

Learning Disabilities: Factsheet

Tower Hamlets Joint Strategic Needs Assessment 2010-2011

Executive Summary

There are approximately 1,000 people aged 14 and over with a learning disability known to services in Tower Hamlets, which is consistent with national estimates. Prevalence of learning disability is higher in the male, Asian and black populations. People with learning disabilities experience higher than average prevalence of a range of health conditions, most notably diabetes, asthma, epilepsy, stroke and all mental health conditions including depression and severe mental illness (SMI).

Local priorities of the Learning Disability Partnership Board include:

- Carers
- Challenging Behaviour
- Communication and engagement with service users
- Employment
- Health Inequalities
- Safeguarding and Community Safety
- Personalisation

1. What are learning disabilities?

Valuing People (2001) defines a learning disability as the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence);
- A reduced ability to cope independently (impaired social functioning);
- Which started before adulthood (before the age of 18), with a lasting effect on development.

This definition is consistent with both International Classification of Diseases (ICD-10) and Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), and encompasses people with a broad range of disabilities. The presence of a low intelligence quotient (IQ of 50-69 is usually classified as mild learning disability; 35-49 moderate; 20-34 severe; less than 20 profound) is not of itself a sufficient reason for deciding on a diagnosis of learning disability and whether an individual should be provided with associated health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining severity and support needs, and historical information also needs to be sought about childhood development.

2. What is the local picture?

Nationally and locally the true prevalence of learning disabilities and coexisting conditions is most likely underestimated. The percentage of the Tower Hamlets population with a learning disability *known to services* (health and social care) ranges from around 0.26%-0.86%, consistent with national estimates of people with moderate or severe learning disabilities. There are most likely to be many more people in the borough with learning disabilities who are not known to the Community Learning Disability Service (CLDS), and they are very difficult to identify. It is possible that people with learning disabilities are less likely to access services because of various communication, social or practical barriers, and therefore health and social care services are less likely to have data on the actual number of people with learning disabilities in the borough.

Table 1 Prevalence estimates of learning disability in the Tower Hamlets population, 2010 (different sources)

Data Source	Age Range Covered	Number of people in Tower Hamlets with a learning disability	Prevalence (percentage of the population)
Special Educational Needs (SEN)	2-17 years	406	0.86%
Community Learning Disability Service (CLDS) ¹	14 years and over	956	0.49%
Social Care (Adults Health and Wellbeing)	18 years and over	625	0.33%
EMIS Web ²	18 years and over	711	0.29%
Quality Outcomes Framework (QOF)	18 years and over	636	0.26%
Expected overall prevalence (moderate or severe learning disabilities)	15 years and over	1,049	0.54%
Expected overall prevalence (all learning disabilities)	15 years and over	4,870	1.89% - 2.77%

Prevalence is expected to be higher in Tower Hamlets (particularly in the younger population) due to the large South Asian community and to high levels of deprivation.

Table 2 Prevalence by ethnicity and gender (CLDS clients aged 14 years and over)³

Ethnicity	Prevalence (14 years and over)		
	Males	Females	Total
Asian or Asian British	0.86%	0.49%	0.68%
Black or Black British	0.95%	0.62%	0.80%
Other	0.55%	0.25%	0.21%
White	0.41%	0.33%	0.37%
Total	0.58%	0.39%	0.49%

Prevalence of learning disabilities is higher in the male population of Tower Hamlets (and nationally). Around 0.58% of the male population aged 14 and over has a learning disability and is known to services, compared to 0.39% of the female age equivalent population.

Age specific prevalence rates are likely to increase nationally over the next twenty years, due to an increased proportion of the population being of South Asian origin, increased survival rates of young people with severe and complex disabilities, and reduced mortality in older people with learning disabilities. Although it is difficult to predict actual figures of adults with learning disabilities in the future, we can assume minimum estimates if prevalence rates remain constant.

Assuming prevalence rates remain constant, the number of people requiring support from CLDS is expected to increase to over 1,040 over the next five years, and to around 1,235 by 2030.

¹ February 2010

² As at 1st April 2010

³ Crude prevalence rates calculated using CLDS ethnicity data and GLA Population Estimates, 2010.

Table 3 Approximate number of CLDS clients, projected to 2030⁴

Year	2010	2011	2012	2013	2014	2015	2020	2025	2030
Expected numbers (rounded)	955	980	990	1010	1025	1040	1145	1210	1235

Learning Disabilities and Co-morbidities

Analysis of GP registered data by condition shows an inequality in the health conditions of people with learning disabilities compared to the general Tower Hamlets population (i.e. a relatively higher prevalence). Notable differences exist particularly with diabetes, asthma, epilepsy, stroke and all mental health conditions including depression and severe mental illness (SMI). There is a 10 times higher recorded prevalence of SMI in the population with learning disabilities compared to the general population.

3. What are the effective interventions?

Policy and service development in the area of learning disabilities is driven by the White Paper, [Valuing People \(2001\)](#) and subsequent strategies, [Valuing People Now \(2009\)](#) and [Valuing Employment Now \(2009\)](#). These strategies focus on promoting and delivering advocacy, employment support, person-centred planning and partnership working to improve the lives of people with learning disabilities. People with learning disabilities must be supported to live an ordinary life in the community in line with human rights legislation, the [Disability Discrimination Act \(2005\)](#) and the [Equality Act \(2010\)](#). Other policies such as [Aiming High for Disabled Children](#) focus on action for children.

National priorities for 2008-2011

Personalisation: to ensure that people have real choice and control over the services they receive and over their lives.

How people spend their time: to ensure that people are included in their communities (with a focus on increased independence and paid work).

Better health: to ensure that people have full and equal access to good quality healthcare for both physical and mental health needs.

Access to housing: to ensure that people have options for housing that they want and need (with a focus on home ownership and tenancies).

Making change happen: to ensure that partnership boards are more effective in delivering policy.

Mencap's paper [Death by Indifference \(2007\)](#) and the subsequent [Six Lives \(2009\)](#) report, published jointly by the Local Government and Parliamentary and Health Service Ombudsmen, highlighted serious failures in health and social care for people with learning disabilities, which all local authorities were required to investigate in their area.

Personalisation, outlined in [Putting People First](#) is changing the way services are commissioned and delivered. It emphasises independence, social inclusion, rights, employment, choice and control. As part of this, person-centred planning and self directed support are required to become mainstreamed. Personal budgets are to be made available to everyone eligible for publicly funded social care support other than in circumstances where people require emergency access to provision.

4. What is being done locally to address this issue?

Prevention

Preventative services for people with learning disabilities focus on providing information and advice, advocacy and other services to enable people to enjoy independent lives. Supporting family carers of people with learning

⁴ Estimates calculated using crude prevalence rates and GLA Population Estimates, 2010.

disabilities is also designed to prevent people requiring long term social or secondary care.

In Tower Hamlets there are several preventative services available to people with learning disabilities. The Tower Project Jobs, Enterprise and Training team (JET) provides support and training for people with disabilities in Tower Hamlets and the City of London seeking employment.

Poetry in Wood is a social enterprise, training and employment scheme for people with learning disabilities. Individuals are trained in woodwork, art and design, developing skills in creativity, research, communication and peer tutorage. Members of the social enterprise project are supported in paid employment, working largely on commission.

MAP Squad offers advocacy support and day opportunities to people with learning disabilities who want to work on their own or in partnership on community projects.

People with disabilities in Tower Hamlets can access advocacy services through Disability Advocacy Network.

Supporting People commission 'housing-related support' to develop and maintain people's ability to live independently, either in their own home or in supported accommodation. Housing related support can include:

- Helping someone to get their correct benefits
- Helping someone to learn to budget properly for rent and bills
- Helping someone to access a GP or dentist
- Helping someone to get on a training or education course
- Helping someone to get a community alarm service
- Helping someone to improve their social network

Work is currently underway with existing providers to develop three community hubs in Tower Hamlets for people with learning disabilities to access information and advice without necessarily meeting FACS criteria. As part of the review of day opportunities there will be an increased focus on preventative and universal services, including advocacy and improved training and employment opportunities.

Health promotion literature produced nationally in easy read is to be made available to GP practices and day services across the borough.

Primary Care

Tower Hamlets organised a 'Six Lives Panel' in November 2009 to address gaps in meeting the health needs of people with learning disabilities. The Panel including senior staff from commissioning and services across health and social care, formed a steering group and commissioned a DVD of people's experiences of health services made by people with learning disabilities. This DVD posed a number of questions for the group which has influenced subsequent development, including the recruitment by Barts and the London Trust of a Learning Disabilities Liaison Office. There is work underway to try and increase the number of people with learning disabilities accessing annual GP health checks to which they are entitled.

Secondary Care

The Six Lives Panel highlighted some issues with secondary care, particularly regarding the involvement of carers during hospital stays. Barts and the London Trust have recruited a Learning Disabilities Liaison Officer to support people with learning disabilities and their carers during admissions to hospital.

Community Services

Tower Hamlets Community Learning Disabilities Service (CLDS) is an integrated health and social care service, comprising social workers, occupational therapists, community nurses, psychologists, psychiatrists, and a team

of Bangladeshi Parent and Carer Advisers. CLDS works with just under 1,000 people aged 14 and over with a range of health and social care needs. There is a dedicated transition team at CLDS, working with young people from the age of 14, going through transition from children's to adults' services.

Social Care

There are no residential facilities for people with learning disabilities in Tower Hamlets, but around 160 CLDS clients are placed in residential care out of borough and around 50 people in supported living (including in-borough).

Over 400 adults with learning disabilities receive either domestic or personal homecare services in Tower Hamlets.

There are several day opportunities accessed by around 250 people with learning disabilities in Tower Hamlets, including Coborn day centre, Apasenth, Blue Skies Project (Redbridge Community Housing Ltd.), the Camden Society, and Tower Project New Dawn. The Tower Project also provides a day service for adults with Autistic Spectrum Disorder, First Start.

Through the Transforming Adult Social Care Programme there is increased focus on choice and control and the use of personal budgets.

Learning Disabilities and the Criminal Justice System

There are no definitive numbers of the number of people with learning disabilities who are arrested and taken into custody, due to the inadequacy of identification, difficulty in diagnosis and the lack of local systematic data collection. However, estimates suggest that there are about 6,000 prisoners in the UK with a learning disability⁵. One study of over 9,000 custody records over a 3-year period in an inner-city police liaison service judged 8.7% of suspects to have a definite or possible learning disability. The Shoreditch ward at the John Howard Centre was opened in June 2009, providing a 14 bed specialist inpatient service for offenders with learning disabilities and complex mental health needs in Tower Hamlets, Hackney and Newham.

5. What evidence is there that we are making a difference?

There are two National Indicators relating to adults with learning disabilities:

- NI 145: The percentage of adults with learning disabilities known to Councils with Adult Social Services Responsibilities (CASSRs) in settled accommodation at the time of their assessment or latest review.
- NI 146: All adults aged 18-69 with learning disabilities that are known to 'Councils with Adult Social Services Responsibilities' (CASSRs) employed as an employee or self employed for one or more hours per week.

In 2009/10 Tower Hamlets performed poorly on NI 145, reporting just 50% of adults with learning disabilities in settled accommodation (a decrease from 77% in 2008/09 and one of the lowest percentages in the country). This compares to a London average of 59% and an England average of 61%, and is lower than both Hackney (65%) and Newham (54%).

In 2009/10 there was a slight increase in the percentage of adults with learning disabilities in employment compared to the previous year (3.4% compared to 3.3% in 2008/09). This is lower than both the London and England averages (8.3% and 6.4% respectively), lower than Hackney (4.8%) and the same as Newham.

In Tower Hamlets only 20% of people registered on GP registers with a learning disability received a health check in 2009/10, compared to 41% nationally and a London average of 37%. This figure was the same in Tower

⁵ Improving Health, Supporting Justice: The National Delivery Plan of the Health and Criminal Justice Programme Board. Department of Health, 2009

Hamlets in 2008/09 and in 2009/10 despite most London PCTs achieving an increase. It is of some concern that more than 1,130 people were registered on GP registers with a learning disability in Tower Hamlets in 2008/09, but only 635 were in 2009/10. This suggests there are serious issues with data recording rather than an actual decrease in the number of people with learning disabilities.

6. What is the perspective of the public on support available to them?

The DVD produced for the Six Lives Panel highlighted some areas of concern within health services, where people had some negative experiences.

A CLDS service user survey conducted in 2008/09 indicated a lack of awareness of information leaflets and of health action plans amongst service users.

A focus group conducted with service users at Coborn Day Opportunities found that people were very positive about a range of activities they took part in, especially activities that involved going out and socializing. People also enjoyed creative activities in the centre and using the kitchen facilities to develop cooking and food preparation skills. People were also very positive about experiences at Poetry in Wood and using Makaton.

A focus group conducted with people at Poetry in Wood identified several people who were keen to move house and get a job. Some people also mentioned that they would like more time with or support from a social worker.

Suggestions from THINK Patient and User Comments include:

- Increased support for young adults with learning disabilities (who are not eligible or could not secure access to day care centres) for independent living as well as access to public places. Specifically, the need to increase the range of facilities available for physical activities and socialisation, and the need to increase support for securing employment were identified.
- More team advocates for young people with learning disabilities.
- More accessible easy-read documents.
- Improved co-ordination between different agencies involved in disabilities services.
- Increased public information on learning disabilities.
- Increased facilities and opportunities for respite care.
- Increased outreach for people with learning disabilities, especially for those at university or attending colleges in the borough.
- Increased support for independent and small community living for people with any disability, including a learning disability.

7. What more do we need to know?

There is no systematic recording in health or social care data of specific diagnosis or type of learning disability. It is currently difficult to estimate the number of people with learning disabilities in Tower Hamlets who have complex needs. This is important in order to predict future numbers for service planning and work is planned with CLDS to audit the number of clients with complex needs, including behavioural issues, mental health conditions and complex physical needs.

8. What are the priorities for improvement over the next 5 years?

- **Carers**
 - To develop a plan of support for carers of people with learning disabilities, to include how carers can be important in helping someone with a learning disability get a job, go to college or try new activities.
- **Challenging Behaviour**
 - To develop a strategy of how best to support people with challenging behaviour, with particular

focus on what services are available, people living out of borough because of their behaviour, and young people with challenging behaviour going through transition.

- **Communication and engagement with service users**
 - To improve service user involvement with the Partnership Board and ensure that people are able to contribute to discussions about important issues.
- **Employment**
 - To ensure that organisations in Tower Hamlets offer work experience and paid work to people with learning disabilities, with focus on monitoring progress of the JET scheme at Tower Project.
- **Health Inequalities**
 - The Health Sub Group of the Partnership Board to write an action plan with recommendations from the Six Lives Project and the Big Health Check Up Day.
- **Safeguarding and Community Safety**
 - To involve the Safeguarding Board in the Partnership Board and to work with the borough's Crime and Disorder Reduction Partnership
 - To work on reducing hate crime, improve support for people with learning disabilities in the criminal justice system, and to work on how to help people feel safer when using public transport.
- **Personalisation**
 - To help people with learning disabilities understand about personalisation and personal budgets, how they can spend them and what choice and control means for them. To ensure that Adults Health and Wellbeing have an understanding of the concerns voiced by people with learning disabilities regarding personalisation.

Longer term, it is hoped that the impact of personal budgets will be a shift away from use of long term social services such as day care and residential care for as many people as possible. It is intended that increased resources for preventative services such as employment support, information and advice, advocacy, leisure opportunities and adult education will promote wellbeing and independence for people with learning disabilities and reduce the need for long term services.

9. Key Contacts & Links to Further Information

The general contact email for JSNA queries is JSNA@towerhamlets.gov.uk

To contact the **Community Learning Disabilities Service**:

Telephone 020 8121 4444 or email learningdisabilities@thpct.nhs.uk

To find out more about **services available for people with learning disabilities and their carers** in Tower Hamlets:

<http://www.liddirectory.org.uk/HomePage.asp?NodeID=89723>

To access useful **national data and reports** on the health and wellbeing of people with learning disabilities:

www.improvinghealthandlives.org.uk

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Date signed off by Senior JSNA Leads:	April 2011	Signed off by (Public Health Lead):	Dr Somen Banerjee	Date signed off by Strategic Group:	n/a	Sign off by Strategic Group:	Learning Disabilities Partnership Board
		Signed off by (LBTH Lead):	Deborah Cohen				