Learning disability (LD) is defined as including the presence of a significantly reduced ability to understand new or complex information, and to learn new skills with a reduced ability to cope independently; and a childhood onset of such difficulties which are life long (Source ICD 10 and DSM V).

Nationally 0.5% of people have a learning disability (0.4% in London), the support needs of this group vary depending on the severity of their learning disability (PHE fingertips).

### Key facts
- Population estimates for the number of people with LD in Camden indicated around 1,075 people in Camden (all ages) with LD.
- There has been a sustained increase in the number of people recorded on the LD register in Camden since at least 2013, due to improvements in the completeness of registers, reaching 1,014 by March 2019 (compared with 788 in 17/18).
- In 2018, 281 adults with LD in Camden required accommodation, equivalent to 0.14% of the Camden adult population.
- In 2017/18, schools in Camden (primary, secondary and specialist) recorded 472 pupils with moderate to severe and profound learning difficulties.
- Amongst the GP-registered population with a learning disability and long term conditions, Epilepsy is the most common co-morbidity.
- Women are less likely to be diagnosed with a LD; they account for 39% of GP-registered LD population whereas men account for 61%.
- Amongst those people with a recorded learning disability, highest proportions are identified from ethnic groups of: White English, White other, Black African, Black Caribbean and Bangladeshi ethnic groups.
- There are 159 people with LD in Camden known to Elfrida Rathbone service, providing care for someone with a learning disability.
- Forty percent of recorded carers are aged over 60, and a similar proportion are aged 40-59. Many older carers are lone parents.

### Measures for reducing inequalities
- Annual health checks (AHCs) for people with learning disabilities help to detect and treat long term conditions. In Camden 75% of GP-registered population with LD aged 14 and over (621 individuals) received an AHC in 2018/19 (compared with 476 in 17/18). AHC uptake has consistently been one the highest in the country.
- People in Camden have reported the need for easy read and accessible information when accessing health, social care and employment services.
- Employment rate for people with LD in Camden is 6.5%.
- In 2017-18, there were 774 learners with LD, who attended the Camden Adult Community Learning service.

### National & local strategies
- **Our Camden Plan** outlines a plan to achieve the Camden 2025 vision, a vision of a Camden where no one is left behind.
- The **Transforming Care** programme aims to support people with a learning disability outside of long stay inpatient care.
- **Supporting People Connecting Communities** is Camden’s adult social care strategy, the strategy prefaces personalised care, the use of community assets and strength based approaches.
Definition of Learning Disability

The term learning disability (LD) is used to describe a significant, lifelong experience that has three components:

– Significantly reduced ability to understand new or complex information, to learn new skills, significantly impaired intelligence, and
– reduced ability to cope independently (impaired social/adaptive functioning), and
– onset before the age of 18 years, with a lasting effect on development (Scottish Government Publications 2000).

This definition encompasses people with a broad range of disabilities, but not all people with a “learning difficulty”.

This definition is based on the World Health Organization (WHO) approach that uses intelligence quotient (IQ), social functioning and age of onset. The IQ element is the conventional cut-off score of 70.

Below this score there are four classifications of LD: mild (50–69), moderate (36–49), severe (21–34) and profound (20 or lower).

GLOSSARY (TERMINOLOGY)

**CLDS:** Camden Learning Disabilities Services, an integrated health and social care service for people with learning disabilities. The service, as part of Camden Council, provides an integrated approach to assessment, care management, care coordination, therapeutic intervention and health professional training and support for people with learning disabilities.” Includes staff from Camden Adult Social Care, Camden and Islington NHS Foundation Trust, Whittington Health and Central and North West London Trust. (Camden LD Joint Commissioning Plan)

**CYPDS:** Children and Young People Disability Service, a specialist Social Care provision for children, young people, young adults (birth to age 25) with complex and profound disabilities and their families, offering a range of statutory and social care support needs (Cindex Organisations in Camden website).

**Young Adults:** people aged 18-25, **Young People:** people aged up to 18

**PHE:** Public Health England is an executive agency, sponsored by the Department of Health and Social care, which exists to protect and improve the nation’s health and wellbeing and reduce health inequalities. (www.gov.uk website)

**CCG:** Clinical Commissioning Groups, which are clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area. 195 CCGs present in England (NHS England, NHS Clinical commissioners website)

**QOF:** Quality Outcome Framework, which is a way of rewarding general practices for provision of quality of care, using specific indicators. Data obtained from practices based on indicators is collected for each financial year. (NHS employers website)
The Equality Act 2010
- Made discrimination on the basis of a protected characteristic (disability included) illegal.

The Care Act 2014
- Determined responsibilities of Local Authorities when providing care and support for adults and carers.

The Children and Families Act 2014
- New SEND support system, covering education, health and social care.

Building the Right Support plan 2015
- Aimed to shift money from inpatient services to the community, and reduce the use of inpatient beds.

The Government’s Mandate to the NHS 2016-17
- Objective for the NHS to close the health gap between people with LD and general population

The Camden Plan 2025 & Our Camden Plan
“Everyone has a chance to succeed and where nobody gets left behind.”
- Housing
- Work
- Community participation
- Environment
- Health

Camden Adult Social Care strategy
Supporting People Connecting Communities Camden 2025
- Community assets
- Strengths based approach
- Personalisation and integration
- Digital innovation
In Camden there were 1,014 people registered as having a learning disability (LD) in primary care at 31 March 2019.

- There has been a significant and sustained increase in the GP LD register in Camden, since at least 2013. In 2013/14, there were 513 people on LD registers in Camden. By March 2019, this had risen to 1,014 individuals. A small proportion may be due to underlying population changes, but this is mainly attributable to improved coding and case finding, linked to ongoing training and support.
- The gap between the size of the LD register and the population-based estimate of expected prevalence (1,075) has accordingly closed significantly.
- A snapshot of the register in November 2018 (when 922 people were on the QOF LD register) found 794 people with LD aged 14 and above and 128 people with LD under age-14.
- Based on national prevalence estimates, Down Syndrome is estimated to account for 0.1% and Autistic spectrum disorder is estimated to account for 1% of the Camden population.

- Amongst all-ages of the Camden LD population, 61% are men and 39% are women. Only in the 75+ age group of Camden individuals with Learning disability, is there a higher proportion of women compared to men.
SETTING THE SCENE: DEMOGRAPHY

Percentage of people with a recorded LD in Camden in 2015, by ethnicity

- LD recorded
- GP reg. population

- White English
- Irish
- Any other white background
- White and Black African
- White and Black Caribbean
- Any other mixed background
- Black African
- Black Caribbean
- Any other black background
- Bangladeshi
- Indian
- Pakistani
- Any other Asian background
- Any other ethnic group

Note: 5 people had no ethnicity recorded and were excluded from this analysis. The category "Any other ethnic background" includes Arab ethnic category. It has been combined due to small numbers.
Source: Camden PH GP Dataset 2015

Numerically White English, Other Mixed, Black African, Black Caribbean and Bangladeshi ethnic groups were the largest ethnic groups among people with LD.

Percentage of people with a recorded LD in Camden in 2015, by main spoken language

- LD recorded
- GP reg. population

- English
- Bengali (with Sylheti and Chatgaya)
- Somali
- Arabic
- Portuguese
- Any other Language (EU)
- All other languages

Note: Only people with a LD and with a main language spoken recorded were included in the analysis. 8 people had no language recorded and were excluded from this analysis. The category "All other languages" includes Albanian, Brawa, Cantonese, Dutch, Ethiopian, Farsi, Greek, Hebrew, Italian, Kurdish, Kutchi, Mandarin, Polish, Russian, Spanish, Swahili, Sylheti, Tigrinya, Turkish and Urdu. They have been combined due to small numbers.
Source: Camden PH GP Dataset 2015
Between 2015 and 2017, proportion of pupils (children residents known to schools) with a learning difficulty is much lower in Camden compared to London and national average.

There has been a gradual decease in the proportion of pupils recorded with LD In Camden in 2016 and 2017, compared to 2015.

Across all years, there are substantially higher proportion of pupils identified to have moderate learning difficulty as opposed to severe or profound/multiple.

Between 2015 and 2017, there was a decrease in the proportion of pupils recorded with moderate learning difficulties.

There was an increase in proportion of pupils identified with severe learning difficulty, although this was not statistically significant.

There was a small reduction in the number of pupils recorded with profound and multiple learning difficulties.

Source: Department for Education statistical collections: Special Educational Needs, local authority tables, 2017
SETTING THE SCENE: DEMOGRAPHY IN YOUNG ADULTS AND YOUNG PEOPLE

YOUNG PEOPLE (AGED 14-17)

Gender

A total of 88 young people (14-17 years old) with learning disability (LD) are registered in Camden. About two thirds (58) of young people with a Learning disability (LD) in Camden are male.

Age group

There is a higher proportion of young people aged 16 years old (32%) with LD compared to other single ages among 14-17 year olds.

Ethnicity

White ethnic groups accounted for just over a third of young people. Young people from Asian and Black communities accounted for 26% each and mixed/other, 13%.

Source: CYPDS register, Camden (2018)

YOUNG ADULTS (AGED 18-25)

Gender

A total of 119 young adults (18-25 years old) with learning disability (LD) is registered in Camden. About two thirds (78) of all young adults with LD in Camden are male.

Age group

There is a higher proportion of young people aged 22 years old (17%, 20) with a learning disability among 18-25 year olds.

Ethnicity

White ethnic groups accounted for 39% of young adults with LD, Black communities 31%, Asian communities 14% and Mixed/Other communities 15%.

Source: CYPDS register, Camden (2018)
SETTING THE SCENE: accommodation NEED IN YOUNG PEOPLE AND YOUNG ADULTS

YOUNG PEOPLE (aged 14-17)

5 of 88 (6%) young people with LD were in residential care, supported living or own flat or shared lives in 2018

9 of 88 (10%) young people who might be in need of future accommodation (supported living/own flat; assessed by commissioner). Some of these children have chronic ill health, multiple and sensory disability, special educational needs, speech communication disorder or may need future accommodation due to current situation (e.g. child protection proceedings).

Total 14 of 88 (16%) of young people with LD were in current and future need of accommodation. This equates to 3.5 young people on average per year.

Out of Borough:
Less than 5 young people

Source: CYPDS register, Camden (2018)

YOUNG ADULTS (aged 18-25)

24 of 119 (20%) young adults with LD were in residential care, supported living or own flat or shared lives in 2018

9 of 119 (8%) young people with LD might be in need of accommodation (supported living/own flat). Less than 5 of these young adults are at risk of significant harm due to inadequate parenting or need of personal care.

Total 33 out 119 (28%) of young adults with LD were in current and future need of accommodation. This equates to 4.1 young people on average per year.

Out of Borough: 19 out 119 young adults (16%)

Source: CYPDS register, Camden (2018)

Potential annual average number of 14-25 year olds with LD who may have adult accommodation needs is 7.6
Setting the scene: Demographics of those with LD in accommodation

These figures include the total number of people with LD in need of accommodation, including those on floating support (i.e. within their home) and in supporting accommodation living outside the borough.

Number and percentage of people with learning disability (LD) in accommodation by sex, 18+, Camden, 2018

There are **281 adult** Camden’s residents with learning disability in accommodation who represent 0.14 per cent of the Camden resident population (18+). **60%** (167) of all adults with Learning disability (LD) in accommodation in Camden were men.

Number and percentage of people with learning disability (LD) in accommodation by age, 18+, Camden, 2018

- Significant proportion of people with LD needing accommodation are **white** (70%)
- Compared to general population, people with LD who are **Asian** and needing accommodation are **underrepresented** (17% vs 5%).

There has been a steady increase of people with LD needing accommodation between 2013 and 2018 in the **65+ age group** (10 more older people).

**Source:** CLDS Mosaic Social Care data extract (October, 2018)
Number and percentage of accommodation type or accommodation-support provided to adults with LD aged 18+, Camden, 2018

- In 2018, the most common types of accommodation or accommodation support provided to adults with learning disability were: **supported living** accommodation (111, 38%), followed by **floating service** (81, 28%, some of whom were also provided with accommodation) and **residential** accommodation (80, 27%).

Number and percentage of people with learning disability (LD) settled in accommodation, 18+, Camden, 2018

- In Camden, 5 residents (1%) with learning disability receiving long term support from the council were classified as 'unsettled' in 2017/18, as defined by national statistical returns. This definition may include unsatisfactory accommodation or accommodation where there is not security of tenure, such as residential care homes.

**Tenure type, adults with LD, receiving services or known to Camden social care**

The table below shows the tenure type for all adults with LD in Camden receiving services from, or known to, Camden social services. The most common residence was the family home (300, 41%), followed by tenancy (council/housing association/private) (160, 22%) and Supported Living (129, 18%).

<table>
<thead>
<tr>
<th>Tenure Type</th>
<th>Number of people</th>
</tr>
</thead>
<tbody>
<tr>
<td>Owner occupier</td>
<td>&lt;5</td>
</tr>
<tr>
<td>Tenancy (council, housing assoc, private)</td>
<td>160</td>
</tr>
<tr>
<td>Supported Living</td>
<td>129</td>
</tr>
<tr>
<td>Family Home</td>
<td>300</td>
</tr>
<tr>
<td>Shared Lives</td>
<td>5</td>
</tr>
<tr>
<td>Sheltered or Extra Care Sheltered Housing</td>
<td>16</td>
</tr>
<tr>
<td>Residential School</td>
<td>&lt;5</td>
</tr>
<tr>
<td>Registered Care Home</td>
<td>83</td>
</tr>
<tr>
<td>Registered Nursing Home</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>31</td>
</tr>
</tbody>
</table>

Source: Camden (CLDS) Mosaic Social Care data extract (May, 2019)
The profile of carers recorded on the Mosaic social care database system indicates a high proportion of older adults among carers. Almost 40% of the recorded carers were aged 60 and over, including 16% aged 70 and over. About 40% of the carers were aged between 40 and 59 years old. There was a lower proportion of younger carers aged between 20 and 39 years old.

Housing Association, and Staying with friends/Shelter house have the highest proportions of no recorded carers (70% and 81% respectively).

The highest proportion (83%) of recorded carers is found in more permanent accommodation as mainstream housing (i.e. living with friends, family and flat share).

Source: Camden Mosaic Social Care data extract (May 2019)
The rate of adults (aged 18 and above) with LD in Camden receiving long-term support from local authorities is **2.28 per 1000** in 2017/18. This was lower than the rate for London (2.91) and England (3.38).

In 2017/18, no supported working-age adults with learning disability (aged 18-64) and receiving long-term support in Camden were reported as living in severely unsatisfactory accommodation (see note below), compared to 0.14% and 0.15% in London and nationally.

**26%** of supported adults with learning disability in Camden (aged 18+ and older adults, receiving long-term support) received direct payments in 2017/18. This is slightly less than England (29%) and London (30%).

The rate of people with LD (aged 18+) in Camden identified as involved in section 42 safeguarding enquiries (i.e. referred to safeguarding) was 34 per 1000 (of GP-registered Camden LD population) in 2017/18. This compares with London (48 per 1000) and statistically lower than England (52 per 1000).

Source: NHS Digital Adult Social Care Data (Fingertips, 2018)

Note: Severely unsatisfactory accommodation is defined as undesirable accommodation for emergency situations (specifically for those who are vulnerable/ in need of support). They include: rough sleeper, night shelter, emergency hostel, refuge, temporary council accommodation (e.g. bed and breakfast or homelessness resettlement).
### Summary of Housing Projection data: Children & Young Adults

- The average number per year of children aged 14 and 17 years old with a diagnosis of LD in need of accommodation in Camden is projected to increase from 3.5 in 2018 to 4.1 in 2025 (16%), and to then decrease from 4.1 in 2025 to 3.6 in 2035 (-10%), based on the children population growth and assuming that there is no change in the prevalence of this diagnosis over time.

- The average number per year of young adults aged 18 and 25 years old with a diagnosis of LD in need of accommodation in Camden is projected to remain fairly stable at 4.1 from 2017 to 2025 (1%), and to increase from 4.1 in 2025 to 4.5 in 2035 (8%).
Demand for future accommodation: population projections in children and young adults with learning disability in need of accommodation

The average number per year of children aged 14 and 17 years old with a diagnosis of LD in need of accommodation in Camden is projected to increase from 3.5 in 2018 to 4.1 in 2025 (+ 16%) before a decrease from 4.1 in 2025 to 3.6 in 2035 (-10%, but similar to the number in 2018), based on the 14-17 year old population growth and assuming that there is no change in the prevalence of this diagnosis over time.

The average number per year of young adults aged 18 and 25 years old with a diagnosis of LD in need of accommodation in Camden is projected to remain fairly stable (from 4.10 in 2018 to 4.14 in 2025) in 2025 (+ 1%), and then to increase from 4.10 in 2025 to 4.50 in 2035 (a further +8% increase).

**Average number per year of children (14-17 years old) with LD in need of accommodation based on the GLA children population projections in Camden, 2018 - 2020, 2025, 2030 and 2035**

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of people with LD</th>
</tr>
</thead>
<tbody>
<tr>
<td>2018</td>
<td>3.5</td>
</tr>
<tr>
<td>2020</td>
<td>3.6</td>
</tr>
<tr>
<td>2025</td>
<td>4.1</td>
</tr>
<tr>
<td>2030</td>
<td>3.8</td>
</tr>
<tr>
<td>2035</td>
<td>3.6</td>
</tr>
</tbody>
</table>

16% increase expected between 2018 and 2025

-10% decrease expected between 2025 and 2035

**Average number per year of young adults (18-25 years old) with LD in need of accommodation based on the GLA young adult population projections in Camden, 2018 - 2020, 2025, 2030 and 2035**

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of people with LD</th>
</tr>
</thead>
<tbody>
<tr>
<td>2018</td>
<td>4.1</td>
</tr>
<tr>
<td>2020</td>
<td>4.1</td>
</tr>
<tr>
<td>2025</td>
<td>4.1</td>
</tr>
<tr>
<td>2030</td>
<td>4.4</td>
</tr>
<tr>
<td>2035</td>
<td>4.5</td>
</tr>
</tbody>
</table>

1% increase expected between 2018 and 2025

8% increase expected between 2025 and 2035

**Source:** Camden Mosaic Social Care data extract (Oct 2018)
Summary of Housing Projection data: Adults

The annual numbers of people entering LD accommodation and those leaving were provided for the period 2013-18, via the MOSAIC system. The data included the type of accommodation. Overall the trend was broadly steady over 2013-17, but 2018 showed a marked difference with recent years both in a smaller number of new entries to accommodation and a higher number of people leaving accommodation.

Trends in the number of adults with LD who require accommodation support (excluding those requiring floating support only) was modelled to examine trends around adult accommodation need.

Projections of future need for accommodation for adults with LD were produced taking account of:

- Expected changes in the LD population in the borough (which gives a general indication of the changes in underlying need).
- Extrapolating recent trends in accommodation, by accommodation type (which gives a general indication of how recent trends in accommodation and accommodation type would look if repeated into the future), with an adjustment for population growth.
- Using both approaches it can be expected that need will increase in net terms by between 7 and 13 by 2025 and by between 11 and 26 by 2035, compared with the median of 215 people with LD in adult accommodation over the period 2013-18.
The increased demand for future accommodation for people with learning disability (LD) is based on predicted population growth. The number of people with a diagnosis of learning disability (LD) in Camden is projected to increase from 744 in 2017 to 789 in 2025 (+6%) and to 818 in 2035 (+10%), based on population growth and assuming that there is no change in the prevalence of this diagnosis over time. During 2018, Camden GPs have reviewed their registers and added more people to their LD registers. Based on November 2018, the LD registers size would increase from 1,014 to 1,075 in 2025 and 1,115 in 2035. The estimated number of people with LD is higher than the actual number recorded at Camden’s GP practices, and is projected to increase from 1,075 in 2017 to 1,140 in 2025 (+6%) and to 1,183 in 2035 (+10%).

**Number of people with LD (all ages) recorded at the Camden’s GP practices based on the GLA projection population, 2018 - 2035**

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of people</th>
</tr>
</thead>
<tbody>
<tr>
<td>2017</td>
<td>1,075</td>
</tr>
<tr>
<td>2025</td>
<td>1,140 (+6%)</td>
</tr>
<tr>
<td>2035</td>
<td>1,183 (+10%)</td>
</tr>
</tbody>
</table>

**Number of estimated number of people with LD (all ages) based on the GLA projection population in Camden, 2017, 2025 and 2035**

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of people</th>
</tr>
</thead>
<tbody>
<tr>
<td>2017</td>
<td>1,014</td>
</tr>
<tr>
<td>2025</td>
<td>1,140 (+10%)</td>
</tr>
<tr>
<td>2035</td>
<td>1,183 (+10%)</td>
</tr>
</tbody>
</table>

**Note:** Camden and Islington PHI team has calculated the projected number of LD (all ages) based on the 2017 GLA projection population.

**Source:** QOF 2017/18

**Note:** Camden and Islington PHI team has calculated the projected number of LD (all ages) based on the 2017 GLA projection population.

**Source:** POPPI & PANSI dataset (2017)
Population projections in adults with learning disability estimated by POPPI & PANSI

Estimated projected number of people with moderate or severe learning disability by age, Camden 2017 and 2035

<table>
<thead>
<tr>
<th>Age Group</th>
<th>2017</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
<th>2035</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>1,075</td>
<td>1,122</td>
<td>1,175</td>
<td>1,235</td>
<td>1,280</td>
</tr>
<tr>
<td>25-34</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35-44</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45-54</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>55-64</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65-74</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>75-84</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>85+</td>
<td></td>
<td></td>
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</tbody>
</table>


<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>All adult (18+)</td>
<td>19%</td>
</tr>
<tr>
<td>85+</td>
<td>114%</td>
</tr>
<tr>
<td>75-84</td>
<td>63%</td>
</tr>
<tr>
<td>65-74</td>
<td>47%</td>
</tr>
<tr>
<td>55-64</td>
<td>43%</td>
</tr>
<tr>
<td>45-54</td>
<td>27%</td>
</tr>
<tr>
<td>35-44</td>
<td>9%</td>
</tr>
<tr>
<td>25-34</td>
<td>22%</td>
</tr>
<tr>
<td>18-24</td>
<td>0%</td>
</tr>
</tbody>
</table>

NOTE: PANSI and POPPI calculated estimated learning disability predictions based on relatively old prevalence rates in a report by Eric Emerson and Chris Hatton of the Institute for Health Research, Lancaster University in June 2004. The authors take the prevalence base rates and adjust these rates to take account of ethnicity (i.e. the increased prevalence of learning disabilities in South Asian communities) and of mortality (i.e. both increased survival rates of young people with severe and complex disabilities and reduced mortality among older adults with learning disabilities). Therefore, figures are based on an estimate of prevalence across the national population; locally this will produce an over-estimate in communities with a low South Asian community, and an under-estimate in communities with a high South Asian community.

Source: POPPI & PANSI dataset (2017)

• The increased demand for future care for people diagnosed with moderate/severe learning disability based on predicted estimates is different across ages.

• Overall, the estimated number of all adults (18+) with moderate/severe learning disability in Camden is estimated to rise from 1,075 in 2017 to 1,280 in 2035 (+19%). This increase is higher than the London (+18%) and England (+9%) averages.

• The greatest percentage increase is expected to be in older people aged 85+, increasing from 7 in 2017 to 15 in 2035 (+114%), although the overall number is low. The next high percentage increase is among older people aged 75-84 years old, increasing from 19 in 2017 to 31 in 2035 (+63%).
Demand for future accommodation: population projections in adults with learning disability by type of accommodation

The increased demand for future accommodation for people with learning disability (LD) is based on predicted adult population growth (18+). Applying the expected adult population growth to average number of adults with LD in residential accommodation in the borough, for example, over the period 2013-18 (87), this would estimate 92 (+6%, 5 people extra) in residential accommodation in 2025 and 97 (+12%) in accommodation in 2035, assuming no changes in approach to accommodation.

Number of adults (18+) with a recorded LD by type of accommodation (excluding people on floating support) based on the GLA projection population, Camden, 2013/18, 2020, 2025, 2030 and 2035

Please note: This trend is based on the total people with LD in Local authority funded accommodation excluding people receiving floating support (i.e. within their own home).

Note: Camden and Islington PHI team has calculated the projected number of LD based on the 2017 GLA projection population. People with LD in supported.
* 6-year average data.
Source: Camden Mosaic Social Care data extract (May, 2019)
Demand for future accommodation: population trajectory in adults with learning disability by type of accommodation

The increased demand for future accommodation for people with learning disability (LD) is based predicted trajectory. Projecting the trend in 2013-18 into the future and adjusted the trajectory with the expected GLA population growth, the total adult LD, for example, in supporting living accommodation (18+) in the borough is projected to increase from an average 100 in 2013-18 to 111 (extra 11 people) in 2025 and 127 (extra 27 people) in 2035.

Number of adults (18+) with a recorded LD by type of accommodation based on the linear trajectory adjusted by the expected GLA population growth, Camden, 2013/18,2020, 2025, 2030 and 2035

Note: Camden and Islington PH team has calculated the projected trajectory of learning disability (18+) based on the actual 6-year trend average data trend between 2013 and 2018. * 6-year average data

Source: Camden Mosaic Social Care data extract (May, 2019)
Demand for future accommodation: adults with LD migration in/out accommodation

There has been year on year variation in numbers entering and leaving accommodation support over the past five years. In most recent years, numbers entering into LD accommodation support outnumbered those leaving. In 2018, there were 22 adults (18+) with a recorded LD in need of accommodation who left the service, and 3 adults who joined the service in the same year. This was a net reduction of 19 adults, markedly different from other recent years. Possible reasons for the smaller number of new entries in 2018 were discussed by LD commissioners. It was noted that the number of deaths in 2018 (10 deaths) were higher than in previous years, and may in part have contributed to the higher number of people leaving accommodation compared with other recent years.

Number of adults (18+) with a recorded LD in need of accommodation with any starting or leaving services in Camden, 2014 - 2018

Net change of the number of adults (18+) with a recorded LD in need of accommodation with any leaving or starting service in Camden, 2014 - 2018

Source: Camden Mosaic Social Care data extract (May 2019)
• People with LD are more likely to have long term conditions by comparison to the Camden general registered population (32% vs 18%)
  - Almost 1 in 4 have Epilepsy
  - 18% have Asthma
  - 13% have hypertension
  - 12% have Depression
  - 12% have SMI (serious mental illness).
• As a proportion of the total registered population, people with LD and at least one LTC comprise 0.28% of GP registers.

Source: GP linked dataset (2015)
• 52% of people with LD in Camden are overweight or obese. This is much higher than the proportion of general Camden GP-registered population who are overweight or obese (combined is 28%);
• The highest proportion of people with LD that were obese or overweight were in the 50-74 age group.

• Across the different BMI categories, there are similar proportions of males and females with LD who are underweight, overweight and of a healthy weight.
• However there is greater percentage of females with LD who are obese than of males (32% compared with 25%).

Note: The number of people with an unknown smoking status (63) was not included in the analysis because it was too small and potentially disclosive when broken down by age. Passive smokers

• 15% of LD individuals are smokers or exposed to passive smoking, which is slightly lower than the general Camden GP-registered population (17%);
• Highest proportion of people with LD who smoke are in the “25-49” age group; however the highest proportion of ex-smokers is amongst those people with LD over the age of 50.

Source: GP linked dataset (2015)
LeDeR programme (Learning Disability Mortality Review) publishes an annual report. The 2016/17 report:
- States “People with LD die, on average, **15-20 years sooner** than people in the general population” and some deaths identified as “potentially amenable to good quality health care”.
- LeDer established to support local areas to review the deaths of people with LD, identify learning from deaths, and to apply this learning as initiatives to improve the service.
- Between 1\textsuperscript{st} July 2016 and 30\textsuperscript{th} November 2017, **total 1311 deaths** notified to LeDer programme nationally.
- Approximately **1 in 10 deaths** were among those in out-of-borough placement.
- 44\% had known cause-of-death. 1/3\textsuperscript{rd} of deaths were due to respiratory causes, including pneumonia.
- Recommendations include improvement in information-sharing between organisations (including electronically), use of health-action plans, mandatory LD awareness training (for all staff), use of a local named health care coordinator (for those with at least 2 long term conditions) and national training for those conducting mortality-reviews.

*Source: LeDer Annual report 2016/17, published December 2017*

**In Camden:**
- the LeDeR programme has identified 11 deaths of people with LD since December 2016 (when reporting to the programme was initiated in Camden).
- In the 5 years leading up to April 2016, the CLDS service identified 30 deaths in people with LD, an average of 6 a year.

*Source: CLDS and Camden LeDeR programme*
LeDer Programme 2017: Learning Disabilities Mortality Review programme (LeDer) with summary of information on deaths notified and attributable factors.

LD Good Practice Project: completed by NVFF (National Values Family Forum) and National Forum (of people with LD) in response to the Winterbourne View Transforming Care recommendations. Sets out to identify services for people with LD which are identified as “good practice”.

LD Health Check Scheme: Department of health (DoH) scheme with aim to reduce the incidence of comorbidities and premature death in people with LD. Encourages practices to identify all patients aged 14 and over with learning disabilities, to maintain a learning disabilities ‘health check’ register and offer them an annual health check, which will include producing a health action plan.

Health Inequalities and People with LD in UK, 2011
Reviews social determinants of poor health, associated health risks, communication and access to health care with Recommendations for Social Care.

Delivering High Quality end of life care for people with LD: Document composed by PCPLD (Palliative Care of People with Learning Disability) network and NHS England; to provide commissioners, service providers and health/social care professionals with resources and tips. Uses various ambitions with tips and structured examples.

Working Together 2: published by PHE and Improving Health and Lives, acts as a resource for hospital staff, families and paid support staff working with people with LD to help them get the care they need, every step of the way from pre-admission planning to discharge.
Camden Joint Commissioning Plan for Adults with LD (2013-2016)
Outlines the framework for commissioning and delivery of health and social care services to those with LD and carers. Includes Core Commissioning Objectives on personalisation, having a life, having a home, safeguarding, good health, complex needs, smooth transition into adulthood and supporting carers.

Camden LD Profile, 2013:
Overview of the Camden LD population at this time and comparison of health indicators.

Supported Housing MTFS Business Case (2018)
LD accommodation and support projects:
- CLDS reviews to reduce over-provision of LD individuals in supported living
- Re-commissioning of supported living services.
- Re-commissioning of floating support

Planning and Commissioning Housing for People with LD 2013:
Toolkit for Local authorities and partners to effectively plan for the housing requirements of local people with learning disabilities and deliver wide range of options..

Making CLDS Promise real: Transforming LD support in Camden (2018-2021)
Review of high cost care packages and floating support, Supported Living retender and review with CLDS innovation site, accommodation Needs Strategy

Transforming employment support for people with mental health conditions 2017:
An evaluation of 2 pilots in Camden
The Camden Learning Disabilities Service (CLDS) is an integrated health and social care service for adults with learning disabilities living in or supported by the London Borough of Camden and/or registered with an NHS Camden GP.

We define learning disabilities according to internationally recognised criteria including those of the World Health Organisation (ICD-10) and American Psychiatric Association (DSM-IV). People with learning disabilities experience life-long impairments in both cognitive and adaptive functioning.

In assessment by CLDS as to whether someone has learning disabilities, both the cognitive and adaptive functioning of the person are considered:

- **Cognitive functioning** is assessed using a standardised measure of intelligence. The measure that is used most often is the Wechsler Adult Intelligence Scale – Fourth Edition. This involves the completion of a number of “Verbal” and “Performance” sub-tests and yields a Full-Scale IQ score. Learning disabilities are partially defined by a Full Scale IQ score of 69 or below.

- **Adaptive functioning** is assessed through interview, observation and/or the completion of standardised checklists such as the Adaptive Behaviour Assessment System (ABAS) or the Assessment of Motor and Process Skills (AMPS). Learning disabilities are partially defined where a significant, life-long impairment in at least two major areas of functioning is identified. The areas assessed by CLDS include communication, community use, functional academics, home living, health & safety, leisure, self-care, self-direction, social and work skills.

There are many people who would score 69 or less on an assessment of cognitive functioning but who do not have significant problems in adaptive functioning, and so these individuals would not be considered by CLDS to have Learning Disabilities.

**EXCLUSIONS (people who are unlikely to be considered to have learning disabilities by CLDS include):**
- people whose impairments in cognitive or adaptive functioning occurred after the age of 12 years, caused by neurological illness or injury, mental health problems or drug or alcohol misuse
- people with specific learning difficulties, including Dyslexia and Dyspraxia, who do not have an IQ score of less than 70.
- people with an Autistic Spectrum Disorder who do not have a learning disability

*Source: CLDS*
WHAT WORKS: BEST PRACTICE PRINCIPLES

NICE, the Department of Health and Public Health England have published guidance and best practice principles when commissioning services or providing care for people with learning disabilities.

<table>
<thead>
<tr>
<th>Principle</th>
<th>Application</th>
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| Personalised care           | • Practitioners working with someone with a learning disability should get to know the person they support and find out what they want from their lives, not just what they want from services (NICE)  
  • Personalisation should not be a cost cutting measure (DOH)                                                                 |
| Coproduced services         | • People should be actively involved in all decisions that affect them (NICE)  
  • Service users should not only be involved in planning services but in some cases, delivering them (DOH)  
  • Assess for Gillick Competence and ensure the 5 principles of The Mental Capacity Act are followed at all times |
| A strengths based approach  | • Support should identify what is possible and positive rather than following a pre-determined approach (NICE)  
  • Services should be provided with a consideration of the things a person can do, rather than the things they cannot do (DOH) |
| Integrated services         | • Bring together health, social care and leisure services for people with learning disabilities (DOH)                                          |
| Capacity building           | • Identify and deliver opportunities for people to gradually rely on more community based support (DOH)                                      |
| Accessible                  | • Deliver services for people with learning disabilities with appropriate reasonable adjustments  
  • Make sure that relevant information is available in easy read formats                                                     |
Evidence supports a number of health care interventions that help people with learning disabilities to achieve good outcomes.

**Hospital Passports**
- A hospital passport provides key information about a patient with a learning disability, including personal details, the type of medication they are taking, and any pre-existing health conditions.
- The passport also includes important information about how a person communicates and their likes and dislikes, which can be crucial when they are first admitted to hospital.

**Annual Health Checks & Health Action Plans**
- People with learning disabilities aged 14 and over are encouraged to have an annual health check with their GP.
- Annual health checks and health action plans help detect and treat manageable long term conditions (Robertson et al., 2014).
- Health action plans should always be provided in an accessible format (PHE quality auditing AHCs).

**Accessible Information**
- The Accessible Information Standard (AIS) was introduced by the government in 2016 to make sure that people with a disability or sensory loss are given information in a way they can understand.
- The Equalities Act 2010 explicitly mandates the provision of accessible information as a reasonable adjustment for people with a learning disability.
- The process of creating and designing accessible health information may bring together different social groups in new ways that might well benefit people with intellectual disabilities.

**Liaison Nurses**
- Learning disability liaison nurses often work in secondary care, they assist people with LD, their families and carers and medical staff throughout time in hospital.
- Liaison nurses are most effective if they have expertise, authority to make decisions that change patient care pathways, access to all clinical areas within the acute trust structures; high visibility and availability and strong support from senior hospital managers (Tuffrey-Wijne I, Giatras N, Goulding L, et al).
WHAT WORKS? INTERVENTIONS IN SOCIAL CARE

Evidence supports a number of health care interventions that help people with learning disabilities to achieve good outcomes.

**Named Worker**
- NICE guidance stipulates that local authorities working in partnership with healthcare professionals should assign a single practitioner, for example, a social worker to be the person’s ‘named worker’. The named worker should get to know the person and coordinate support to meet their needs over the long term.

**Floating Support**
- Housing-related support can be permanently attached to a particular tenancy (for example, sheltered accommodation), or can be provided on a ‘floating’ basis. Floating support services are linked to individuals, rather than their accommodation.
- Floating support services are effective when provided in a flexible way that responds to service users’ needs, they can be put in place quickly and enable people to remain in their own home (Watters, Gray, Clarke, 2012)

**Shared Lives**
- Shared lives schemes support adults with learning disabilities, mental health problems or other needs that make it harder for them to live on their own.
- Shared lives schemes help people with learning disabilities to learn the skills they need to live independently, to establish a connection to a community and to move into a place of their own.

**Personal Budgets & Direct Payments**
- Benefits of personal budgets and direct payments include the ability to personalise support, tailor activities to suit individuals and ensure that the timing and structure of services work for individual needs.
Cancer Screening

- Overall uptake of Cervical cancer screening in women (aged 25-64) in Camden with Learning disability is 33%, whereas in general Camden population, this is 66%. This has been obtained from NHS digital 2016/17.
- Local GP extract data has suggested that only 15% of eligible women with LD in Camden have been screened for Breast Cancer as opposed to 23% in the general population, although this may be under-representative.

![Percentage of women in receipt of cervical screening over 5 years, eligible registered population aged 25 - 64, Camden, 2012/13 - 2016/17](chart)

Percentage of women in receipt of cervical screening over 5 years, eligible registered population aged 25 - 64, Camden, 2012/13 - 2016/17

- 90% of females and 84% of males with learning disability in Camden were in receipt of Blood pressure screening over 5 years 2013-17
- This was greater than the proportions of women (67%) and men (53%) in the general Camden GP-registered population in receipt of blood pressure screening.

Vaccinations:

- In 2016/17, 39% of people with LD were vaccinated against Seasonal Influenza. This is lower than the average uptake for people in Camden in the "at-risk" Camden population who require influenza vaccination (70% aged over 65, 50% in 65 and under)
Annual Health Checks in primary care

- Overall, there were 521 out of 720 (72%) people diagnosed with a learning disability who had their annual checks completed in 2017-18.
- There was a wide range of completed health checks across 34 practices; the percentage of 8 practices achieved 100% uptake of annual health checks; 6 practices less than 40%.

**NOTE:** It should be noted that the average number of people with LD on a practice register is relatively small, and therefore, large percentage variations between practices may be due to small numerical differences in coverage. Similarly, any practice with patients with LD under 14 could not achieve 100% coverage, since LD Health Checks are only indicated for patients aged 14 and over.

**Source:** NHS Camden CCG.
ASSETS AND SERVICES: SECONDARY CARE

Summary of secondary care presentations
- Amongst 644 secondary-care presentations of people with LD in Camden in 2014/15:
  - 49% (314 presentations) were outpatient-based, 32% (205) were A&E-spells and 19% (125) were inpatient admissions.
  - Note: LD is likely to be undercoded in secondary care, and so may be higher than recorded here.
  - These are similar to the proportions of secondary care use amongst general Camden population: 51% outpatient, 32% A&E-spells and 17% inpatient admissions.

Hospital admissions for LD individuals in Camden

Percentage of hospital admissions by provider (where LD was recorded), 2014/15

- Royal Free London: 23%
- The Whittington Hospital: 11%
- University College London: 35%
- Other: 22%

Note: 1% of all hospital admissions amongst people in Camden in 2014/15 were to Camden and Islington NHS Foundation Trust. Lack of admissions noted at UCL may be related to under-coding.

Source: GP linked dataset (2015) and SUS data (2014/15)
ASSETS AND SERVICES: EDUCATION AND EMPLOYMENT

EDUCATION:
- As of 2017/18 academic year, the Camden Adult Community Learning Service recorded 774 learners with learning disability/difficulty e.g. dyslexia etc. (accounts for 19% of the total 4060 learners seen by the service). Of these 774 learners:
  - 56% were aged 19-59 i.e. a wider definition than Learning Disability; and 44% aged 60+.
  - 67% were female, 33% were male
  - This accounted for 22720 hours of student hours and total 1451 course-enrolments.
- Providers accessed by majority of the LD individuals included: General Community Learning, Community Learning and Westminster Kingsway College.

EMPLOYMENT:
- In 2015/16, NHS digital adult social care data estimated that:
  - The employment rate for supported working-age people with a learning disability in Camden was 6.5%. The London average was 7.5% and England average was 5.8%.
- Furthermore, it was noted in the work with “Transforming employment support for people with physical or learning disabilities - An evaluation of a pilot in Camden” in October 2017, that:
  - People with a learning disability are significantly less likely to be in work than those without. Previously in England, 17% of all adults with Learning disability were estimated to be in paid work (CeDR report 2008).
  - At present, there are employment support services available for people with learning disabilities (e.g. Camden Society) and physical disabilities (e.g. Clarity - Employment for Blind People and Scope) but none that combine the two. There are no services that support employers in looking at their organisational approach towards employing people with learning disability.

Camden Ability Pilot, 2017: From January 2016 to December 2017, Camden Ability have been involved in a Pilot to support people in Camden with physical and/or learning disabilities into employment. 63 people received support from an employment advisor and as a result, 11 started employment.
ASSETS AND SERVICES: VOLUNTARY AND COMMUNITY SECTOR ORGANISATIONS

CENTRE 404
- Charity that provides person-centred support for people with LD. Includes one-to-one support, support for families, personal budgets, supported housing projects, group activities and day opportunities.
- Currently they support **984 carers** (for people with LD) across Camden, Islington, Hackney, Haringey and others. **14%** of their service-users receiving care are in Camden. **62%** of families are lone-parents and **one-third** of carers are aged 41-50.
- *(Source: Centre 404 website, data from Centre 404)*

ELFRIDA RATHBONE
- Charity that focuses on achieving independence, personal development and empowerment for children/young people and adults with disability, as well as their families. Services:
  - Educational project work for young people (aged 16-25) with autism/LD
  - Young People for Inclusion (provide specialised training, consultancy for businesses/organisations to improve access and inclusion)
  - Camden Futures services to support families with significant needs (with children aged up to 18).
- *(Source: Elfrida Rathbone website)*

BETTER LEISURE CAMDEN
- 7 day timetable, hosting different sessions at Talacre Sports Centre, Swiss Cottage Leisure Centre, Kentish Town Sports Centre and Pancras Square Leisure Centre.
- Sessions include swimming, rock-climbing, multi-sports tailored to those with disability. Many sessions free or subsidised.
- **196 pre-paid** members who have LD attend the service.
- *(Source: Data from Better Leisure Camden team)*

CAMDEN SOCIETY
- Charity that support generate new opportunities for people with disability; work with 600 people across London and Oxfordshire.
- Include supported living services, employment and learning services (e.g. apprenticeships, training), short breaks, community and leisure services.
- *(Source: Camden Society Website)*
ASSETS AND SERVICES: ELFRIDA RATHBONE

Demographics

There was no significant difference by gender or age.

44% 56%
Percentage of female (n=69) Percentage of male (n=88)

Disability type and severity

<table>
<thead>
<tr>
<th>Disability Type</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderate Learning Disability</td>
<td>5</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>6</td>
</tr>
<tr>
<td>Learning Difficulty</td>
<td>7</td>
</tr>
<tr>
<td>BESD (Behavioural, Emotional and Social Difficulties)</td>
<td>9</td>
</tr>
<tr>
<td>ADHD (Attention deficit hyperactivity disorder)</td>
<td>10</td>
</tr>
<tr>
<td>Mental Health</td>
<td>10</td>
</tr>
<tr>
<td>Other</td>
<td>13</td>
</tr>
<tr>
<td>ASD (Autism spectrum disorder)</td>
<td>14</td>
</tr>
<tr>
<td>Unknown/Refused</td>
<td>83</td>
</tr>
</tbody>
</table>

Note: Attention deficit hyperactivity disorder (ADHD), Behavioural, Emotional and Social Difficulties (BESD), Autism spectrum disorder (ASD).

Source: Elfrida Rathbone - Data extracted in August 2018.
Camden 2025 (2018)
Produced following discussions with citizens of Camden on the vision for 2025. Further sets out specific goals to this vision in the Camden plan below.

These are some aspirations set out by Camden Council, as to what they hope to achieve in the next 4 years to make Camden a better borough. The document reiterates the goals of Camden 2025 vision:
1) Homes and Housing (everyone to be able to have a place that they call “home”, which is affordable, well-maintained, well-managed and suits their needs.)
2) Strong growth and access to growth (strength and inclusivity - everyone being able to access work that is appropriate for them).
3) Safe strong and open communities (for Camden to be safe, open and for everyone to be able to contribute towards their community; includes supporting people with disabilities to live independently e.g. the use of the Centre for Independent Living).
4) Clean, vibrant and sustainable place (for Camden to be a clean, vibrant and sustainable place e.g. reducing carbon emissions).
5) Health and Independent lives (health and wellbeing to be placed at the forefront e.g. reducing prevalence of mental health and prevention of long term conditions but also support those with either)

Connecting Camden Communities
Gives an overview of Camden’s population changes, financial context, relationships between the council and residents and key strategic goals with measures of outcome:
1) help for residents to stay well and connected (e.g. measured by proportion of LD individuals registered with Camden GP, who received an Annual health check)
2) help for residents when needed (proportion of those LD adults in paid employment, wait for referral to CLDS<18 weeks and number of those accessing short-term floating support)
3) ongoing support for those who need it (e.g. adults with LD who need support to live in their own home or with their family)
4) Help for adults to stay safe (e.g. patient-centred safeguarding practice empowering residents who have experienced harm/abuse)
5) Use of resources
- **STOMP (Stopping Over Medication of People with LD, 2016)**
  High proportion of those with LD and/or autism estimated to be taking antipsychotic/antidepressant medication without appropriate clinical indication. Aim of this document is the use of steps and algorithms to assist key professionals to reduce or stop psychotropic drugs inappropriately used in LD individuals. Created by NHS England, Royal Colleges and Societies.

- **Transforming Care of People with LD (2015)**
  Jointly produced by several organisations including CQC, NHS England (in response to Winterbourne Review) with the aim to committing to transforming care for people with LD. Includes specific goals such as: empowering people and families (e.g. the use of Care and Treatment Review), getting the right care in the right place (supported discharges, inappropriate-admission avoidance, implementing new service models) regulation and inspection (to improve quality) and workforce development (delivering person-centred care and support for LD individuals).

- **Learning Disability Annual Health Checks Overview and Target**
  Sets out the evidence base of health checks and encourages practices to ensure that all individuals with LD aged 14 and above have a health-check (physical and mental health needs) and be added onto the GP learning disability register. Key ambitions to see a **10% increase in those identified on GP LD register year-on-year and for 75% of those on register** to have had their AHC by 2020 (those eligible), with improvement in quality of health check.

  Sets out the mandate to NHS England and includes 7 specific NHS England objectives and measures of how NHS England’s performance will be assessed. Objective 6 and the overall 2020 goal: to **close the health gap between people with mental health problems, learning disabilities and autism and the population as a whole**. Goal for improvement is Increase in people with learning disabilities/autism being cared for by community not inpatient services.
Service-user engagement with Centre 404
representatives joint from Camden, Haringey and Islington:
- Continuity and a relationship with a GP highlighted as a key concern for people with LD and their carers
- Key feedback regarding annual health checks: issues regarding invitation and quality and carers/parents of people with LD unaware of AHC entitlement
- Recommendations to include LD health checks in LD-friendly settings and need for reasonable adjustments. Providing training to practices

Source: Service User Engagement with Centre 404

Feedback from Camden LD residents about employment (2013)
- Identified challenges to seeking employment, e.g.: stigma (LD individuals were worried of consequences of telling their employer about disability) and lack of roles within organisations to suit those with LD.
- However service helped staff reflect on attitudes towards disability and employers to learn about types of disability.

Source: Transforming employment support for people with physical or learning disabilities - An evaluation of a pilot in Camden October 2017

Feedback from Camden Ability Pilot (2017)
- In 2013, 8% were in paid employment.
- From the remaining 360 unemployed residents with LD, when asked 65% said they would like to work.

Source: Transforming employment support for people with physical or learning disabilities - An evaluation of a pilot in Camden October 2017

Feedback from Carers (Planning Together Meeting, July 2018)
- Representatives discussed feedback from carers on barriers to employment such as difficulty completing forms, lack of correspondence with Department of Work and Pensions, inclusivity/assessment style.

Source: Planning Together Meeting Minutes, July 2018

Feedback from Carers (Planning Together Meeting, October 2018)
- Meeting with CLDS, Council, DWP, local organisations and parents/carers of those with LD.
- Feedback and key agenda points from meeting included: nomination of a parent/carer representative for “supported employment forum”, presentation on the “housing and support plan”, responses to questions regarding shared lives, housing management, floating support and trial of health-guide app.

Source: Planning Together Meeting Minutes, October 2018

Role for Advocacy Groups:
- **Camden People First**: aim to empower people with learning difficulties to speak up for themselves. They provide training to organisations such as local authorities and the NHS on awareness of learning difficulties and educate policy makers of the needs of people with learning difficulties.
- **Learning Disabilities POhWER Advocacy service** includes community LD advocacy service (assistance with making choices, understanding rights and to help LD individuals “be heard”) and independent health complaints advocacy (support to make complaint about NHS or service provider).
- **SYNERGY (LD Experts by Experience Project)**: team employed by Camden Disability Action; work with Centre of Independent Living and in the housing-needs consultation) and also raise awareness/advocate for people with LD by meeting with different organisations regularly.
Some immediate things that have come up so far in the process of review include:

- **Uptake of Annual Health Checks** is at 72%. There is however, significant variation between practices. With the recent increase in number of people on the LD register in Camden to 922, there will be a need to maintain uptake of annual health checks.

- **Diagnosed prevalence** in general practice is significantly below national and London average (data obtained from GP-registered population), as well as below the expected prevalence in the population. Whilst there may be underlying differences in the Camden LD population, this is a significant and it could be because practices may not have been identifying people with LD and so we need to optimise identification of those with LD.

- **Increase in future adult LD population size** with estimated projection to 1140 individuals (65 additional people) by 2025. Need to optimise resources at CLDS (including accommodation-need, support) accordingly to cope with the increased list of registered people in Camden with LD.

- **Significant percentage of accommodation is out-of-borough** (108 people with LD, which is 38% of total 281 who are in accommodation). Need to optimise housing within Camden, suitable for people with LD.

- **Screening rates** for breast and cervical cancer are well below general population. There are some limitations on obtaining data from GP practices on cancer screening data in this population. Need to optimise screening rates in the cohort of individuals with LD.

- **Highest comorbidities in people with LD** are Epilepsy, hypertension, asthma, depression and serious mental illness. Need to consider screening of these long-term conditions in LD population, especially mental health needs.

- **Over half of 644 secondary-care presentations** amongst people with LD in Camden were to A&E (205 presentations) or inpatient-based (125 presentations). Need to continue optimising health of people with LD to prevent A&E presentation/hospital admissions.

- **Low employment rate** of 6.5% in the LD Camden population (amongst people receiving support) despite majority with a desire to work. Need to improve access to gaining employment.
RECOMMENDATIONS

Based on the Gaps identified in the Needs assessment, we have made the following recommendations

**Recommendation 1: IMPROVE IDENTIFICATION OF PEOPLE WITH LD, for inclusion of the LD register**

The number of people with LD identified in Camden is significantly lower than national and London average and this may suggest that there are people in Camden with LD who are not yet diagnosed and therefore not on the LD register.

We need to improve identification of people with LD, understand their needs and continue to complete the LD register with ongoing provision of health checks and completion of health action plans.

**Recommendation 2: MAINTAIN UPTAKE OF Annual Health Checks amongst people on the LD register.**

With recent increase in number of people identified on LD register in Camden, there is a need to maintain uptake of Annual health checks.

**Recommendation 3: INCREASE accommodation WITHIN CAMDEN, for people with LD**

We have projected in the number of people in Camden with LD, who will require accommodation in the future. Furthermore, significant number in accommodation are currently out-of-borough. Therefore, we need to optimise accommodation within Camden for people with LD.

We also need to continue empowering/supporting people with LD and their families to live independently. We need a system in place to meet the accommodation needs of those young people/adults in transition. We also need to measures to identify age of carers or those living in the family home to help predict future risk of needing accommodation.

**Recommendation 4: OPTIMISE SCREENING OF PEOPLE WITH LD for LONG-TERM CONDITIONS and CANCER Screening**

Improve screening of people with LD for conditions such as Epilepsy and Serious Mental Illness. This could be achieved by training of key-workers and practices who work with people with LD to be able to identify these conditions. Furthermore, we need to optimise screening of breast and cervical cancer and identify methods of auditing breast cancer screening in this population.

**Recommendation 5: IMPROVE ACCESS AND SUPPORT TO EMPLOYMENT FOR PEOPLE WITH LD**

As only 6.5% of people in Camden with LD (receiving support) are in employment, we need to optimise access and support into employment. This can be achieved by commissioning the use of services such as Camden Ability and working closely with Voluntary and Community sector organisations, to tailor employment to individual’s need. E.g. assistance with job application forms.
We would like to thank the following for their help and contributions in completing this needs assessment:

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- Jo Mackie (Centre 404)
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- Mark Isherwood (Camden Adult Community Learning Service)
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- Alana Pash (Better Leisure/GLL)
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- Brendan Leahy (Synergy)

About Camden’s JSNA

Open Data Camden brings together information held across the organisations into one accessible place. It provides access to evidence, intelligence and data on the current and anticipated needs of Camden’s population and is designed to be used by a broad range of audiences including practitioners, researchers, commissioners, policy makers, Councillors, students and the general public.

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