

Learning Disabilities: *Factsheet*

Tower Hamlets Joint Strategic Needs Assessment

UPDATED: 2016

Executive Summary

In June 2016 there were 760 people aged 18 with a learning disability known to the Tower Hamlets Community Learning Disabilities Service with a further 25 people currently being assessed. Whilst this factsheet references some information and data to do with children and young people, the primary purpose and focus is on adults. There is a separate Tower Hamlets JSNA factsheet on children with disabilities and work being carried out on Preparing for Adulthood. This factsheet does not consider people with specific learning difficulties which is a term used commonly in education and refers to conditions such as dyslexia which are distinct from a learning disability.

Comprehensive national data on the number of people with learning disabilities across the lifespan in England is unavailable. Latest estimates from Public Health England¹ suggest that in England in 2013, there are 1,068,000 people with learning disabilities, including:

- 224,930 children (identified at School Action Plus or Statemented as having either a primary or secondary Special Educational Need associated with learning disabilities);
- 900,900 adults, of whom 206,132 (23%) are known to GPs as people with learning disabilities.

This equates to a prevalence of 2.17% of the general adult population². Around one in five of these people are known to learning disabilities services, meaning 0.5% of the total adult population nationally are known by Councils or GPs to have a learning disability³. For Tower Hamlets this figure would be 4,848 of the total adult population, with approximately 1,100 expected to be known to services. It is possible that there are people in Tower Hamlets with a learning disability who are not accessing services from which they could benefit. People are not known to services for various reasons, which could include a combination of a decrease in surveillance in post-education health and social care agencies, and associated stigma and eligibility criteria for adult social care support.

On average people with learning disabilities have poorer health and die younger. In part this is because they are more exposed to causes of ill health through greater levels of material deprivation, poorer health related behaviours and physical conditions often associated with causes of learning disabilities. There has been a range of guidance which has been published in recent years which have added to the policy context of learning disabilities, including the Winterbourne Review. Much of the policy context had been in relation to ensuring that the premature mortality of those with learning disabilities is addressed and that these health inequalities are reduced. There has also been a move to ensuring that those with challenging behaviour are given the opportunity to remain in local settings.

Recommendations

Recommendations have been developed through consultation with members of the Tower Hamlets Learning

¹ Hatton C, Emerson E, Glover G, Robertson J, Baines S & Christie A (in press) *People with learning disabilities in England 2013* London: Public Health England

² Ibid

³ Ibid

Disabilities Partnership Board and other key stakeholders (including clinicians in this field), who were consulted. Full details of the comments received at the wider stakeholder workshop are included in Appendix D.

Below are a list of the prioritised recommendations, under each key theme generated, that have been developed through the process of the JSNA and subsequent consultation (those in *italic* taken from Improving :

- **Commissioning, quality assurance and outcomes**

Ensure that evidence-based interventions are considered in any procurement and commissioning decisions and that more innovative approaches are considered as part of these processes.

Ensure that we are effectively monitoring local performance and outcomes measures using national benchmarking data.

Pooled budgets are an important way of developing shared ownership⁴

- **Local intelligence and future need**

Ensure that access to services are equitable.

Use transitions data to try and understand what future trends might look like and the potential impacts on our services.

- **Health inequalities**

Improve access to health checks and health action plans.

Ensure that physical health services (universal and targeted) are accessible for people with learning disabilities and that they are being enabled to access these services early.

The full range of mental health services should be accessible to people with learning disabilities and mental health problems, and mental health and learning disability services should work together to ensure that there is a single point of access and robust local pathways for people with overlapping needs that are delivered in the least restrictive way possible

- **Transitions**

Ensure that care planning is carried out in advance and that all appropriate stakeholders are engaged in the process.

Using transitions data to try and understand what future trends might look like and the potential impacts on our services.

- **Response to Winterbourne Review and supporting challenging behavior/Criminal Justice System**

Implement local plans from the Winterbourne Review.

Assessment to be carried out on further actions needed for people with challenging behaviour.

Build on work with local police and the criminal justice system to ensure that people with learning disabilities are identified early and appropriately supported.

- **Employment and accommodation**

Further training and employment opportunities to be explored, especially within healthcare settings.

Support and address identified barriers to employment, such as education around the impacts of working and benefits.

Increase in-borough residential provision and capacity, especially for young people and those with challenging

⁴ Improving the Health and Wellbeing of People with Learning Disabilities: An evidence-based commissioning guide for CCGs (November 2013)

behaviour.

Commissioners should also work with their local authority colleagues to develop a range of responsive local services which can prevent admissions to hospital or any other large institutional settings, and allow any existing patients to be moved to better settings, closer to home

- **Service users, carers and innovation**

Increase our understanding of carers' perspectives in services and on the information available to them. Include learning disabilities in the development of the Tower Hamlets carers' strategy.

For a more detailed series of recommendations, please see section 9.

1. What are Learning Disabilities and the associated health issues?

Valuing People⁵ (2001) defines a learning disability as the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (significantly impaired intelligence);
- a reduced ability to cope independently (significantly 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 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 IQ of 50-69 is often considered as a mild learning disability; 35-49 moderate; 20-34 severe; less than 20 profound. However, these scores on cognitive tests must always be integrated with information about social and health functioning when determining support needs.

A child of compulsory school age or a young person has a learning difficulty or disability if he or she—
(a) has a significantly greater difficulty in learning than the majority of others of the same age, or
(b) has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions⁶.

1.1 Causes

Conditions which cause learning disabilities could arise at conception, during pregnancy, labour and after birth. They could be genetic, infectious, metabolic, traumatic or environmental. For people with severe learning disabilities, the cause is sometimes known, but for those with milder learning disabilities the underlying cause is more often unknown. The higher prevalence of learning disabilities in South Asian communities has been linked to increased levels of material and social deprivation, combined with poor access to maternal health care and higher rates of environmental or genetic risk factors⁷.

1.2 Prevalence

In Tower Hamlets we would expect the numbers of people with learning disabilities to be approximately 4,850 of the total adult population, with approximately 1,100 expected to be known to services. Currently 760 people are recorded as having a learning disability by the Tower Hamlets Community Learning Disabilities Service.

Comprehensive national data on the number of people with learning disabilities across the lifespan in England is unavailable. Latest estimates from Public Health England⁸ suggest that in England in 2013, there are 1,068,000 people with learning disabilities, including:

- 224,930 children (identified at School Action Plus or statements in DfE statistics as having either a primary or secondary Special Educational Need associated with learning disabilities);
- 900,900 adults, of whom 206,132 (23%) are known to GPs as people with learning disabilities and 21% known to learning disability services and 429,530 (48%) were recorded by Department of Works and Pensions as being eligible to receive either Disability Living Allowance or Attendance Allowance.

Adults with learning disabilities not identified as such within health and social care are likely to be adults

⁵ Valuing People A New Strategy for Learning Disability for the 21st Century (2001), Department of Health

⁶ Children and Families Act, 2014

⁷ Mir, G., Nocon, A., Ahmad, W., *et al* (2001) *Learning Difficulties and Ethnicity* London: Department of Health.

⁸ Hatton C, Emerson E, Glover G, Robertson J, Baines S & Christie A (in press) *People with learning disabilities in England 2013*. London: Public Health England

ineligible for social care support, but still at high risk of experiencing social determinants of poor health⁹. Prevalence of learning disability is higher in males (at all ages), Asian (Pakistani and Bangladeshi) and 'traveller' populations¹⁰.

1.3 Health Issues

NHS England's report - Reducing premature mortality in people with Learning Disabilities: Effective interventions and reasonable adjustment¹¹ recognises that people with learning disabilities have been largely excluded from mainstream medical research which has resulted in a paucity of evidence concerning the effectiveness of health interventions specifically for people with this disability.¹¹ It has been shown that people with learning disabilities are not accessing GP services to the extent that their health requires, they are 70% more likely to be admitted to hospital as an emergency and are less likely to access a broad range of screening programmes¹².

On average people with learning disabilities have poorer health and die younger. In part this is because they are more exposed to causes of ill health through greater levels of material deprivation, poorer health related behaviours and physical conditions often associated with causes of learning disabilities. It is also partly as a result of poorer understanding of physical changes and problems that indicate illnesses or conditions that could be treated and of how to get help from health services¹³. This means that many people with learning disabilities have health problems for which they do not seek help. In addition, some people with learning disabilities with specific genetic or chromosomal syndromes are subject to age-related health risks, e.g. Downs Syndrome and an increased risk of early dementia of the Alzheimer's type.

People with learning disabilities experience higher than average prevalence of a range of health conditions, most notably diabetes, asthma, epilepsy and stroke. The prevalence of mental health problems in people with learning disabilities is considerably higher than the general population. In addition to mental illness, people with learning disabilities often have coexisting autistic spectrum disorders, behaviours that challenge services, offending behaviour, or physical health conditions. It is often hard to distinguish between these conditions especially when people have more severe intellectual impairments¹⁴.

People with learning disabilities also have a high prevalence of dementia even when specific at-risk groups such as people with Downs Syndrome are excluded. It can be difficult to distinguish between mental health and other conditions particularly among people with more severe intellectual impairments¹⁵. This can be further complicated by problems with communication of feelings, poor detection, misdiagnosis and the effects of medication. Table 1 below taken from Joint Commissioning Panel for Mental Health indicates the levels of mental illness experienced by people with learning disabilities.¹⁶

⁹ Emerson E & Hatton C (2013) *Health inequalities and people with intellectual disabilities* Cambridge: Cambridge University Press

¹⁰ Hatton C, Emerson E, Glover G, Robertson J, Baines S & Christie A (in press) *People with learning disabilities in England 2013* London: Public Health England

¹¹ <https://www.england.nhs.uk/wp-content/uploads/2014/09/info-ld-interventions.pdf>

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¹³ Kenney A, Turner S, Glover G & Hatton C (March 2014) *Making reasonable adjustments to primary care services – supporting the implementation of annual health checks for people with learning disabilities* London: Public Health England

¹⁵ Joint Commissioning Panel for Mental Health (May 2013) *Mental health services for people with learning disabilities*

¹⁶ <http://www.jcpmh.info/wp-content/uploads/jcpmh-learningdisabilities-guide.pdf>

Table 1: Estimated prevalence rates of mental health problems of adults with learning disability¹⁷

Disorder	Rate
Schizophrenia	3%
Bipolar affective disorder	1.5%
Depression	4%
Generalised anxiety disorder	6%
Specific phobia	6%
Agoraphobia	1.5%
Obsessive –compulsive disorder	2.5%
Dementia at 65yrs and over	20%
Autism	7%
Severe problem behaviour	10-15%

1.4 Employment

In 2012/13 7% of working age adults with learning disabilities was reported to be in some form of paid or self-employment with most people working for less than 16 hours per week (70.3%). Men were more also found to be more likely to be employed than women¹⁸

¹⁷ Guide for commissioners of mental health services of people with learning disabilities (May 2013) Joint Commissioning Panel for Mental Health

¹⁸ https://www.improvinghealthandlives.org.uk/securefiles/160601_1402//People%20with%20learning%20disabilities%20in%20England%202013.pdf

2. What is the policy context?

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 focused 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).

Premature mortality

Mencap's paper 'Death by Indifference: 74 deaths' (2012) published jointly by the Local Government and Parliamentary and Health Service Ombudsmen, was a 5 year progress report from the original review in 2007 which highlighted serious failures in health and social care for people with learning disabilities, which all local authorities were required to investigate in their area. These issues identified have led to the launch of a new Health Charter for social care providers, designed to improve the wellbeing of vulnerable people. To support organisations as they put the charter into practice, there is also guidance for providers and commissioners and, specifically for social care staff and a self-assessment tool that reinforces the steps in the charter.

There is consistent evidence that people with learning disabilities in England die much younger than the rest of the population. The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)¹⁹ has driven a lot of the policy development in this area. It found that people with learning disabilities die 16 years younger. Death rates submitted suggested that on average the death rate is a little more than twice that in the general population²⁰, although the median age of death has risen steadily from 2008 to 2012 from 54 years to 58 years.

When considering the health and social care needs of the people with learning disabilities, it was apparent that they were a very vulnerable group and that the effectiveness of health and social care given to people with learning disabilities was deficient in a number of ways. People with learning disabilities had a considerable burden of ill-health at the time of their death. Key issues that appeared to be problematic were the lack of co-ordination of care across and between the different disease pathways and service providers, and the episodic nature of care provision²¹. In addition professionals in both health and social care commonly showed a lack of adherence to and understanding of the Mental Capacity Act, 2005, in particular assessments of capacity, the process of making 'best interest' decisions and when an Independent Mental Capacity Advocate should be appointed²².

Improving Health and Lives (IHAL)

The Learning Disabilities Observatory was established as a three year programme following one of the recommendations of the Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities, also known as the Michael report²³.

The observatory has published a series of excellent reviews and policy documents that can be used for reference in relevant areas and work streams, including:

- Health checks for people with learning disabilities: including young people aged 14 and over, and

¹⁹ <http://www.bris.ac.uk/cipold/fullfinalreport.pdf>

²⁰ Hatton C, Emerson E, Glover G, Robertson J, Baines S & Christie A (in press) *People with learning disabilities in England 2013* London: Public Health England

²¹ Confidential Inquiry into premature deaths of people with learning disabilities (Executive Summary), 2013

²² Ibid

²³ Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities (2008) Department of Health

- producing health action plans (Feb, 2015)
- CQC inspection reports of NHS trusts - How do they address the needs of people with learning disabilities? An interim analysis (Feb, 2015)
- People with Learning Disabilities in England 2013 (Dec 2014)²⁴
- Joint Strategic Needs Assessments 2014 How well do they address the needs of people with learning disabilities? (Nov 2014)
- The Uptake of Learning Disability Health Checks 2013 to 2014 (Nov 2014)
- Guidance for social care providers and commissioners (to support implementation of the health charter) (March 2014)
- Improving the health and wellbeing of people with learning disabilities: An evidence-based commissioning guide for Clinical Commissioning Groups (CCGs) (Nov 2013)

Winterbourne Review

Following a July 2012 BBC Panorama investigation into abuse at an institutional setting, the Government pledged to move people with learning disabilities out of Assessment and Treatment Unit's into community resources by June 2014. Every area was to put in place a locally agreed joint plan for high quality care and support services for people of all ages with challenging behaviour, which accords with the model of good care. These plans should ensure that a new generation of inpatients does not take the place of people currently in hospital.

Offenders

There is currently no standardised measure used to identify offenders with learning disabilities. Differences in definition and identification mean that the prevalence of learning disabilities and difficulties is very hard to estimate and precise information about prevalence among BME groups is virtually non-existent. Estimates of prevalence of learning disability among offenders in the UK range from 1% to 10%²⁵.

The Care Act & Personalisation

The Care Act represents the most significant reform of care and support for more than 60 years, putting people and their carers in the control of their care and support. The Care Act simplifies legislation and tries to make it clear exactly what care people can expect. The Care Act also states that Councils will have to give people better information to help them get good care. This should include providing accessible information for people with learning disabilities.

Personalisation, outlined in *Putting People First*²⁶ 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.

²⁴ Information on the characteristics of people with learning disabilities, the services and supports they use and their carers is collected by several government departments and made publicly available through a number of diverse channels. The aim of this report is to provide a concise summary of this information and to provide links to key data collections

²⁵ Loucks N., (2007) *The prevalence and associated needs of offenders with learning difficulties and learning disabilities*

²⁶http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081119.pdf

3. What are the effective interventions?

3.1 Intervention to improve health and reduce mortality

As shown, the CIPOLD reported that the two major factors contributing towards avoidable deaths in people with learning disabilities were diagnoses of health problems being delayed or not made at all, and effective treatments being delayed or not being made at all²⁷.

The CIPOLD report made a series of recommendations to improve the health outcomes for people with learning disabilities which included:

- *the clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems;*
- *accessible information for people with learning disabilities and carers;*

NHS England highlighted key principles of working on health issues with people with learning disabilities which should include :

- Patient held records for those with multiple conditions
- Named health care coordinator for those with complex health needs
- Accessible processes for those with learning disabilities to obtain appointments
- More time given to appointments and planned for at the beginning or end of the day to reduce waiting times
- Partnership with families and carers when making ongoing health decisions
- Making reasonable adjustments in the acute setting when a person with learning disabilities is admitted or seen as an outpatient.
- Ongoing awareness of the needs of people with learning disabilities entering into the health system for health professionals

Commissioners should work with their local authority colleagues to develop a range of responsive local services which can prevent admissions to hospital of any other large institutional settings and allow existing patients to be moved to better settings, closer to home. Pooled budgets are an important way of developing shared ownership²⁸

Annual Health Checks in General Practices

Annual health checks for people with learning disabilities are a key intervention as they are seen as being effective at detecting unmet health needs and triggering further health **investigations and treatment, although coverage is currently running at approximately 50%** of eligible people with learning disabilities²⁹. These are provided within general practices and are part of a general practitioners contract.

Primary care liaison nurses/health facilitators have been found to have a significant impact on enabling people with learning disabilities to access primary care, and work with GPs and primary care staff to support the implementation of the health checks³⁰. The outcome of the health check should include a clear health improvement plan

General practices should be promoting access to health improvement and screening services for people with

²⁷ Confidential Inquiry into premature deaths of people with learning disabilities (Executive Summary), 2013

²⁸ <http://www.jcpmh.info/good-services/learning-disabilities-services/>

²⁹ <https://www.england.nhs.uk/wp-content/uploads/2014/09/info-ld-interventions.pdf>

³⁰ Improving the Health and Wellbeing of People with Learning Disabilities: An evidence-based commissioning guide for CCGs November 2013

learning disabilities in the same way as to the general population as Early detection and treatment of any health problems is important.

There is some evidence to show that health checks can identify health problems in a significant proportion of people who display behaviour that challenges. Some of the challenging behaviours may result from health problems or pain associated with untreated health conditions and these can also lead to costly physical complications³¹

3.2 Interventions for people with learning disabilities who have mental health problems

Members of the community learning disability service require skills to appropriately assess and support of people with learning disabilities who have additional mental health problems. This needs to include risk management and the provision of community-based support to people who present with additional needs.

A full range of mental health services should be accessible to people with learning disabilities and mental health problems. Mental Health and Learning Disabilities services need to work together to ensure that there is a single point of access. Robust pathways are required for people with overlapping needs and delivered in the least restrictive way possible.³²

Currently NICE (National Institute for Health and Care Excellence) are producing guidance and recommendations on effective interventions for Mental health problems in people with learning disabilities which is due to be published in September 2016 and will consider prevention, assessment and management of mental health problems in people with learning disabilities.

Interventions for people with learning disabilities who have challenging behaviour

Recent NICE Guidance³³ has been produced (May 2015) 'Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges' making the following recommendations on the following areas:

- General principles of care including- working with families/cares, assessing if possible in a familiar environment, offering advocacy to the person with learning disabilities and of to the carer /family, having health and social care services to promptly respond
- Support and interventions for family members or carers including – recognising the carers/families difficulties in this situation and providing skills training and emotional support to the person with learning disabilities.
- Early identification of the emergence of behaviour that challenges including recognising the risks which could lead to behaviour which challenges both from a physical and environmental perspective.
- Assessment of behaviour that challenges including that the assessments are flexible, person centred and ongoing when required, involve carers/family members, and support plans are sustained as a result of the assessment.
- Psychological and environmental interventions including – personalised interventions are developed based on behavioural principles and a functional assessment, with clear targeted behaviours with agreed outcomes with timescales.

³¹ Ibid

³²

https://www.improvinghealthandlives.org.uk/securefiles/160601_1653//RCGP%20LD%20Commissioning%20Guide%202013%20revised%20.pdf

³³ <https://www.nice.org.uk/guidance/ng11/chapter/Key-priorities-for-implementation>

- Medication only being offered when other support has not worked or when the risk is to the person or others is severe.

CR175 - *Enabling people with mild intellectual disability and mental health problems to access healthcare services* (November 2012)³⁴. This is aimed at staff providing the psychiatric and learning disability services encouraging regular interface between both groups of professionals through training and collaborative patient pathways

3.5 Transitions planning

Well planned, person centred transition is important, not least because poor transition can lead to serious health outcomes following disengagement with health services and subsequent costs to health services. Identifying a care coordinator or navigator is important, and is valued by families and young people. The navigator works with the young person, their family and the multidisciplinary team (including the GP) to coordinate the plan. *Pathways to Getting a Life*³⁵ includes a health pathway but sets in the context of holistic transitions planning, personalisation and support planning³⁶. The transitions planning for young people with mental health needs is also key and should include:

- Planning for transition early, listening to young people and improving their self-efficacy;
- Providing appropriate and accessible information and advice so that young people can exercise choice effectively;
- Focusing on outcomes and improving joint commissioning, to promote flexible services based on developmental needs.

3.6 Forensic services and the Criminal Justice System (CJS)

Forensic services need good links with other services such as mental health, social care and the criminal justice system, and the involvement of agencies such as housing, employment and education, to facilitate pathways away from the Criminal Justice System³⁷³⁸³⁹.

Prevention and early intervention to avoid vulnerable children and adults entering the criminal justice system should clearly be the overriding objective, as well as supporting a reduction in re-offending. Safer Neighbourhood Teams would seem to be the ideal forum for looking at mental health and learning disability issues, and the early identification of people at risk of offending, particularly utilising the role of the community support officer as the 'eyes and ears' of the police in local areas. Training at all levels is recommended.

³⁴ <http://www.rcpsych.ac.uk/usefulresources/publications/collegereports/cr/cr175.aspx>

³⁵ <http://gettingalife.org.uk/downloads/2011-Pathways-to-getting-a-life.pdf>

³⁶ Improving the Health and Wellbeing of People with Learning Disabilities: An evidence-based commissioning guide for CCGs (November 2013)

³⁷ Improving the Health and Wellbeing of People with Learning Disabilities: An evidence-based commissioning guide for CCGs (November 2013)

³⁸ Completed by the Prison Reform Trust,

The No One Knows programme has explored the experiences of people with learning difficulties and disabilities at each key stage of the criminal justice system

³⁹ http://www.centreformentalhealth.org.uk/pdfs/Bradley_report_2009.pdf

4. What is the local picture?

The percentage of the Tower Hamlets population with a learning disability *known to services* (health and social care) ranges from around 0.28%-0.38%, slightly lower than national estimates.

It is clear that the majority of adults with learning disabilities do not use learning disabilities services. While some people may not require these specialist services, there is likely to be some unmet need within the population. The proportion of people known to services as having a learning disability drops from 3% among children in the education system, to 0.6% among adults aged 20-29. This is likely to reflect the impact of a combination of factors which include:

- A decrease in health/disability surveillance in post-education health and social care agencies;
- The eligibility criteria for specialised social care support differs for adults and for children;
- Stigma associated with learning disability can reduce willingness to access specialised services or self-identify as having learning disabilities;
- Outside of the education system, the impact of intellectual impairments associated with learning disabilities may be less visible⁴⁰.

Table 2 outlines the recorded prevalence of learning disabilities in Tower Hamlets by data source available and shows the variation of information recorded on registers.

Table 2: Learning disability prevalence by varying data sources, Tower Hamlets

Data Source	Age Range Covered	Number of people in Tower Hamlets with a learning disability	Prevalence (percentage of the population ⁴¹)	Comparison to national population
Special Educational Needs (SEN)	0-19 years	1805 (statemented ⁴²)	3.8% ⁴³ (of the school population)	
Children with severe Learning Disability		108	2.4 per 1000	3.7 per 1000
Children with moderate learning disability		411	9.2 per 1000	15.6 per 1000
Children with profound learning disability		138	3.1 per 1000	1.3 per 1000
% of Children in Schools with any Learning disability		972	2.18%	2.87%
Community Learning Disability Service (CLDS) ⁴⁴	18 years and over	760 (+ 25 going through assessment)		
Social Care (Adults Health and Wellbeing)	18 years and over	645	3.3 per 1000	4.3 per 1000
EMIS Web ⁴⁵ (General Practice)	All ages	849 (April 2014)	0.30%	

⁴⁰ http://base-uk.org/sites/base-uk.org/files/knowledge/People%20with%20Learning%20Disabilities%20in%20England%202013/people_with_learning_disabilities_in_england_2013.pdf

⁴¹ Different denominators are used depending on the data source e.g. for the QOF/EMIS data the denominator is the practice population, whereas for SEN it is the proportion of the registered school population

⁴² A significant proportion of statemented individuals will have a learning disability, although not all as the figure will also include those with physical & sensory impairments or emotional difficulties

⁴³ This prevalence estimate has been and continues to rise

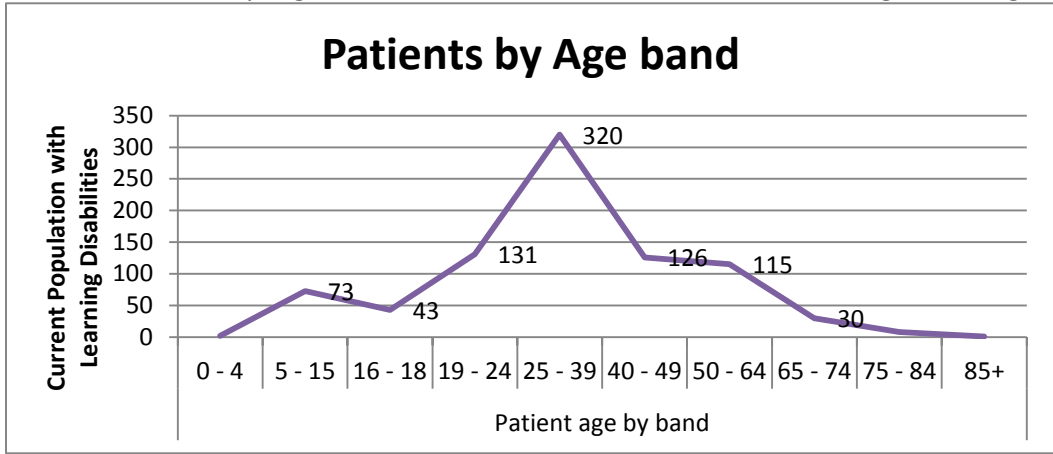
⁴⁴ June 2016

Data Source	Age Range Covered	Number of people in Tower Hamlets with a learning disability	Prevalence (percentage of the population ⁴⁶)	Comparison to national population
Quality Outcomes Framework (QOF)	18 years and over	746 (13/14)	0.3%	0.5%
Overall expected prevalence (should be known to services)	18 years and over	1117	0.5%	
Expected overall prevalence (all learning disabilities)	18 years and over	4848	2.17%	

NB: Expected prevalence is thought to be an underestimate, which does not take into account local high risk factors of social deprivation and large South Asian population.

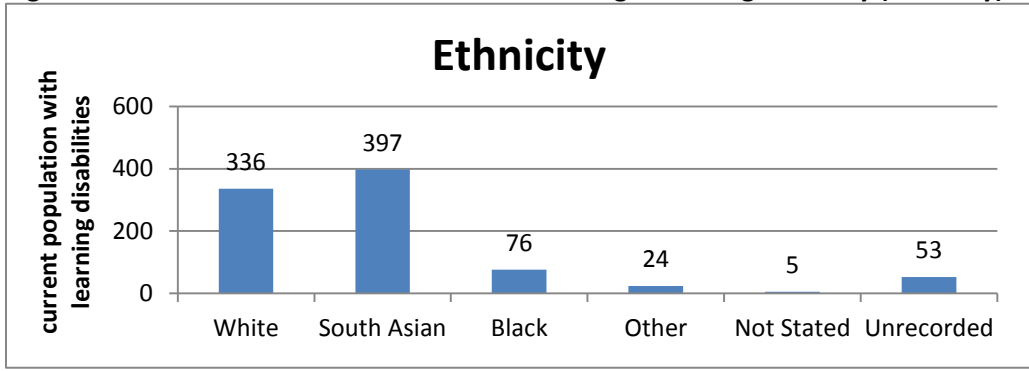
4.1 Observed prevalence in primary care

Of the total number of people on the EMIS⁴⁷ system (849) 37.7% are aged between 25-39⁴⁸ and 46.8% are of South Asian ethnicity. **Figure 2: Patients on EMIS web identified as having a learning disability (age)**



Source: CEG, April 2014

Figure 3: Patients on EMIS web identified as having a learning disability (ethnicity)



Source: CEG, April 2015

⁴⁵ As at 1st April 2010

⁴⁶ Different denominators are used depending on the data source e.g. for the QOF/EMIS data the denominator is the practice population, whereas for SEN it is the proportion of the registered school population

⁴⁷ EMIS Web allows healthcare professionals to record, share and use vital information, so they can provide better, more efficient care and is the system used by primary care in Tower Hamlets

⁴⁸ There is a discrepancy in the way that the data is collected and so the reported age bands are not equal. However, there are still a higher number of people represented in the 25-39 age band

2 Observed prevalence in the Community Learning Disabilities Service (CLDS)

Figures from the Community Learning Disabilities Service can be used to calculate crude prevalence estimates of learning disability in Tower Hamlets, by gender and ethnicity.

Table 3 a: Prevalence of learning disability in Tower Hamlets by ethnicity (CLDS clients aged 18 years and over)

Ethnicity (18+)	LD Numbers	Projected population 2015	Prevalence
Asian or Asian British	338	73,751	0.46%
Black or Black British	52	18,425	0.28%
Other	35	7,920	0.44%
White	203	114,219	0.18%
Total	633 ⁴⁹	223,407	0.28%

Source: [©]GLA 2013 Round Ethnic Group Population Projections for the year 2015 – over 18

Table 3b Prevalence of learning disability in Tower Hamlets by ethnicity (CLDS clients aged 18 years and over) taken from GP registers

Ethnicity (18+)	LD Numbers	Projected population 2015	Prevalence
Asian or Asian British	397	73,751	0.54%
Black or Black British	76	18,425	0.41%
Other	34	7,920	0.42%
White	336	114,219	0.29%
Total	891	223,407	0.39%

Using the data from Table 3a, the adult learning disability prevalence is showing higher in the Asian population. Prevalence of learning disabilities is higher in the male population nationally, but interestingly in Tower Hamlets the split is about equal. However Table 3b using data from GP registers suggests that of the 891 on the primary care register 539 are male (60%) and 353 female (40%) which is more in line with national estimates.

4.2 Projections of people with learning disabilities

Prevalence rates are likely to increase nationally over the next twenty years, due to improving life expectancy and population growth.

Although it is difficult to predict actual figures of adults with learning disabilities in the future, if we assume prevalence rates remain constant, the number of people aged 18 and over requiring support from CLDS is expected to increase to over 950 over the next five years, and to around 1,118 by 2030.

Year	2015	2020	2025	2030

⁴⁹ Minus "Not Recorded"(29)

Expected numbers	850	972	1078	1118
Projected population	(223,414)	(255,870)	(283,608)	(294,091)

Source: ©GLA 2013 Round Ethnic Group Population Projections for the year 2015

In order to understand fully the picture of growth, we would need to understand the increased numbers over the years in children's services and transitions for effective future planning. Anecdotally there has also been comment that many of the new cases being seen in children's services are increasing complex also, therefore it is important to remember that it is not just about the potential increase in numbers, but also factor in complexity.

4.3 Learning disabilities and other illnesses 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, stroke and all mental health conditions including depression and Serious Mental Illness. 0.9% of the general population has a severe mental illness compared to 9.3% of the population with a learning disability. Learning disability patients have over twice the rate of cancer prevalence compared to the practice registered population. Smoking rates appear similar to those recorded in other adult patients. Morbidly obese case rates, however, among Learning disability patients, are considerable higher.

Figure 4a: Crude disease prevalence per 1000 population by long term condition in Tower Hamlets

Disease	All patients with disease	Learning Disability patients with specific disease
Asthma	47.5	78.9
Cancer	11.7	27.1
Chronic Obstructive Pulmonary Disease	12.7	5.9
Coronary Heart Disease	17.1	10.6
Diabetes	52.2	91.9
Hypertension	78.4	93.1
Learning Disabilities	3.0	3.0
Obesity (BMI>30)	105.4	286.2
Morbid Obesity (BMI>40)	12.3	60.1
Serious Mental Illness	9.2	93.1
Smoking	180.2	164.9
Stroke	7.5	15.3

Source: CEG, April 2014

Figure 4b Rate of prevalence within specialist care groups, and relative rate of disease in that group to standard learning disability prevalence

Disease	All	Serious Mental Illness	Deaf Affected	Profoundly Deaf	Registered Blind
Learning Disabilities rate within group		30.0	81.7	67.6	27.6
Increase in rate over standard prevalence	1	10 times	26 times	23 times	9 times

Source: CEG, April 2014

Figure 4b shows patients within certain care groups those with learning disabilities have much higher rates than in the population as a whole. Patients who are registered blind have a prevalence rate of learning disability of 27.6, which is about 9 times higher than the rate across Tower Hamlets as a whole. People with learning difficulties are 5 times more likely to be housebound than the general population⁵⁰.

Figure 4c Rate and number of people with learning disabilities included in the national screening programmes as compared with the rate in the general population in 2014

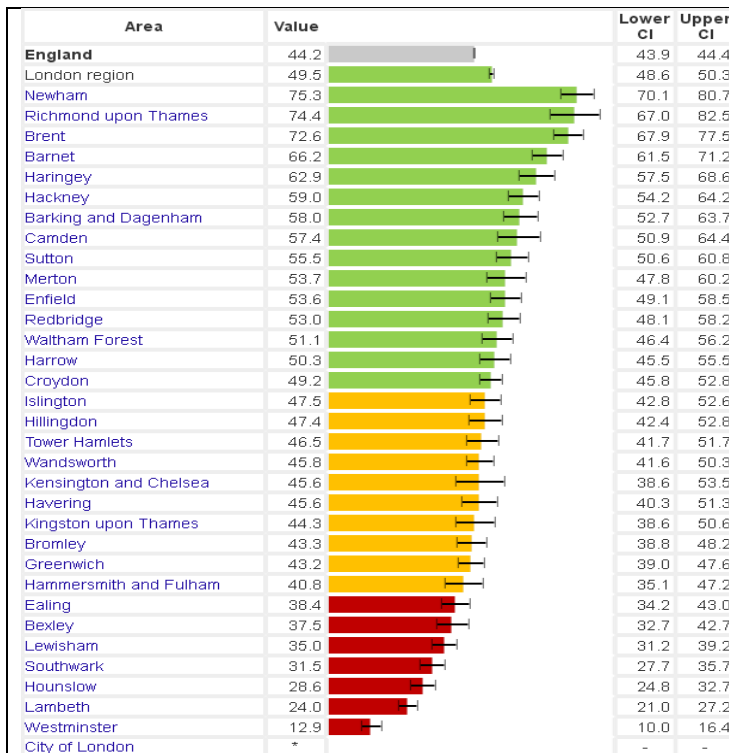
National screening programme	Learning Disabilities	General Population (Tower Hamlets)
Cervical screening	40.40%	69% (PHE finger tips cancer services March 2014)
Breast screening (53-70)	11%	61.5% PHE figure tips cancer services March 2014

Source: *Learning disabilities self assessment return 2014 for Tower Hamlets*

The data in Figure 4c was obtained from the self-assessment forms completed by Tower Hamlets LA in 2014 which indicates that those with learning disabilities are well below the Tower Hamlets averages for cervical and breast screening uptake. Currently Tower Hamlets has the lowest bowel screening figures in the country for all the eligible population.

Figure 4d Levels of coverage of people with learning difficulties attending a GP Health Check*

⁵⁰ <http://www.towerhamlets.gov.uk/Documents/Public-Health/TH-JSNA-Health-Equity-in-Primary-Care-2014.pdf>



Source: Calculating Quality Reporting Service (QRS), end of year download for 2013 to 2014

* Each year GPs are supposed to offer annual health checks to make sure important problems are identified and treated. CCGs report to the Department of Health how many people there are on GP practice lists known both to their GP and the local social services department to have a learning disability and how many have received a health che

4.4 Learning disabilities and employment

Figure 4e : 2015/16 (1st quarter) employment figures for people with learning disabilities who are known to Tower Hamlets Council

Gender	Employed		Not in paid employment			Total
	In paid work under 16hrs	In paid work over 16 hours	seeking wk	not actively seeking work	Unknown	
Male 18-64yrs	0	1	22	44	193	260
Female 18-64 yrs	12	15	9	38	241	315
TOTAL	12	16	31	82	434	575

Source SALT returns for Tower Hamlets 2015/16⁵¹

Figure 4e highlights that only 4.9% of adults with learning disabilities are currently in paid employment and just over 50% of these are engaged over 16 hours of work per week and only 1 male is in paid employment. The total numbers with paid work in 2014/15 were exactly the same as 2015/16 however none were working over 16hrs and there were more males (19) than females (9) working.

The employment figures of 2014/15 of 4.9% for Tower Hamlets was shown to be lower than a comparator group (similar demography in other part of the country) which showed 6.6% employment level and lower than the average for England 6.0% as demonstrated in the SALT (Short And Long Term) returns for that year .

⁵¹ http://www.hscic.gov.uk/media/15887/SALTGuidancev17/pdf/SALT_Guidance_v1_8.pdf

4.5 Learning disabilities and housing

In Tower Hamlets, we know of 613 people with learning disability that were FACS eligible. Their housing situation is included below in Figure 4f

Figure 4f types of housing accommodation for Tower Hamlets adults with learning disabilities

Overview of type of accommodation type	No of users
Settled mainstream housing with family/friends	283
Registered Care Home	132
Local Authority / ALMO / RSL	68
Supported Accommodation	64
Staying with family / friends as a short term guest	27
Sheltered / Extra Care Housing	19
Tenant - Private Landlord	8
Adult Placement Scheme	5
Owner Occupier / Shared ownership	5
Residential Education	3
Registered Nursing Home	2
Grand Total	613

Data taken from Framework-i in February 2015

A majority of the people with learning disabilities fall into the first 4 categories of accommodation highlighted in Figure 4f. Proportionately the figures are similar to those found at a national level which is highlighted in a Mencap Report⁵² Housing for people with a learning disability, although Tower Hamlets does have a larger percentage of people with learning disabilities remaining in the family home.

Figure 4g Comparison of the provision of supported living provided across NE London boroughs

Current	Newham	City and Hackney	Tower Hamlets	Waltham Forest	Total
Average adults in supported living	115	258	60	122	555

Data from Inner North East London Transforming Care Partnership Plan – April 2016

Figure 4g does highlight that Tower Hamlets provides a significantly lower levels of supported living accommodation than neighboring boroughs. A serious gap in support living in Tower Hamlets has been identified in the provision for young people wanting to move back into the borough following an out of borough residential-education placement. This was highlighted in an audit conducted with all young people in these placements undertaken in April 2015.

5. 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 families and carers of people with learning 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, providing training and employment schemes for people with

⁵² http://www.glh.org.uk/wp-content/uploads/2013/04/2012.108-Housing-report_V7.pdf

learning disabilities. Individuals are trained in woodwork, art and design, developing skills in creativity, research, communication and peer tutoring.

- 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.
- There is a new hub called Phoenix Blend based in Bell Lane which is run by Vibrance.
- People with disabilities in Tower Hamlets can access advocacy services through REAL.

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
- Helping someone to maintain their tenancy and avoid eviction
- Helping someone to access specialist services (drugs, alcohol, mental health etc.)

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

Primary Care

We have a DES (Directly Enhanced Service) in place locally which includes:

The GP practice will establish and maintain a learning disabilities 'health check register' of patients aged 14 and over with learning disabilities. This should be based on the practice's QOF learning disabilities register (QOF indicator: LD003) and any patients identified (and not already on the QOF LD register) who are known to social services

- The practice providing this service will be expected to have attended a multi professional education session (training is mandatory for any new practices wishing to participate in this service and should be updated as the practice requires)
- The practice will invite all patients on the register for an annual health check and produce a health action plan.

For 2013 -2014 the proportion of those with learning disabilities who received a health checks was 46.5% in Tower Hamlets as compared to 44.2% across England and 49.5% across London. There is work currently underway to try and increase the number of people with learning disabilities accessing the annual GP health checks to which they are entitled.

Secondary Care

There is a lead nurse for learning disabilities for Barts Health that covers local hospitals. There is a pathway for people with learning disabilities in the emergency department. The lead nurse has a strategic role, implementing the Learning Disability Strategy based on the recommendations of the Jonathon Michael Report 'Healthcare For All'. Operationally the lead nurse responds to referrals from patients, carers and staff, in particular where there are complex issues related to admission and discharge. There is a close working relationship between the lead nurse for learning disabilities and Community Learning Disability Service. Work is being done on development of a Carer Policy, and Planned admission pathway.

Community Services

Whilst nationally there has been a trend of more people being admitted than discharged, locally this has not been the case, with Tower Hamlets having no individuals in inpatient settings, but all placed within the community. As such, Tower Hamlets is recognised by the Government as an area of good practice leading nationally on supporting people with challenging behaviour to live in the community as the first option. This is made possible by supporting families, carers and local providers to work together so this can happen.

Tower Hamlets Community Learning Disabilities Service (CLDS) is an integrated health and social care service, comprising social workers, occupational therapists, speech and language therapists, community nurses, psychologists, psychiatrists, and a team of Bangladeshi Parent and Carer Advisers. There is also a Front Door service which has been expanded to meet the Care Act requirements⁵³.

CLDS works with approximately 850 people aged 18 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.

Health and Social Care

There are four supported living accommodations in the borough which are specifically for clients with learning disability. These contracts are listed below along with the number of units they each provide, currently around 43 units are occupied:

Old Ford Road and Vulcan Square – 15 Units

Mary Jones Court – 20 Units

Albert, Fenton and Buckfast Street - 16 Units

Huddleston Close – 7 units

Local data indicates that there are around 140 people who are in registered care (this includes care home, supported living, extra care and adult placements). However, there is a lack of accommodation-based services for people with challenging behaviour leading to high-cost out of borough placements: in particular children and young people with challenging behaviour are having to move considerable distances out of the borough.

Autism Service

Through the recently commissioned Autism Diagnostic and Intervention Service launched in 2014, one of the key outcomes is to deliver on employment opportunities supported by an autism employment advisor supporting the project and referrals received into it.

Day Opportunities

There are several day opportunities accessed by around 250 people with learning disabilities in Tower Hamlets, including CREATE, Vibrance, APASEN, BPCA, Look Ahead (complex needs centre at Antill Road) and Tower Project New Dawn. The Tower Project also provides a day service for adults with Autistic Spectrum Disorder, First Start.

In Tower Hamlets over the last 2 years a greater emphasis has been placed on supporting learning disability day opportunities to further support training, social enterprise and employment opportunities for adults accessing services. This has been through revised service specifications with an expectation for providers and the promotion of social enterprises which enable the creation of training and employment opportunities. This can be seen through social enterprises such as Phoenix Blend café through Vibrance, Eat Up café being set up in Create and the Spotlight Café supported through Tower Project. Projects such as APASEN day opportunities are also in the process of developing a social enterprise focused on a bakery project which will feed into supplying bread to local cafes and partner day opportunity cafés.

⁵³ Their vision is included in Appendix B

Further existing Training and Employment projects are available such as Poetry In Wood. A further pilot project has been commissioned working across Children's and Adults with the Rix Centre focused on developing Wiki's and interactive support plans. This project has been expanded with the expectation that trained wiki makers can then use this skill and market to local businesses the offer of creating user friendly and accessible wiki pages to represent them. Tower Project is delivering this service as part of the Job, Enterprise and Training Service.

Through the Transforming Adult Social Care Programme there is increased focus on choice and control and the use of personal budgets. A number of service users with a cash personal budget also access services not directly commissioned through the Council such as Core Arts Project which delivers a Media, Music and performance programme.

Worth noting that through the Employment Sub Group a Basic Skills Assessment was carried out on service users attending day opportunities and readiness into training and employment opportunities. It was found that further training was required to support individuals even at pre entry level qualifications. With discussion in the sub group with Tower Hamlets College, additional entry level numeracy and literacy courses were provided for 2014 intake.

Learning Disabilities and the Criminal Justice System (CJS)

There are no definitive numbers of the number of people with learning disabilities who are arrested and taken into police custody, due to the inadequacy of identification, difficulty in diagnosis and the lack of local systematic data collection. However, national estimates suggest that there are about 6,000 prisoners in the UK with a learning disability⁵⁴. 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.

Locally there has been preventative work carried out with the police in order to keep people out of the criminal justice system. See the offenders' factsheet for more information.

Learning Disabilities and housing

To address some the issues and gaps of the provision of suitable accommodation in the borough the Tower Hamlets Accommodation Plan for People with Learning Disabilities (2016-19) is soon to be published by Tower Hamlets council and will be available on the council web site.

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

There are three national outcome indicators relating to adults with learning disabilities⁵⁵:

NHS Outcomes Framework

Indicator 1.7 Reducing premature death in people with a learning disability – excess under 60 mortality rate in adults with a learning disability

This indicator is in development via NHS England as of 2015/2016⁵⁶.

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

⁵⁵ Previous national indicators were:

- 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

⁵⁶ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/385749/NHS_Outcomes_Framework.pdf

6.2 Public Health Outcomes Framework

PHOF Indicator 1.06i: Adults with a learning disability who are in stable and appropriate accommodation

In 2013/2014 Tower Hamlets performed below the national average with 64% (410) of people with learning disabilities living in settled accommodation, compared to 77% in Newham and 76% in Hackney, with an England average of 74%. However, the number and rate has increased over the last 2 years

PHOF Indicator 1.08ii: Gap in employment rate between those with learning disabilities and overall employment rates

The previously used national indicator on employment measured the number of adults with learning disabilities in employment. In 2012/13 there were 681 known adults with learning disabilities, with 53 in paid employment (7.9%). In 2013/14 there were 647 known adults with learning disabilities with 40 in paid employment (6.2%).

The recent outcomes framework indicator measures the gap in employment as a new measure. In 2011/12 Tower Hamlets scored 58% versus London 58.7% & England averages of 63.2%. In 2013/14 this had increased only slightly to 58.4%, whilst the employment gap in London and England averages had risen more (61.3% and 65.1% respectively). The Tower Hamlets rate was only slightly lower than Hackney and Newham (59.2% and 59.1%) respectively.

Primary Care & Health Checks Direct Enhanced Service

In 2009-10 Tower Hamlets only 20% of people registered on GP registers with a learning disability received a health check compared to 41% nationally. By 2013/14 this figure had increased to 46% compared to 44% nationally and a London average of 49%. This equates to around 343 health checks received out of 746 adults registered. The practice participation rate (number of practices returning data for at least 1 patient was 78% which is above the England average.

Figure 5 : Number of people with learning disabilities who have been diagnosed with the following long-term conditions in general practices in Tower Hamlets in 2014

Currently registered	CHD	Stroke/TI A	Active Asthma	Diabetes Type 2	Hypertension	COPD	Cancer	Epilepsy	Diabetes - Type 1 (All ages)	PAD
891	8	15	85	85	80	9	21	116	9	6

Source CEG 2014

Figure 5 indicates the numbers of people with learning disabilities who have been diagnosed with a long-term condition in primary care and who will be receiving medical attention as part of primary care packages delivered by general practices in Tower Hamlets.

Figure 6: Comparing the total patients in GP care packages to those in care packages with learning disabilities on specific disease management indicators (October 2014)

Disease Management Indicator	Total patients in GP care packages	Learning Disabilities
Diabetes : HbA1c <7.5mmols/l (age17+)	55%	39%
Diabetes: BP<140/80 (age 17+)	69%	62%
Diabetes: attendance at retinopathy screening (age 17+)	76.8%	65.9%
Stroke: cholesterol <5mmols/l	80.7%	64.3%
Stroke: BP <140/90	80.2%	92.9%

Source Health Equity in Primary Care in East London (JSNA)

Figure 6 demonstrates the level of control for specific disease management indicators for those with learning disabilities. This table does indicate that the level control of glucose (indicated by HbA1c) and of cholesterol in the blood stream significantly need to improve for those with learning disabilities⁵⁷.

Hospital admissions

Emergency hospital admissions rates

Ideally, people who need treatment in hospital should be admitted before their illness reaches a critical stage where they have to be admitted as an emergency. Where illnesses are left to a late stage, this often involves more suffering on the part of the patient and poorer outcomes of treatment. Emergency admissions are also less satisfactory as less advance planning is possible. Lack of advance planning is particularly relevant for people with learning disability where it is helpful if staff can make reasonable adjustments in anticipation. People with Learning disabilities are nationally more likely to be admitted via emergency services for ambulatory care sensitive conditions that might have been prevented by primary care⁵⁸.

Tower Hamlets population has over the past 5 years had a rate of emergency hospital admissions about 10% lower than the national average⁵⁹.

Identifying people with learning disability in general hospital statistics

Hospitals can only make appropriate reasonable adjustments for people with learning disability if they know they need to. Recording this statistically is also important to the hospital first so it can check reasonable adjustments are being made and second because in many cases the hospitals get paid more for treating people who have a learning disability, as more care is needed.

We currently don't have our local comparative data on the rates of hospital admissions for people with learning disability. Data is collected nationally on a monthly basis as part of the NHS's "Assuring Transformation" programme⁶⁰, and numbers of admissions and discharges, care settings and planning methods are compiled and available⁶¹, but no clear interpretation of needs, types of illness and variance to the general population is provided.

Inpatient Admissions to Mental Health Services

A national census of over 3000 cases has established evidence of significantly high numbers of admissions to Mental Health In-patient beds among those on Learning Disabilities registers⁶². The key findings nationally were that there was a large proportion of Learning Disability patients in hospital who were detained under criminal justice provisions of the Mental Health Act and there is high proportion of patients for whom there seemed to be no current discharge planning. We currently do not have details of the local evidence of these statistics.

⁵⁷ <http://www.towerhamlets.gov.uk/Documents/Public-Health/TH-JSNA-Health-Equity-in-Primary-Care-2014.pdf>

⁵⁸ Glover – IHAL 2013 http://www.improvinghealthandlives.org.uk/securefiles/151016_1211/IHAL-2013-02%20Hospital%20admissions%20that%20should%20not%20happen%20ii.pdf

⁵⁹ PHE – Fingertips – public health profiles

⁶⁰ NHS HSCIC Assuring Transformation <http://www.hscic.gov.uk/assuringtransformation>

⁶¹ Assuring Transformation Aug 2015 Learning disability services reference tables:

<http://www.hscic.gov.uk/catalogue/PUB18486/ldsm-aug-15-ref-tables.xls>

⁶² http://www.improvinghealthandlives.org.uk/securefiles/151016_1022/PHE%20report%20on%202013%20LD%20census.pdf

Social care

The adult social care outcomes framework (domain 1) – *enhancing quality of life for people with care and support needs* also has two outcomes measures for people with learning disabilities:

Proportion of adults with a learning disability in paid employment

The measure is intended to improve the employment outcomes for adults with a learning disability, reducing the risk of social exclusion. There is a strong link between employment and enhanced quality of life, including evidenced benefits for health and wellbeing⁶³ and financial benefits⁶⁴.

Paid employment is measured using the following two categories:

- Working as a paid employee or self-employed (16 or more hours per week); and,
- Working as a paid employee or self-employed (up to 16 hours per week).

In 2013/14 Tower Hamlets had 40 people (6.2%) of its Learning Disabilities clients in employment⁶⁵.

Proportion of adults with a learning disability living in their own homes or with their families

'Living on their own or with their family' is intended to describe arrangements where the individual has security of tenure in their usual accommodation, for instance, because they own the residence or are part of a household whose head holds such security⁶⁶.

In 2014-15 68.4% of Tower Hamlets Learning Disability clients met this criteria, compared to a national rate of 73.3%, suggesting that there are more people with learning disabilities living in less stable living conditions.⁶⁷

7. What is the perspective of the public?

In February 2014, 603 Tower Hamlets service users, with a learning disability, who were in receipt of long term social care and support, were asked to complete a survey. The survey asked for feedback on people's quality of life and experience of social care. Of the 603 surveys sent out, 199 were returned which equates to a 30.3% response rate.

Some of the possible actions from the survey were:

Health Sub Group

Continue to work with GPs and other health providers, in conjunction with CLDS, to provide training and raise awareness around the issues for people with learning disabilities, with a view to improving how people rate their own health in the 2015 UES Survey.

Employment Sub Group

Link in with the work that this group is doing, together with TH College and Tower Project JET, in promoting Pre-Entry and Entry Level Numeracy and Literacy skills, with a view to improving people's ability to deal with finances and paperwork.

Have Your Say Group

Work with the service users to find out how we can make things easier for them to find information about

⁶³ Vigna, E., Beyer, S. and Kerr, M. (2011) *The role of supported employment agencies in promoting the health of people with learning disabilities* Cardiff: Welsh Centre for Learning Disabilities

⁶⁴ Beyer, S. (2008) *An evaluation of the outcomes in supported employment in North Lanarkshire* North Lanarkshire Social Work Service

⁶⁵ PHE Fingertips Adults with learning disabilities in employment

⁶⁶ Does not include those in registered care or nursing homes (as well as several other criteria which can be found at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/345631/20140801_Final_Handbook_of_Definitions_-_ASCOF_1_2.pdf)

⁶⁷ NASCIS Tower Hamlet 2014-15

https://nascis.hscic.gov.uk/Portal/Reports/Pdf.ashx?r=N008_711_01_2016.pdf&t=PublishedReport&type=standardreports

support, services and benefits and how we can improve social care information and advice.

Run more workshops with service users regarding cash personal budgets, with the focus on having service users who already have cash personal budgets, talking about their own experiences.

In September 2014, as part of the Community Plan Consultation, service user feedback was requested on:

Question 1: What could the Council do to support people to be independent as possible?

Question 2: Could the Council make use of technology e.g. provide services online?

Question 3: What other things are important for Tower Hamlets?

The full results are attached as Appendix A.

Have Your Say Group

Service user feedback from the Have Your Say Group highlighted 4 areas that people wanted the Learning Disabilities Partnership Board to focus on:

Employment – support in finding a job, employment courses, job hunting and making your own email

Health - Make GP/hospital services better for people with LD, access to health information, simplify the appointments process

Information - Learning how to handle money, information on bank use/access

Activities – Safe evening outings/activities, day trips with friends (Southend)

Carers

Nationally The Personal Social Services Survey of Adult Carers in England (2012/13) found that 48% of carers of an adult with learning disabilities spend 100 or more hours a week caring for that person and 73% of carers of an adult with learning disabilities had been caring for more than 20 years. 29% were not in paid employment because of their caring responsibilities.

Locally there has been some engagement of carers with regards to the development of the Short Break (Respite Care) Policy, but nothing specific for carers of those with learning disabilities.

8. What more do we need to know?

Some of the identified gaps are:

- There is currently no systematic recording in health or social care data of specific diagnosis (diagnostic coding) or related co-morbidities, making it 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.
- There are also data issues around the accessing of different systems in different organisations (Barts Health, ELFT) etc. What are the current data sharing agreements and can they be improved going forward?
- There has been a reported increase in the number of safeguarding alerts over the past year – can we gather a deeper understanding of why that might be?
- There appears to be a gap in high support learning disabilities accommodation for younger people and a need to consider the provision that might be required for the likely increase in older people, who may also have associated dementia needs.
- There is a gap in the engagement of carers of those with learning disabilities – more local surveys to be considered, perhaps through engagement with local Healthwatch.

- What is the profile of people in the Tower Hamlets criminal justice system with learning disabilities and how can they be better supported?
- The numbers of people with learning disabilities who are entering secondary care and the reasons for their attendance / admission.

9. What are the priorities for improvement?

The priorities for the improvement below build upon the already existing priorities for the Learning Disabilities Partnership Board. For existing priorities, see Appendix C.

Area	Rationale/Evidence for effective intervention	Recommendations
Process and systems	Ensure that all relevant people are aware of the national and local picture that the JSNA outlines, and the identified priorities for improvement/recommendations.	<ul style="list-style-type: none"> - Use JSNA factsheet and subsequent recommendations to inform LDPB work planning for 15/16 and further - Share learning disabilities JSNA factsheet with key stakeholders and relevant frontline staff - Ensure that the Public Health annual JSNA summary includes data on people with learning disabilities
Commissioning, quality assurance and outcomes	<p>Currently the Community Learning Disabilities Service (CLDS) is being re-procured, the JSNA factsheet can help to inform some of the specification and future requirements for delivery from this service.</p> <p>To ensure that Tower Hamlets is meeting best practice for its learning disabilities population, there should be plans in place to quality assure our local performance. This could be done in a range of areas and these would need to be prioritised,</p> <p>Benchmarking data, whilst not always entirely accurate and has caveats attached to it, however it is a good way of starting to think about a move to more of an outcomes focussed way of monitoring local progress.</p>	<p><i>Re-procurement of CLDS</i></p> <ul style="list-style-type: none"> - Ensure that effective interventions are considered in the re-procurement of the CLDS. Including: ensuring that members of the CLDS are skilled in the assessment and support of people with learning disabilities who have additional mental health problems, liaison around employment and support for wider issues such as the criminal justice system are integrated within the service model* <p><i>Quality Assurance</i></p> <ul style="list-style-type: none"> - Audit our local performance against best practice guidance (e.g. CIPOLD - Reasonable adjustments, Health Charter for Social Care providers - self assessment tool, NICE guidance on challenging behaviour and learning disabilities) <p><i>Outcomes</i></p> <ul style="list-style-type: none"> - LDPB to move to outcomes focussed monitoring of local progress against key indicators through the introduction of a set of indicators/dashboard that brings together national and any locally relevant indicators for LDPB to monitor*.
Local intelligence and future need	<p>It is important that we have access to high quality data, intelligence and information in order to inform our JSNA process, work planning and service delivery.</p> <p>There are potential gaps in who our services are reaching. For</p>	<ul style="list-style-type: none"> - To review what local data is collected and decide what is relevant for publication in conjunction with the JSNA process and report for Tower Hamlets. - Consider if there are gaps in provision and unmet need within the CLDS service.

	<p>example, there are fewer males than you might expect in the CLDS, less people known to services than you might expect and a large number of people who are not known to services.</p> <p>We know that demand will continue to increase and in order to plan effectively for this; we should be looking at our transitions data. We also know people with learning disabilities are living longer.</p> <p>There is limited data from secondary care on those with learning disabilities entering into this system and the outcomes of their care</p>	<ul style="list-style-type: none"> - Using transitions data, estimate the future need for social care among adults with learning disabilities*. - Carry out a mapping exercise of current provision for older people with learning disabilities, including any dementia needs*. <p>Need to work more closely with the Learning Disabilities lead in the acute sector to identify how to obtain accurate data on this population group from this sector.</p>
Health Inequalities	<p>The physical health of those with learning disabilities is poor, especially when compared to the general Tower Hamlets population.</p> <p>The evidence suggests that health checks and health action plans are a critical component to reducing health inequalities and that they support a detection of unmet health needs. Making reasonable adjustments to support healthcare practices are also evidenced as crucial for people with learning disabilities, to be able to make effective use of existing healthcare programmes (including screening).</p>	<ul style="list-style-type: none"> - Improve access to health checks and health action plans*. - Ensure that Health Passports are used effectively. - Primary care lead (GP) for learning disabilities to advocate for an improvement in the uptake of health checks, screening and encourage onward referrals. - Undertake a parity of esteem stocktake to understand the physical health offer for those with learning disabilities and what actions we can take to improve the long term physical health outcomes. This should include a wide range of physical health services (including health screening), especially those that we know impact disproportionately on those with learning disabilities such as vision health.
Transitions	<p>There is still considerable number of people that are 'lost' between children and adult services.</p> <p>Statutory transition planning should start at the year 9 review (age 13/14), should be person centered, and should include health, independent living, employment and social inclusion.</p>	<ul style="list-style-type: none"> - Try and gain a better understanding of those locally who are 'lost' between childrens and adults services and may not meet the criteria for accessing adult service. Consider those who no longer qualify at transitions and what happens to them e.g. are we effectively promoting self-care early on. - Ensure that transitions planning and work is being carried out with all key stakeholders (service user, family or carer, careers, education, children & families)*. - Using transitions data, estimate the future need for social care among adults with learning disabilities. - The needs, including mental and physical health, of young

		people with LD in transition to be considered early in order to prevent hospital admission and associated costs*.
Response to Winterbourne View and supporting challenging behaviour/Criminal Justice System	<p>Continue the good work in Tower Hamlets of supporting people with challenging behaviour to live in the community as the first option, continuing the move away from institutional settings. Prevention (rather than crisis management) should be key.</p> <p>Prevention and early intervention to avoid vulnerable children and adults entering the criminal justice system should be the overriding objective, as well as supporting a reduction in re-offending.</p>	<ul style="list-style-type: none"> - Ensure that the local plan for Winterbourne review is progressed and that the charter of rights for people with learning disabilities is developed locally*. - Carry out an assessment of what further resources are needed to support people with challenging behaviour, with particular focus on what services are currently available (including for specifically for women), people living out of borough on account of their challenging behaviour, and young people with challenging behaviour going through transitions*. - Better understand the needs of people with learning disabilities within the Criminal Justice System (CJS) and consider what we are doing to ensure local police engagement on this issue*. - JSNAs should include information about people with learning disabilities at risk of offending/reoffending - Early identification of people with LD and people with MH in the CJS should be a priority rather crisis management (may require training e.g. the Safer Neighbourhood Teams)
Employment and accommodation	<p>We know that the data shows that we have lower rates of people in employment and stable and appropriate accommodations locally than national averages. Whilst there have been major improvements made, we need to continue to build upon these successes.</p> <p>Current entry criteria remains out of reach for many people with learning disabilities trying access opportunities and for those seeking paid employment.</p> <p>There has been an identified need to build local capacity in appropriate premises for people with learning disabilities. The TH Accommodation Plan for People with Learning Disabilities (2016-19) will provide the strategic priorities for the next 3yrs once published.</p>	<ul style="list-style-type: none"> - 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. - There is an identified need to skill up adults in order to progress onto specific training and courses. Dedicated work with Tower Hamlets College to be commenced to address this need. - Work with colleagues in health to carve out prospective job opportunities*. - Support and clarity required for service users and their families in regards to the impact of working and benefits, as this can prove to be a deterrent to progressing into paid employment. - The needs analysis of accommodation is completed and recommendations are commissioned to allow people to live independently and where possible consider in-borough placements, including for those with challenging behaviour. To ensure that service user feedback inform this needs assessment*. - Review the OOB cases with a view to look to reduce the number of people with learning disabilities living in residential settings out of borough; especially for younger people.
Service users, carers and innovation	<p>Making sure that the contribution of service users is recognised and integrated into our work</p> <p>Not much information readily</p>	<ul style="list-style-type: none"> - Co-production to be a more integral part of service development and ensure that when service users provide feedback that this it is demonstrated back to them how their feedback has made a demonstrable impact*. - Understand the perspective of carers on the information that

	<p>available in on the perspectives of carers', for those with learning disabilities.</p> <p>Important to consider not only the perspective and feedback from the service user, but also of those involved in caring roles e.g. on respite provision.</p>	<p>and service provision that they have access to for those that they are caring for and themselves*.</p> <p>- Ensure that learning disabilities is featured in the carers strategy to be developed this year and think about how we might better identify those in a caring role, who may not be self-identifying.</p>
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*those recommendations that were considered as a priority area by the Learning Disabilities Partnership Board and appear in summary at the beginning of this document.

10. Contacts / Stakeholder Involvement

Contacts

	NAME	CONTACT DETAILS
UPDATED BY	Rakhee Westwood	Senior Public Health Strategist
SIGNED OFF BY	Abigail Knight	AD Public Health

Stakeholders – The Tower Hamlets Learning Disabilities Partnership Board was the governance forum through the development and sign off of this JSNA factsheet.

Appendices

Appendix A - COMMUNITY PLAN CONSULTATION - SERVICE USER FEEDBACK

Learning Disabilities Partnership Board
Monday 22nd September 2014

Question 1: What could the Council do to support people to be independent as possible?

- Service users with learning disabilities want more information/communication on services available in the borough such as social clubs and other specifically tailored provision for this group.
- More accessible transport especially trains and larger buses.
- Personal safety when using public transport is a particular area of concern for this group, who feel vulnerable to being exposed to substance misuse, theft and other forms of anti-social behaviour that can take place on buses and trains. Safer transport and travel training especially during social hours (evening and weekends) would enable people with learning disabilities to travel independently and provide their carer(s) with a reprieve. The Council should also give workshops around travel training to parents and carers.
- Social workers to be in a position where they can offer more time to their clients to discuss the transition to independent living.
- The Council to provide more college courses that focus on teaching life skills such as cookery classes which can support people with learning disabilities to complete everyday tasks like shopping. Furthermore, course guides need to have greater clarity so that this group can understand what options are available to them including details

on fees and entitlement(s).

- Both carers and people with learning disabilities want personalisation – choice and control.
- Carers and service users are concerned with the areas that the Council is looking to make efficiencies in – particularly around services that they think are vital for supporting vulnerable groups such as people with learning disabilities. Carers are of the perception that the Council is biased towards positive. Independent travel for those unable to do so was cited as an example.
- The Council should prevent reducing care package hours and sending service users away long distances to receive support.
- Carers in the borough are ageing and a lack of respite opportunities can cause emotional stress, which can in turn negatively impact on caring responsibilities. The Council should provide more supported living in the borough and increase care provision through better respite planning to alleviate this.
- Better communication with parents/carers of people with learning disabilities is needed. An audit of residents with learning disabilities (age and needs assessment) should be undertaken as a first step towards this.
- The Council should protect vulnerable and disabled people from cuts.
- The Council should recognise and acknowledge that people with learning disabilities want to work (help overturn stereotypes of them as solely benefit recipients) and request colleges to develop more courses that focus on employment to achieve this.
- The Council should deliver workshops to local businesses on working with people with learning disabilities so that any potential myths are dispelled.
- More local doctors to help people with learning disabilities live independently.
- More street signage so that people with learning disabilities can feel safe knowing their locations.

Question 2: Could the Council make use of technology e.g. provide services online?

- Service users with learning disabilities feel that this is a valid approach that the Council can adopt in future but in order to make it feasible will need to offer support/training to people with learning difficulties to access online services. However, carers have expressed concern since not everyone is digitally literate and maintain that frontline services should remain for vulnerable groups who require physical contact.
- User interface for online services should be easy to understand, accessible and supplemented with infographics for service users with learning disabilities.
- The safety of service users with learning disabilities when using technology (smart phones and laptops) will also need to be taken into consideration as they are more likely to be victims of theft.
- Online services can make a positive difference where verbal communication is difficult, as there will be no need for the service user to travel to make contact with the Council.
- Free Wi-Fi in public places will support people with learning disabilities to become more independent. For instance, locating bus/tube routes on their mobile phones and tracking their locations as safety is an important issue for this group.

Question 3: What other things are important for Tower Hamlets?

- Housing and personal safety are key priorities for people with learning disabilities. Accommodation units should take into account the needs of people with learning disabilities – developing two bedroom units even if carers are residing in supported living, in addition to help around accessing housing.
- Police visibility and enforcement to make the borough a safer place to live and visit in areas such as parking control and public transport. As well as providing general assistance.
- Increased awareness and understanding on the subject of learning disabilities is required, especially amongst the police who have not always been sensitive to their needs.
- Recreational spaces like parks and swimming centres with dedicated sessions for this group.
- Cultural needs
- More community support from community officers.

Appendix B – The Community Learning Disabilities Service Vision

THE CLDS aims to support adults with learning disabilities in Tower Hamlets to:

Have a place to live
 Have a job
 Have positive relationships with friends and family
 Go out, have fun and meet new people
 Get around and be respected in the community
 Understand money
 Support families and carers in their caring role
 Support carers to have a better life
 Live an independent and safe life
 Live a healthy life
 Make decisions and choices

Appendix C – Local priorities of the Learning Disabilities Partnership Board

Local priorities of the Learning Disability Partnership Board are:

- Employment and Training - to ensure that more people with learning disabilities are supported to find work and get work experience
- Accommodation- to support people with learning disabilities to have more choice about where they want to live
- Health - improve performance around annual health checks and health action plans and ensure that they are consistent and of a good quality
- Carers - to improve support for carers and young carers and take account of the implications of the new Care Bill, understanding the perspectives of carers
- Challenging Behaviour - look at ways of supporting people with challenging behavior and their families, local provision
- Keeping Safe - ensure that all service users feel safe and know how to ask for help
- Choice & Control/Personalisation- ensure that all service users understand about Personalisation & how to access it if they are eligible (what is the criteria)
- Transition - improve experience of transition from children's to adults, planning of those coming through the system who may not be FACS eligible and support service planning

Appendix D – Learning Disabilities in Tower Hamlets Workshop Notes (15th April 2015)

1. What are the gaps? Known or presumed?
2. What are your priorities for the JSNA factsheet/Learning Disabilities Partnership Board action plan for 15/16 (and the future?)

Group 1

Local intelligence

- Need for a register of people with LD needs/regular data set for: a) known CLDS users b) those with LD needs
- Alignment of records and discrepancy between cross-service records
- Read codes addressing/distinguishing between those who have learning disabilities and learning difficulties
- Mortality rate locally – research task? Can we do a retrospective case audit? It was felt that much of this relates to unmet need in respiratory

Health Inequalities

- How carers/parents can recognise pain? Not being to explain anxieties. Evidence is that carers are systematically overlooked
- Parents with LD needs picked up because 'not meeting needs of children'. Approx. 20 referrals per month often referred by children's social services and they are often borderline on criteria for need. Lack of resource to support through child's changing needs
- Genetic risks
- Forced marriage and capacity
- Simpler version of Health Action Plan (HAP), highlighting what works with HAPs

Transitions

- More joint work with voluntary sector and accommodation/education and employment where these are out of borough

Winterbourne View/Criminal Justice System

- Interventions for these issues hand-in-hand with challenging behaviour
- Families require OOH support - should we be commissioning GP services for this group? Assertive outreach team for dual diagnosis? First resort is often police and this reduces sense of empowerment for families
- John Howard Centre useful where co-morbidities need a clear, focussed approach.
- Training with forensic services is needed. I.e. people who behave in a way that contravenes the law – managing behaviours – more guidance needed to train police service on what they should do

Employment and accommodation

- Inappropriate accommodation due to lack of choice
- More of an issue for younger adults
- Increase in falls (older people)

Service users/carers/innovation

- Lack of support parents and carers (across all LD groups)
-

Pathways issues

- Parenting support and practical teaching
- Training/consultation is done where possible

Group 2

What are the gaps?

1. Client experience in acute mental health inpatient settings

- Lack of reasonable adjustments
- Lack of support
- Expertise of inpatient staff
- Need for more liaison nurses and LD champion (make a priority for CLDS)
- Better working with RAID
- Better implementation and use of health passports
- Need reclaim core nursing role for LD nurses

2. Lack of expertise with challenging behaviour

- Implementation of NICE (existing) guidance
- PBS/Communication
- Social care training

3. Lack of respiratory service for complex clients

- Address through CHS procurement
- Develop skills and advocacy role in CLDS
- Prioritise within CLDS
- More about people with complex physical health needs

3 priorities

- Transitions – keep with CLDS to ensure capacity to assess complex cases
- Health Inequalities – Acute hospitals and CHS
- Winterbourne – very close links needed with adult mental health and accommodation