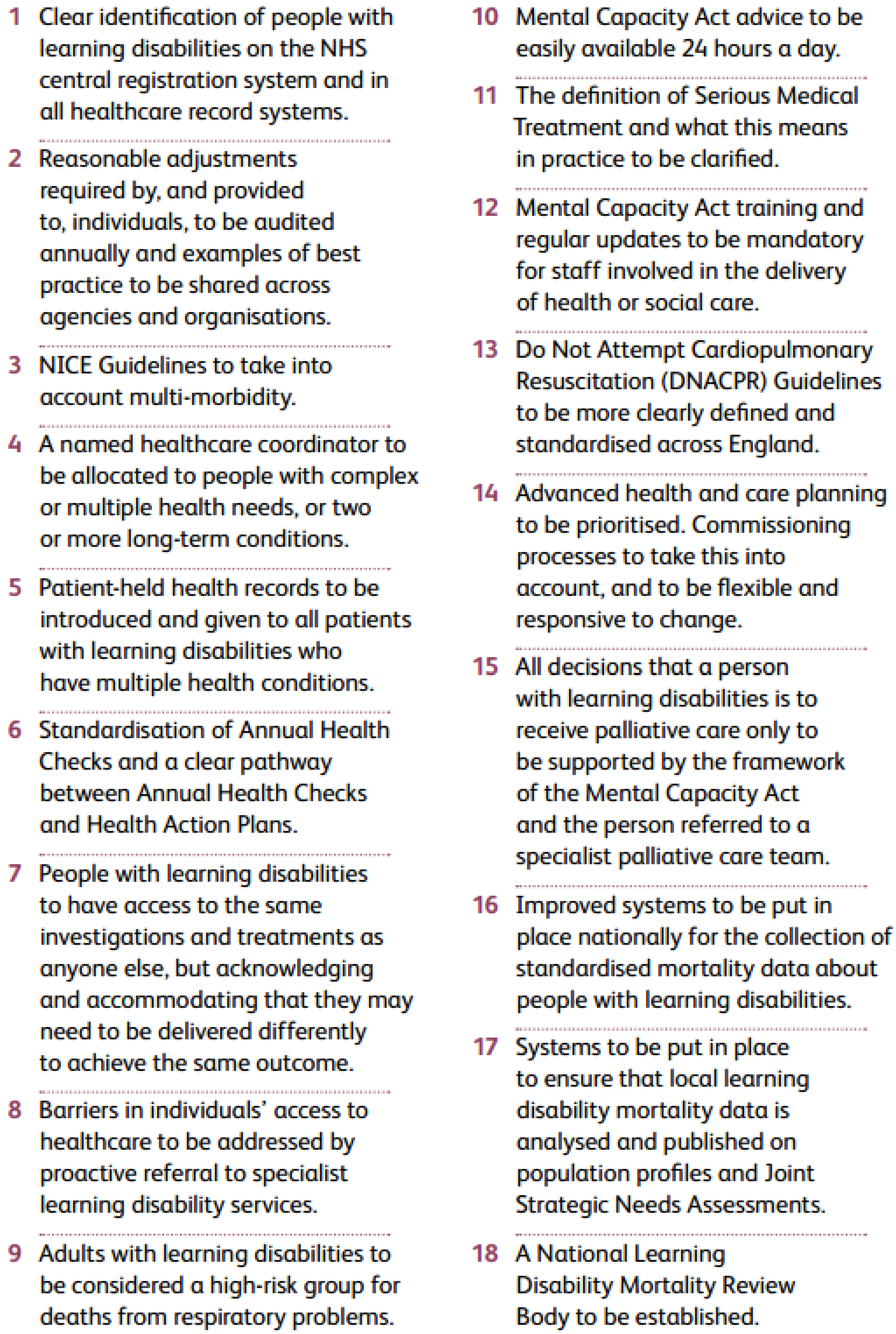
- *Smoking* leads to poor placental function and growth restriction of the baby, which as discussed previously is linked to development of learning disabilities.
- *Illegal substance misuse,* specifically opiate use during pregnancy, affects brain development and leads to changes in neurology and behaviour. [198]
- *Malnutrition* (poor nutrition) during pregnancy has been shown to lead to a lower IQ in children later in life who are also more likely to have special educational needs. [199]

Early childhood infections and trauma

Infections which are linked to the development of learning disabilities include central nervous system infections (e.g. encephalitis, meningitis) and rarer infections (such as measles & polio).

Traumatic brain injury in childhood is also a cause of learning disability. People with brain injury or trauma sustained in adulthood would not fall within the definition of a learning disability, as the onset was not before the age of 18.

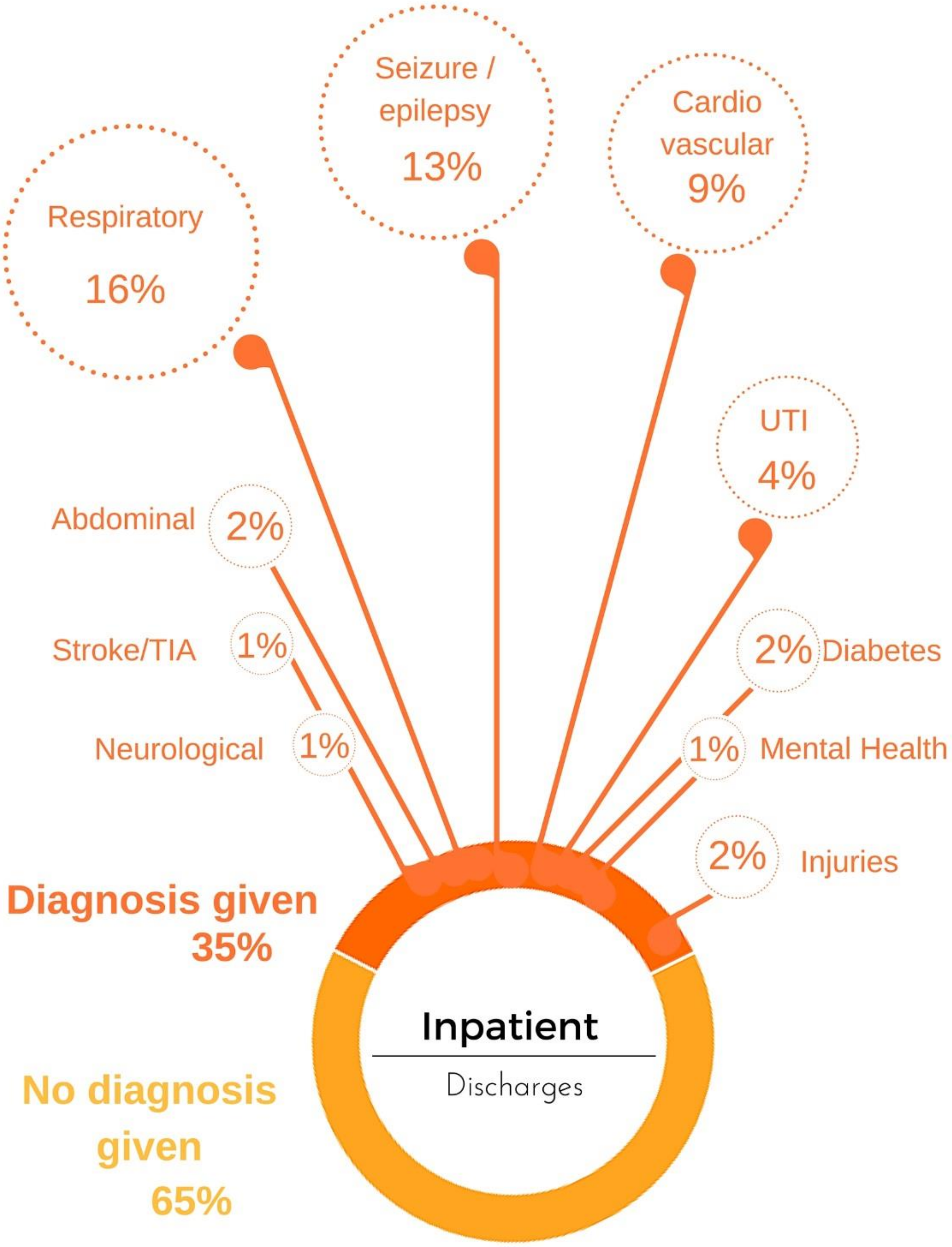
11.2 Appendix B: Key recommendations form the CIPOLD review



1. Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems.
2. Reasonable adjustments required by, and provided to, individuals, to be audited annually and examples of best practice to be shared across agencies and organisations.
3. NICE Guidelines to take into account multi-morbidity.
4. A named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions.
5. Patient-held health records to be introduced and given to all patients with learning disabilities who have multiple health conditions.
6. Standardisation of Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans.
7. People with learning disabilities to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome.
8. Barriers in individuals' access to healthcare to be addressed by proactive referral to specialist learning disability services.
9. Adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems.
10. Mental Capacity Act advice to be easily available 24 hours a day.
11. The definition of Serious Medical Treatment and what this means in practice to be clarified.
12. Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care.
13. Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Guidelines to be more clearly defined and standardised across England.
14. Advanced health and care planning to be prioritised. Commissioning processes to take this into account, and to be flexible and responsive to change.
15. All decisions that a person with learning disabilities is to receive palliative care only to be supported by the framework of the Mental Capacity Act and the person referred to a specialist palliative care team.
16. Improved systems to be put in place nationally for the collection of standardised mortality data about people with learning disabilities.
17. Systems to be put in place to ensure that local learning disability mortality data is analysed and published on population profiles and Joint Strategic Needs Assessments.
18. A National Learning Disability Mortality Review Body to be established.

11.3 Appendix C: Homerton inpatient data infographic

Figure 76: Analysis of learning disabled inpatient discharges from the Homerton Hospital



11.4 Appendix D: The Care Act 2014

This appendix provides a summary of the Care Act 2014 and the definition of 'need' in relation to eligibility criteria for adult social care in England (The Care Act, 2014)

(1) An adult's needs meet the eligibility criteria if—

(a) the adult's needs arise from or are related to a physical or mental impairment or illness;

(b) as a result of the adult's needs the adult is unable to achieve two or more of the outcomes specified in paragraph (2); and

(c) as a consequence there is, or is likely to be, a **significant impact** on the adult's well-being.

(2) The specified outcomes are—

(a) managing and maintaining nutrition;

(b) maintaining personal hygiene;

(c) managing toilet needs;

(d) being appropriately clothed;

(e) being able to make use of the adult's home safely;

(f) maintaining a habitable home environment;

(g) developing and maintaining family or other personal relationships;

(h) accessing and engaging in work, training, education or volunteering;

(i) making use of necessary facilities or services in the local community including public transport, and recreational facilities or services; and

(j) carrying out any caring responsibilities the adult has for a child.

(3) For the purposes of this regulation an adult is to be regarded as being unable to achieve an outcome if the adult—

(a) is unable to achieve it without assistance;

(b) is able to achieve it without assistance but doing so causes the adult significant pain, distress or anxiety;

(c) is able to achieve it without assistance but doing so endangers or is likely to endanger the health or safety of the adult, or of others; or

(d) is able to achieve it without assistance but takes **significantly** longer than would normally be expected.

(4) Where the level of an adult's needs fluctuates, in determining whether the adult's needs meet the eligibility criteria, the local authority must take into account the adult's circumstances over such period as it considers necessary to establish accurately the adult's level of need.

11.5 Appendix E: Community questionnaire for adults with learning disability

Do you have a learning disability?

☺ ☐ Yes

😐 ☐ Not Sure

☹ ☐ No

How old are you?

☐ 18 to 24

☐ 25 to 34

☐ 35 to 44

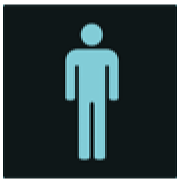
☐ 45 to 54

☐ 55 to 64

☐ 65 to 74

☐ 75 or over

Are you a man or a woman?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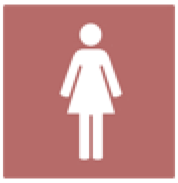
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⚥ other ☐

Do you eat 5 portions of fruit or vegetables a day? Have you done this over the last 7 days?

Are you overweight, average weight underweight?

☐ Obese

☐ Overweight

☐ Average weight

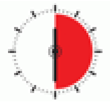
☐ Underweight

In the last week, have you done exercise that has made you breathless?

☐ Yes

☐ No

If you answered yes, how long did you exercise for?

☐ Under 30 Minutes 

☐ 30 Minutes to 1 hour 

☐ More than 1 hour

Do you have friends who you see often? We mean those people who are not your support workers or family.

☐ Yes

☐ No

Do you have a job?

☐ Yes

☐ No

If you have a job, do you get paid for your job?

☐ Yes

☐ No

Would you like a job?

☐ Yes

☐ No

Have you heard of the Hackney Learning Disability Forum? (held 4 times per year)

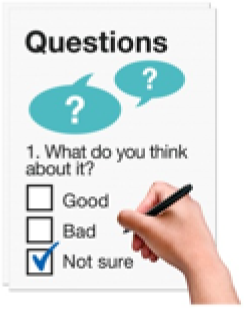
☐ Yes

☐ No

Have you ever attended the Hackney Learning Disability Forum?

☐ Yes

☐ No



Do you have any questions or comments?

11.6 Appendix F: Learning disability partnership board terms of reference (Sep 2014)

What does the Partnership Board want to achieve?

The Partnership Board will work as a team with people and organisations to give people with learning disabilities and family carers better choices and opportunities in their lives.

The Partnership Board will make sure that the changes and improvements made are the ones that are important to people with learning disabilities.

The Partnership Board will promote the independence, rights and choice to include people with learning disabilities and family carers who live or are registered with a doctor in Hackney.

The Partnership Board will look at local policies and how services are delivered. It will aim to make sure that the needs of people with learning disabilities family carers are met alongside that of the person in the community.

The Partnership Board is a place where Council Departments, Health Services and other providers can share information about what is happening in the local area.

The members of the Partnership Board will be responsible for making sure that the views and wishes of the people with learning disabilities, family carers and their families are heard.

This information will then be used to help people have a say so that they get the lives they want.

Partnership Board Meetings

Meetings will take place four times a year.

Each Partnership Board Meeting will last for a maximum of two hours.

The meetings will be co-chaired by a person with learning disability and the Head of Learning Disability Services.

Standard Agenda Items:

The agenda will be set and agreed during the pre-meeting between the Service users and the Joint Commissioner, two to three weeks before each Partnership Board meeting. The agenda will be a mixture of service user, carer and council issues. The members may need to agree the most important of the issues.

The Standard Agenda will be:

- Introductions
- Apologies
- Minutes & Actions of the previous meeting (These would have already been agreed before final circulation).
- Agenda Items to Joint Chair who set and agree
- Information exchange, what have we all been doing?
- Date of next meeting
- AOB (where applicable)

Rules of the Partnership Board Meeting:

- Mobile phones must be turned off or put on silent.
- We will have a break half way through every meeting if everyone agrees for 10 minutes.
- All paperwork and presentations will be put into easy read and to be kept confidential.

The Core Membership will be:

- Individuals with a Learning Disability and Carers
- Representatives from:
- Housing
- Transport
- Children
- Self Advocacy Lead plus Self Advocacy Group
- Carers Lead plus three Carers
- Service Providers
- Hackney Health Services NHS Trust
- The Joint Community Learning Disability Team (JCLDT)

Guests:

Guests can be invited to the Partnership Board meeting for a topic related item or supported to be a Board member to attend the meeting

A maximum number of two guests can be invited to each meeting.

Anyone who wants to bring a guest for support on a topic has to get the permission of the Joint Chairs.

Guests cannot vote.

How to make sure people can be involved?

The Chair will have a meeting with people with learning disabilities and carers before the start of the main meeting. They will look at what happened at the last meeting and what will be talked about.

Any documents needed for meetings, notes and agendas will be done in easy read formats for the Partnership Board members.

Documents, agendas and notes will be sent to members at least two weeks before the meetings.

Traffic light cards will be used during every meeting to help everyone have their say.

The Partnership Board will not accept any last minute paperwork or presentations on the day of the meeting. The only time this may be allowed is, if an urgent issue has to be discussed.

If this happens, then at the start of the meeting, the Partnership Board would have to agree what would not be talked about and be taken off the agenda.

The chair may call for an additional meeting of the Partnership Board if they think this is needed.

If someone has 'an interest' in an area that we may talk about or make a decision on, they must tell the Board. If this happens they cannot take part in that decision or vote.

An interest might be:

A connection with an organisation contracted to provide services by the Local Authority or the (Clinical Commissioning Group (CCG)

A personal relationship or connection where someone could personally benefit from a decision.

A connection with a financial interest.

What is private and not for sharing?

The Partnership Board might hear private information about people or services. This information should not be shared outside of the meeting. The people present have to keep this confidential.

How we will know we are making a difference?

We will check that our work is making a difference for people in Hackney.

We will ask for feedback from people with learning disabilities, family carers, services and learn from what they say to us.

We will write a good news report once a year to let people know what we have been doing and to show the outcomes of that work.

Communication, Engagement and Information

The Partnership Board is responsible for making sure that as many people as possible get to know about its work and how to get involved.

All members of the Partnership Board will have to make sure they represent other people and not just give their own views, although this is also important and useful.

Review of Terms of Reference

The Co-Chairs will review these terms of reference annually and make recommendations to the Partnership Board about all proposed changes.

11.7 Appendix G: British psychological society “Learning disability: definitions and contexts”

People with learning disabilities do not constitute an homogeneous group. However, in terms of diagnosis and classification there are a number of features of learning disability which have gained widespread acceptance across professional boundaries within the UK.

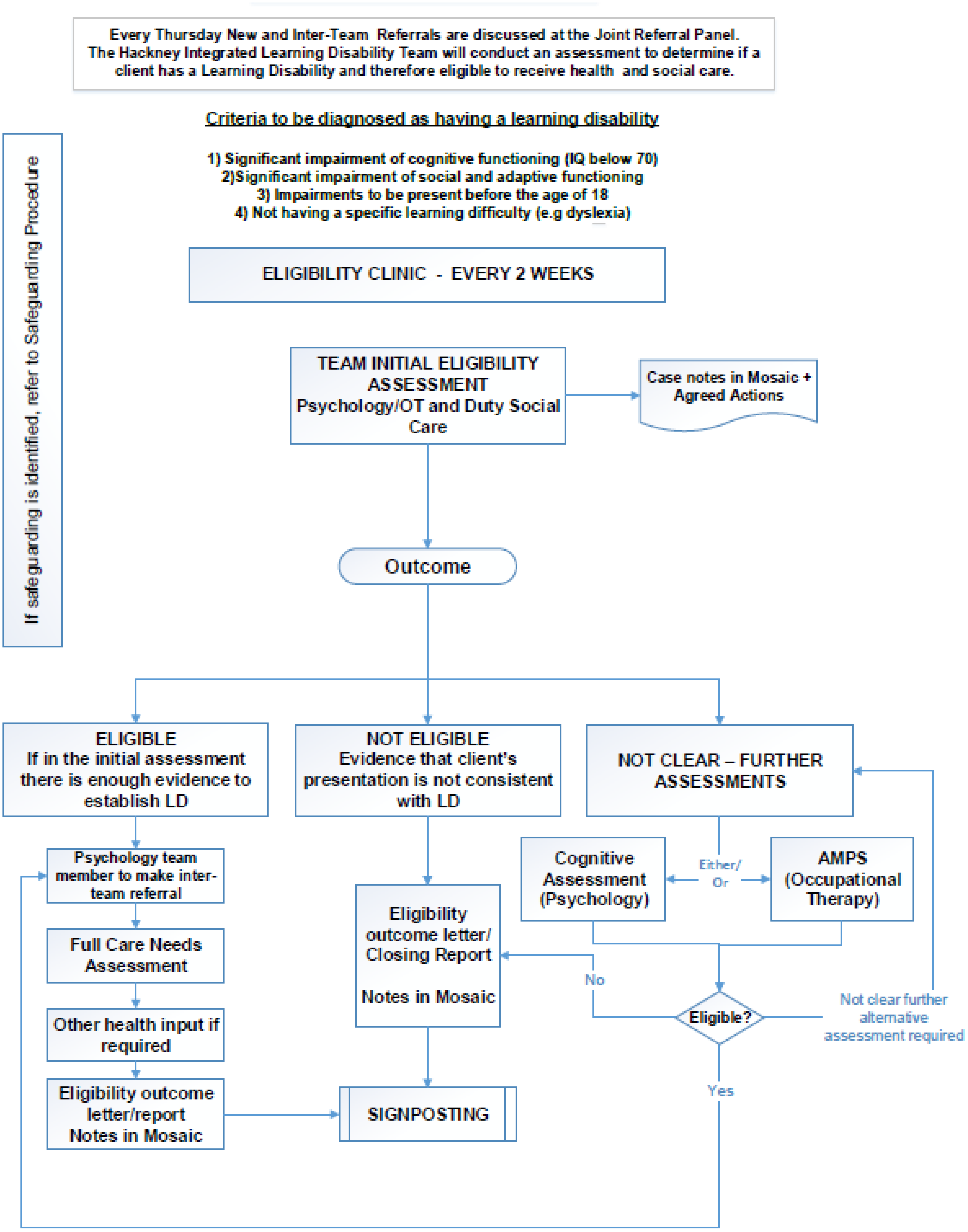
Irrespective of the precise terminology, or the wording in the various definitions, there are three core criteria for learning disability:

- Significant impairment of intellectual functioning;
- Significant impairment of adaptive/social functioning;
- Age of onset before adulthood.

All three criteria must be met for a person to be considered to have a learning disability. Difficulties in assessing adaptive/social functioning have contributed, in the past, to a tendency amongst clinicians to concentrate on assessment of intellectual functioning only. The assumption has been that, provided a significant impairment of intellectual functioning has been demonstrated, similar deficits in adaptive/social functioning are likely. However, this is not always the case.

The Society recommends that, in accordance with the various definitions, classification of learning disability should only be made on the basis of assessed impairments of both intellectual and adaptive/social functioning which have been acquired before adulthood. [3]

11.8 Appendix H: Eligibility pathway for the City and Hackney Integrated Learning Disability Service



Every Thursday New and Inter-Team Referrals are discussed at the Joint Referral Panel. The Hackney Integrated Learning Disability Team will conduct an assessment to determine if a client has a Learning Disability and therefore eligible to receive health and social care.

<u>Criteria to be diagnosed as having a learning disability</u>

1) Significant impairment of cognitive functioning (IQ below 70)
2) Significant impairment of social and adaptive functioning
3) Impairments to be present before the age of 18
4) Not having a specific learning difficulty (e.g dyslexia)