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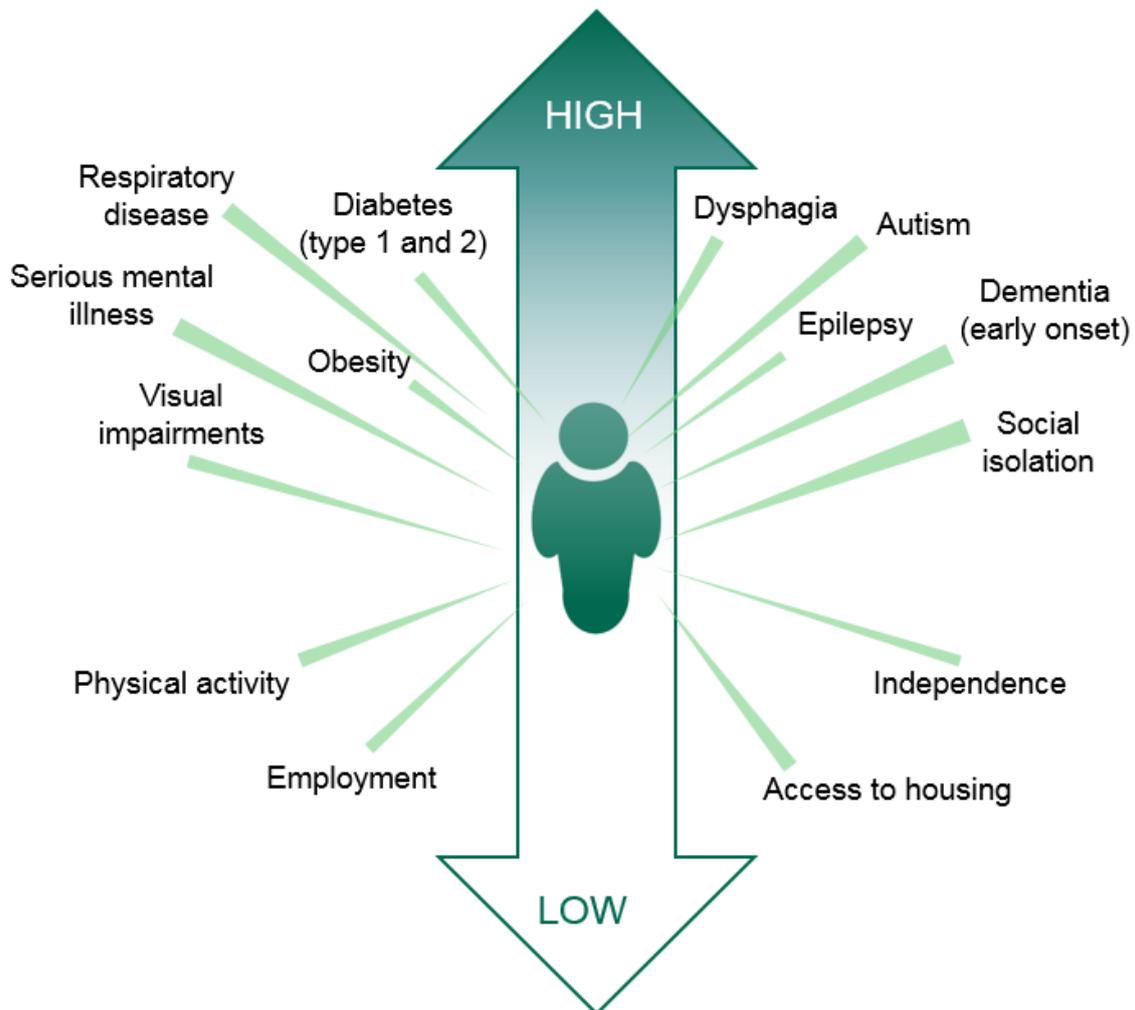
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2 Learning disability

2.1 Introduction

Adults with learning disability are at increased risk of poor physical and mental health (see Figure 1), are disproportionately affected by socio-economic disadvantage (including unemployment, poverty and social isolation) and have a significantly lower life expectancy than average. [1] [2] They are less likely to attend regular health checks or take up population screening programmes, and may experience significant untreated morbidity due to delays and problems with diagnosis and treatment, as well as poor response to changing needs within the health and care system. The failure of the health and care system to fully 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'. [3] [4]

Figure 1: A summary of the health and wellbeing needs of adults with learning disability



Source: Adult learning disability needs assessment.

A population needs assessment for Hackney and the City in 2016 investigated the health and wellbeing needs of the adult learning disabled population and gives a full description of policy, guidance and recommendations from the time. This section uses recently published data and literature to update local information on the topic and refresh the evidence where relevant. [5]

2.1.1 Definition of learning disability

Learning disability is an umbrella term used to encapsulate a range of conditions with the following three attributes: [6] [7] [8]

- reduced social and adaptive functioning, leading to reduced ability to cope independently
- a lower than average intelligence (generally an IQ of below 70)
- onset was in childhood and has a lasting effect on development.

Box 1: Note on terminology: learning difficulty, learning disability and intellectual disability

'Learning difficulty' is not the same as learning disability. The term 'learning difficulty' is often used in educational settings and refers to individuals who have specific differences in the way they learn, such as dyslexia or dyscalculia. However, many people with learning disability 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'.

For the purposes of the JSNA, the term 'learning disability' will be used. [9]

Learning disability affects people in very different ways. The majority of classification tools used in health and social care systems involve an assessment of the extent to which a person's wellbeing and ability to perform routine daily tasks is affected by living with the condition. Subjective judgements are generally performed to assess the impact on wellbeing. Available prevalence estimates use several sources of data (both educational and social care) to predict the number of people living with the condition.

*Box 2: Definitions/criteria used to identify learning disability by organisation type [6] [9]***Educational settings**

'Special education needs and disability' (or SEND) is the collective term for students who may require additional support in the learning environment. The SEND system classifies pupils by the type of need as opposed to a diagnosis. There is no specifically named SEND category that covers 'learning disability'. Broad areas of need are grouped by the following topics: [10]

- communication and interaction
- cognition and learning
- social, emotional and mental health difficulties
- sensory and/or physical needs.

Detailed SEND topics (under cognition and learning) include identifying students with 'learning difficulties'; however, this categorisation may include students with dyslexia and dyscalculia (see Box 1).

Social care settings

Access to adult social care services in England is regulated through eligibility criteria set out in the Care Act 2014. [11] Eligibility is based on the level of 'need' experienced by an individual having a significant impact on their wellbeing. A person with learning disability who does not experience a significant level of need would not be eligible for social care services. People who are eligible for social care services will have the 'primary support reason' listed on their records; for people with learning disability this may or may not be identified as the primary reason for receiving social care support.

Clinical settings

There are several different coding systems used in health and care services to identify patients with health conditions (including learning disability). The main systems used in this report are QOF¹ (primary care, based on 'read codes') and ICD-10² (secondary care). The National Information Board recommended that all care settings utilise the SNOMED CT coding system by April 2020.

2.2 Causes and risk factors

Learning disability is an umbrella term that is used to describe a range of individual conditions that affect someone's ability to learn and adapt. A learning disability happens when a person's brain development is affected, either before they are born, during their birth, or in early childhood.

Learning disability has a number of causes and risk factors, including:

- inherited learning disability – where certain genes are passed from the parent(s) to the child

¹ Quality and Outcomes Framework is a payment and performance system administrated by NHS England

² World Health Organization international statistical classification of diseases and related health problems, 10th revision

- genetic conditions – including Down’s syndrome and Fragile X [12] [13] [14] [15] [16] [17]
- labour complications – low birth weight and prematurity increase risk of learning disability; prolonged lack of oxygen affects brain function [18] [19]
- maternal infections during pregnancy – including toxoplasmosis, rubella, cytomegalovirus and herpes simplex virus [20]
- maternal lifestyle/behaviour during pregnancy – include foetal alcohol syndrome, smoking, opiate use and malnutrition [21] [22] [23] [24]
- early childhood infections – including meningitis and encephalitis, as well as measles and polio [20] [25]
- early childhood injury – specifically, traumatic brain injury.

2.3 Local data and unmet need

This subsection describes local data on the number of people affected by learning disability in Hackney and the City of London.

As elsewhere in the JSNA, GP-recorded data reported here cover adult (age 18+) residents of Hackney and the City who are registered with a GP in Hackney, the City of London, Tower Hamlets or Newham. Learning disability in patients is identified in QOF reporting.

Social care data primarily refer to service users receiving ‘long-term support’. This includes people in receipt of home care, day care, meals, direct payments, professional support, residential care, nursing care, or ‘other’ services (including transport). These services are described in further detail in Section 2.7.

2.3.1 Numbers affected – known to services

Primary care (GP) records

In 2017, 1,002 Hackney and the City (resident) patients were recorded by their GP as having learning disability (0.44% of all adult GP patients). Due to small numbers, data for the City of London are not separately reported.

Social care services

In March 2017, there were 470 adults with learning disability receiving a long-term support care package in Hackney. Almost all of them (90%) had been receiving this support for over one year. In the City of London, 14 adults with learning disability were receiving a long-term support package, and of these 11 had received that support for over a year.

2.3.2 Numbers affected – estimates

Estimates for Hackney and the City combined are that a total of 5,407 individuals (aged 18+) with learning disability live locally (Table 1). Just over one fifth (22%) – or

1,193 adults – are estimated to have a moderate or severe form of the condition, and are thus deemed more likely to be known to local services (Figure 2). [26] [27]

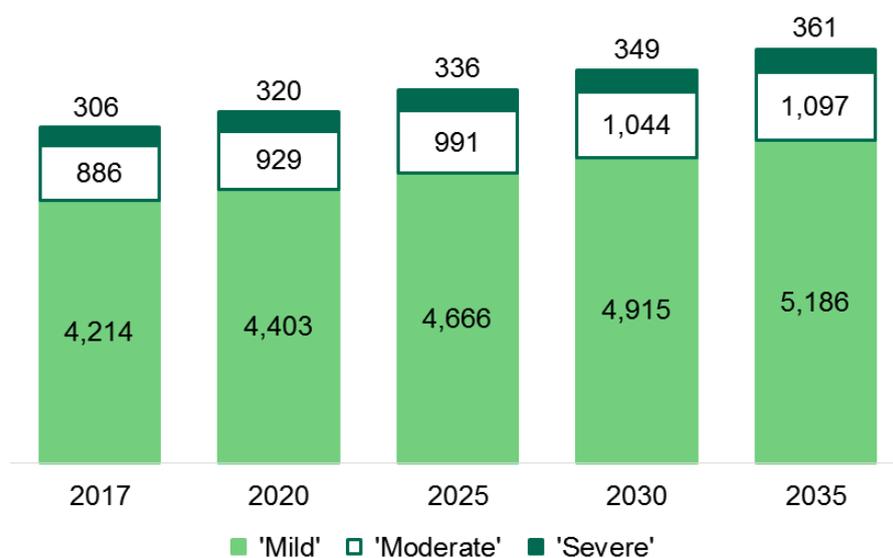
Figure 2 shows that, in line with population growth, the number of adults living with a learning disability is expected to increase by 22% by 2035.

Table 1: Estimated number and prevalence of Hackney and the City residents with learning disability (age 18+, 2017)

Locality	Estimated prevalence	Estimated population number (2017)
City of London	2.8%	183
Hackney	2.4%	5,224
Hackney and the City	2.5%	5,407

Source: Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information (POPPI), Oxford Brookes University. [26] [27]

Figure 2: Estimated number of Hackney and the City residents with learning disability, by severity of condition and over time (age 18+, 2017 — 2035)



Source: PANSI and POPPI. [26] [27]

Note: Figures may not add up to the exact value in Table 1 due to rounding of values (required when applying percentages to population numbers).

2.3.3 Unmet need

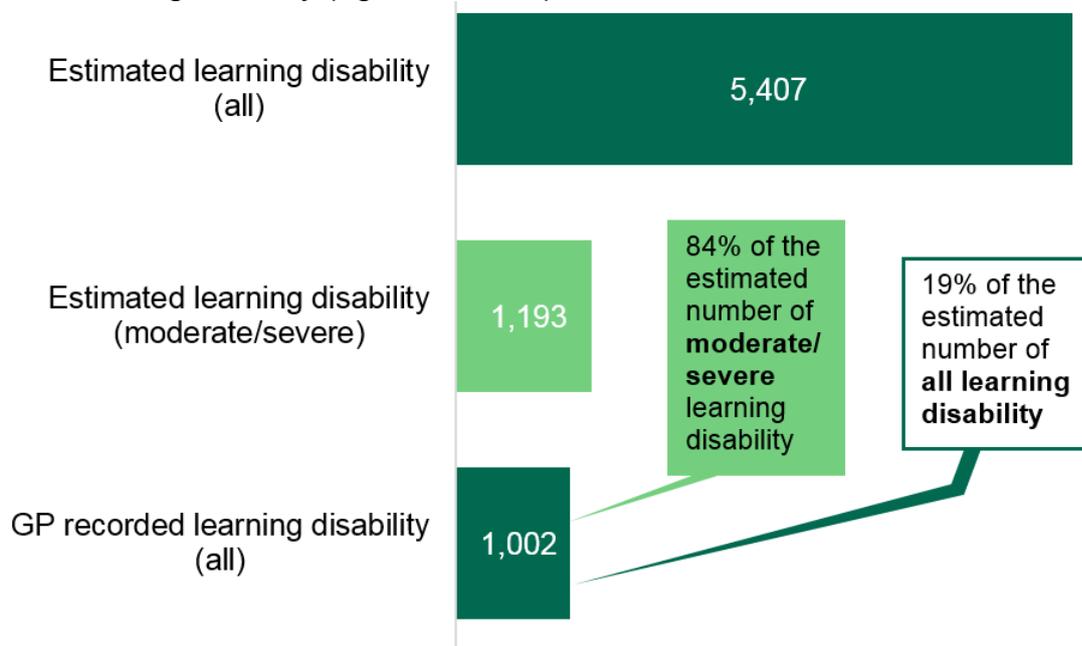
The presentation of unmet need in this section is purely indicative, as the sources of information used are not strictly comparable.

Due to small numbers in the City of London, we are unable to present data on unmet need for Hackney and the City separately.

Local estimates indicate significant potential unmet need in adults with learning disability, with just 19% of the estimated total number of adults with learning disability recorded as such on GP records locally (Figure 3). The majority of unmet need is likely to be in adults with ‘mild’ conditions who have lower needs that may be being met through family support. The role of family support is commonly an important feature of whether an adult is known to local health and social care services.

Figure 3 shows that 84% of the estimated number of adults with moderate or severe disability (and more likely to be known to services) are recorded with learning disability by their GP.

Figure 3: Estimated and recorded number of Hackney and the City adult residents with learning disability (age 18+, 2017)



Sources:

- GP-recorded data extracted by Clinical Effectiveness Group (CEG), Blizard Institute, April 2017. Data cover residents of Hackney and the City registered with a GP in Hackney, the City of London, Tower Hamlets and Newham. [28]
- Estimates derived from PANSI and POPPI where rates from the literature have been applied to Office for National Statistics (ONS) population projections. [26] [27]

2.4 Inequalities

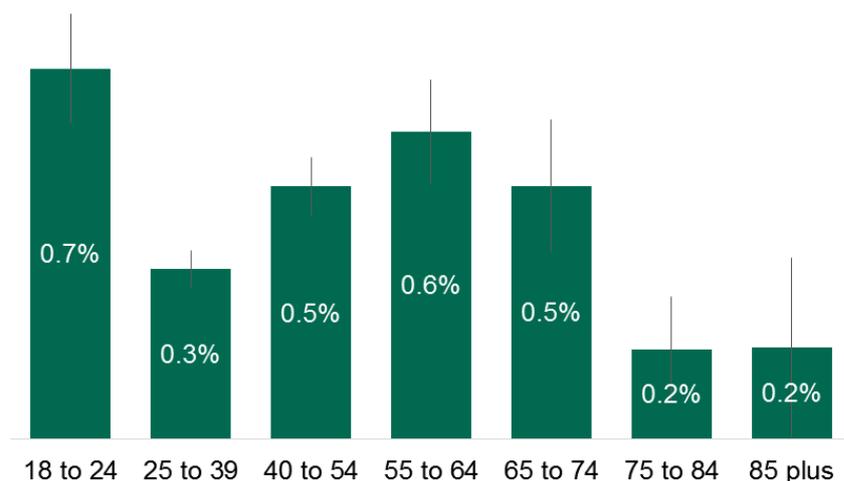
Data used to describe learning disability inequalities (see below) are combined for residents of Hackney and the City of London, due to the low numbers of (and potentially identifiable) people with learning disability living in the City.

2.4.1 Age

Around 80% of local GP patients with a learning disability are under the age of 55, which is linked to the lower life expectancy of people affected as well as the young age profile of the wider population of Hackney and the City. [1]

Figure 4 shows that the recorded prevalence of learning disability is much higher among 18–24-year-olds than 25–39-year-olds, which may reflect enhanced procedures for capturing information relating to disability at school-leaving age (facilitated through education, health and care plans). [29]

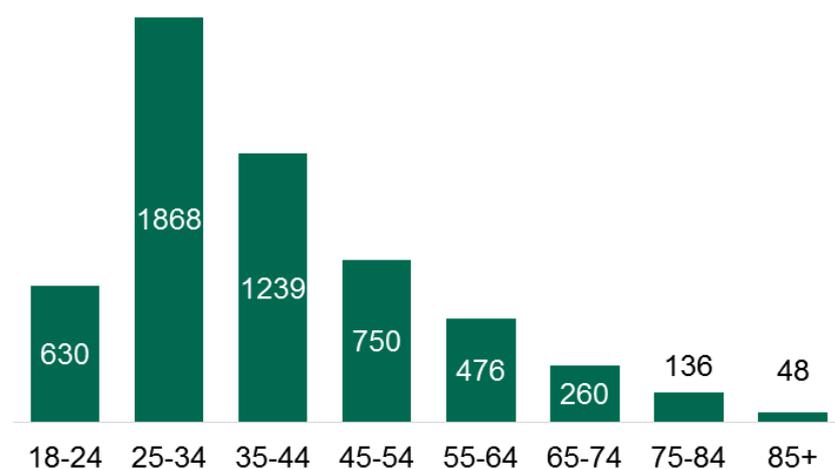
Figure 4: Percentage of Hackney and the City adult residents with GP-recorded learning disability, by age group (age 18+, 2017)



Source: Extracted from the local GP register by CEG, Blizard Institute, April 2017. Data cover residents of Hackney and the City registered with a GP in Hackney, the City of London, Tower Hamlets and Newham. [28]

The estimated number of people with learning disability is highest in the 25–34 age group (see Figure 5). Local GP records show a similar age distribution of patients with learning disability (compared to estimates), with the highest absolute number of learning disabled people again recorded in the 25–34 year age group.

Figure 5: Estimated number of Hackney and the City adult residents with learning disability, by age group (18+, 2017)

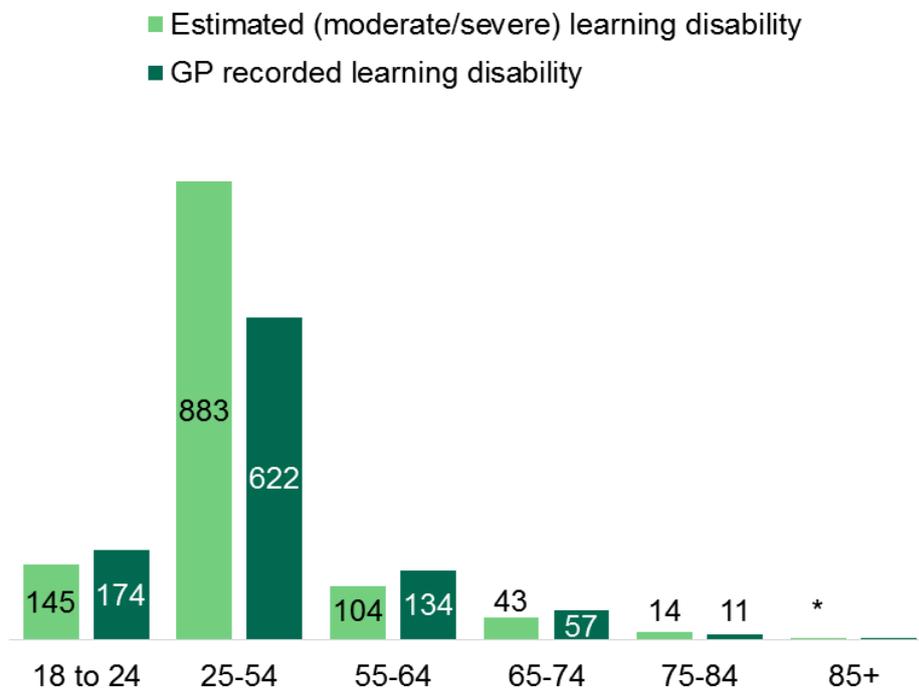


Source: PANSI and POPPI. [26] [27]

Figure 6 shows that the vast majority of adults with moderate or severe learning disability (both estimated and recorded) are under the age of 65. This is also reflected in adult social care data: in Hackney, virtually all adults (92%) with learning disability who receive long-term support are under the age of 65, compared to half (49%) of the total adult caseload receiving such support; in the City of London, all learning disabled adults receiving long-term support are under the age of 65.

Figure 6 also suggests that the greatest unmet need among adults with moderate or severe disability (in terms of the difference between the number of adults known to services and the numbers estimated to be living locally) is in the 25–54 age group.

Figure 6: Estimated number of Hackney and the City adult residents with moderate/severe learning disability (age 18+, 2017)

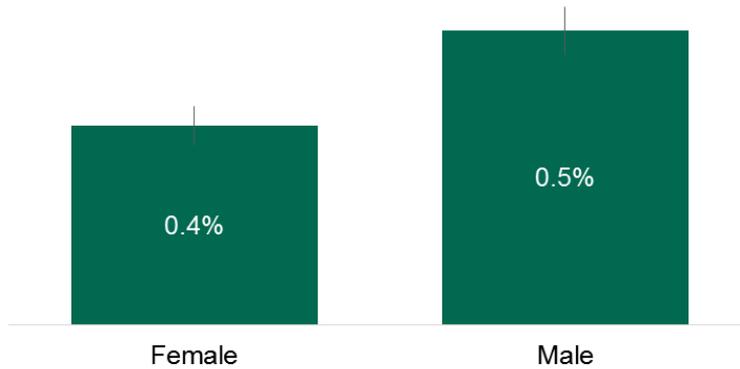


Source: Extracted from the local GP register by CEG, Blizard Institute, April 2017. Data cover residents of Hackney and the City registered with a GP in Hackney, the City of London, Tower Hamlets and Newham. [28] PANSI. [26] POPPI. [27]

2.4.2 Gender

There is a slightly higher prevalence of GP-recorded learning disability in adult males compared to females (see Figure 7); the male:female gender ratio is 1.4:1. This gender ratio is similar for learning disabled patients accessing inpatient care at Homerton Hospital. [29] Among learning disabled social care service users, the gender ratio is slightly more pronounced, at 1.6:1. [30]

Figure 7: Percentage of Hackney and the City residents with GP-recorded learning disability, by gender (age 18+, 2017)



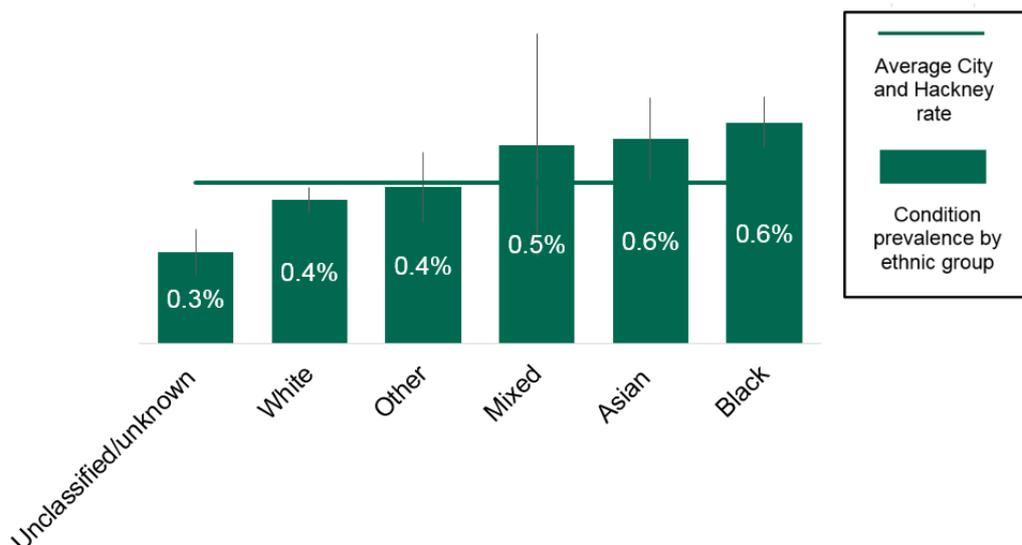
Source: Extracted from the local GP register by CEG, Blizard Institute, April 2017. Data cover residents of Hackney and the City registered with a GP in Hackney, the City of London, Tower Hamlets and Newham. [28]

2.4.3 Ethnicity

The highest number of Hackney and the City patients recorded with learning disability are coded as White (n=476), followed by those of Black ethnicity (n=289).

The prevalence of GP-recorded learning disability per ethnic group is higher in people of Black and Asian ethnicity (Figure 8). This is likely, at least in part, to reflect the age and socio-economic profile of these populations locally.

Figure 8: Percentage of Hackney and the City residents with GP-recorded learning disability, by ethnic group (age 18+, 2017)



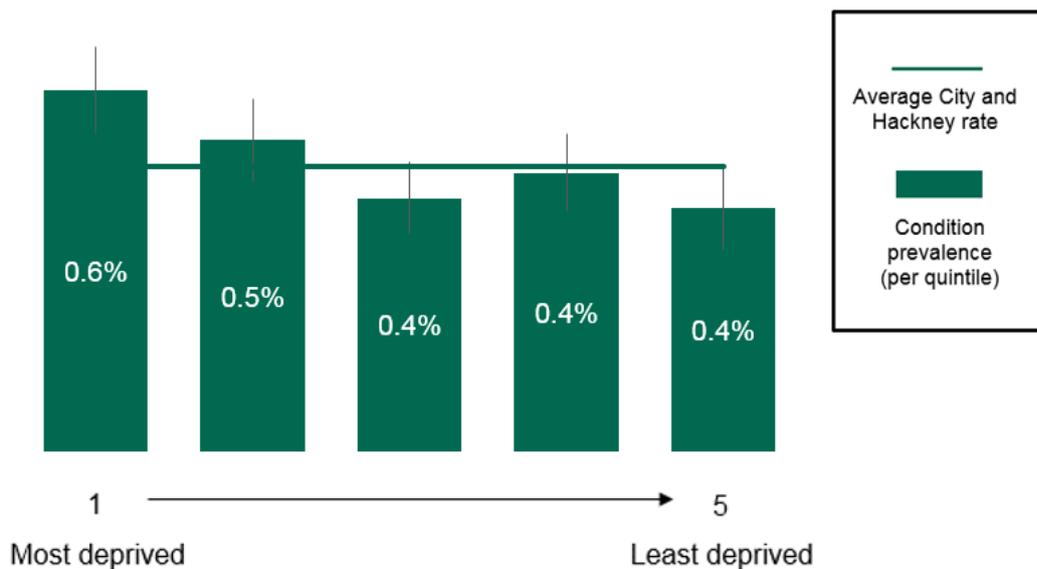
Source: Extracted from the local GP register by CEG, Blizard Institute, April 2017. Data cover residents of Hackney and the City registered with a GP in Hackney, the City of London, Tower Hamlets and Newham. [28]

Based on slightly different ethnicity coding, adult social care data from Hackney show that more than half of people with learning disability accessing support describe themselves as White, with the next most common ethnic group being those who identify as 'Black or Black British' (20%). This is similar to the ethnic profile of the wider adult population. [31]

2.4.4 Socio-economic disadvantage

GP-recorded prevalence of learning disability is highest in the most deprived areas of Hackney and the City, and lowest in the least deprived (or more affluent) areas (Figure 9). This trend is also described in national reports into the health of people with learning disability in England. [32] A number of different factors may contribute to this, linked to the social patterning of some of the causes and risk factors described in Section 2.2. For example, maternal smoking and malnutrition, as well as other pregnancy and early years risk factors for learning disability, are linked with deprivation. [21] [22] [23]

Figure 9: Percentage of Hackney and the City residents with GP-recorded learning disability, by deprivation quintile (age 18+, 2017)



Source: Extracted from the local GP register by CEG, Blizard Institute, April 2017. Data cover residents of Hackney and the City registered with a GP in Hackney, the City of London, Tower Hamlets and Newham. [28]

Notes: Deprivation is defined using the Index of Multiple Deprivation 2015 (IMD). IMD is a measure of relative deprivation for small areas that combines 37 separate indicators, each reflecting a different aspect of deprivation experienced by individuals living in an area. Deprivation groupings are reported from 1 (most deprived) to 5 (least deprived).

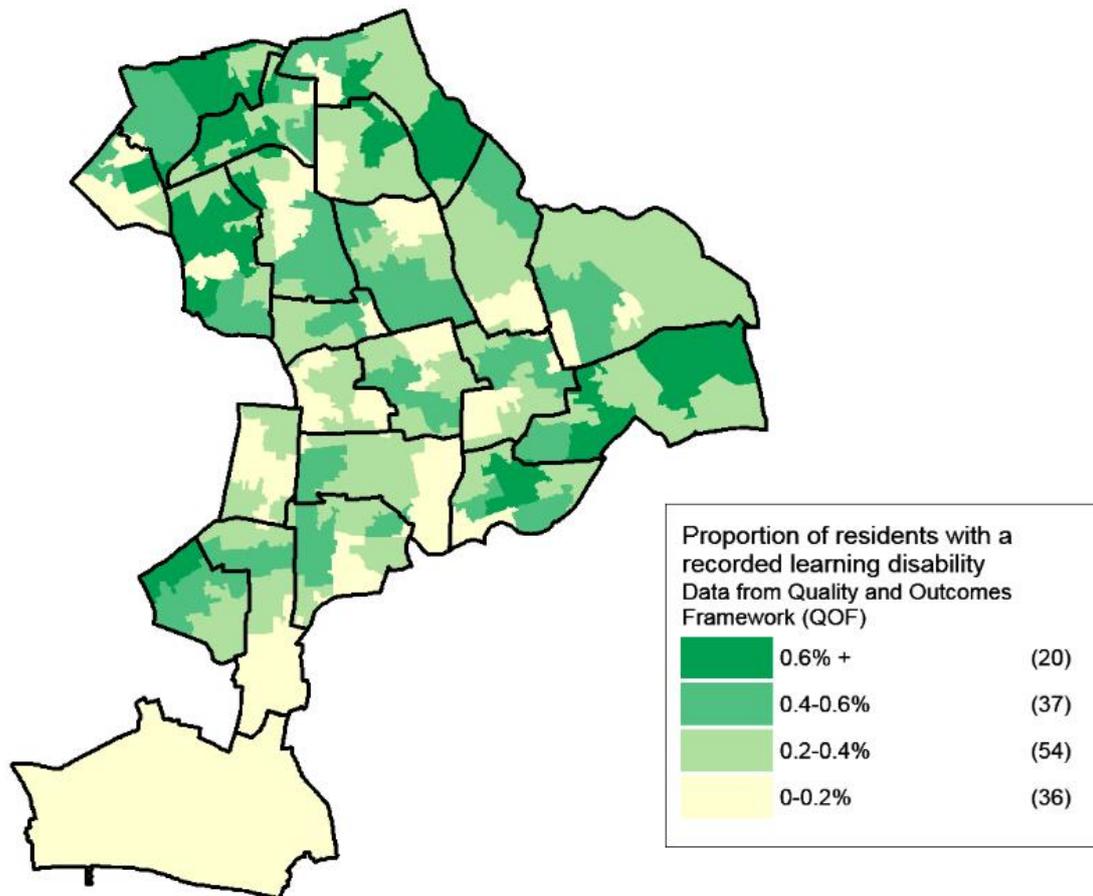
2.4.5 Location within Hackney and the City

Figure 10 shows that prevalence of GP-recorded learning disability is comparatively high in the north west of Hackney (0.77% in Stamford Hill West compared with 0.44% on average across Hackney and the City). This area of relatively high recorded prevalence is also a locality with high levels of relative deprivation (see Hackney Profile [33]). There are also relatively high rates of recorded learning

disability towards the south east of Hackney near Homerton Hospital; this area has several supported living accommodations in the vicinity which may explain this finding.

The reasons for the geographical patterns observed in Figure 10 cannot be fully understood from the available data, but may reflect variation in the underlying prevalence of learning disability in different localities and communities and/or variations in recording practices by GPs.

Figure 10: Percentage of Hackney and the City residents with GP-recorded learning disability, by lower layer super output area (LSOA³) (age 18+, 2016)



Source: Extracted from the local GP register by CEG, Blizard Institute, April 2017. – Data cover residents of Hackney and the City registered with a GP in Hackney, the City of London, Tower Hamlets and Newham. [28]

In 2017, 20% of people receiving long-term adult social care support in Hackney had their care needs met through services out of the borough (n=467). There are a number of reasons for this, with a common reason being the lack of suitable specialist facilities in the local area to meet some of the most complex health and care needs. Out-of-borough care, however, can lead to service users being separated from family and social networks. In addition, the local authority incurs a

³ Lower Layer Super Output Areas (LSOAs), are geographic areas that are part of a hierarchy designed to report small area statistics in England and Wales. One LSOA contains an average population of 1,500 people

greater cost for out-of-borough placements, due to increased staff time and travel costs associated with client assessments. Trends in out-of-borough placements are discussed in Section 2.5.2.

2.5 Comparisons with other areas and over time

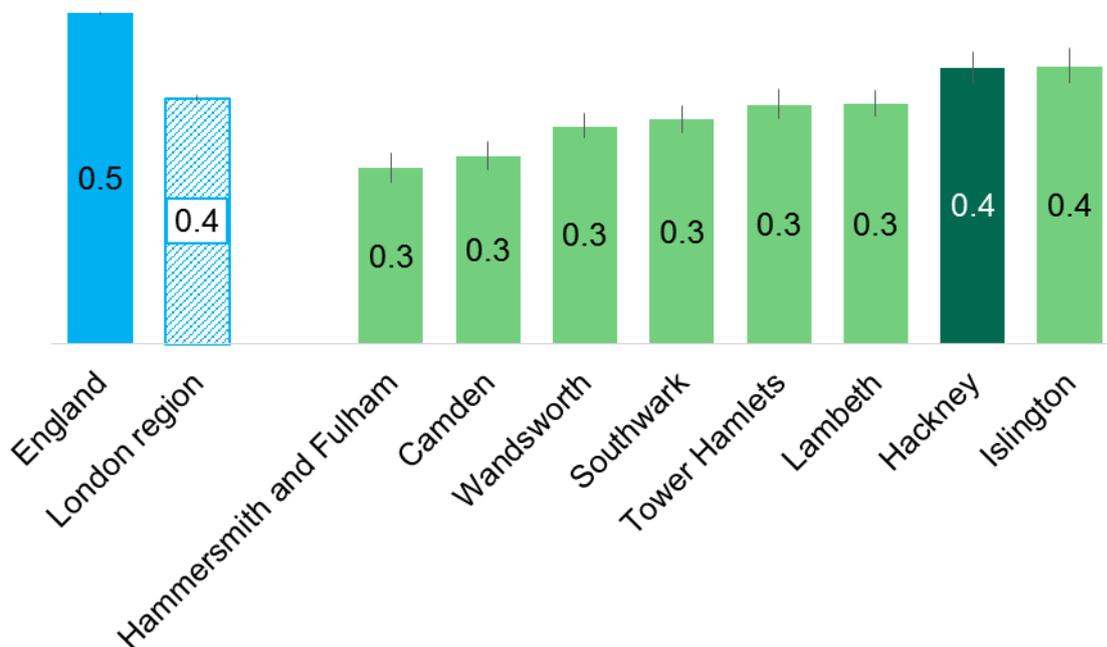
For the purposes of comparison, the GP-recorded prevalence data presented here are taken from a different source to that used earlier in this section. In addition, the available data are based on all ages (not age 18+). Local figures presented below therefore differ from those reported in Sections 2.3 and 2.4.

Data for the City are not available due to small numbers.

2.5.1 Prevalence

GP-recorded prevalence of learning disability in Hackney is higher than most similar areas in London but lower than the England average (Figure 11). Higher recorded prevalence may indicate higher underlying prevalence or reflect different recording practices across different areas.

Figure 11: Prevalence (%) of GP-recorded learning disability, by local authority (all ages, 2016/17)



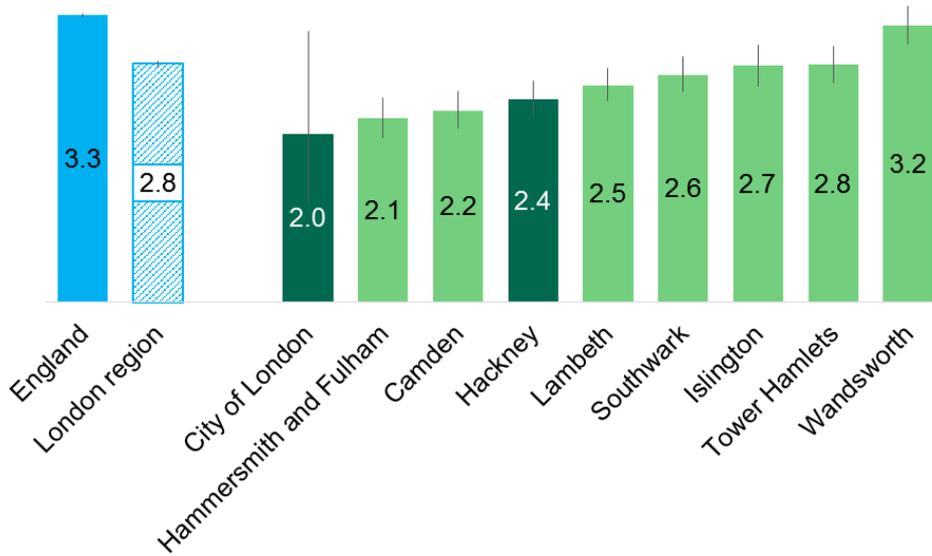
Source: PHE Fingertips. [32]

2.5.2 Social care

Figure 122 shows that the rate (per 1,000 population) of adults with learning disability receiving long-term social care support in Hackney is below the London and England average, but not very different from most of its statistical peers.

The number of people receiving long-term learning disability support per 100 adults known to have a learning disability by their GP is significantly lower in Hackney than England, London and similar local areas (Figure 13).

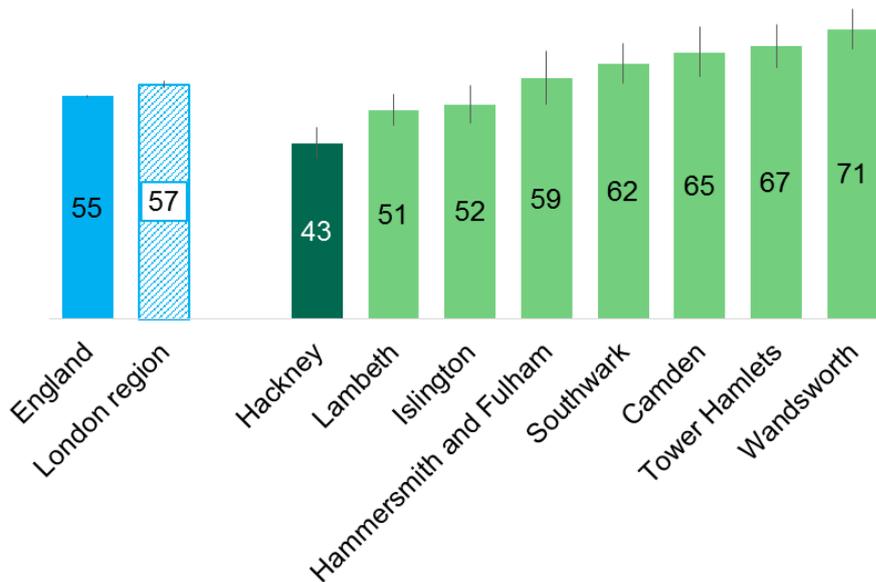
Figure 12: Rate of people with learning disability receiving long-term social care support, by local authority (per 1,000 population, age 18+, 2015/16)



Source: Public Health Outcome Framework.

Note: Confidence intervals not provided. 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 .

Figure 13: Rate of people on local GP learning disability (QOF) registers receiving long-term social care support, by local authority (per 100 people on QOF register, age 18+, 2015/16)

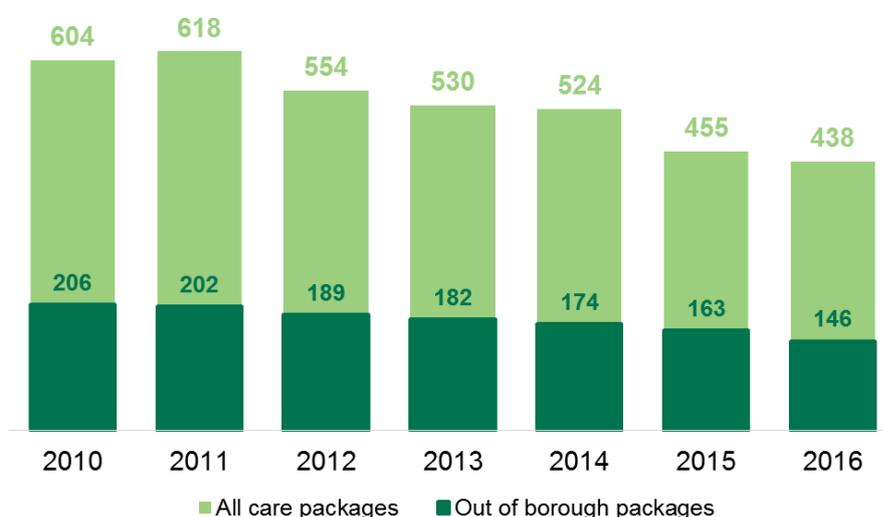


Source: Public Health Outcome Framework.

Note: Data not available for the City of London.

As reported in Section 2.3.1, there were 470 adults with learning disability receiving long-term support in Hackney as of March 2017, with 90% receiving support for over one year. Since March 2010, the number of adults with learning disability receiving a care package has decreased by almost 30%. 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 borough (due to limited employment and housing options) and are often being cared for by family living locally. [30] The proportion receiving care out of the borough has remained broadly constant over this time (see Figure 14).

Figure 14: Number of Hackney adults with learning disability receiving a care package over time (age 18+, 2010 – 2016)



Source: Adult learning disability needs assessment.

2.6 Evidence and good practice

The following subsection summarises and updates the key findings of a policy and evidence review published in the City and Hackney adult learning disability needs assessment. [5]

2.6.1 Policy review

A number of key policy documents have been published in recent years that aim to protect and promote the health and wellbeing needs of people with learning disability. 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 disability within the health and care system: [29]

- 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.

2.6.2 Organisation of health and care services

A summary of best practice and evidence-based recommendations on the organisation of health and care services for adults with learning disability is provided below. [5]

- All people with learning disability should be offered support to access mainstream services through reasonable adjustments.⁴ 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 disability.
- People with learning disability 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 disability 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.
- Transition support for young people moving from children's to adult services should be a purposeful and planned process, and services should be based on recommendations from the National Institute for Health and Care Excellence (NICE). [34]
- A new guideline from NICE aims to ensure that people with learning disability are given the help they need to access a range of services as they grow older, so they can live healthy and fulfilled lives. It covers identifying changing needs, planning for the future, and delivering services, including health, social care and housing. [35]

⁴ 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 disability 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. For more detailed information, see the 'Carers' section of this chapter of the JSNA.

2.6.3 Managing the health needs of adults with learning disability

The findings of a rapid review of the evidence on effective management of specific health needs of adults with learning disability are summarised below. [5]

- 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 comorbidities 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 the person's 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 disability can help to address significant unmet need in this population.
- On average, adults with learning disability are less likely to be physically active, and 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 (swallowing difficulties) in people with learning disabilities.

2.6.4 Housing support

The following provides an overview of effective and best practice approaches to meeting the housing support needs of adults with learning disability. [5]

- Planning for future housing needs in a local area must take account of the adequacy of accommodation available for people with learning disability.
- 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 read' format.
- People with learning disability 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 disability 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 disability and their carers.

2.6.5 Education and employment support

The following summarises key recommendations for effectively meeting the education and employment support needs of adults with learning disability. [5]

- Improving access to employment for adults with learning disability 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 disability are 'incapable' of employment must be challenged.
- Further education must prepare people with learning disability 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 disability to gain and retain paid work.
- The needs and objectives of people with learning disability and employers should be taken into account when planning employment options.

2.7 Services and support available locally

2.7.1 Introduction

This subsection provides an overview of key services available to learning disabled adults (and their families) living in Hackney and the City of London, focusing specifically on specialist services. More detail can be found in the 2016 needs assessment report, as referenced earlier. [5]

Given the increased risk of severe mental illness and dementia among adults with learning disability (see Section 2.1), they are more likely than average to come into contact with specialist mental health services. These services are described in the

'Mental health and substance misuse' JSNA chapter. Mainstream services for other conditions that are prevalent among adults with learning disability (including respiratory disease, diabetes and sensory impairment) are covered in the 'Adult health' chapter of the JSNA.

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 from residents of Hackney. Due to the small number 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 subsection.

2.7.2 Organisation of health and care services

Direct enhanced service (DES) annual health checks

All GP practices in the Hackney and the City 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 disability
- 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 Hackney and the City since 2014; previously the Quality and Outcomes Framework (QOF) register was the main method of capturing the details of patients with learning disability. 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.

City and Hackney Integrated Learning Disability Service (ILDS)

The ILDS is comprised of health and social care professionals 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 when suitable.

Note: Only the health elements of this service are available to eligible City residents.

The ILDS offers a range of specialist health services to any eligible adult with learning disability 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 at Homerton Hospital.

The ILDS also manages access to funding for social care services, with eligibility defined in the Care Act 2014. 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.

As described in Section 2.3.1, there were 470 adults with a learning disability receiving a care package in Hackney in March 2017.

Adult with complex needs

For adults with more complex needs, there are various housing and care options available, depending on the level of assistance required. These include the following.

- Day services: a planned programme of activities designed to promote wellbeing through social and health-related activities and services.
- Housing with care and supported living: generally located in a large block of apartments, with small units for individuals along with shared space areas, often for dining/activities.
- Residential home placements: provided for people with care needs that cannot be supported within a community setting.
- Nursing home placements: provided for those with a health need.
- Inner North East London Transforming Care Partnership (TCP): aims to reduce inpatient bed usage for people with learning disability.

The majority of adult social care clients are likely to receive a support package that covers support with daytime activities.

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.

Hackney Ark

The Hackney Ark is a centre for children and young people with special educational needs and disability (SEND). It is funded by the Homerton University Hospital NHS Foundation Trust 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 Hackney Ark also runs the small Transition Health Outreach service, which works with young people aged 14–19 with a disability who are not in education, employment or training (NEET). The service supports young people who would not

normally qualify for social care and do not have dedicated support from professional services such as social workers.

Services to support young people moving from children's to adult services

Hackney has a newly developed transitions pathway, which is described below.

The transitions steering group will strategically direct and manage Hackney's local transitions offer, and strengthen the care pathways for young people with disabilities aged 14 to 25 who are eligible to receive services from the Integrated Learning Disabilities Service or from adult social care services. This steering group will ensure that local partnership arrangements and commissioning activities are sufficiently adequate to support the Preparing for Adulthood programme core outcomes of:

- maintaining good health
- independent living
- social inclusion
- training for employment.

The steering group is supported by the post-16 commissioning panel, which is a joint panel made up of commissioners from education, health and social care. This panel is responsible for ensuring that the level of support for young people in transition is appropriate and that plans are sustainable and affordable for the longer term.

The transitions case management group sits below the post-16 commissioning panel. The purpose of this group is to identify young people with disabilities aged 14+ who are likely to transition into adult services when they turn 18. This multidisciplinary group, made up of professionals from children's and adult services, will discuss individual cases and their specific support needs and plan to transition them to the most appropriate care pathway. See Box 3 for the objectives and expected outcomes of this group.

*Box 3: Objectives and expected outcomes of the transitions case management group**Objectives*

- To facilitate safe and smooth transition from children's into adult services/ILDS.
- To ensure that the young person meets the eligibility criteria for adult services/ILDS and that screening or assessment takes place before their 18th birthday.
- To ensure that care packages are tailored to meet the young person's needs and that they promote independence, skills development, choice and control.
- To make recommendations to the post-16 commissioning panel in relation to care packages and/or health provision.

Expected outcomes

- Services will appear joined up from the user's perspective.
- Transfers will be well planned and timely.
- Service users and carer expectations will be managed appropriately and the stress of transition will be reduced.

In addition to the transitions steering group, the Preparation for Adulthood steering group has been established to discuss cases and monitor the transition process. This group has a specific focus on education and meets quarterly 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).

The City of London does not have a formal transitions service, although there is a transitions forum that meets regularly to discuss all transition cases.

Learning Disability Partnership Forum

The Learning Disabilities Partnership Forum for Hackney was launched in May 2018. The forum is designed to be a platform for people with learning disability to discuss local services and strategy in relation to the rights, level of choice, independence and inclusion of adults with learning disability.

Carer support

City and Hackney Carers Centre has a support group that is specifically for those who care for people with learning disability. More information about general services and support for carers can be accessed in the 'Carers' section of this JSNA chapter.

2.7.3 Managing the specific health needs of adults with learning disability

Community and Special Care Dental Service

The Community and Special Care Dental Service (CDS) is run by Barts Health NHS Trust and aims 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.

Right Choice sexual health clinic

The Right Choice Connect Hackney clinic is a sexual health service specifically aimed at people with learning disability in Hackney. The service is a collaboration between Homerton University Hospital NHS Foundation Trust sexual health services and the Family Planning Association (FPA). The FPA has a range of experience in helping to establish sexual health clinics for people with learning disability.

The Right Choice clinic is an appointment-only service run from the Ivy Centre at St Leonard's Hospital and aims to ensure that people with learning disability:

- have access to good quality, accessible, non-judgemental information about sex, sexual health and relationships
- have adequate time with 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.

2.7.4 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 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).

Social housing services in Hackney and the City are universally available through the relevant teams in each area. People with 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.

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 these criteria, specialist provision can be purchased on the open market.

Floating support services provide housing-related support for adult with learning disability to help them manage their accommodation, sustain stable tenancies/home owner agreements, and live independently in the community. Floating support in Hackney is available for any person aged 16+ who has learning disability.

The Targeted Preventative Service (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 – including adults with learning disability.

2.7.5 Education and employment support

Hackney has three special schools (Stormont House, The Garden and Ickburgh) that cater for children with learning disability up to the age of 19; and Hackney Community College provides specialist support for students aged 16–25 with learning disability.

Employment rates among people with learning disability in Hackney and the City of London are low. The percentage point gap in the employment rate between those with learning disability and the overall employment rate in 2016/17 was 68.6% in Hackney and 82.1% in the City of London. [36]

The Hackney Works service is run by the council and aims to generate employment opportunities within the borough. Within Hackney Works there is a supported employment service that targets residents who experience the greatest barriers to work, including people with learning disability. For more information on this service, see Box 4.

There are also a number of schemes within the voluntary sector that offer supported employment and volunteering opportunities for adults with complex needs, including learning disability and mental health needs.

Box 4: Case study – Hackney Works Supported Employment service⁵

The aim of this service is to provide targeted support to improve the employment opportunities and outcomes for residents with health and social care needs. It offers pre-employment support, job matching and in-work support.

Intended service outcomes include:

- more people with health and social care needs are supported to gain and sustain paid or self-employment
- to promote and enable employment for more than 16 hours per week
- all working-age people with health and social care needs consider work as a viable option, and this is demonstrated in their person-centred plans, support plans, reviews and transition plans
- to improve the quality of life for people as a result of being employed
- to ensure that people are supported into employment that matches their skills and abilities
- employers are supported to understand, and are enabled to accommodate, the needs of people with health and social care needs as well as carers.

⁵ For more information, visit <https://hackneyworks.hackney.gov.uk/support>

2.7.6 Advocacy

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, while not giving their personal opinions or those of the organisation that employs them.

A new advocacy service for adults with learning disability in Hackney was launched in April 2018. The service will have a single point of access for all statutory advocacy needs in the borough. The Advocacy Project is providing this service. There are also a range of other advocacy services that adults with learning disability can access locally, including the Hackney Informed Voices Enterprise (HIVE) and Hackney People First.

All statutory advocacy services in the City of London are provided by an organisation called POhWER (commissioned by the City of London Corporation).

2.8 Service gaps and opportunities

As noted in Section 2.6.2, all people with learning disability should be offered support to access mainstream services through reasonable adjustments. However, despite mainstream services having a legal obligation to provide such reasonable adjustments, this does not always happen.

Until recently, there was no formal transitions service in Hackney and the City of London catering for the health and social care needs of people moving from children's to adult services. To address these gaps in Hackney, existing arrangements have been reviewed and a programme of work is now underway to improve transition pathways. This is described in detail in Section 2.8.

More generally, the new Hackney and the City integrated commissioning system provides a fresh opportunity to bring together commissioners, providers and residents to redesign health and care services to better meet the needs of local people. Improving support for people with learning disability, and their carers, is a major priority within the new system.

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