LEARNING DISABILITIES Fact Sheet

Background

‘Valuing People’, the 2001 White Paper on the health and social care of people with Learning Disabilities (LD), defined 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

This definition is broadly consistent with that used in the current version of the World Health Organisation’s International Classification of Disease (ICD-10). Further classification based on cognitive impairment is described by the ICD-10 diagnosis coding system, though in reality the severity/category of learning disability is rarely used outside of specialist learning disability services and generally limited in its use:

1 See Fig. 1 in the accompanying Learning Disabilities Data Sheet.

The definition encompasses people with a wide range of disabilities including adults with learning disabilities who also have autism, exclusive of those with high level functioning autism – such as people with Asperger’s Syndrome (see separate Autism Fact Sheet). This definition does not include people who have a ‘learning difficulty’.

Learning disabilities can be subdivided into those conditions that arise at conception, during pregnancy and after birth. The aetiology of causes fall into three main categories: genetic, infective and environmental. However, no aetiological cause is found in approximately 30% of cases of severe learning disabilities.

People with Learning Disabilities have the same right as any other citizen to be treated as individuals within their communities and society. They have the right to equal treatment and services which can help them maintain a good quality of life. They are amongst the most vulnerable in society often facing social exclusion, stigmatisation and have higher health needs which differ qualitatively from the rest of the population. At the same time, they may

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have a lack of recognised health and social care needs which are therefore unmet. Social exclusion within communities affects many with learning disabilities through factors such as high unemployment and restricted living conditions, relationships and life opportunities.

Mild learning disabilities are strongly associated with parental social class and family instability. However, no relationship is reported between these factors and severe learning disabilities, suggesting that deprivation may be a contributory factor for mild but not severe learning disabilities.\(^2\)

Prevalence rates for severe learning disabilities are higher in South Asian groups in the UK, with rates approximately three times higher among 5-34 year olds compared to non-Asian communities. Reasons for this higher prevalence are not clearly understood, but could be due to:

- Inequities in access to maternal healthcare
- Mix-classification due to the confounding effects of language and bilingualism
- Higher rates of genetic abnormalities and/or exposure to environmental factors

People with learning disabilities have poorer health than their non-disabled peers, differences in health status that are, to an extent, avoidable. As such, these differences represent health inequalities. The health inequalities faced by people with learning disabilities in the UK start early in life and result, to an extent, from barriers they face in accessing timely, appropriate and effective health care.\(^3\)

**Key health issues nationally include:**\(^4\)

- People with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population
- Coronary heart disease is a leading cause of death amongst people with learning disabilities with rates expected to increase due to increased longevity and lifestyle changes associated with community living
- Respiratory disease is the leading cause of death for people with learning disabilities (46-52%), with rates much higher than for the general population (15-17%)

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\(^3\) MENCAP (2012) Death by indifference, 74 deaths and counting: A progress report 5 years on, MENCAP.

Recent data extracted from GP information systems in England indicate higher rates of Type 1 and Type 2 diabetes among adults with learning disabilities

A recent UK study has reported that adults with learning disabilities experience higher rates of injuries and falls when compared to the general population

People with learning disabilities are 8-200 times more likely to have a visual impairment compared to the general population and approximately 40% of people with learning disabilities are reported to have a hearing impairment, with people with Down’s Syndrome at particularly high risk of developing vision and hearing loss

There is an increased risk of acute and chronic pain among people with learning disabilities as a result of high rates of co-occurring health conditions and physical impairments

The prevalence of dementia is higher amongst older adults with learning disabilities compared to the general population and is associated with a range of potentially challenging behaviours and health problems. People with Down’s Syndrome are at particularly high risk of developing dementia, with the age of onset being 30-40 years younger than that for the general population

The prevalence rate of epilepsy amongst people with learning disabilities has been reported as at least 20 times higher than for the general population, with seizures commonly being multiple and resistant to drug treatment

A recent systematic review reported estimated prevalence rates of sleep problems in adults with learning disabilities ranging from 9% to 34%, with an estimated prevalence of 9% being reported for significant sleep problems. Sleep problems were associated with the following factors: challenging behaviour; respiratory disease; visual impairment; psychiatric conditions; and using psychotropic, antiepileptic and/or antidepressant medication

Challenging behaviours (such as aggression, destruction and self-injury) are shown by 10-15% of people with learning disabilities

The prevalence of psychiatric disorders is also significantly higher among adults whose learning disabilities are identified by GPs, when compared to general population rates

One in three adults with learning disabilities and four out of five adults with Down’s Syndrome have unhealthy teeth and gums
People with moderate to profound learning disabilities are more likely than the general population to die from congenital abnormalities and a number of syndromes associated with learning disabilities also have additional specific health risks.

It is widely accepted that the main reasons for poorer health are not solely because of the learning disability per se but because people with learning disabilities are more likely than their nondisabled peers to be exposed to a range of ‘social determinants’ of poorer health such as:

- Less than 1 in 5 people with a learning disability work (compared with one in two disabled people generally), but we know that at least 65% of people with a learning disability want to work. Of those people with a learning disability that do work, most only work part time and are low paid.
- 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.
- In 2009/11 British adults with self-reported impairments of learning or understanding 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.

In particular, considerable attention has been drawn to the importance of inequalities in relation to timely access to appropriate and effective health care. A range of barriers to accessing healthcare and other services have been identified. These include:

- Scarcity of appropriate services.
- Physical and informational barriers to access.
- Unhelpful, inexperienced or discriminatory healthcare staff.
- Increasingly stringent eligibility criteria for accessing social care services.
- Failure of health care providers to make ‘reasonable adjustments’ in light of the literacy and communication difficulties experienced by many people with learning disabilities.
- ‘Diagnostic overshadowing’ (e.g. symptoms of physical ill health being mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person’s learning disabilities).
Specific concerns based on current research and knowledge includes:

- Lack of accurate and consistent data across a range of indicators including; health, social, care, education, housing, poverty and crime
- Low uptake of health promotion or screening activities
- Primary care access rates for people with learning disabilities are lower than might be expected
- People with learning disabilities have an increased uptake of medical and dental hospital services but a reduced uptake of surgical specialities compared to the general population
- People with learning disabilities with cancer are less likely to be informed of their diagnosis and prognosis, be given pain relief, be involved in decisions about their care and are less likely to receive palliative care
- Concern has been expressed with regard to the availability of and access to mental health services by people with learning disabilities. However, a very high proportion of people with learning disabilities are receiving prescribed psychotropic medication, most commonly anti-psychotic medication. Anti-psychotics are most commonly prescribed for challenging behaviours rather than schizophrenia, despite no evidence for their effectiveness in treating challenging behaviours and considerable evidence of harmful side-effects

Other issues likely to impact on the care and wellbeing of people with learning disabilities include:

- At least half of all adults with a learning disability live in the family home – meaning that many don’t get the same chances as other people to gain independence, learn key skills and make choices about their own lives;
- 7 out of 10 families caring for someone with profound and multiple learning disabilities have reached or come close to 'breaking point' because of a lack of short break services;
- 29,000 adults with a learning disability live with parents aged 70 or over, many of whom are too old or frail to continue in their role. In only 1 in 4 of these cases have local authorities planned alternative housing;
- People with learning disabilities in the UK have more restricted social networks than their non-disabled peers;
There is considerable evidence that people with learning disabilities are likely to have less healthy lifestyles in particular in relation to diet, physical activity, and weight;

- People with learning disabilities may have poor bodily awareness and a minority may have depressed pain responses. In addition, limited communication skills may reduce their capacity to convey identified health needs effectively to others;

- Prevalence of learning disabilities amongst offenders is higher than the general population, with 7% of prisoners in the UK having learning disabilities as determined by an IQ score of less than 70.

- Discrimination and safeguarding are two very important risk factors to take into account when considering adults with learning disabilities, in a commissioning and education capacity.

The Local Picture
There are no official statistics reporting on the number of adults in the UK with a learning disability, and establishing a precise figure is a complex exercise, due to the social construct of the condition and often confusing the term learning disabilities and learning difficulties. However estimates suggest that approximately 2% of the UK adult population have a learning disability.\(^5\)

In the 2011 census, the London Borough of Sutton was reported to have a population of approximately 190,146, with an estimation of 3,000 adults having a learning disability of which a large proportion are not known to services. This is particularly true of adults with mild to moderate learning disabilities that live on their own, or with their families who may at times take sole responsibility for their care. The majority of adults with learning disabilities known to local health and social services have moderate, severe to profound and multiple learning disabilities. See Fig. 4 on the LD Data Sheet.

Some data collected can be found at the Public Health England Learning Disability Profiles; http://fingertips.phe.org.uk/profile/learning-disabilities

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**Prediction**

The Office for National Statistics projects that the population of Sutton will rise to 216,000 (15%) by 2021. Over the next seven years by 2021, it is predicted that the learning disabled population aged 18-64 and an increase amongst those aged 65 and over. This is in line with the overall ageing population of the UK. It is estimated by 2030 the number of adults’ aged 70+ using social care services nationally for people with learning disabilities will more than double. With increasing age will come increasingly complex needs, therefore more support is likely to be needed to help people with learning disabilities remain independent and living in their own homes. An older learning disabilities population will have significant impact on provision of care. See Fig. 3 on the Learning Disabilities Data Sheet.

Services for older people with learning disabilities may need further development given the expected rise in numbers and current evidence that social care services for older people are more limited than those for younger people.

There is still limited knowledge on the needs of people with learning disabilities from BME communities.

One of the big issues facing Health and Social Care is the transition from Children’s to Adult services. A ‘Life Course’ approach to care of those with learning disabilities is recommended to ensure they stay in touch with services that allow their health and social care needs are met as smoothly and effectively. This is addressed further in the Transitions Factsheet.

**Sutton progress**

Prevention of ill health is as important for adults with learning disabilities as it is to the general population. Increasing the uptake of preventative services such as immunisations, health screening and health promotion would be valuable in the drive to improve health status of adults with learning disabilities.

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GP and Primary Health Care Services
It is widely considered that people with learning disabilities have higher levels of unrecognised health needs than the general population. Local data and information on this population health needs and inequalities is not currently gathered. There is a need to gather this information and when available, it will require analysis and monitoring, particularly in relation to newly-identified health needs being diagnosed in the LD population.

At operational level, the Sutton Clinical Health Team for people with learning disabilities is commissioned to offer specialist support to local mainstream and other specialist agencies to meet the needs of people with learning disabilities. They aim to facilitate access to mainstream health services including GP/Primary Health Care and promote wider community links for adults with learning disabilities.

Health Screening and Health Promotion
Data collected as part of the Joint Health and Social Care Self-Assessment Framework’ in November 2013, indicated that around 20% of the learning disabled population eligible for cervical screening/smear tests actually received the test. In the general population, 40% of those eligible received the test, indicating a lower level of uptake amongst the learning disabled population. Figures on breast screening, bowel and Chlamydia are not available. This is an area where further work is needed to understand any health inequality that might exist for the learning disabled population.

Long Term Conditions
Data and information on long term conditions is not routinely collated. This is an area where further work is needed to understand any health inequality that might exist for the learning disabled population.

Access to Community services
In 2014-15, for Adults with Learning Disability aged 18-64 receiving community services, England’s rate is 766.2, London is 733 and Sutton's rate is lower at 659.8. See Fig. 9. Sutton’s rate is significantly lower than for England, but in line with London.

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Housing and stable accommodation
Sutton has a lower percentage of adults with a Learning Disability who live in stable and appropriate accommodation than for London and England. Fig. 8 shows that in 2014-15 the England average was 73.3%, London 69%, whilst Sutton was 66%.

Income and Employment
The direction of travel in Sutton is to fully deliver on the Personalisation agenda and make it a reality for people with learning disabilities to have access to personal budgets. Sutton commissions a supported employment service to help drive/increase employment opportunities for people with learning disabilities.

What Works
Specialist Learning Disability Health Service
The Clinical Health Team for people with learning disabilities is multi-disciplinary and part of the London Borough of Sutton’s Adult Social Services, Housing and Health Directorate.

The team works with individuals and their carer's in a variety of settings and promotes good health and well being with main responsibilities for:

- The delivery of health inputs provided by trained clinicians specialist in the field of learning disabilities where needs cannot be met by mainstream services alone
- Promoting well being through activities such as health promotion and preventative lifestyle activity
- Facilitating access to mainstream services and supports such as; primary care; acute care; leisure opportunities: housing; etc.
- Contributing to service developments and using knowledge about needs; effectiveness of current services and future demand to inform and contribute of strategic commissioning
- Imparting skills to others by teaching and training others such as social care providers; voluntary sector staff; and other health professionals

GP and Primary Health Care Service
All 27 GP practices in Sutton have a Quality and Outcomes Framework Learning Disabilities Register. As part of the Learning Disability Direct Enhanced Scheme (LD DES), Sutton GPs are encouraged and supported to offer Annual Health Checks (AHC) to people with learning

disabilities on their register. Based on NHS Digital, current figures indicate there are 974 people with Learning Disabilities on the GP registers, compared to an estimated prevalence of 3,000 people. This suggests a high number of people with learning disabilities are not being identified accurately on the register and more work is needed to understand the actual number of people with Learning Disabilities living in Sutton.

In 2013-2014, all but three of the 27 GP Practices in Sutton signed up to the Learning Disabilities Direct Enhance Service (LD DES). The LD DES requires GP practices to offer annual health checks (AHC) to patients with learning disabilities that are known to Adult Social Care and Health services primarily due to their learning disability. In Sutton AHC is offered to those on the QOF register and every GP practice has been offered the services of a named Learning Disability GP link Nurse. The LD GP Link Nurses work in partnership with GP practices to promote better Primary Care experiences and supporting GP compliance with the delivery of the AHC. Fig.10 shows that in 2013-14 the proportion of eligible adults with a learning disability having a GP health check was significantly higher for Sutton (55.5%) than for London (49.5%) or England (44.2%).

Learning Disability awareness training is also offered to staff in GP practices and community based health services. Please see Fig 9 on the Data Sheet.

Based on local feedback (Big Health and Social Care Day - November 2013), there are inconsistencies in the delivery of the AHC and Health Action Planning (HAP). The quality of AHC and HAP are variable; ranging from poor, good and excellent in some services. There is no standard assurance process for the quality of the AHC and HAP and therefore is inconsistent across Sutton.

Work is ongoing in primary and community health services to improve services for people with learning disability; to make reasonable adjustments and be more accessible to meet individual needs. There are three enhanced service contracts in place; for the provision of dentistry, ophthalmology and dysphagia services.

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9 NHS Digital, QOF. http://content.digital.nhs.uk/QOF

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Secondary Acute Care Services and hospital admissions
The Learning Disability Acute Liaison Service is provided at the local acute hospital, Epsom and St Helier University Hospital NHS Trust. This service is provided on the hospital wards and includes duties such as advising staff, patients and carers in both in and outpatient wards and the accident and emergency department about any learning disabilities issues, for example consent, DOLS and reasonable adjustments. The LD Liaison nurse also supports people by maintaining links into primary care, community teams and ensuring continuity of support from outpatient/pre-assessment to admission and eventual discharge.

Activity data for people with learning disability at the local hospital is being developed and will need further improvement so that it can inform future commissioning of this service.

Continuing Health Care
Continuing Care is provided over an extended period of time to meet complex physical and mental health needs and involves support for receipt of NHS care and at time with social care services. Fully-funded NHS ‘continuing care’ is a package of care arranged and funded solely by the NHS, whereas 'Continuing health and social care' is a joint package of care that includes services from both the NHS and social care. This service is currently supported by the LD specialist commissioning services based in London Borough of Sutton.

Mental Health Services
People with Learning Disabilities who also have mental health needs that often GPs, primary health care and mainstream mental health services cannot fully meet can access the Sutton the Mental Health and Learning Disability Services. This service is commissioned by the local CCG, is located and managed by the South West London and St Georges Mental Health NHS Trust.

Other Specialist services
The Sutton Inclusion Centre is a fully accessible service for people with learning disabilities including those with profound and multiple learning disabilities. Specialist aqua therapy and creative therapy services are offered on site. This service is located and managed by the Clinical Health team for people with learning disabilities in London Borough of Sutton,
Social Care Services
Sutton aims to ensure that people with learning disabilities known to Social services and social care are supported in the community rather than in residential care. Sutton social care service provision is based on and support the concept of independent living in a variety of community based settings and includes services such as:

- Direct Payments/Personal Budgets
- Independent Living and Supported Housing Schemes
- Shared Lives and Adult Placement Schemes
- Community Support
- Respite care/short-term breaks
- Home Care

Direct Payments/Personal Budgets
Sutton aims to maximise and maintain individual rights, control and choices to independence. All users of adult social care services have a personal budget equivalent to the cost of services. The aim of a direct payment is to provide more flexibility in how services are provided. It enables people to spend their personal budget in the way that choose to meet their needs.

The number of people with a learning disability aged 18-64 years receiving a direct payment has been steadily increasing and was 25.8% in Sutton 2014/15; significantly higher than for London or England.

Employment
The London Borough of Sutton commissions a supported employment service to help people with people with learning disabilities into employment. LB Sutton only collate data on how many people of working age with a learning disability known to the Council are in paid or voluntary employment. ‘Known to the Council’ means that LB Sutton have assessed or reviewed the person in the year or that LB Sutton are providing services to him or In order to complete the return we therefore rely on information given to us from the supported employment service. Clearly, not all LD people in employment will have gone through this service so the numbers in the ASCOF return are likely to be an underestimate of the true number. The ASCOF measure is the number of people in paid employment divided by the overall number of working age people with LD who are known to the Council.
Employment data for the whole of Sutton’s LD population is currently beyond the council reporting mechanism. However, the council can report on the number of adults with learning disabilities known to Social Care in Sutton in paid employment. In 2014/15 this was 3.1% compared with London (7.7%) and England (5.9%). This is significantly lower than for London or England. To gain an accurate picture of the level of employment of this population group in Sutton, further work would need to be commissioned.

**Access to Community services**
Adults with Learning Disabilities aged 18-64 receiving community services
England’s rate is 749.7, London is 669.5 and Sutton is 616.1. See Fig. 9. Sutton’s rate, although lower than London and England overall, is not significantly different to England.

**Safeguarding**
The Sutton Safeguarding Adult Board and Safer Sutton Partnership provide leadership in safeguarding and local policing in areas such as the Disability Hate Crime Campaign. There is a multi agency work programme in place and the Council takes a lead role in this area of work.

**Stakeholders: People with LD and their Carers**
Adults with Learning Disabilities should receive access to health and social care services without being discriminated against. The Sutton Health and Wellbeing board has the responsibility to ensure People with Learning Disabilities in Sutton do not face any barriers to enjoying a good quality of life, with access to good and social care services. Health and Social Services need to ensure people in Sutton have access to services that keep them healthy, safe and living well (Joint Health and Social Care Self Assessment Framework 2013).

“Local authorities should ensure that adults with profound intellectual and multiple disabilities are able to take part in a wide range of meaningful activities – including employment, education and leisure activities”.11

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Sutton Council commissions a *User Involvement Service* to support people with learning disabilities to have stronger voices; be involved and engaged in the scope, design and quality of local services. This self-advocacy group is; Speak Up Sutton Partnership.

Sutton has a *Learning Disability Partnership Board* with a number of sub groups involved in design and planning of services; Sutton LD Carers Group, LD Health Sub Group and Multi Agency Leisure Group (MALG). The LD Partnership board is in the process of evolving into a Special Interest Group for People with Learning Disabilities. The direction of travel is to enhance involvement and engagement of people with LD, through development of the Learning Disability Special/Self Interest Group.

**Key indicators and targets**
Within the Public Health Outcomes Framework there are two indicators for Adults with Learning Disabilities. Both come under Domain 1: Improving the Wider Determinants of Health.

Objective: Improvements against wider factors that affect health and wellbeing and health inequalities

- Adults with a learning disability / in contact with secondary mental health services who live in stable and appropriate accommodation
- Employment for those with long-term health conditions including adults with a learning disability or who are in contact with secondary mental health services

It is also worth noting that there is an indicator entitled Social Isolation. Whilst not specific to this population group it should be considered in relation to adults with learning disabilities who are often left out of the community and have little social contact.

**Sources and links to further information**

- See also the *Transitions Factsheet*
- *People with learning disabilities*, Annual report of the Director of Public Health 2008, Sutton and Merton Primary Care Trust
- *‘I Count’ Register for People with Learning Disabilities*, October 2010, Report 18, Sutton and Merton Primary Care Trust

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Recommendations and Priorities for Sutton

Over the past three years, there has been a national campaign to develop a comprehensive and standardised benchmarking tool for understanding and evidencing local strengths, weaknesses and quality of health and social care services for people with learning disabilities. This tool called “Joint Health and Social Care Assessment Framework” is an nationally validated measure enforced by both Association of Directors of Adults Social Services (ADASS) and NHS England. It consists of 27 indicators which although ambitious, is nevertheless a useful tool to provide a basis for addressing local gaps and therefore can be used as an effective gap analysis for commissioning of good quality health and social care services for people with learning disabilities. In this document, the Joint Health and Social Care Self Assessment Framework, is used to formulate commissioning and service priorities for Sutton.

The following areas of priorities are derived from the three main measures of the Joint Health and Social Self Assessment Framework, which are:

- Stay Healthy
- Safe
- Living Well

Priorities for commissioners

1. Commission work to improve quality of information and data across local services such as health and social care agencies to provide accurate and up-to-date local population health needs profile for people with learning disabilities.
2. Commission support to develop robust system to identify and flag patients with learning disabilities, including moderate/mild learning disabilities in mainstream
Primary GP services, Secondary and Tertiary health service provisions and develop protocols to ensure care pathways are reasonably adjusted.

3. Commission a review of the provision of annual health checks for people with learning disabilities to ensure equal access, quality and consistency across the borough.


5. Continue support to providers of key services in mainstream health and wider social care, leisure, sports, education, to ensure services are accessible to adults with learning disabilities, e.g. healthy eating, exercise/diet/weight management.

6. Commission services to support mainstream health, wider social services and directly commissioned services to ensure and demonstrate ‘reasonable adjustments’ are embedded in day to day delivery of services to people with learning disabilities.

7. Continue to promote development of accessible information and advice including the service directory to assist people with LD in using their personal budgets to purchase cost-effective support.

8. Review the commissioning of employment support with aim to increase the number of adults with learning disabilities in employment.

9. Review support to people with learning disabilities, families and carers to enhance their involvement in the commissioning, planning and decision making process.

10. Commission future health and social care services in line with expected increase in prevalence of children and older adults with complex needs over the next 10-15 years.