| Topic information | |
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| **Topic title** | *Adults with Learning Disabilities* |
| **Topic owner** | *LD JCG* |
| **Topic author(s)** | *Liz Pierce Insight Specialist Public Health*<br>*Nick Romilly Insight Specialist Public Health* |
| **Topic quality reviewed** | *November 2016* |
| **Topic endorsed by** | *Learning Disability Joint Commissioning Group* |
| **Current version** | *November 2017* |
| **Replaces version** | *Adults with Learning Disabilities 2011* |
| **Linked JSNA topics** | This chapter focuses on Adults with Learning Disabilities. Adults with physical disability and sensory impairment, Children and young people with special educational needs and disability and carers of adults with learning disabilities are considered in other chapters. |

## Executive summary

### Introduction

Learning disability (LD) is defined as the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence, often defined as an IQ level of 70 or less), with
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.

Adults with learning disabilities are one of the most vulnerable groups in society, experiencing health inequalities, social exclusion and stigmatisation. In general, adults with learning disabilities have greater and more complex health needs than the general population, and often these needs are not identified or treated. Adults with learning disabilities may need extensive support from family, informal carers or paid care staff to live independently or safely. Social care for adults with learning disabilities is one of the highest areas of spending for local authorities at a time when funding to local authorities is reducing.

Life expectancy of this group is shorter than the general population, although this has increased recently. In addition, a number of national reports have highlighted that

adults with learning disabilities often experience barriers to accessing healthcare services and experience poor levels of care. Adults with learning disabilities are more likely to die from a preventable cause than the general population. Following the, 'Confidential Inquiry into Deaths of People with Learning Disability' in the Bristol area, a national mechanism for monitoring deaths is being developed by NHS England with local partners, and will be implemented by CCGs from 2017.

The scandal at Winterbourne View highlighted that some people with Learning Disability (LD), and often with autism spectrum conditions, were remaining for long periods in specialist hospital care, often far from home. The 'Transforming Care' programme looks to redress this at local level through a programme of 'Care and Treatment Reviews' with those individuals affected. This work has prompted investigation into ways of providing more responsive, bespoke care to meet individual needs, enabling people to exercise choice and control and how best to prevent needs escalating to a degree that might require hospitalisation.

For the wider group of people with LD, the Equality Act 2010 requires that 'reasonable adjustments' be made across services to enable access for this group. Public sector organisations are required to 'advance equality of opportunity', 'eliminate discrimination, harassment and victimisation' and 'foster good relations' with regard to people with learning disability and the wider population.

Nottingham has developed mechanisms to understand the local population with learning disability, and has jointly undertaken a health and social care self-assessment overseen by ADASS and Public Health England. This considers not only health and social care needs but also wider social inclusion, for example in leisure and transport. SPLAT, the Learning Disability Partnership Board has evolved to have a structure that enables engagement and inclusion of people with LD and their carers in the governance process of LD locally, including through the self-assessment.

A vibrant and creative voluntary sector supports novel ways to engage and include people with learning disabilities. In many areas, Nottingham fares well for healthcare and social inclusion, however against national comparators the number of people with LD in paid work is very low and warrants additional focus. A recent strategic commissioning review has identified that the use of residential care in Nottingham is high in comparison to other areas and consideration is being given to exploring greater use of supported living options.

**Unmet need and gaps**

**Population health**

- Although the number of people with LD having an annual health check has increased, the proportion of people with LD having a health check at GP practices is variable and many people do not receive a full check or the associated health action plan.

- In recent years, a good infrastructure of liaison services within primary care and secondary acute care that support improvements in reasonable adjustments for people with LD has been established and should be maintained. The hospital liaison team has seen an increase in demand for their services over time.

- The proportion of people with LD who are obesity and overweight is higher than the general population.

- As illustrated by the Confidential Inquiry there are likely to be unmet health needs and preventable early deaths in people with LD.

- There is a risk that concentration of activity on Transforming Care could limit developments to improve the health of the wider group of people with LD.

**Accommodation and Support**

- There is higher use of residential care in Nottingham City and low use of supported living.

- The Transforming Care agenda has demonstrated challenges in identifying flexible, skilled provision in the market for those whose behaviour challenges.

- There is likely to be a rise in demand for services due to demographic changes but also due to changes in family structure and changing expectations.

**Social Inclusion**

- There are low levels of employment in people with LD.

- The LD Communication strategy requires refreshing in the light of the new legislation, and more services need to proactively develop and use easy read materials.

- Level of social vulnerability cannot be predicted by the level of LD. People with mild LD may be at increased risk of social vulnerability, such as hate crime, homelessness, exploitation or substance misuse, as well as experiencing the impact of welfare reform.

**Recommendations for consideration by commissioners**

**Population Health**

- Ensure actions across the Health and Wellbeing Strategy recognise the needs of people with learning disabilities.

- Partnership arrangements need to be established with NHS England to improve uptake and monitoring of the annual health check programme.

- Ensure health and care services are joined-up to support people with a combination of physical health needs and LD e.g. diabetes, cancer, asthma, end of life care, obstetric care.

- As a result of SEND reforms, specifically the increase in the age supported up to 25 years, and changes to the health check programme, now offered from age 14 years and upwards, commissioners and providers should work together to ensure that healthcare is joined up during the transition period.

- Ensure health promotion and prevention initiatives are actively promoted and inclusive for people with LD, and those supporting them, particularly regarding weight management, healthy eating and physical activity.

- All relevant services should cooperate with NHS England and local Safeguarding Boards in plans for the Learning Disabilities Mortality Review Programme.

- The infrastructure that supports people to access mainstream health services should be maintained and consideration given to whether capacity there is sufficient in the hospital LD liaison service.

- Continue to monitor the overall picture of people with LD in Nottingham through GP data audit including the Miquest audit.

- Public health, the CCG and secondary care should work together to better understand use of the urgent care system by people with LD

**Accommodation, care and support**

- As the life expectancy of people with LD increases consideration should be given to the aging population of carers and adults with LD including preventative early intervention approaches.

- Commissioners should consider a strategic approach to reducing dependence on residential care for people with LD and develop a vision for increased use of more supported living options, with increased choice and independence.

- Continue to explore person centred solutions for the small number of individuals in long term hospital care as part of the Transforming Care agenda.

- Ensure the aspirations of the Care Act 2014, in terms of promoting wellbeing and taking a preventative approach, are embedded into the care system for people with LD.

- Establish a local system for predicting future needs of people with LD and anticipated demand for services based on the current needs of both children and adults.

**Social Inclusion**

- Commissioners should ensure people with LD are included in initiatives to increase quality employment in disabled people.

- Ensure the voice of people with LD are heard through the LD Partnership Board (SPLAT) process, and ensure this is inclusive of BME communities and those in residential care settings.

- Take opportunities to explore ways of including a 'whole life disability' approach where possible recognising that LD is a lifelong disability.

- Champion the social model of disability with partners, with a strong emphasis of people with LD (and their carers) as a specific group under the Equality Act 2010.

- Ensure learning and good practice from Transforming Care agenda informs the planning of care and support for the wider LD population not just those whose needs have resulted historically in prolonged hospitalisation.

- Improve the knowledge of the needs of Nottingham's diverse population including quickly the communities that may not be picked up through routine ethnicity monitoring such as Polish, Rumanian or Roma communities identified in monitoring as other European.

- Ensure initiatives in Nottingham to reduce financial hardship are inclusive of people with LD.

- Explore the impact of the Accessible Information Standard, which all NHS care and or publicly funded adult social care services have a duty to implement since August 2016 for people with a learning disability in Nottingham.

## What do we know?

### 1) Who is at risk and why?

**Learning Disabilities –definition of terminology**

There are a number of definitions of Learning Disability and terminology used in this field can lead to confusion (Emerson and Heslop 2010). Changes in definition reflect a move from a purely medical definition based on measurement of IQ to one that reflects a wider social model of disability. Valuing People Now (DH 2001) defined Learning Disability as follows

*'Learning disability includes the presence of:*

- *a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;*
- *a reduced ability to cope independently (impaired social functioning);*
- *which started before adulthood, with a lasting effect on development'*

However recent NICE guidance (NICE 2015) retains reference to IQ
'*A learning disability is defined by 3 core criteria: lower intellectual ability (usually an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood'.*

In the UK the term *Intellectual Disability* is also used interchangeably with *Learning Disability* and is now used by some local providers of services. *Learning Difficulties* is a term used in children's services and education settings such as school, and in some cases this would be compatible with *Learning Disability* in the adult population, except for *Specific Learning Difficulties* such as dyslexia which do not include an element of lower intellectual ability.

The term learning disability encompasses a very broad range of functioning. Further classification based on cognitive impairment is described by the International Classification of Disease coding system ( ICD-10), though in reality the severity/category of learning disability is rarely used outside of specialist learning disability services:

| Level of learning disability | Associated IQ |
|---|---|
| Mild | 50-69 |
| Moderate | 35-49 |
| Severe | 20-34 |
| Profound | <20 |

Source: WHO, 2007

For the adult population in Nottingham the term Learning Disability is used and is sometimes abbreviated to LD.

**The Learning Disabled Population**

The number of people in the UK adult population who have a Learning Disability is not known, however it is estimated that 2% of the adult population are affected (Emerson & Hatton 2004). This estimate is based on better knowledge of the learning difficulties reported in the child population through the annual school census. However, the majority

of those adults likely to be affected are not expected to be known to adult social care or health services, and are unlikely to self-identify as having a Learning Disability. This group is likely to have mild LD, be socioeconomically disadvantaged with low literacy levels and, if employed, be in poorly paid work. If this group come into contact with services it is likely to be for reasons other than Learning Disability, such as social housing, maternity services, homelessness, substance misuse, or the criminal justice system (often as victims).

A quarter of the total estimated number of adults with Learning Disabilities (about 0.5% of the adult population, 1 in 200) are the group who are known to one or more local services as having a Learning Disability. It is this group on whom most of the literature regarding the needs of people with LD is focused.

Research shows that males are more likely than females to have both a mild learning disability and severe learning disability (1.2 males: 1 female and 1.6 males: 1 female respectively), due to some conditions associated with learning disability having a sex-linked genetic cause (Emerson et al 2001). The ratio decreases with age as women typically live longer.

Mild learning disabilities are strongly associated with parental socio-economic status, but this relationship is not clear for more severe learning disabilities, suggesting that deprivation may be a contributory factor particularly for mild learning disabilities (Emerson et al 2001).

Knowledge about the prevalence of LD in Black and Minority Ethnic groups in the UK is better understood through the recording of children's needs in school. In 2013, 74% of children with a primary Special Educational Need (SEN) of moderate LD were recorded as 'white British' compared with 71% of children with a primary SEN of severe LD and 64% of children with a primary SEN of profound or multiple LD. These differences primarily reflect the higher rates of severe and profound multiple learning difficulties among Pakistani and Bangladeshi children and remain evident when deprivation is taken into account (Emerson 2012 in Hatton et al 2014). Previous studies had reported higher rates for severe learning disabilities in South Asian groups in the UK with rates approximately 3 times higher among 5-34 year olds compared to non-Asian communities (Emerson et al 1997). Reasons for this higher prevalence are not clearly understood, but potential factors are:

- Inequities in access to maternal healthcare
- Higher rates of genetic abnormalities and/or exposure to environmental factors

Consanguineous marriages (usually defined as being related as second cousins or closer) increase the risk of having a child with learning disabilities.

**Patterns of health need**

The Learning Disabilities Health Observatory, known as 'Improving Health and Lives' was until recently part of Public Health England, and published most recent papers on the health outcomes of people with LD. The site is now archived and most recent published reports will be available from Public Health England here. Over a number of years a series of reports have described poor health outcomes, and experiences of poor healthcare, and have highlighted these inequalities as an equality and human rights issue. An overview of the health inequalities experienced by people with LD (Emerson et al and PHE 2016) describe the following key aspects compared to the general population:

- Lower life expectancy – people with learning disabilities have an increased risk of premature death compared to the general population, (figs 1&2) although life expectancy is rising. The median age at death of people identifiable as having learning disabilities in death certificates has risen steadily from 2008 to 2012 from 54 to 58 years.

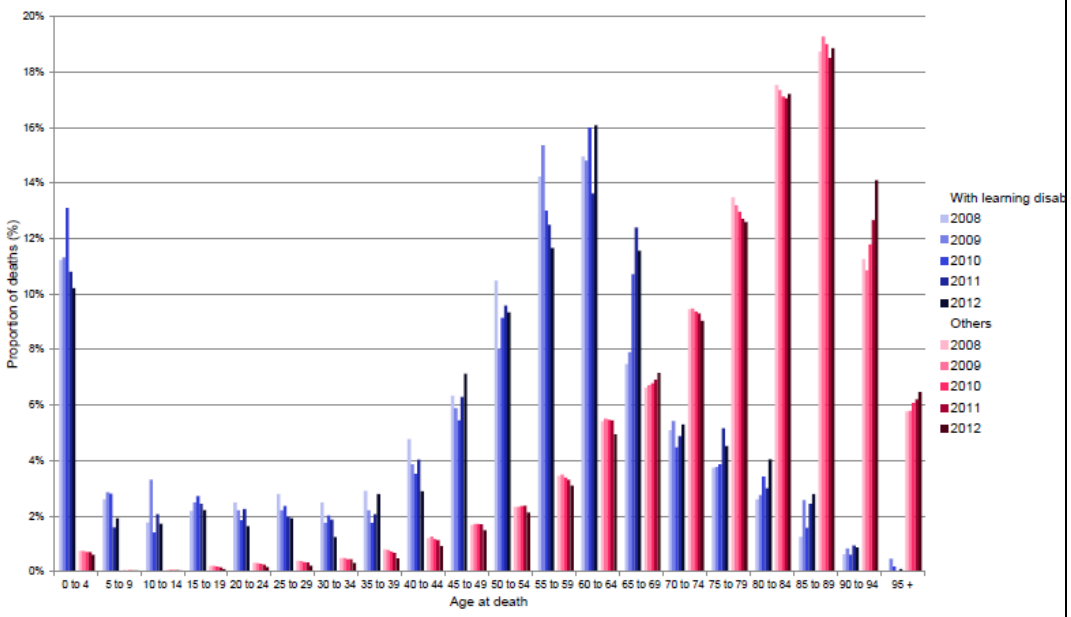



**Figure 1**:Annual proportion of deaths for people with learning disabilities compared with others 2008-2012 ( Source Hatton et al 2013)

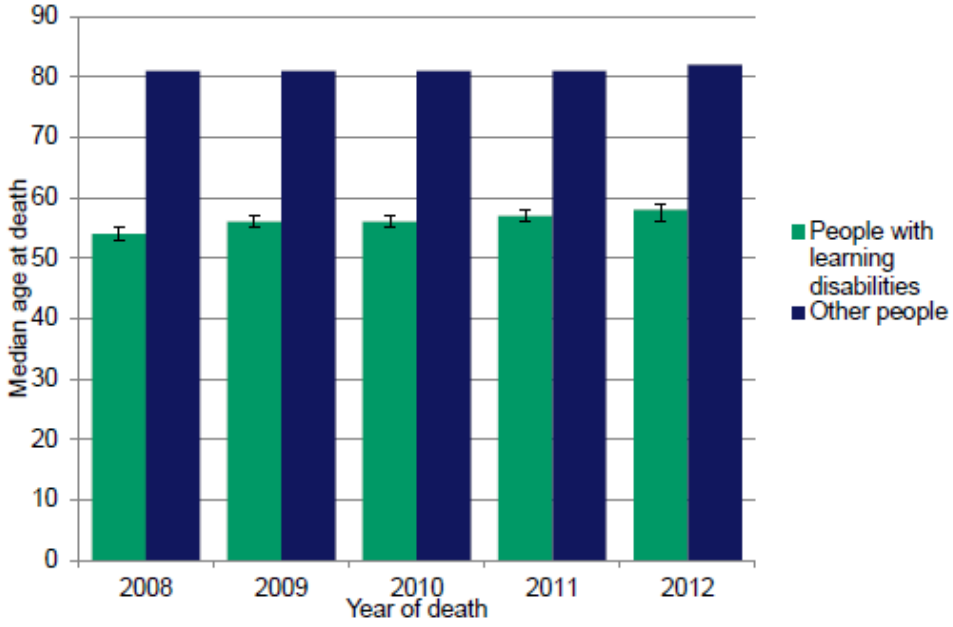



**Figure 2**:Median age of death for people with learning disabilities compared with others 2008-2012 ( Source Hatton et al 2013)

- There is to date no national system to understand premature mortality of people with LD but the 2013 Confidential Inquiry (CIPOLD study, Heslop et al 2013) in the Bristol area has informed national plans for a Learning Disability Mortality Review system by NHS England. The CIPOLD study found that men with learning

disabilities died on average 13 years younger than men in the general population and women 20 years younger. It identified that 42% of the deaths studied were judged premature, with the most common reasons being delays or problems with diagnosis or treatment, and problems with identifying needs and providing appropriate care in response to changing needs. The median age at death varied according to the level of learning disability, being 67.5 years for mild LD, 64 years for moderate LD, 59 years for severe LD and 46 years for profound disability. People with Down's syndrome have a shorter life expectancy than people with learning disabilities generally, although life expectancy in this group is also increasing.

- Emerson (2012) described different patterns in causes of death – including potentially preventable causes such as aspiration pneumonia and seizures. In the CIPOLD study the most common certified underlying causes of death were heart and circulatory disorders (22%) and cancer (20%). These are also the two most common causes in the general population where they account for 29% and 30% of deaths respectively. Amongst the learning disability population 37% of deaths were at ages and from causes categorised by ONS methods as likely to be amenable to prompt and good quality healthcare, meaning that people with a learning disability are more likely to die from a preventable cause than the general population.

- Higher levels of physical and mental health needs are present, with a risk of unmet needs due to barriers to identifying them. Epilepsy is at least 20 times higher than the general population and respiratory problems (including asthma) are more common. Conditions such as cancer and dementia are increasing as the population ages, with people with Down's syndrome at risk of developing dementia at a younger age.

- People with LD have higher levels of additional physical and sensory impairments. There may be complications of reduced mobility, with people who are non-mobile having sevenfold increase in mortality and 14 times more likely to have musculoskeletal impairments. There is also international evidence of greater osteoporosis. Sensory impairment is far more common, with 40% of people with LD reported to have hearing impairment. Communication difficulties mean that unreported pain is a risk for people with LD and this in turn can lead to behavioural problems due to underlying problems not being resolved.

- It is estimated that 20-33% of people with Learning Disability known to Social Care will also have an Autistic Spectrum Condition (ASC), described as developmental difference in social communication (Emerson and Baines 2010) and this proportion is higher in people with LD in hospital or residential care. This compares to an estimate of 1.1% of the total population being on the Autistic Spectrum.

- Behaviours that challenge (such as aggression, destruction and self-injury) are shown by 10%-15% of people with learning disabilities, with age-specific prevalence peaking between ages 20 and 49 (NICE 2015)

- Poor dental health and higher dental health needs are described with higher rates of untreated decay and a greater number of extractions in people with LD than the general population.

- Difficulties with eating, drinking and swallowing affect 8-15% of adults known to LD services. Forty per cent of those with learning disabilities and dysphagia (problems with swallowing) experience recurrent respiratory tract infections, and this can lead to other negative health consequences including asphyxia, dehydration and poor nutritional status. Another common health problem in this group is Gastro-Oesophageal Reflux Disease (GORD), which can cause pain and may contribute to sleep disturbance, problem behaviour, anaemia and risk of oesophageal cancer. Constipation has been reported among two-thirds of a sample of people living in institutions with moderate and severe learning disabilities in international studies.

- For women with LD there may be challenges associated with the management of menstruation, ensuring contraception choice, pregnancy options and menopause treatment, meeting individual needs in line with the Mental Capacity Act.

- People with LD may experience barriers in accessing health services, which will impact on medical treatment and management. Barriers can include problems with communication, inadequate facilities, rigid procedures, a lack of appropriate interpersonal skills among mainstream health professionals and a lack of accessible information (Alborz et al 2005). Uptake of cancer screening amongst people with learning disabilities is lower than the general population.

- Healthy lifestyles; there is a risk that a lack of opportunities to gain appropriate knowledge and understanding due to a lack of accessible health promotion information may mean that adults with learning disabilities have limited understanding about health risks and consequently are unable to determine their own healthy lifestyle choices. Healthier choices may also be limited by the person's living arrangements and care or support network as health behaviours are often mediated by family or paid carers. Access to physical activity opportunities may be limited due to transport or support arrangements required to participate, as well as financial or accessibility considerations. In general adults with learning disabilities

    - have higher levels of obesity than the general population
    - are less likely to participate in the recommended levels of physical activity than the general population
    - are less likely to eat a healthy diet with an insufficient intake of fruit and vegetables than the general population
    - have lower rates of smoking and harmful drinking than the general population

- Access to appropriate sexual health services. IHAL describe a lack of UK research into the sexual health needs of people with LD, but describes recent work on attitudes in Northern Ireland (FPA 2014). This highlighted that sexual health education, sexual expression and relationships, as well as risks of sexual abuse

were important key features of any service. The same full range of services as the wider community is necessary but with a person centered approach to ensure the service takes account of aspects of additional vulnerability or risk, for example with regard to capacity to consent. There is a gap in information about the healthcare needs of pregnant women with LD, other than care will need to be highly individualised and there may be a complex balance of the needs of the woman/parents and the child.

**Wider determinants of health**

The layers of influence on health are often depicted as a rainbow such as that described by Barton & Grant (fig 3).

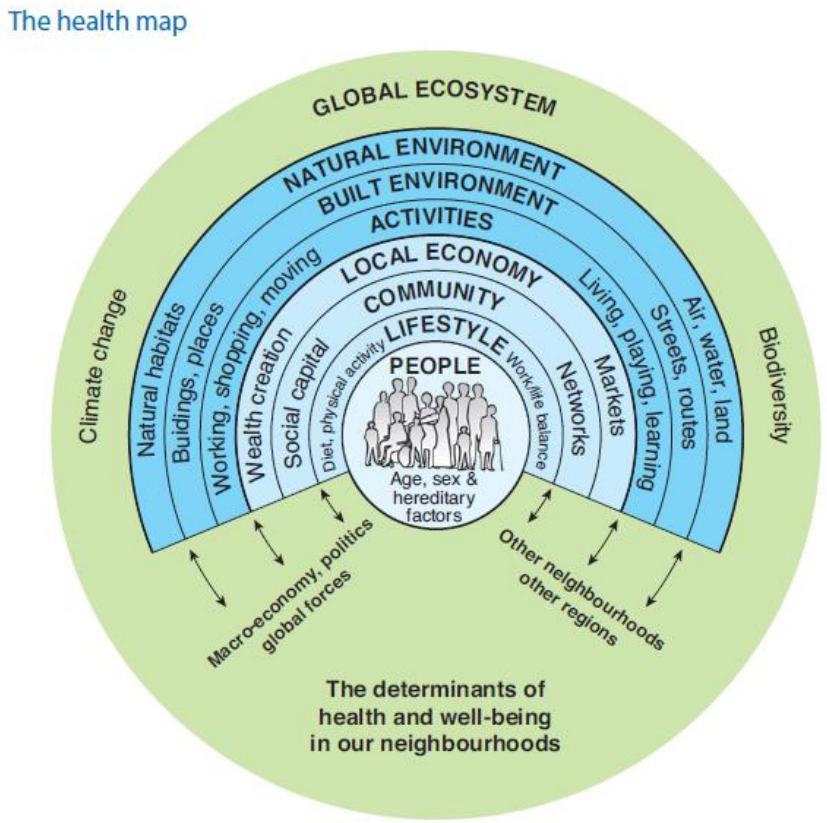



**Figure 3** Source Barton and Grant 2006

For people with Learning Disabilities there is the possibility of multiple layers of disadvantage in addition to genetic or syndrome specific causes, including the social and economic impact on carers and families. Socioeconomic deprivation is an underlying risk factor, as discussed, for mild LD, and LD, in turn, may lead to increased socioeconomic disadvantage due to low educational attainment, less family social mobility, dependency on benefits, poor employment opportunities for both the person and family members with caring responsibilities,

“Over time families with a child with learning disabilities are more likely to be poor or become poor and are less likely to escape from being poor than other families” (Emerson et al 2010)

There may also be restricted housing options, more likelihood of living in areas with higher crime levels, and experience of disability discrimination or hate crime.
In 2009/11 British adults with self-reported LD were nearly three times more likely than their non-disabled peers to have been a victim of violent crime over the last year and nearly seven times more likely to have been a victim of hate crime (Emerson and Roulstone 2014).

People with mild LD are less likely to be recorded in GP systems as having a learning disability but recent analysis of lifestyle surveys has identified that they are also at risk of poor health, unhealthy behaviours and material disadvantage (Emerson et al in PHE 2016a).

In addition, those with LD from particular BME backgrounds may have additional influences on their health outcomes, including the experience of racism, and carers/family members who experience challenge in understanding or navigating health and care systems, particularly if their use of English is limited. Nationally, in 2014 to 2015 only 6% of working age adults with learning disabilities were reported to be in some form of paid or self-employment, and most of these worked for less than 16 hours per week. National reports have also highlighted the level of unidentified Learning Disability in the criminal justice system, including prison, (Bradley 2009) highlighting gaps in support needs.

The full impact of the combined austerity measures and welfare reform on people with learning disabilities has not been quantified at population level, however the United Nations is requesting that the UK look into the cumulative effect of reforms on marginalised groups including disabled people (United Nations 2016).

**The organisation of health, care and support**

It is acknowledged that people with LD may be vulnerable to abuses of power in the organisation of their care and support. This has been brought to light through some shocking exposures of abuse, neglect, organisational indifference and discrimination such as the BBC Panorama investigation into the care of people in a long stay hospital called Winterbourne View and the Mencap report, 'Six Lives'.

In March 2017, 3,840 people with LD and/or autistic spectrum conditions in England were in LD specialist inpatient hospitals. Of these, 1,795 were in secure settings, 34% had been in hospital for over two years and 74% were subject to the Mental Health Act.

The Equality and Human Rights Commission published *Hidden in Plain Sight* (EHRC 2011) to highlight how commonplace disability harassment is, and described 'a systemic failure by public authorities to recognise the extent and impact of harassment and abuse of disabled people' The CIPOLD study also includes examples of unresponsive services in preventing or investigating premature death.

The Mental Capacity Act 2005 gives the legal context to issues of capacity and consent with regard to adults with learning disabilities. Since 2009, care providers have had to seek approval from the Local Authority if they need to deprive an individual lacking capacity of their liberty, as part of their care and/or treatment. This is referred to as

‘Deprivation of Liberty Safeguards’ ( DOLS). Recent supreme court judgments ( Cheshire West) on the application of DOLS has led to a national increase in DOLS requests for people with LD from 1,403 in 2013/14 to 16,645 in 2014/15. Latest statistics on DOLS are published by NHS Digital.

**2) Size of the issue locally**

Public Health England has published a Learning Disability Profile that will be updated with the latest information available at national level and this allows comparison with other areas in the region and with comparable areas.

Social care comparisons are available on the Adult Social Care Efficiency Tool which allows for comparison with comparable areas.

**Estimated total population with LD**

The total number of adults in Nottingham City with LD can be estimated based on the research that 2% of the overall population will have Learning Disability ( based on Emerson and Hatton 2004 as above). Based on 2015 population estimates this gives 5,060 adults likely to be affected, The large number of higher education students in the City, who will not by definition have LD, would mean that this is an overestimate, but the high level of deprivation in the city and ethnic diversity would imply an underestimate. The ‘PANSI’ tool (IPC2014) uses an adjusted model to estimate this figure based on increased ethnic diversity and they calculate the figure for Nottingham to be 6,059, but this does not take into account the student population. The prevalence of LD in the school census could give an improved prevalence estimate, but these figures vary greatly from year to year implying that the recording of ‘moderate learning difficulty’ in schools is subject to local variation and variation over time. Therefore, for planning purposes it is acknowledged that there are likely to be between 5-6,000 adults who have a Learning Disability, but, like all other areas in the country, services, such as GPs and Social Care would only expect to be aware of up to a quarter of this group.

**LD population known to primary healthcare services**

From national data 0.46% of the population would be expected to be known to GP services as having a Learning Disability. GPs maintain an LD register for the Quality and Outcomes Framework. Up to April 2014 this was limited to those 18+ and was 1,552 people in total for Nottingham City. This is an increase from the 2011 reported figure of 1,239 but this likely to be due to better recognition and improved registers and not necessarily a true increase in prevalence. Figure 4 below illlustrates the variation in number of people per GP practice and figure 5 illustrates the variation in prevalence rate by GP practice. Prevalence in Nottingham is 0.54% overall based on GP registers, however this does include student practices where the prevalence is exceptionally low (0.03%). Nottingham has a particularly high number of higher education students. If the 3 predominantly student practices are removed from the calculation Nottingham City GP records demonstrate a prevalence of 0.67 %, reflecting the higher deprivation and greater ethnic diversity than the UK as a whole.

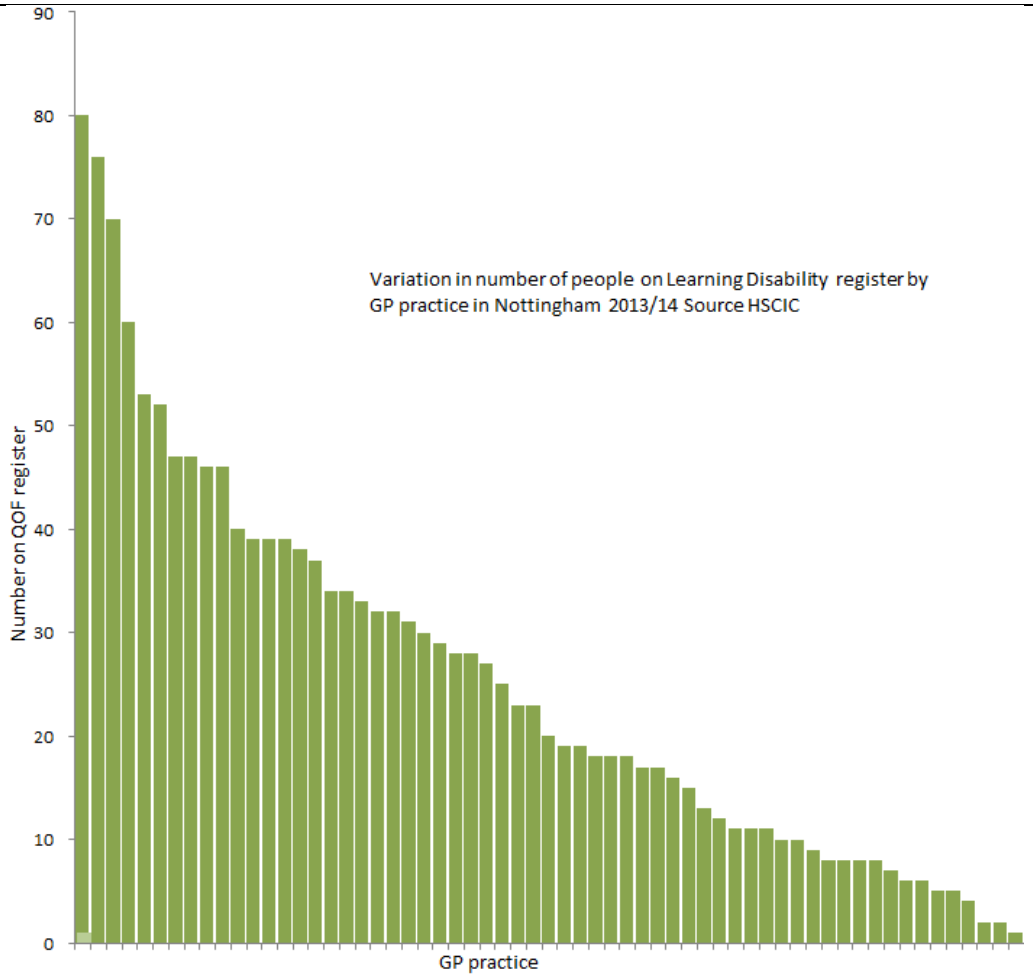



**Figure 4:**

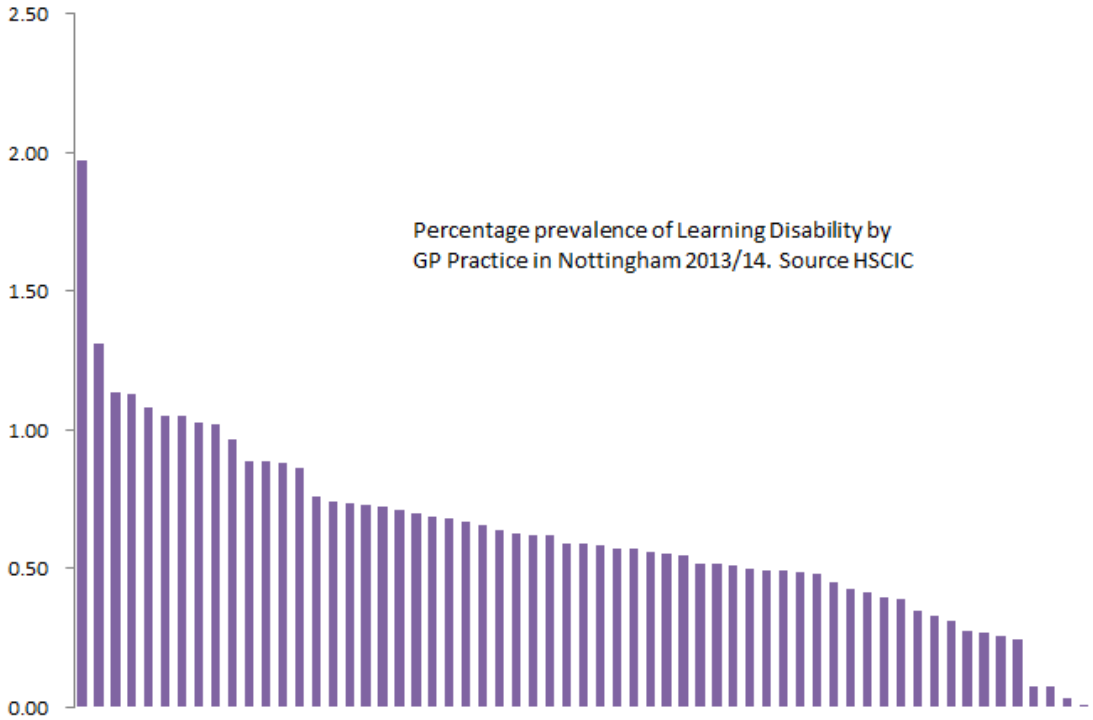



**Figure 5:**

Figure 6 below illustrates geographical distribution across the city of GP practices and their relative prevalence of LD. To some extent this will be affected by concentration due to residential care homes and by some practices developing a positive reputation with people with LD and their families.

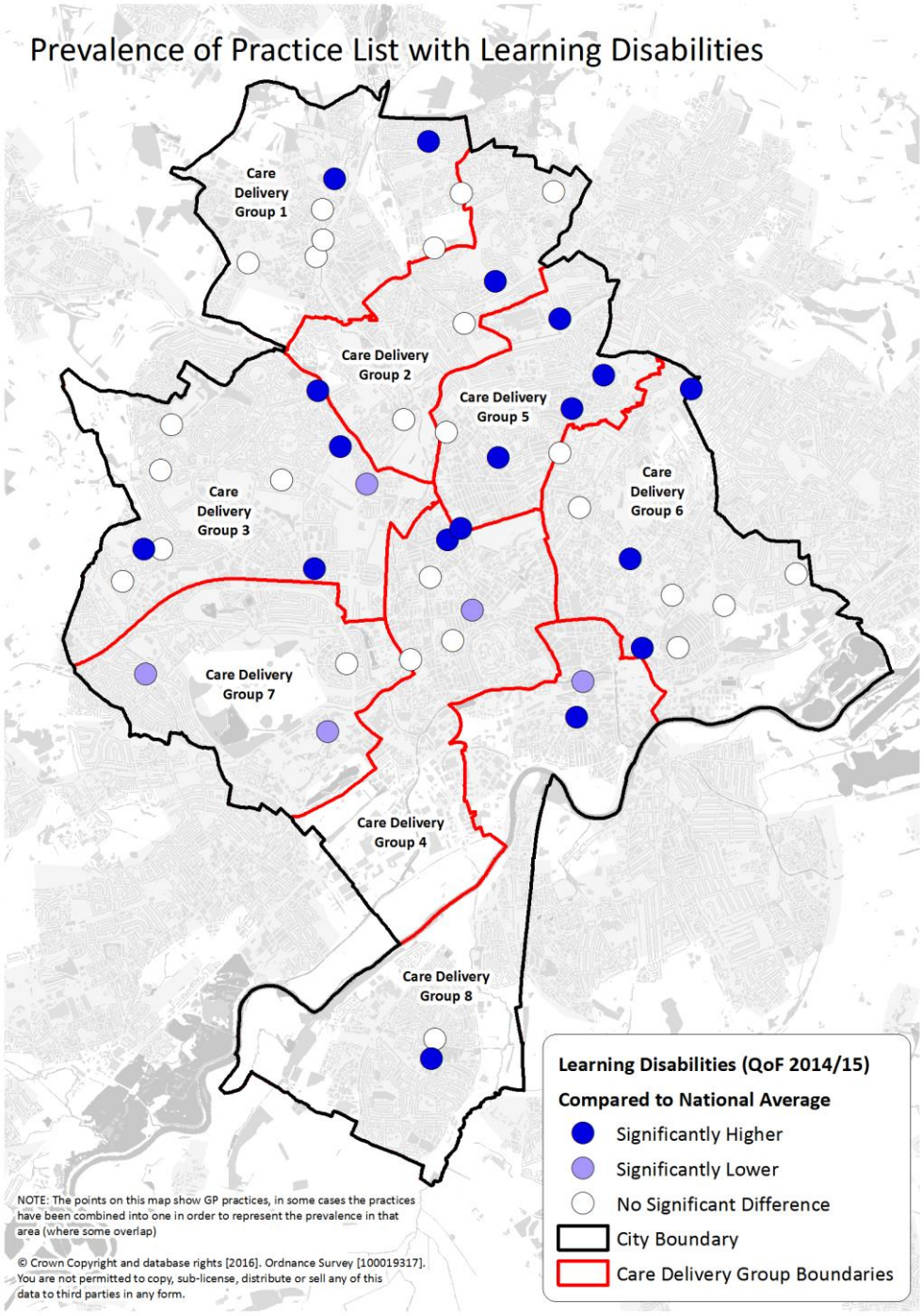



**Figure 6**

Nottingham City has taken part in the annual self assessment to identify needs and gaps with regard to LD. To support this process an annual audit of GP records ( Miquest, supported by TCR Nottingham) has been undertaken and this gives the most comprehensive overview of the characteristics and key health statistics of those people known to GPs locally. The most recent audit in 2014 covered 89% of the general

population and 87% of the LD population (identified through QOF registers). The search reports LD by gender, age, ethnicity, level of LD and autism, as well as a range of other information about health status and intervention. Ethnicity was recorded for 62% of those with LD in primary care. Level of LD was only recorded for 25%, although this has improved from under 10% two years previously, due to work done to improve recording- including read codes in consultant letters, support from primary care LD liaison nurses and prompts in the new electronic template.

**Strategic Commissioning Review**

As part of a recent strategic commissioning review (SCR) Nottingham City has brought together the figures of those known to adult social care (ASC), specialist LD health services, and GP QOF/Miquest audit. (Fig 7) The people in specialist hospital placements considered as part of the Transforming Care programme (in response to Winterbourne View) were also included, as well as the estimated wider group of people unknown to health and care services. The most recent data available for this comparison is 2013-14.

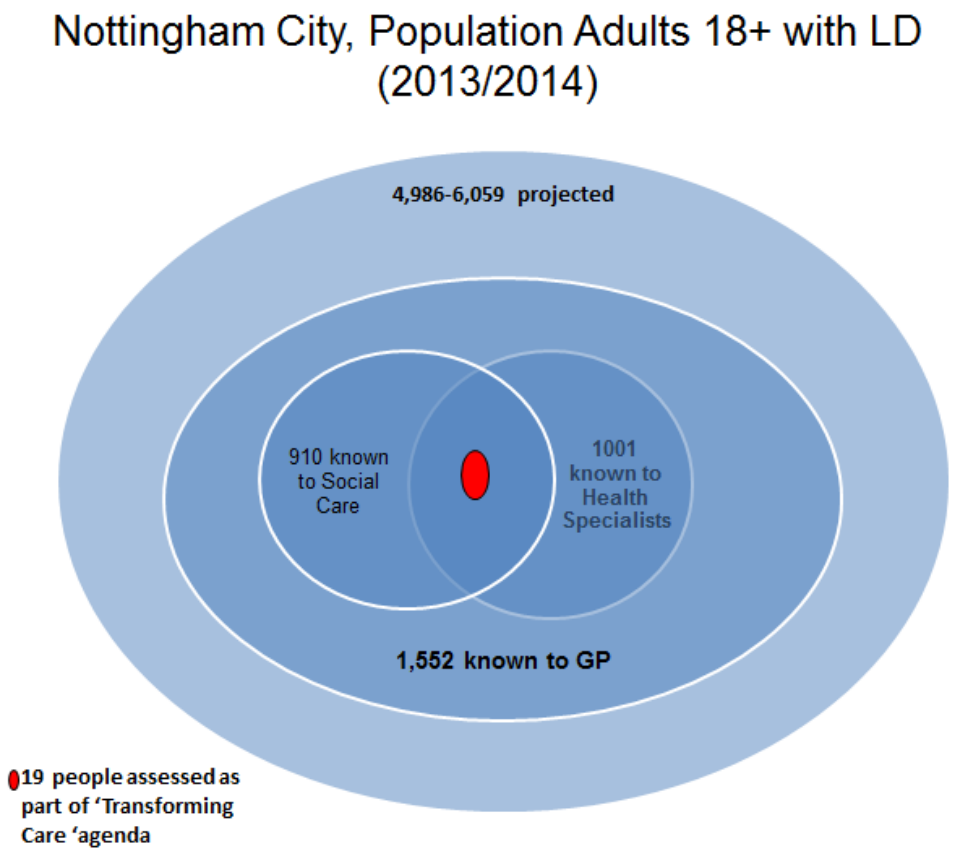



**Figure 7**

From 2014 onwards social care national submissions (Short and Long Term Care 'SALT' returns) have changed so are not directly comparable with previous years. In 2015-16 Nottingham City's submission identified 866 people with a primary need of learning disability. 115 of this group were 65 years or above. In 2017 a snapshot of social care records in Nottingham showed 1145 adults known to adult social care as having a learning disability, 1007 of whom were receiving an active service. It is possible that the primary

reason for support of some of these people may be a reason other than their learning disability, hence the reason for a higher number than in the previous SALT return.

**Gender**

As described in the national literature there are slightly more men than women who are known to services in Nottingham, and this difference is slightly greater in those people using specialist health services. A comparison was made as part of the SCR(figure 8)

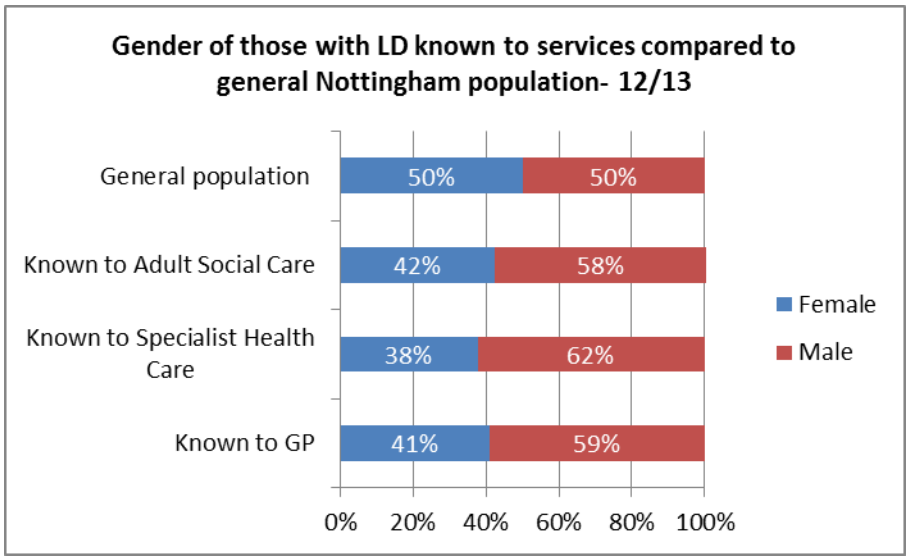



**Figure 8**

The 2017 social care snapshot continues to show similar figures with 59% male and 41& female.

**Age**

The age profile of adults with LD differs from the Nottingham population as demonstrated in figure 9 below. This would be expected from the national information on shorter life expectancy, but also reflects the large number of higher education students in the Nottingham population, which is not reflected in the LD population. Prevalence of LD across the 18+age ranges varies as illustrated in table 1 below (this does include the student practices).

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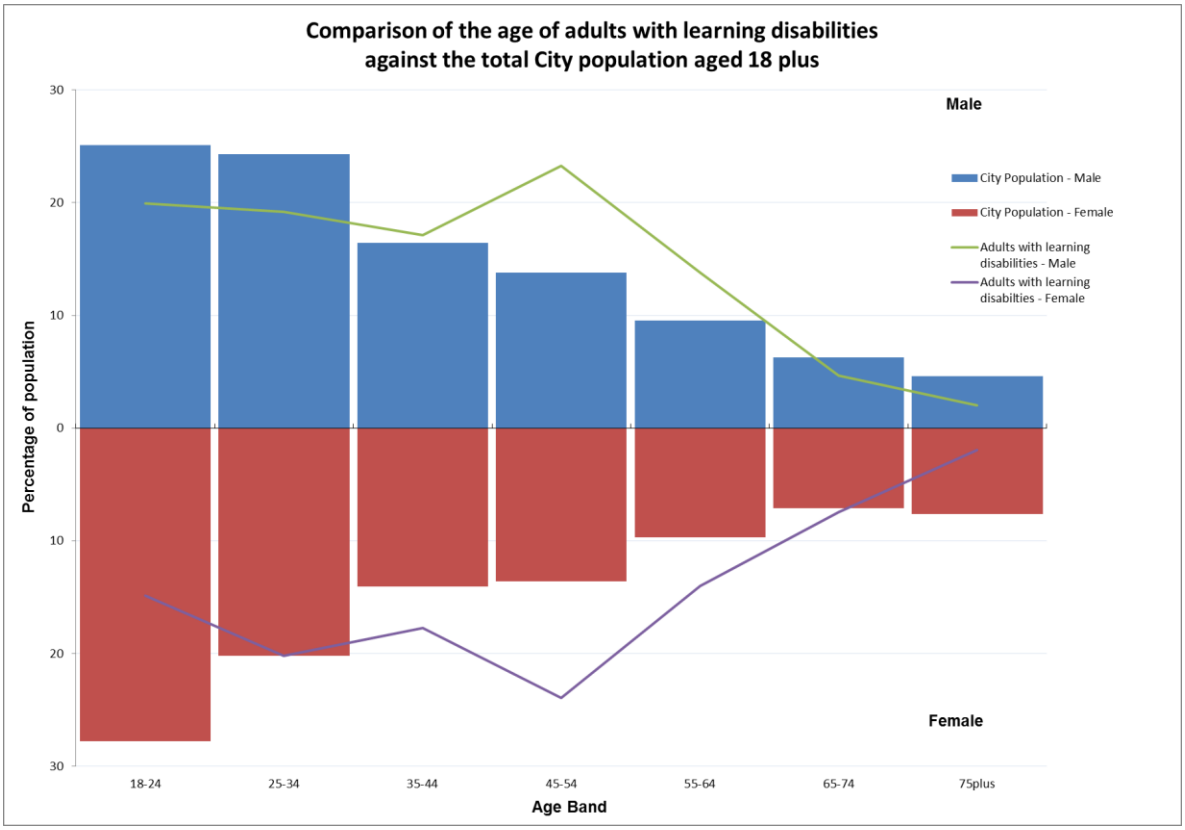



**Figure 9**

The 2017 social care snapshot shows the percentage aged 18-25 has increased to 24% of the LD population and the 45-54 age group has decreased relatively to 20%.

| Prevalence of Learning Disability by age group and gender, Nottingham City 2014, source GP Miquest audit | | | |
|---|---|---|---|
| male | | female | |
| **18-24** | 0.49% | **18-24** | 0.24% |
| **25-34** | 0.49% | **25-34** | 0.45% |
| **35-44** | 0.65% | **35-44** | 0.57% |
| **45-54** | 1.05% | **45-54** | 0.80% |
| **55-64** | 0.90% | **55-64** | 0.65% |
| **65-74** | 0.47% | **65-74** | 0.47% |
| **75+** | 0.27% | **75+** | 0.12% |

**Table 1**

As part of the SCR an analysis of the age of family carers was undertaken to understand the age profile of this group. This identified 152 carers over 60 years of age, 32 of whom

were over 80 (table 2). As carers age it may be likely that they will no longer be able to support their family members as they have done previously and often people require support to transition to needing alternative care as family members are no longer able to support them.

| Age Group of Carer | Number of Citizens |
|---|---|
| **Over 60** | 84 |
| **Over 70** | 36 |
| **Over 80** | 32 |
| **Total** | 152 |

**Table 2**

**Ethnicity**

Recording of ethnicity in primary care is not comprehensive, but adult social care records have a high level of recording, but of a smaller group. As part of the SCR the variation in recorded percentage of Black and minority ethnic (BME) people with LD were compared across the different recording methods (figure 10). A snapshot of those known to social care in April 2017 shows a higher percentage of BME adults (figure 11).

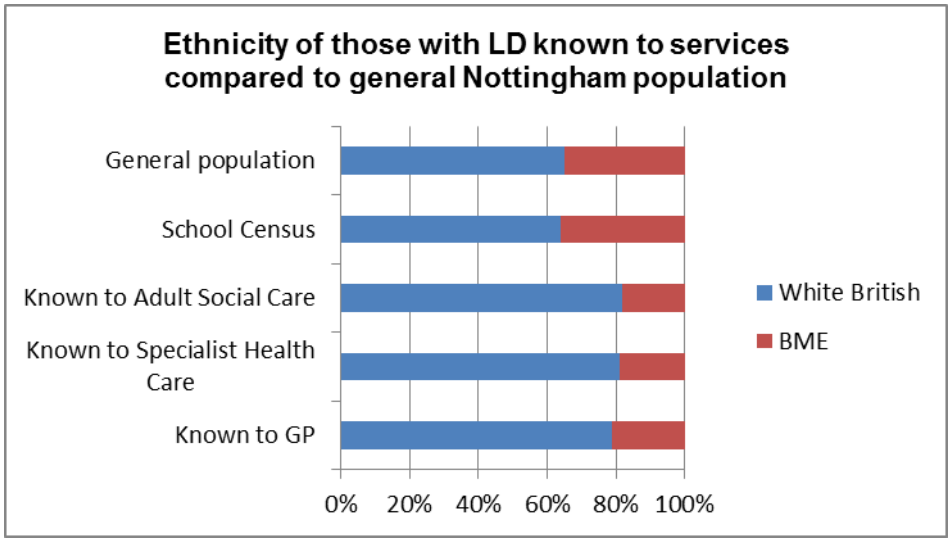



**Figure 10**

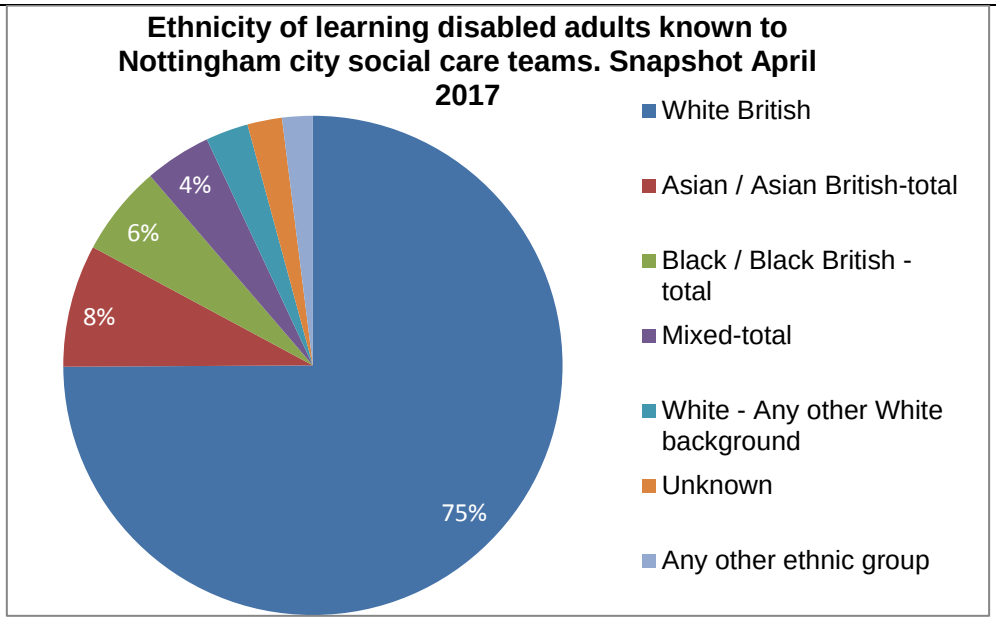



**Figure 11**

**Level of Learning Disability**

The level of Learning Disability is recorded in 25% of records at GP level. Assessment of level of LD is not undertaken for all people, and testing of IQ would only take place in specialist services. Specialist services have taken a more person centred approach that describes a person's needs and abilities in a more detailed way reflecting a less medically focused approach. However, local services have been working together to ensure that GP records do reflect those who have the highest level of needs and to understand at population level the prevalence of needs at each level. It is also important to note that level of LD does not always equate to complexity of care or support needs, nor to vulnerability to other risk factors. The miquest identified 86 adults with severe or profound LD, but it is known that is an underestimate. PANSI predict 338 to have severe LD. In 2011 a case audit of files was undertaken across specialist LD services which identified 130 people with profound and multiple LD.

The Nottingham school census has recorded level of 'severe learning difficulty' and 'profound and multiple learning difficulty' in 2015 at 0.43% and 0.16% respectively. The PMLD rate in children may not reflect the needs of adults due to improvements in health outcomes for this group during childhood, or poorer health outcomes in this group as adults.

The level of LD is not recorded in social care data systems in a way that can be extracted to give an overall picture.

**Accommodation**

The mix of accommodation in Nottingham City of those known to adult social care services has been investigated as part of the SCR and is summarised in (fig 12) below

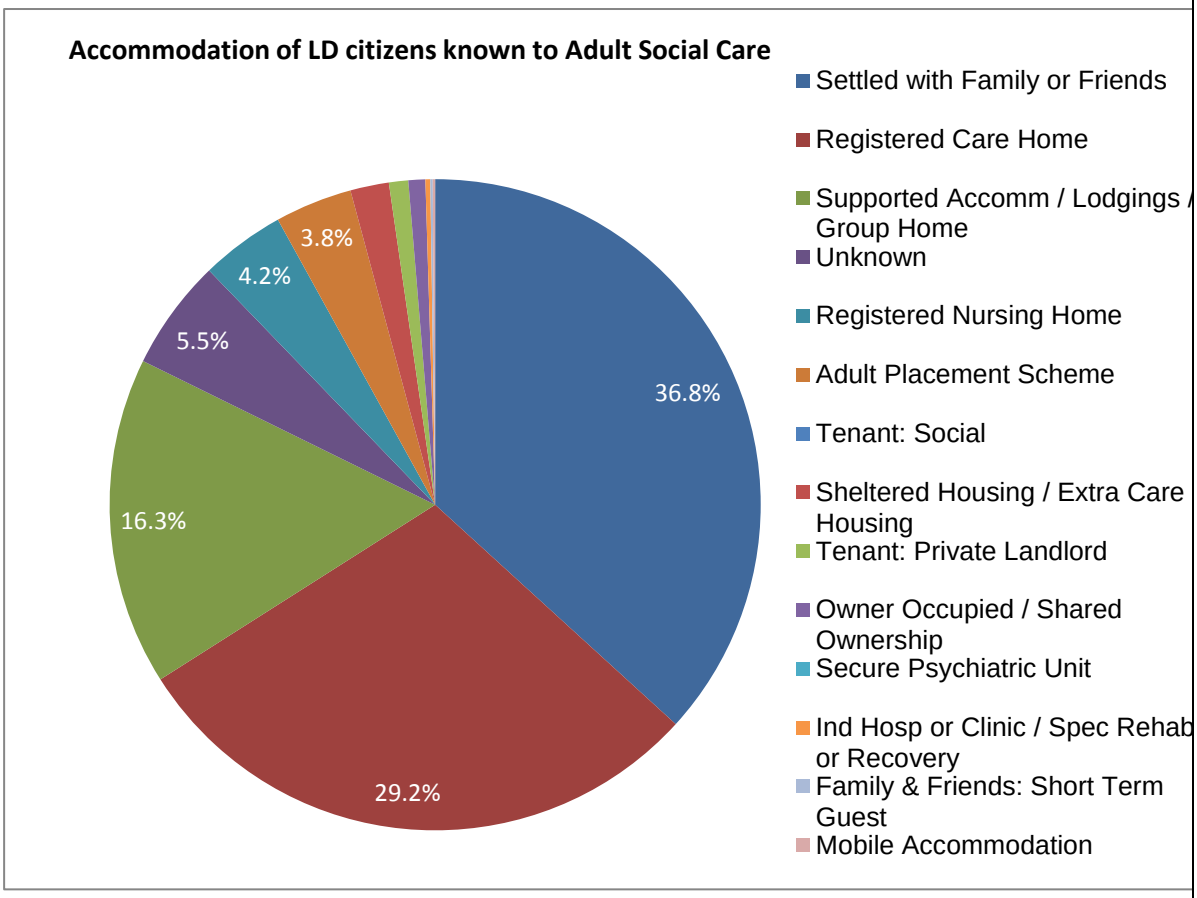



**Figure 12**

In comparison to similar areas the proportion of people in residential care is high according to 2013/14 figures from the Adult Social Care Efficiency Tool as illustrated in fig 13 below

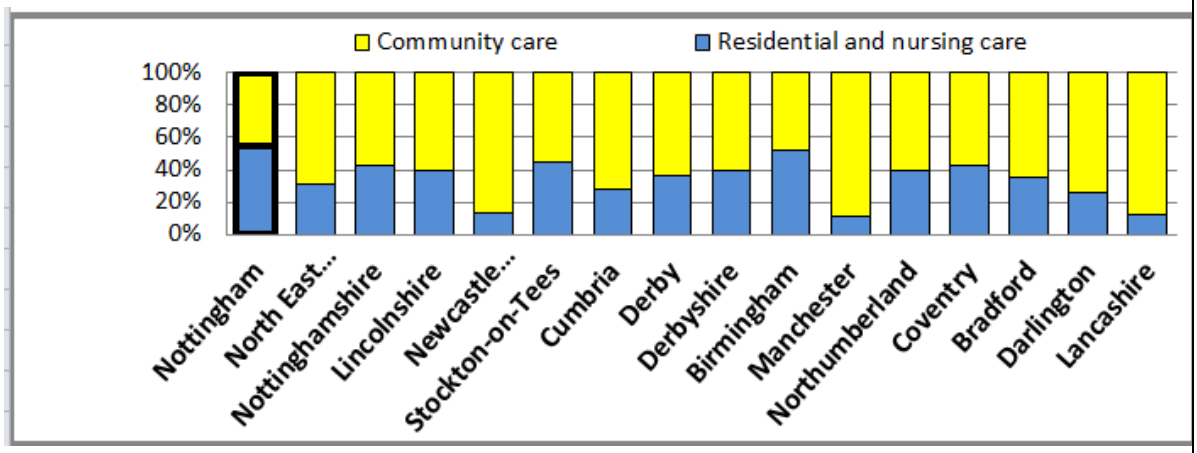



**Figure 13**

Most recent figures as part of the SALT return for 2015-16 described above indicate that of those aged 18-64 known to adult social care in Nottingham City for the primary reason of learning disability, 42% received long term support through nursing or residential accommodation.

**Health needs-primary care**

Since the previous JSNA the GP Miquest audit gives a much more detailed picture of the health needs of people with LD. In many cases numbers are small therefore confidence intervals were calculated to identify whether prevalence of particular health needs differed to the general population. There is variation in the reliability of coding of information in primary care systems, with medical conditions covered by QOF registers being more consistent than some of the lifestyle or intervention recording.

**Table 3 Prevalence of health conditions 18+ LD population, 2014 GP audit**

| Nottingham City | General population | People with LD | Comment | Evidence of health monitoring |
|---|---|---|---|---|
| **diabetes type1** | 0.40% | 0.64% | No significant difference between LD group and general popln | similar levels for retinopathy screening and recording of blood glucose in both groups |
| **diabetes type 2** | 4.45% | 8.51% | LD popln have significantly higher rates at younger age groups | as above |
| **asthma** | 5.26% | 10.22% | Significantly higher in 18-34 year olds with LD than general population and in middle aged women | |
| **epilepsy** | 1.09% | 20.87% | significantly higher in LD popln across the age ranges | 1.5X more recording of seizure frequency in LD population |
| **depression** | 12.72% | 14.37% | similar rate in LD and general population but significantly higher in women than men | |
| **dysphagia** | 0.57% | 1.50% | significantly higher in LD popln, but concern that not well coded in primary care | |
| **psychosis** | 1.05% | 7.01% | significantly higher in LD, particulalry in older age range. | |
| **dementia** | 0.56% | 0.93% | significantly higher in LD popln, 55-74 year olds | |
| **BMI 30+** | 26.26% | 39.89% | significantly higher overall and specifically in younger adults | LD population 1.8 times as likely to have BMI recorded and 1.6x more likely to have BP recorded overall, with significant difference to the general population up to age 64 |
| **BMI 40+** | 4.10% | 8.59% | significantly higher overall | |

In 2016 NHS Digital published summary data taken from GP records at a national level in a similar way to the local Nottingham Miquest search in order to give a picture of need, However the search included a low number of Nottingham GPs due to the GP systems used locally, and therefore does not add further insight to the local picture.

**Smoking**

Levels of smoking are reportedly lower in LD populations, particularly in those with higher levels of need. However the miquest in Nottingham showed that people with LD are more likely to have a smoking status recorded, and to have similar levels of current smoking to the general population. It also showed significantly lower levels of 'ever smoking' in the LD population, and significantly lower levels of ex smoking than the general population. It is possible that smokers in the LD population are more likely to have their smoking status recorded as they undergo more health monitoring, but further investigation is needed to ascertain if this does reflect the accurate level of smoking in the LD population.

**Use of secondary health services**

In 2011 a detailed Health Needs Assessment (Nottingham and Nottinghamshire PCTs 2010) was undertaken based on adults with learning disabilities known to social care which reviewed local patterns of health need and service use, with the following findings

- Pneumonia was the most common cause of death responsible for 43% of deaths in which learning disabilities was recorded on the death certificate, with aspiration pneumonia and cardio-respiratory failure the second most common causes of death (10% each)
- Adults with learning disabilities in Nottingham City were 1.9 times more likely to be admitted to secondary care than the general population. Adults with learning disabilities across Nottinghamshire were significantly more likely to be admitted for a number of conditions, including for mental health conditions, *epilepsy, diabetes, oral health, hearing problems and bladder problems [*denotes significantly higher in Nottingham City population].
- Adults with learning disabilities in Nottingham were 2.1 times more likely than the general population to be admitted to secondary care with an ambulatory care sensitive condition (ACS). ACS conditions are illnesses (mainly chronic diseases) that have been identified as contributing most to unnecessary emergency hospital admissions.
- Adults with learning disabilities in Nottingham City were 2.2 times more likely to attend Emergency Department (ED) than the general population. Adults with learning disabilities in Nottingham were significantly more likely to attend ED for cerebrovascular conditions, contusions/abrasions, gastrointestinal conditions, lacerations, Central Nervous System conditions (excluding strokes), psychiatric conditions or dislocation/fracture/joint injury/amputation and were also significantly more likely to have their attendance at ED recorded as 'nothing abnormal detected', 'diagnosis not classifiable' or diagnosis code left blank than the general population.

**Mortality**

At a local level there is not a recognised measure of excess mortality in people with LD. A previous review of death certificates between 2004 and 2008 that included reference to LD gave a median age of death of 56 across Nottinghamshire compared to 80 in the general population. The Miquest does now include deaths of people on the LD register at practice level but to date numbers are too small to draw conclusions at local level, however they will contribute to the national overview as part of the self-assessment.

**Behaviour that challenges**

Nice (2015) estimate that between 5% and 15% of people known to have LD will have behaviour that challenges services. Based on the 1,590 adults known to GPs this would be between 80 and 240 people in Nottingham City. Other research says that 4-5 people in 10,000 will have behaviour that challenges, which would be 112 people (Lowe et al 2007).

An audit of records in 2011 ( Nottingham and Nottinghamshire PCTs) as part of the local response to the Mansell report (2010) identified 227 people displaying such behaviour, although there was variation in reporting across teams which may suggest that it was not consistently reported across different teams.

Based on GP records in Nottingham, 7% of the Learning Disability population are recorded as also having a psychosis. There are also higher rates of Autism Spectrum Condition and dementia than in the general community. PANSI predict similar rates per year going forward but in an increasing and more diverse population these are likely to be underestimates. The majority of these people are not part of the Transforming Care Programme group at present, although some will be likely to be in higher level specialist services ( such as secure hospital settings). Therefore there is an important role in supporting these people remain well in their current settings as a preventative approach and that needs do not escalate. The Transforming Care programme cohort for Nottingham City (those people in long term hospital care for whom Nottingham City CCG were the responsible commissioner) at the outset was 19 people. The needs of these people were considered on an individual basis to identify whether they continued to need inpatient treatment or could be discharged to a community setting. The needs and experiences of this small group are known individually to commissioners as part of their care and treatment review process, and the complexity of needs in order to live safely in the community has informed the Nottinghamshire Transforming Care plan.

Numbers of people receiving inpatient care as a result of their learning disability was recorded from 2013 to 2015 as part of the LD census and from 2016 is routinely collected and reported as part of the Mental Health Services Dataset and Assuring Transformation Dataset which gives more detailed information on Transforming Care partnerships. Monthly figures are now published and in March 2017 35 specialist inpatient spells were reported where Nottingham City CCG was the responsible NHS commissioner (NHS Digital).

**Deprivation of Liberty Safeguards (DOLS)**

As described in the national picture the applications for DOLS has increased markedly in the two most recently reported years, although rates of DOLS in Nottingham are similar to

England. In 2015/16 there were 1,020 applications for DOLS, and national figures would suggest that approximately 11% would be for people with LD.

**3) Targets and performance**

Public Health England have developed the Learning Disability Profile that should report most up to date performance against national targets..

**LD Self-Assessment**

Nottingham City took part regularly in the national joint health and social care self-assessment process led by ADASS and Public Health England. The last time this process was requested was in 2014/5. As part of this process an assessment is made of key questions related to health, social care and wider aspects of quality of life (e.g. access to culture and transport). There is a verification process by the LD Partnership Board ahead of submission. LD Health Observatory published overview reports on the findings, and Nottingham city most recent report is published here.

**Outcomes Frameworks**

There are shared outcomes indicators in the Public Health Outcomes Framework and the Adult Social Care Outcomes Framework as below

- Proportion of adults with learning disabilities in paid employment (ASCOF 1E, PHOF 1.8, NHSOF 2.2)
- Proportion of adults with learning disabilities who live in their own home or with their family (ASCOF 1G, PHOF 1.6 ) NB PHOF uses the terminology 'stable and appropriate accommodation' but both definitions exclude residential care settings.

Published figures for Nottingham City confirm low levels of employment and higher rates of residential care as described in previous section. Figures for 2015/16 indicate a drop in employment levels and an improvement in accommodation but require further verification.

| Indicator | Period | Nottingham | | Region | England | England | | |
|---|---|---|---|---|---|---|---|---|
| | | Count | Value | Value | Value | Worst/ Lowest | Range | Best Highe |
| Supported adults with learning disabilities living in settled accommodation (%) | 2014/15 | 490 | 63.6% | 73.3 | 72.9 | 0.0% | | 94.4 |
| Supported adults living in unsettled accommodation (%) | 2014/15 | 280 | 36.4% | 28.8 | 26.7 | 64.9% | | 0.0 |
| Supported adults whose accommodation status is not known to LA (%) | 2014/15 | 35 | 4.5% | 4.6 | 5.6 | 56.6% | | 0.0 |
| Supported adults whose accommodation status is severely unsatisfactory (%) | 2014/15 | 0 | 0.00% | 0.24 | 0.14 | 1.18% | | 0.00 |
| Supported adults with learning disability in paid employment (%) | 2014/15 | 15 | 1.9% | 3.2 | 5.9 | 0.0% | | 28.6 |
| Supported adults (age 18-64) receiving direct payments (%) | 2014/15 | 110 | 14.3% | 23.3 | 17.4 | 0.0% | | 78.2 |
| Rate of referral of people with learning disability for adult safeguarding | 2014/15 | 60 | 33.3 | 43.8 | 62.2 | 0.0 | | 207 |

**Figure 14** (source PHE)

The NHS Outcomes Framework includes the following outcome, but to date it is not agreed how this will be measured or reported. Once published it will be included in the PHE profile described above.

- *Reducing premature death in people with a learning disability*

  1.7 Excess under 60 mortality rate in adults with a learning disability

**Delivery of annual health check programme**

GP practices deliver the LD annual health check programme as part of an enhanced service commissioned by NHS England. 3 practices in Nottingham City do not offer the health checks. Local data suggests an increase in number of health checks from 530 in 2010/11 to 798 in 2014/15 (NHS England), but eligibility has increased, and there are concerns that nationally reported claims for doing the checks do not reflect activity accurately. It is estimated that approximately half of those people eligible receive the check.

Detailed analysis of uptake by practice in 2012/13 (fig 15) illustrated variable practice, which did not depend on the number of people eligible. Due to changes in commissioning arrangements these are the most recent figures available

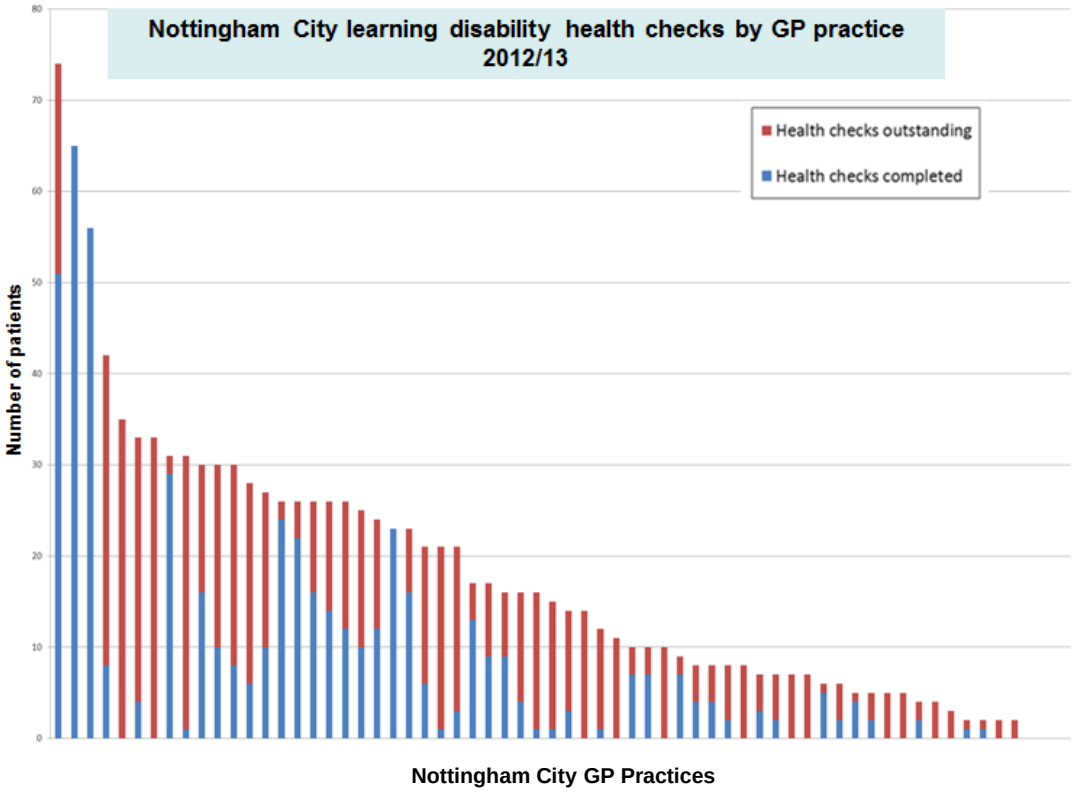



**Figure 15**

## Cancer Screening

The General Practice Miquest audit includes a focus on cancer screening. Data from the 2014 audit indicates that in Nottingham City:

Bowel screening

- The rate of bowel screening amongst people with LD has increased from 2013
- The rate of bowel screening is higher amongst people with LD than the general population
- 35% more people having bowel cancer screening in the LD population than the general population

Breast screening

- The LD population have a lower rate of breast screening than that of the general population

- The LD population experience 85% of the screening rate of that of the general population.

Cervical screening

The Miquest audit gives a range of estimates for cervical cancer screening depending on the query used.

- The LD population have a lower rate of cervical screening than that of the general population
- The LD population experience between 52% and 72% of the rate of cervical screening of that of the general population.
- The national screening programmes are not able to identify people with learning disabilities in their systems so insight into progress in this area is difficult with published data.

The gap between the LD population and the general population is greater for cervical cancer screening than that of the other two screening programmes. Therefore has the most potential for improvement in addressing health inequalities for LD women in Nottingham.

**4) Current activity, service provision and assets**

**Learning disability self-assessment**

The regular stocktake of services against national expectations is undertaken as part of the self-assessment, which includes a consideration of health, social care and wider community provision such as access to transport and culture. Nottingham city's most recent report is published here This includes an overview of a range of wider support to live a full and meaningful life. The wide range of community and voluntary organisations which provides services or opportunities to people with LD are brought together by Nottingham CVS as the Vulnerable Adults Provider Network (VAPN).

**Universal services with reasonable adjustments**

For the majority of people with learning disabilities health care will be coordinated by their GP and they will need access to the full range of prevention, health improvement and treatment services available to the general population. In line with the Equality Act (2010) all services are then required to make reasonable adjustments to their services to enable the disabled person to benefit. A summary of good practice in this regard is published by Public Health England here. There are also examples of health information in more accessible formats such as easy read in many health areas and specific national services such as Easy Health.

In response to the higher level of health needs and the risk of problems going unrecognised annual health checks are offered by GPs as part of a national programme funded by NHS England as an enhanced service. To support the annual health check a local template has been devised that supports primary care to ensure all aspects that may be relevant are included. The health checks include nurse and GP assessment and

should lead to the development of a health action plan. Levels of delivery of health checks are discussed above.

National screening and immunisation programmes are relevant to people with LD and may need to be offered or delivered differently, and in some instances may be more necessary (e.g. flu immunisation in care home settings). All health services need to consider how they will meet the individual needs of people with LD, including issues of informed consent in the context of the Mental Capacity Act.

Some health services have developed specialised offers for people with learning disabilities (e.g. audiology and special needs dentistry) but the majority of services that people with LD will access will be the same as the wider population. Guidance on reasonable adjustments in pharmacy services and ophthalmology services is available from PHE. In practice, families and people with LD will informally share details of providers who meet their needs, as well as checking feedback on access through websites such as Disabled Go.

People with learning disabilities will also be able to access the full range of health improvement services as the wider population, and in some instances they are highlighted as a priority group in service specifications (e.g. weight management service).

**Liaison services**

Liaison services have been established to support access to mainstream services, through the provision of professional advice, training and support to wider healthcare teams.

Citycare provide a small team of *LD primary Care liaison nurses* who link to groups of GP practices to advise and assist them to improve the number of health checks and ensure eligible people are identified. They also advise a wide range of community health services on reasonable adjustments and can support individuals in accessing appropriate primary health care. There have been a number of examples of this team supporting developments such as personalised health action plans and the electronic health check template as well as proactive work to improve levels of cancer screening.

In the acute hospitals under Nottingham University Hospital, a small team provided by Nottinghamshire Healthcare Trust are embedded as LD acute liaison nurses. They are able to support the hospital to respond to the needs of people with learning disabilities through provision of advice, training and support with forward planning. They link with the hospitals' safeguarding team and the department of psychological medicine and support strategic work as well as working with individual patients. They have taken forward developments such as the *traffic light hospital passport* and advise on a range of reasonable adjustments as well as the Mental Capacity Act. The service has seen increases in demand and has received requests to support patients with Asperger's syndrome in addition to those with LD.

**Specialist health services**

Specialist health services for people with LD in Nottingham are provided by Nottinghamshire Healthcare NHS Foundation Trust (NHFT) through services for intellectual and developmental disability (IDD). These include multidisciplinary teams working together to support people in the community as part of community learning disability teams ( CLDT). Disciplines such as dietetics, speech and language therapy,

occupational therapy, physiotherapy, psychology and psychiatry can support people whilst they are living in the community or in hospital. These services can respond to the wide range of individual physical, communication and psychological needs of people with LD and their carers. Speech and Language therapy services support communication, and also can assess and advise on dysphagia ( difficulty swallowing). 1,015 people from Nottingham City were known to IDD services (NHS digital, MHSDS) in May 2017.

Some learning disabled people have additional physical and sensory impairments which may require specialist mobility and postural care assessment, as well as appropriate continence and tissue viability services. (see Adults with physical disability and sensory impairment). Specialist physiotherapy is provided by NHFT as well as a specialist epilepsy service.

For people displaying behaviour that challenge services, often a combination of learning disability and developmental disability or mental health problem, an Intensive Community Assessment and Treatment Team aims to support people to remain in the community. If this is not possible the Horizon day assessment and treatment service can support people with complex needs, and the Orion Unit, at Highbury Hospital provides for people with LD in need of in-patient assessment and treatment. Transforming Care aims to reduce the number of people and time spent in inpatient settings for people with LD. Current use of inpatient settings is detailed in local needs section. In May 2017, 20 Nottingham City people with LD were subject to the Mental Health Act and 15 were recorded as being detained (NHS Digital).

Mental health and learning disability services for those in prison or police custody are commissioned by NHS England specialised commissioning. A Liaison and Diversion Service provides trained health professionals available to those in police custody.
For those people under the care of the forensic mental health services, NHS England commission secure learning disability services, including the national high secure service at Rampton Hospital, medium secure at Wathwood hospital and low secure service at Wells Road, Nottingham. 'Locked rehabilitation' services provide a model of stepped down care from secure accommodation, such as Alexander House.

**Adult Social Care**

Nottingham City Council responds to the social care needs of the learning disabled population and their carers in line with the Care Act. Access to social care is through the health and care point. 1,145 learning disabled people were known to Nottingham City Social Care teams in April 2017 with 1,007 receiving an active service. This is higher than the figure reported in the SALT return, which was 866 people with the primary support reason of LD. It may be that a number of people with LD have greater support needs relating to physical disability or mental health.

Two community learning disability teams (CLDT) include social work assessment teams specifically focussed on the needs of people with learning disabilities. Previously the CLDTs worked with people with moderate LD or greater needs, but they now work with all people with LD who require social care support. As previously described the level of support needed is not dependant on the level of learning disability, as some people with mild LD can be highly vulnerable and risk exploitation, homelessness and substance misuse problems. Assessment of social care needs may, for example, lead to a package of care to support a person stay independent with a personal budget, or may identify that a person needs accommodation based support. Nottingham City Council provides some

care directly, such as day services and residential care, but the majority will be sourced from the private or voluntary sector and funded through personal budgets, direct payments or commissioned contracts.

Many people continue to live with family carers, 295 reported through the latest SALT return, and 22 people were living as part of the Shared Lives scheme which offers accommodation and support in approved family homes. Supported living arrangements where a person has their own tenancy and often shares support hours with other people are seen as positive models of care but there is concern that there is not adequate provision or sufficient experienced providers to deliver the City's aspirations to move to more supported living. Positive examples of supported living often bring together social landlords and support providers to build individualised response to needs. Accommodation based support includes a wide range of residential services and some nursing homes. As previously described, Nottingham has high use of residential care, although there is an ambition to move to more independent living arrangements. All care homes will be registered with the CQC (see Care Homes JSNA chapter) and, as with the national debate about social care provision there is concern about the availability of skilled staff and providers for people with LD, and in some cases levels of care. Direct payments are also possible to enable people and carers to directly employ their own support.

Nottingham City Council has had framework agreements for the provision of accommodation, care support and enablement, and day/evening provision. This means there should be a choice of provider or service to meet individual needs. Nottingham City Council has in-house day provision at centres through the city, although not all activities will be centre-based. Commissioners are currently reviewing care support and enablement as well as homecare and have announced moving to a system of accreditation for day and evening services, and services are flagged as such on the Ask LION directory. A lower level of support is offered by Independent living support services', funded through housing related support. These services provide low level support to help people live independently, including help with budgeting and practical skills. The service specifically targeted at learning disabled people is Include. Support for carers through provision of Short Breaks and respite care is detailed in the carers chapter of the JSNA. Overnight respite provision is currently provided by a range of residential providers and some dedicated respite services provided by the private sector. The City Council is currently developing a new internal residential respite service which will provide provision for those with complex needs.

It is anticipated that there will be increased use of Integrated Personal Budgets (combining health and social care budgets) in the future.

Nottingham City Council also coordinates the Safeguarding response for vulnerable adults in the City who may be at risk of abuse or neglect and Citycare provide the DOLS service to protect the rights of people deprived of their liberty.

Providers of services to adults with learning disabilities are supported by the Nottingham CVS VAPN through a forum to enable them to engage with local commissioning organisations and the Health and Wellbeing Board.

**Hearing the voice of people with learning disabilities**

Under The Care Act there is a requirement to ensure access to advocacy for people in certain circumstances. Nottingham City Council have commissioned this service from POhWER who provide all statutory advocacy in the city. This no longer includes access to

less formal help to support people to 'have their say' as the requirement for statutory advocacy has increased, but volunteers to support informal advocacy are being encouraged and supported. All health and care services have mechanisms for patient involvement, and there has been good practice in this regard at Citycare, NUH and Nottinghamshire Healthcare Trust, for example training peer 'experts by experience' to encourage feedback. Complaints systems, however, do not routinely report by type of disability.

The Nottingham City Learning Disability Partnership Board, SPLAT-'Speak, Listen, Act Together' has been supported recently by Vox CIC to provide a structure to engaging with and empowering people with LD to collectively engage with key issues that affect them, such as housing, transport, health and employment. The current contract for support to SPLAT ends in March 2018 and the Board is identifying options for the future.

**Employment support**

Increasing the number of people with LD in employment is a key priority for Nottingham City Council. Recent work has been undertaken to explore specific ways of increasing employment by a social care manager, and learning disability has been included in wider discussions in Nottingham on health and employment. Futures offer advice and guidance, including with young people and during transition. DWP has relaunched Disability confident and is aiming to build links with employers to improve employment of disabled people. There are good examples locally of small social enterprises which develop to offer work experience, e.g. in café or hospitality settings. Specific support to disabled people is available through Remploy. Woodfield Industries is a supported employment part of Nottingham City Council, which has developed to provide more training opportunities as well as supported employment. Volunteering and training are recognised as important steps towards employment, and innovative community opportunities such as horticultural experience on community allotments may be valued. Often such opportunities require skilled support staff and so sometimes are only available to those with a personal budget to fund the support. The new directory askLiON is also building further information on work and disability.

**Social Inclusion**

A safe and accessible local environment is necessary for wellbeing and social inclusion. Particular work in Nottingham has resulted in improved accessible public transport and support to learn how to use it. Information on transport support is available from the City Council.

Nottingham Mencap have raised awareness of disability hate crime through the 'Smile stop hate crime' project and have also developed the Safe Places scheme to build confidence in learning disabled people that there is a network of supportive organisations available to help if the need arose. Funding for this scheme has recently ended therefore ways of maintaining the progress are being explored.

Nottingham Mencap also have expertise in accessible information and this service was commissioned until recently by Nottingham City Council, however the funding is no longer available. Accessible information can include DVD, social media, photography, and use of specialist easy read symbols. Due to The Accessible Information Standard described below all health and care organisations must ensure they communicate appropriately

based on individual needs. It is not yet clear what the impact of this standard has been for learning disabled people in Nottingham.

Social inclusion is also supported through the increased network of Changing Places toilets in Nottingham, and wider afield.

**Full and equal life**

Learning disabled people have the same range of interests as the general population and access to wider cultural, leisure, sporting and social activities are essential to wellbeing and to live a full life. In most instances this may need no additional adjustment, or may need minimal changes to make an opportunity accessible to a learning disabled person. Under the Equality duty all services are required to make reasonable adjustments to enable disabled people to benefit. Much of the impact of this has been on physical accessibility or provision of accessible toilets, but attitudes and response of staff can be as important. Social care packages now recognise that some people may welcome support to access evening opportunities and not be limited by traditional day services model, and a wide range of sporting and leisure providers will ensure their opportunities are accessible. In the self-assessment a wide range of good practice was detailed including access to swimming, theatre, cinema and cultural activities which were sometimes offering additional screenings ( e.g. relaxed performances).

In addition there are specific social, cultural and sporting activities which have been developed by the learning disabled community and voluntary sector and by learning disabled people themselves. These range from social activities such as Nottingham Mencap's Gettaway club to special football sessions and choirs. Recent theatre performances have been written and performed locally by learning disabled people e.g. *Devotion* at Lakeside Arts Theatre. Further examples of the range of organisations and opportunities will be available through AskLiON and Nottingham CVS

**5) Evidence of what works**

**National strategic drivers**

The Valuing People (2001) White Paper set out the Government's commitment to improving the life chances of people with learning disabilities, through close partnership working to enable people with learning disabilities to live full and active lives.

Valuing People Now (2009) retained the principle outlined in Valuing People that people with learning disabilities are people first, and re-emphasised the need for agencies to work together to achieve the best outcomes for people with learning disabilities.

Mental Capacity Act 2005 is designed to protect and empower individuals who may lack the mental capacity to make their own decisions about their care and treatment. It includes assessment of capacity, best interest decisions and deprivation of liberty safeguards (DOLS). Recent court judgements on the application of DOLS have broadened their use significantly.

The Equality Act 2010, in addition to legislating against discrimination and harassment of disabled people, includes the duty to make adjustments so that disabled people can benefit from services and brought in the Public Sector Equality Duty to advance equality of opportunity.

Think Autism 2014, updated national strategy for adults with autism

The Care Act 2014 gives the legislative background to the assessment and provision of social care, and has specific relevance to services such as advocacy, as well as introducing the duty to promote wellbeing. The Act sets out a clear legal framework for how local authorities and other parts of the system should protect adults at risk of abuse or neglect and describes new safeguarding duties.

Special Educational Needs and Disabilities (SEND) reforms from 2014 mean that Education, Health and Care Plans replace statements of SEND, and may be in place up to a young person is 25 years of age.

There is a national programme to develop Integrated personal commissioning, as part of the aim to increase personalisation across health and social care.

The Accessible Information Standard came into force in July 2016 and aims to make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand with support so they can communicate effectively with health and social care services.

Guidance on what Local Authorities should understand about their Learning Disabled population is detailed by Black (2014).

The Government is consulting on a green paper on Work, health and disability: improving lives in preparation for a white paper in the future on how best to support disabled people to benefit from work.

The National Audit Office ( DH 2017) has published an overview of the current picture with regard to the learning disabled population and the balance between meeting the needs of the wider population and the input required to meet the needs of the group requiring highly specialist input as part of the Transforming Care agenda.

**Local Strategic Drivers**

Nottingham Vulnerable Adults Strategy 2012-2015 ( currently being refreshed)

Happier Healthier Lives Nottingham Joint Health and Wellbeing Strategy 2016-2020

Nottinghamshire Transforming Care Programme

Nottingham Autism Strategy; One Size Fits One

**Learning from the experience of poor care**

In many cases the detail of how services for learning disability can improve has been learnt from examples of services that have failed people. The current landscape of Transforming Care and the Learning Disability Mortality Review are based on emerging evidence over the years of factors that limit the health and lives of people with learning disability.

Death by Indifference published by Mencap followed up the deaths of 6 people believed demonstrated institutional discrimination towards people with learning disabilities within the NHS, leading to shortcomings in care received that ultimately resulted in the death of the patients. This resulted in Healthcare for all (2008), the report of the Independent Inquiry into Death by Indifference by Sir Jonathan Michaels concluded that people with learning disabilities appear to receive less effective care than they are entitled to, with evidence of a significant level of avoidable suffering and a high likelihood that deaths are occurring that could be avoided. Six Lives (2009), the report of the Health Ombudsman into the cases highlighted in Death by Indifference highlighted some significant and distressing failures in health and social care services, leading to situations where people with learning disabilities experienced prolonged suffering and inappropriate care. As a

result of this a national system of initially LA and then Joint self-assessment arose. One of the outcomes of which raised awareness of health inequalities and the establishment of the Department of Health-funded Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD), published in 2013, which showed preventable deaths in people with learning disabilities. Mazars independent report into investigation of deaths at Southern Health NHS Trust published in 2015 showed low levels of investigation into deaths of learning disabled people.

These independent reports have now informed the development of the local systems, to be established from January 2018, the Learning Disability Mortality Review Programme. The University of Bristol and NHS England have published learning from the pilot sites in 2017. Also relevant, in 2017, the National Quality Board published National Guidance on Learning from Deaths. A Framework for NHS Trusts and NHS Foundation Trusts on Identifying, Reporting, Investigating and Learning from Deaths in Care.

The experience of care and treatment of people with learning disabilities who display behaviour that challenges, and the resulting long stay in hospitals, often far from home, as well as the risks of abuse and invisibility to commissioners, were highlighted by the Panorama programme on Winterbourne View. As a result the Transforming Care Programme was developed to bring in a programme of care and treatment reviews and to identify person centred solutions for long term placements in the community where possible. Building the Right Support describes the strategic approach. Guidance from the Transforming Care Programme includes Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition and Building the right home: Guidance for commissioners of health and care services for children, young people and adults with learning disabilities and/or autism who display behaviour that challenges (NHS England, LGA and ADASS 2015b and 2017)

**The Learning Disability Mortality Review Programme (LeDeR)**

The LeDeR Programme was established in response to one of the key recommendations of the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). CIPOLD reported that for every one person in the general population who dies from a cause of death amenable to good quality care, three people with learning disabilities will do so.

The Learning Disability Mortality Review (LeDeR) Programme (2015-2018) aims to guide improvements in the quality of health and social care service delivery for people with learning disabilities. It is co-ordinated by the University of Bristol, and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. The LeDeR programme will enable local areas to meet their requirements as laid out in the NHS Operational Planning guidance 2017/18 includes the following “must do” for NHS England;

- Reduce premature mortality by improving access to health services, education and training of staff, and by making necessary reasonable adjustments for people with a learning disability and/or autism

A key part of the LeDeR Programme is to facilitate local reviews of deaths of people with learning disabilities aged 4 – 74 (inclusive) registered with a GP in England at the time of their death. All deaths will be reviewed, irrespective of the cause or place of death. Deaths amongst children (ages 4-18) will be reviewed at CDOP first.

These local reviews of deaths are intended to help health and social care professionals and policy makers to:

- Identify the potentially avoidable contributory factors related to deaths of people with learning disabilities.
- Identify variation and best practice in preventing premature mortality of people with learning disabilities.
- Develop action plans to make any necessary changes to health and social care service delivery for people with learning disabilities.

There has been a phased roll-out of implementing reviews across regions with all areas nationally being compliant by January 2018. Locally the process commenced in October 2017 and has an established steering group, local area coordinators and a pool of trained reviewers.

**Profound and multiple learning disability**

The needs of the small group of people with profound and multiple learning disabilities were described in the report by Mansell 2010, Raising our sights: services for adults with profound intellectual and multiple disabilities, which highlighted factors to be taken into account when planning and delivering support for people with highly complex needs. For people with multiple health problems related to their learning disability ( e.g. dysphagia, mobility, postural problems, sensory impairment, specialist feeding and personal care needs) personalised care plans within the context of reasonable adjustments will need to be established to support the individual maximise health, independence and quality of life. Recent NICE guidance, Multi-morbidity: clinical assessment and management (NG56) is relevant in this instance.

**Evidence and Professional Guidance**

The National Institute for Health and Care Excellence (NICE) includes guidance and quality standards relevant to people with learning disabilities. In many types of guidance there is reference to groups of people for whom services will need to make adjustments, e.g. due to communication or consent problems or due to people with LD being at higher risk. For this reason it is not possible to list all NICE guidance that may be relevant to people with LD as they may experience the full range of health and social care needs experienced by the wider population. There are however two sets of guidance that are specific to people with learning disabilities:

- Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (NG11) (2015) and the related Quality Standard QS101
  This guidance highlights the importance of trained and experienced staff using responsive and least restrictive approaches that aim to understand the function of

behaviour that challenges, and develop behaviour support plans. The guidance stresses that challenging behaviour often demonstrates an unmet need. The guidance references LaVigna and Willis (2012) on the role of Positive Behavioural Support.

- Mental health problems in people with learning disabilities: prevention, assessment and management (NG54) (2016) and the related Quality Standard QS142
  This guidance explains that mental health problems are commonly overlooked in people with LD. It describes how person centred approaches are needed that take account of the person's level of LD, their decision making capacity, their means of communication, and stresses the role of the key worker for a person with LD and serious mental illness. Appropriately trained staff are again described as a priority.

Two sets of guidance are in preparation:

- Care and support of older people with learning disabilities publication 2018
- Social work interventions for adults with complex needs (including adults with learning disabilities) and mental health needs publication date not confirmed

In addition there are some NICE guidelines where people with LD are highlighted throughout, as below

- Obesity: identification, assessment and management CG 189 (2014)
- Autism spectrum disorder in adults: diagnosis and management CG 142 (Aug 2016)
- Epilepsies: diagnosis and management (CG137)

The Public Health England Learning Disability Health Observatory, formerly known as Improving Health and Lives, was established to build the knowledge base and share good practice**.** It includes examples of reasonable adjustments, as well as updates on current evidence. A series of briefings on how services can be adjusted to support learning disabled people are available here. They include recommendations related to constipation, dysphagia, weight management and cancer screening, and more will be added to the series. Public Health England (2015) has published a series of reports on improving the health of people with Learning Disabilities as part of the *All Our Health* programme.

The NHS annual LD health check programme is referred to in the LD specific NICE guidance above and in the NHS England 'Improving Health' programme. Lennox et al and Jones et al describe the impact of such programmes, identifying that they can pick up on unmet health need. The Royal College of General Practitioners (2017) have also published a toolkit to support health checks.

Guidance for the nursing profession has been published including:

- Connect for Change an RCN update on learning disability services in England (2016).
- Dignity in health care for people with learning disabilities aims to improve dignity in health care for people with learning disabilities.
- Meeting the health needs of people with learning disabilities is guidance defining learning disabilities, outlining some specific health needs and explaining relevant legislation, which includes obtaining consent.

- Provision of mental health care for adults who have a learning disability provides guidance for nurses and nursing students in mental health services in delivering high-quality health care to people with learning disabilities.
- Learning from the past – setting out the future: Developing learning disability nursing in the United Kingdom sets out the key issues and actions required, both now and in the future, to enable learning disability nursing to develop and progress in line with the increased demand on its services.

Specific guidance for adjustments related to pharmacy care was published in 2017 by Public Health England.

Equal access, equal care: guidance for prison healthcare staff treating patients with learning disabilities (NHS England 2015) is an introduction for all prison healthcare staff about the main points to consider when treating or managing a patient with known or suspected learning disabilities.

Communication Standards have been developed by the Royal College of Speech and Language Therapists to highlight how services should make reasonable adjustments to aid communication.

The NDTI (2013) published a toolkit to support services to audit provision for people with LD in mental health settings. NHS England have produced a bite size guide Helping People With a Learning Disability to Give Feedback

**Measurement of outcomes**

There are a number of tools that are used to monitor outcomes in LD settings. The HONOS LD outcomes scale was developed by the Royal College of Psychiatrists and is relevant to identifying change in response to treatment for people with LD and mental illness. NHS England wants to identify patient-centred outcomes measures and pilot sites have been identified. The National Development Team for Inclusion have developed a Health Equalities Framework that looks for improved outcomes across the domains which are known to be factors in the health inequalities experienced by people with LD. Some care providers have developed local ways of capturing goals and outcomes from a person centred point of view ( e.g. see Living the Life by Choice Care Group). The East Kent Outcomes System ( EKOS) brings together an agreed care plan with appropriate indicators to monitor patient outcomes.

**Local evidence**

Local evaluations have taken place since the last JSNA on specialist dentistry, using innovative communication techniques and on primary care health facilitation and acute liaison services. A detailed report was prepared locally in response to the Mansell report on complex needs (Nottingham and Nottinghamshire Public Health 2011). Local resources have been developed in Nottinghamshire to support improved practice in supporting people with LD such as improving End of Life care, development of local Health Action Plan resources, GP electronic health check template, and hospital 'traffic light ' tool. Local guidelines have been developed to support services for pregnant women and new mothers with a learning disability.

## 6) What is on the horizon?

**Projected service use and outcomes in 3-5 years and 5-10 years**

Needs for Learning Disability services are influenced by background demographic changes, changes to the incidence of learning disability and reductions in mortality of people with LD. The evidence from research (Emerson and Hatton 2011) describes how future need for services is likely to be dependent on a rising, aging and more diverse population. Estimates all suggest sustained growth of on average 3.2% per year. The expectation is that BME groups will represent a higher proportion of people requiring care. The research stated that "by 2030 the number of adults aged 70+ using social care services for people with learning disabilities will more than double." For people with profound and multiple LD national estimates suggest an average percentage increase up to 2026 of 1.8% per year ( Emerson 2009), however this is expected to be higher in areas with a younger demographic profile and a greater proportion of citizens from Pakistani and Bangladeshi communities.

Emerson and Hatton point out that their predictions are based on *need* rather than *demand* for services, which they predict will rise at a faster rate:

"Changes in demand are likely to outstrip changes in need due to a variety of factors combining to reduce the capacity of informal support networks to provide care, networks that have primarily relied on the unpaid labour of women."

Emerging trends are not only affected by numbers of people but particularly level of need; it is important to note that this is not always predicted by level of learning disability, for example people with mild LD may be more exposed to changes in risks related to social exclusion, substance misuse, homelessness or exploitation. People with LD are also influenced by the prevailing trends that affect the wider population e.g. rising obesity and increased recognition of dementia.

The Institute of Public Care (2014) publish PANSI, a tool to illustrate future predictions of social care need by local authority. The most recently published data is below, however for the following reasons they are likely to be underestimates. These figures were last updated in 2014 based on 2012 population estimates so will underestimate the size of the background population and they also state that the estimates they give will be underestimates in areas of high ethnic diversity. The tool publishes estimates of numbers of people with LD by severity and by age group, with additional estimates of those with challenging behaviour and on the autistic spectrum. In order to consider numbers likely to be known to LD services it is recommended to look at the section of those with moderate or severe LD. PANSI data is due to be updated in 2017 and it is expected that Nottingham City figures will be higher than below. The figures published by PANSI show that it is in the older age groups (over 55) that the greatest percentage increases in LD population will occur. Such projections are not available by gender.

**Adults predicted to have a moderate or severe learning disability: Nottingham City**

Source PANSI 2014

| | 2015 | 2020 | 2025 | 2030 |
|---|---|---|---|---|
| 18-24 | 386 | 371 | 376 | 416 |
| 25-34 | 263 | 269 | 267 | 257 |
| 35-44 | 233 | 236 | 247 | 256 |

| | | | | |
|---|---|---|---|---|
| **45-54** | 191 | 188 | 179 | 183 |
| **55-64** | 135 | 151 | 163 | 158 |
| **65-74** | 68 | 75 | 80 | 90 |
| **75-84** | 26 | 26 | 31 | 34 |
| **85+** | 10 | 11 | 12 | 13 |
| **Total** | **1,310** | **1,327** | **1,354** | **1,407** |

**Percentage change in adults predicted to have a moderate or severe learning disability: Nottingham City**

**Source PANSI 2014**

| | **2015** | **2020** | **2025** | **2030** |
|---|---|---|---|---|
| **18-24** | 0% | -4% | -3% | 8% |
| **25-34** | 0% | 2% | 2% | -2% |
| **35-44** | 1% | 2% | 7% | 11% |
| **45-54** | 1% | -1% | -5% | -3% |
| **55-64** | 2% | 15% | 23% | 19% |
| **65-74** | 2% | 13% | 19% | 35% |
| **75-84** | -1% | 1% | 17% | 29% |
| **85+** | 0 | 9% | 19% | 33% |
| **Total** | 0% | 2% | 4% | 8% |

**People aged 18-64 with a learning disability, predicted to display challenging behaviour, by age, projected to 2030: Nottingham City** **Source PANSI 2014**

| | **2015** | **2020** | **2025** | **2030** |
|---|---|---|---|---|
| **18-24** | 28 | 27 | 27 | 30 |
| **25-34** | 22 | 23 | 23 | 22 |
| **35-44** | 17 | 17 | 18 | 18 |
| **45-54** | 16 | 16 | 15 | 15 |
| **55-64** | 12 | 14 | 15 | 14 |
| **Total** | 96 | 96 | 97 | 99 |

As a lifelong disability, the best predictors for local need related to LD in the future should be developed locally based on knowledge of the needs of young people and of adults already known to social care and primary care. The Strategic Commissioning Review identified that knowledge of current citizens does not inform future planning adequately, for example in identifying numbers of people who live with aging family.

**Impact of policy change**

It is important to note that future changes to the level of support for people with LD can be altered by both national and local policy decisions, whether related to welfare changes,

Care Act or Equality Duty considerations or following exposure of poor quality care such as at Winterbourne View. Young people with LD may now have a Health and Care Plan that continues to young adulthood, and aspirations for full lives lived as independently as possible will influence future planning of services.

**7) Local Views**

Analysis of generic feedback on services by people with LD is limited by the fact that consultations do not always provide the opportunity for a person to identify as having a learning disability nor are all consultations routinely publicised in formats that are accessible. Even if an easy read version of a consultation is available, this will only be accessible for a proportion of people with LD. Therefore, in line with the Equality Duty for reasonable adjustments, services need to find varied ways for people to express their views, including making comments and complaints. In practice this has been developed further by services specifically for people with LD than by generic services. There are examples of the use of 'Talking Mats' in evaluations, and proactive use of ipads used by peer advocates in specialist services. Nottinghamshire Healthcare Trust bring together feedback at a specific website which has summary reports by service area and includes feedback which uses the Patient Opinion website where LD services locally can be specified.

The Learning Disability Partnership Board is known as SPLAT (Speak, Listen, Act Together) and provides a structure to involve people with LD (self-advocates) and carers with relevant organisations with the aim of improving the lives of people with LD in Nottingham. Regular listening events are held to explore issues in interactive ways and videos are produced to share the views developed. In 2015-16 these have included considerations of health and work, advocacy and transport, amongst others. Videos and updates are available to view on the SPLAT website. Self-advocates views were compiled to support the most recent (2016) self-assessment process (SAF), where red/amber green ratings were voted on for key areas of life and examples sought (further details available from SPLAT).

As part of the consultation for the 2016 Health and Wellbeing Strategy all previous engagement with SPLAT was looked at for key themes related to health and wellbeing. This was presented to the SPLAT Board for confirmation and challenge. The following key themes were agreed as priorities for SPLAT members.

- Friends and family, relationships matter
- Doing enjoyable things
- Having enough money
- Having information to make choices
- Independence
- Being safe from bullying and hate crime
- Having support from people who understand you
- Respect
- Activities that are good for your health
- Well trained staff who understand LD and Autism
- Help to get work
- Advocacy-someone to help you have your say

Nottinghamshire Transforming Care Partnership undertook a wide public consultation during 2015 and the full report on results is available here. There was wide support for care to be more community based rather than hospital but there were areas of concern about the impact of this which they highlighted and would like addressed if the new model is implemented. In summary these were:

- good support from well trained, qualified and skilled staff, from joined-up agencies and multi-disciplinary teams, and from good 'packages' of care.
- good communication, and of receiving the right information
- effective transition arrangements
- properly funded services-there was a view that proposed changes may be a cost cutting exercise
- good quality housing provision
- support out of hours
- safety for the person and wider community
- importance of social activities to reduce risk of social isolation and poor mental health.

In addition to the local systems above there are additional mechanisms for people with LD who use services to express their view, for example through Healthwatch or through the inspection regime of the Care Quality Commission, but at present these are not brought together in a thematic way to enable them to be presented here. However the CQC website can be searched by care provider.

**What does this tell us?**

**8) Unmet needs and service gaps**

**Population health**

Although numbers of checks have increased, the proportion of annual health checks at GP practices is variable and many people do not receive a full check or action plan.

There has been a good infrastructure of liaison services within primary care and secondary acute care to support improvements in reasonable adjustments for people with LD, and this needs to be maintained. There is increased demand for the support offered by the hospital liaison team.

Obesity and overweight are disproportionately high in the LD population

As illustrated by the Confidential Inquiry there are likely to be unmet health needs and preventable early deaths in people with LD.

There is a risk that concentration of activity on Transforming Care could limit developments to improve the health of the wider group of people with LD.

Estimates (based on general mortality rates and the numbers of people with LD registered with GP) suggest that there is on average 45-50 deaths of people with LD per year across Nottingham and Nottinghamshire. Early findings from the LeDeR review process nationally has identified the 3 leading causes of death are pneumonia (18%), aspiration pneumonia (14%) and sepsis 13% based on the 473 deaths up to May 2017.

**Accommodation and Support**

There is higher use of residential care in the city and low use of supported living.

Transforming Care agenda has demonstrated challenges in identifying flexible, skilled provision in the market for those whose behaviour challenges.

There is likely to be a rise in demand for services due to demographic changes but also due to changes in family structure and changing expectations.

**Social Inclusion**

There are low levels of employment in people with LD

The LD Communication strategy requires refreshing in the light of new legislation such as the Accessible Information Standards, and more services need to proactively develop and use easy read materials.

Level of social vulnerability cannot be predicted by the level of LD. People with mild LD may be at increased risk of social vulnerability, such as hate crime, exploitation or substance misuse, as well as being impacted by welfare reforms.

**9) Knowledge gaps**

Since the previous JSNA a number of key pieces of work have added to the knowledge base such as the Miquest search of primary care as part of the self assessment process.

There is scope to better understand use of the urgent care system by people with LD.

Previous needs assessment work is not possible to replicate due to information governance changes across the NHS and Public Health.

The system for claiming payment of annual health checks by General Practice is not sufficient to identify how well the health check system is working or the quality of health checks provided.

The needs of the wider group with mild LD who are not known to services are not well documented, but this group are likely to be in the most deprived socioeconomic groups.

Local knowledge of the extent of the early mortality of people with LD is limited.

**What should we do next?**

**10) Recommendations for consideration by commissioners**

**Population Health**

Ensure actions in the Health and Wellbeing Strategy take the needs of people with learning disabilities into account.

Partnership arrangements need to be established with NHS England to improve uptake and monitoring of the annual health check programme

Ensure health and care services are joined up to support people with a combination of health needs and LD e.g. diabetes, cancer, asthma, end of life care, obstetric care

As a result of SEND changes (up to age 25) and changes to the health check programme (14 upwards) ensure that healthcare is joined up during the transition period

Ensure health promotion and prevention initiatives are actively promoted and inclusive for people with LD, and those supporting them, particularly regarding weight management, healthy eating and physical activity.

Cooperation with NHS England and local Safeguarding Boards in plans for Learning Disabilities Mortality Review Programme

Maintain infrastructure that supports people to access mainstream health services and consider whether capacity is sufficient in the hospital LD liaison service and the primary care liaison team.

Continue to monitor the overall picture of people with LD in Nottingham through the General Practice Miquest query.

Aim to better understand use of the urgent care system by people with LD.

**Accommodation, care and support**

Establish local system for predicting future needs based on current needs of both children and adults.

Demographic changes - take account of the needs of an aging population of carers and adults with LD, to include preventative early intervention approaches.

Take a strategic approach to reducing dependence on residential care for people with LD in the city, and develop a vision for increased use of more supported living options, with increased choice and independence.

Continue to explore person centred solutions for the small number of individuals in long term hospital care as part of the Transforming Care agenda.

Ensure the aspirations of the Care Act in terms of promoting wellbeing and taking a preventative approach are embedded into the care system for people with LD.

**Social Inclusion**

Ensure people with LD are included in initiatives to increase quality employment in disabled people.

Ensure the voice of people with LD is heard through the LD Partnership Board (SPLAT) process, and ensure this is inclusive of BME communities and those in residential care settings.

Take opportunities to explore ways of including a whole life disability approach where possible as LD is a lifelong disability.

Champion the social model of disability with partners, with a strong emphasis of people with LD (and their carers) as a specific group under the Equality Act

Ensure learning and good practice from Transforming Care agenda informs the planning of care and support for the wider LD population.

Improve knowledge of needs of quickly changing diverse communities that may not be picked up through ethnicity monitoring (e.g. Eastern European communities)

Ensure initiatives in Nottingham to reduce financial hardship are inclusive of people with LD

Explore the impact of the accessible information standard for disabled people in Nottingham

**Key contacts**

Helene Denness, Consultant in Public Health, Nottingham City Council

Nick Romilly Insight Specialist Public Health, Nottingham City Council

Clare Gilbert, Commissioning Lead, Nottingham City Council

Charlotte Reading, Head of Commissioning – Children and Learning Disabilities, Nottingham City Clinical Commissioning Group

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