

JSNA: Learning disabilities

Introduction

Valuing People, the 2001 White Paper on the health and social care of people with learning disabilities, included the following definition that learning disability includes the presence of:

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

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

ICD-10	Level of learning disability	Associated IQ
F70	Mild	50-69
F71	Moderate	35-49
F72	Severe	20-34

The definition encompasses people with a wide range of disabilities but does not include all people who have a 'learning difficulty'. It includes adults with autism who also have learning disabilities, but not those with high functioning autism – such as some people with Asperger's Syndrome (see separate Autism JSNA Chapter).

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

The estimates in this chapter are related to the overall estimates of limiting long-term illness and disability presented in the Limiting Long Term Illness and Disability in Adults JSNA Chapter.

Implications for commissioning

Improve the quality of primary care learning disability registers, including improving the recording of people with moderate/mild learning disabilities on practice registers.

Review the provision of annual health checks for people with learning disabilities to ensure equal access and consistency across the borough.

Implement the action plan identified following the Health Self-Assessment in 2012.

Improve the co-ordination of employment support in order to increase the numbers of adults with learning disabilities in employment.

Work with providers of key services to ensure they are accessible to adults with learning disabilities e.g. weight management and exercise referral schemes.

Ensure mainstream services are demonstrating 'reasonable adjustments' to ensure that they are meeting known needs, and having staff who understand how to make these adjustments.

Increase the numbers of people with learning disabilities in employment.

Continue to develop accessible information and advice including the service directory to assist people in using their personal budgets to purchase cost-effective support.

Continue to develop targeted preventative health initiatives for people with learning disabilities.

Ensure an appropriate system is in place to identify and flag patients with learning disabilities in acute care and protocols to ensure care pathways are reasonably adjusted.

Commissioners can demonstrate that people with learning disabilities, families and carers are involved in the process of planning and decision making, so that their needs, choices and preferences are understood, and services are available to reflect individual choice.

Commission services in line with the expected increase in prevalence of adults with a learning disability over the next 10-15 years.

Who's at risk and why?

Adults with learning disabilities are one of the most vulnerable groups in society, experiencing health inequalities, social exclusion and stigmatisation.

Mild learning disabilities are strongly associated with parental social class and family instability, but no relationship is reported between these factors and severe learning disabilities, suggesting that deprivation may be a contributory factor for mild but not severe learning disabilities¹.

¹ Emerson, E. et al (2001) *Health Inequalities & People with Learning Disabilities in the UK: 2012 Durham: Improving Health and Lives*, Learning Disabilities Observatory.

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

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

People with learning disabilities have poorer health than their non-disabled peers, differences in health status that are, to an extent, avoidable. As such, these differences represent health inequalities. The health inequalities faced by people with learning disabilities in the UK start early in life and result, to an extent, from barriers they face in accessing timely, appropriate and effective health care².

Key health issues nationally include³:

- People with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population;
- Coronary heart disease is a leading cause of death amongst people with learning disabilities with rates expected to increase due to increased longevity and lifestyle changes associated with community living;
- Respiratory disease is the leading cause of death for people with learning disabilities (46-52%), with rates much higher than for the general population (15-17%);
- Recent data extracted from GP information systems in England indicate higher rates of Type 1 and Type 2 diabetes among adults with learning disabilities;
- A recent UK study has reported that adults with learning disabilities experience higher rates of injuries and falls when compared to the general population;
- People with learning disabilities are 8-200 times more likely to have a visual impairment compared to the general population and approximately 40% of people with learning disabilities are reported to have a hearing impairment, with people with Down's Syndrome at particularly high risk of developing vision and hearing loss;
- There is an increased risk of acute and chronic pain among people with learning disabilities as a result of high rates of co-occurring health conditions and physical impairments;
- The prevalence of dementia is higher amongst older adults with learning disabilities compared to the general population and is associated with a range of potentially challenging behaviours and health problems. People with Down's Syndrome are at particularly high risk of developing dementia, with the age of onset being 30-40 years younger than that for the general population;

² MENCAP (2012) *Death by indifference, 74 deaths and counting: A progress report 5 years on*, MENCAP.

³ Emerson, E. et al (2001) *Health Inequalities & People with Learning Disabilities in the UK: 2012* Durham: *Improving Health and Lives*, Learning Disabilities Observatory.

- The prevalence rate of epilepsy amongst people with learning disabilities has been reported as at least 20 times higher than for the general population, with seizures commonly being multiple and resistant to drug treatment;
- A recent systematic review reported estimated prevalence rates of sleep problems in adults with learning disabilities ranging from 9% to 34%, with an estimated prevalence of 9% being reported for significant sleep problems. Sleep problems were associated with the following factors: challenging behaviour; respiratory disease; visual impairment; psychiatric conditions; and using psychotropic, antiepileptic and/or antidepressant medication;
- Challenging behaviours (such as aggression, destruction and self-injury) are shown by 10-15% of people with learning disabilities;
- The prevalence of psychiatric disorders is also significantly higher among adults whose learning disabilities are identified by GPs, when compared to general population rates;
- One in three adults with learning disabilities and four out of five adults with Down's Syndrome have unhealthy teeth and gums;
- People with moderate to profound learning disabilities are more likely than the general population to die from congenital abnormalities and a number of syndromes associated with learning disabilities are also associated with some specific health risks.

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

- Less than 1 in 5 people with a learning disability work (compared with one in two disabled people generally), but we know that at least 65% of people with a learning disability want to work. Of those people with a learning disability that do work, most only work part time and are low paid;
- Over time, families with a child with learning disabilities are more likely to be poor or become poor and are less likely to escape from being poor than other families;
- In 2009/11 British adults with self-reported impairments of learning or understanding were nearly three times more likely than their non-disabled peers to have been a victim of violent crime over the last year and nearly seven times more likely to have been a victim of hate crime.

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

- Scarcity of appropriate services;
- Physical and informational barriers to access;
- Unhelpful, inexperienced or discriminatory healthcare staff;
- Increasingly stringent eligibility criteria for accessing social care services;

- Failure of health care providers to make ‘reasonable adjustments’ in light of the literacy and communication difficulties experienced by many people with learning disabilities;
- ‘Diagnostic overshadowing’ (e.g. symptoms of physical ill health being mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person’s learning disabilities).

Specific concerns include:

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

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

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

- People with learning disabilities may have poor bodily awareness and a minority may have depressed pain responses. In addition, limited communication skills may reduce their capacity to convey identified health needs effectively to others;
- Prevalence of learning disabilities amongst offenders is higher than the general population, with 7% of prisoners in the UK having learning disabilities as determined by an IQ score of less than 70⁴.

The level of need in the population

There are no official statistics reporting the number of adults in the UK with a learning disability, and establishing a precise figure is not easy due to the social construct of the condition and its wide spectrum. However estimates suggest that approximately 2% of the UK adult population have a learning disability⁵.

Planning4Care estimates that in 2013 there are:

- 5,586 adults with learning disabilities in Bolton, approximately 2.6% of the population;
- 100 adults with profound and multiple learning disabilities – 86 aged 18-64 years and 14 aged 65+ years;
- 814 adults with severe learning disabilities - 719 aged 18-64 years and 95 aged 65+ years;
- 4,672 adults with moderate learning disabilities – 3,767 aged 18-64 years and 905 aged 65+ years;
- Approximately 1.4% of adults with severe/moderate learning disabilities (78 people) are likely to have serious challenging behaviour;
- 120 people aged 18-64 years in Bolton are expected to have Down's Syndrome. Due to the early mortality of people with Down's Syndrome, the number of those above the age of 65 is expected to be nil. Of those with Down's Syndrome, approximately 10-20 people are expected to have early onset dementia;
- 70 people in total in Bolton are expected to have early onset dementia; 10 aged 25-49 years and 60 aged 50-64 years.

Planning4Care indicates that Bolton has a slightly higher proportion of the population with a moderate learning disability than the national and regional averages (2.1% compared with 1.9% for England and the North West), although the proportions with profound and multiple learning disabilities (0.05%) and severe learning disabilities (0.38%) are similar to national and regional averages.

⁴ Prison Reform Trust (2013)
<http://www.prisonreformtrust.org.uk/>

⁵ Emerson, E. and C. Hatton (2008) *Estimating future need for adult social care services for people with learning disabilities*, Centre for Disability Research.

Planning4Care also provides estimates of the numbers of young people with learning disabilities aged 14-17 years who may be expected to be in transition between children's and adult services:

- There are 407 people aged 14-17 with learning disabilities in Bolton;
- Of these, 14 will have profound and multiple learning disabilities, 68 severe learning disabilities and around 325 with moderate learning disabilities;
- 6 will also have severe/moderate learning disabilities with serious challenging behaviours;
- There are estimated to be 11 people aged 14-17 with Down's Syndrome.

The Institute of Public Care (PANSI) estimates the age profile for all adults with learning disabilities in Bolton in 2013 as follows:

- 18-24 years 13.3%;
- 25-34 years 18.2%;
- 35-44 years 18.1%;
- 45-54 years 17.9%;
- 55-64 years 13.8%;
- 65-74 years 11.1%;
- 75-84 years 5.6%;
- 85+ 2.0%;
- *Total* 100.0%.

The Public Health England Learning Disability Observatory indicates there are likely to be more male than female adults with learning disabilities in Bolton (males 60%, females 40%) reflecting national ratios where more males are likely to have severe learning disabilities than females (average ratio 1.2 males: 1 female) and mild learning disabilities (average ratio 1.6 males: 1 female).

Current services in relation to need

Primary care

All GP practices in Bolton have a Quality and Outcomes Framework Learning Disabilities register and all but one GP practice has signed up to the Learning Disabilities DES that requires practices to offer annual health checks to patients with learning disabilities that are known to Adult Social Care and Health services primarily due to their learning disability.

The prevalence of learning disability in adults according to primary care QOF registers in Bolton in 2012 was 0.3% (963 people). The prevalence has remained unchanged over the last five years and indicates under-reporting of learning disability in primary care. The number of adults with learning disability known to GPs in Bolton per 1,000 population was 4.00 in 2010-11, significantly lower than the North West (4.61) and England (4.33) average.

The Public Health England Learning Disability Observatory estimates that 23% of all people with learning disabilities in Bolton are likely to be known to health or social care services. It is likely people from a BME background are under-represented currently.

In 2010-11, 248 people with learning disabilities in Bolton received a health check, 29.7% of those eligible. This was significantly lower than the proportion receiving health checks in England (48.6%) and the North West (47.2%). The 2011/12 learning disability health self-assessment indicates that some GPs are only undertaking health checks every two years based on a clinical rationale. Almost everyone that has a health check has a Health Action Plan which has individualised health improvement targets and is written in an accessible format.

There are a number of local initiatives to ensure the primary health needs of people with learning disability are met, including specialist dental and audiology clinics. There are also links with podiatry services to ensure needs are met for those people who are unable to access or tolerate clinic treatments or who may require additional treatment at more frequent intervals than the standard twelve week cycle allowed within mainstream services.

All community based health staff attend mandatory learning disability awareness training.

Secondary care

A Learning Disability Liaison Nurse is based at the hospital to support people with learning disabilities by maintaining links to community teams to ensure continuity of support from outpatient/pre-assessment to admission and eventual discharge.

Some departments within our secondary care provider excel in recognising learning disability status and providing reasonable adjustments. This includes the audiology IT system which records learning disability and adjustments required, pre-op assessment which identifies learning disability and completes the 'keep me safe' document and specialist dental service who provide individualised theatre sessions with additional time allowed and multi-procedure treatments.

In 2008/09, 49.4% of hospital admissions (excluding psychiatric hospitals) for people with learning disabilities in Bolton were emergencies, very similar to the national average (49.9%) but higher than the North West average (44.7%). The numbers are substantially larger than for people who do not have learning disabilities (50.0% compared to 31.1%).

Specialist learning disability services

Adult Disability Teams (Health and Social Care)

A multi-disciplinary/multi-agency service located and managed by the Council. The overall aim of the service is to work with individuals and their carers, in a variety of settings, to

promote independence, social inclusion, good health and wellbeing. The teams work in partnership with the Local Authority, Education, Primary and Secondary Care, Housing, Employment, Leisure, Voluntary Sector, etc, in a person centred way. The treatment programmes involve assessments and interventions from a range of clinicians including: Learning Disability Nurses, Physiotherapists, Occupational Therapists, Speech and Language Therapists, Psychologists, Social Workers and Assistant Practitioners.

Social Care

In 2011/12, a total of 650 people with learning disabilities – 583 aged 18-64 and 67 aged 65+ were supported by Social Care services in Bolton. The number of people with a learning disability aged 18-64 years known to social care rose steadily from 2006/07 (635) to 2010/11 (680) but decreased by 4% in 2011/12, possibly as a result of the change in the eligibility criteria for social care where moderate needs are no longer met by the local authority. In 2010/11, 4.18 adults per 1,000 aged 18 to 64 were known to the Council with learning disabilities, very close to the England average (4.27) but slightly lower than the North West average (4.71).

Almost all (97%) of people with learning disabilities known to Social Care in Bolton in 2011/12 were supported in the community rather than in residential care (this compares with a national average of 79%). A variety of community based services are provided to people with learning disabilities as follows:

- Supported Housing;
- Adult Placement;
- Day Care;
- Respite care/short-term breaks;
- Home Care;
- Direct Payments

Analysis of the service mix provided to people with learning disabilities in Bolton in comparison with the national pattern across all local authorities indicates:

- Of those aged 18-64 years supported in the community a lower than average proportion attend a day care service (30.7% compared with 46.3% nationally);
- People with learning disabilities over 65 years receive a more restricted range of services than younger adults – primarily home care (69.2% compared with 54.0% nationally). Home care includes Supported Housing.

Direct payments are cash payments made to individuals who have been assessed as needing services, in lieu of social service provision. The aim of a direct payment is to give more flexibility in how services are provided. By giving individuals money in lieu of social care services, people have greater choice and control over their lives, and are able to make their own decisions about how their care is delivered. The number of people with a learning

disability receiving a Direct Payment has been steadily increasing and was 165 people in Bolton in 2011/12.

In 2011/12, 81.6% of adults with learning disabilities known to social care in Bolton were living in their own home or with their family compared with the national average of 70.0% and 77.8% across the North West. In February 2013, 180 people with learning disabilities were living in supported tenancies – 63% in houses where support is provided by the Council and the remainder where support is provided by the independent sector.

The proportion of adults with learning disabilities known to Social Care in Bolton in paid employment in 2011/12 was just 1.1% compared with the North West average of 5.4% and the national average of 7.1%.

Around 40.0% of referrals to adult social care safeguarding in 2012/13 were for people with learning disabilities.

Continuing Care

Continuing Care is provided over an extended period of time to meet physical and mental health needs and involves support for receipt of NHS and social care services. Fully-funded NHS 'continuing care' is a package of care arranged and funded solely by the NHS, whereas 'Continuing health and social care' is a joint package of care that involves services from both the NHS and social care.

Specialist hospitals

A total of 21 people with learning disability and/or autism are currently (March 2013) funded in specialist hospital placements by Bolton CCG with a breakdown as follows:

- Two in medium secure;
- Six in low secure;
- Two in step-down;
- Eleven in enhanced.

This number is constantly changing as individual needs are re-assessed and people are discharged to alternative settings.

Mental Health

Greater Manchester West Mental Health NHS Trust hosts a Consultant Psychiatrist for Learning Disability in Bolton, commissioned by the CCG.

Other

The Bolton One health and leisure complex, which is fully accessible, provides services for people with learning disabilities including those with profound and multiple learning disabilities e.g. hydrotherapy.

In 2011 the Be Safe Bolton Partnership launched the 'I'm Not Laughing' Disability Hate Crime Campaign, which challenges disability hate crime in a proactive manner. New Openings, a self-advocacy group for people with learning disabilities, was closely involved in the development of the campaign.

Projected service use and outcomes

Estimates suggest that the prevalence of people with learning disabilities in England will increase over the next few years, driven by three main factors⁶:

1. The increase in proportion of younger adults who belong to South Asian communities, as these communities have a higher prevalence of severe learning disabilities;
2. Increased survival rates among young people with severe and complex disabilities, due to improved medical care;
3. Increased longevity among adults with learning disabilities, due to improvements in medical care and reduced mortality.

Planning4Care indicates there is likely to be a 2.5% increase in the total number of adults aged 18-64 years with learning disabilities in Bolton over the next five years which is lower than the increase expected across the North West (6.8%) and England (7.6%). There is expected to be a larger increase (9.9%) in the number of older people with learning disabilities aged 65+ years in Bolton over the next five years but this is also lower than the expected increase across the North West (13.8%) and England (16.3%).

Estimated future numbers of people with learning disabilities aged 18-64 years in Bolton (Planning4care)					
	2013	2018	2023	2028	2033
Profound and Multiple LD	90	100	110	120	
Severe LD	720	730	750	780	800
Moderate LD	3680	3770	3850	3940	
Total	4490	4600	4710	4840	
Severe/Moderate with Challenging Behaviour	70	70	70	70	

⁶ Emerson, E. and C. Hatton (2008) *Estimating future need for adult social care services for people with learning disabilities*, Centre for Disability Research.

Estimated future numbers of people with learning disabilities aged 65+ years in Bolton					
	2013	2018	2023	2028	2033
Profound and Multiple LD	10	10	20	20	
Severe LD	100	110	110	120	130
Moderate LD	900	990	1070	1170	
Total	1010	1110	1200	1310	
Severe/Moderate with Challenging Behaviour	10	10	10	10	

In terms of transition between adults and children's services, the population aged 14-17 years with learning disabilities in Bolton is expected to remain unchanged over the next five years (400 people) although there is expected to be an increase in the number of young people with profound and multiple learning disabilities (from 10 to 20 people) which is likely to have a significant impact on local services. In comparison, the number of young people in transition is expected to fall across the North West (-5.9%) and England (-4.0%) over the next five years.

There is not expected to be any significant change in the number of adults with Down's Syndrome including those with early onset dementia over the next five years.

The increase in the population of people with learning disabilities is expected to have some impact on social care services in Bolton, with an expected 3.0% increase in the number of adults aged 18-64 years and a 12.5% increase in the number of older people aged 65+ requiring support.

Evidence of what works

The Valuing People (2001) White Paper set out the Government's commitment to improving the life chances of people with learning disabilities, through close partnership working to enable people with learning disabilities to live full and active lives. *Valuing People Now* (2009) (and *Resource Pack* (2009)) retained the principle outlined in *Valuing People* that people with learning disabilities are people first, and re-emphasised the need for agencies to work together to achieve the best outcomes for people with learning disabilities,

Death by Indifference (2007) detailed six cases that Mencap believed demonstrated institutional discrimination towards people with learning disabilities within the NHS, leading to shortcomings in care received that ultimately resulted in the death of the patients. *Healthcare for all* (2008), the report of the Independent Inquiry into Death by Indifference concluded that people with learning disabilities appear to receive less effective care than they are entitled to, with evidence of a significant level of avoidable suffering and a high likelihood that deaths are occurring that could be avoided. A total of 10 recommendations were made, all of which were accepted by the Department of Health in *Valuing People Now*.

Six Lives (2009), the report of the Health Ombudsman into the cases highlighted in *Death by Indifference* highlighted some significant and distressing failures in health and social care services, leading to situations where people with learning disabilities experienced prolonged suffering and inappropriate care. The report required all NHS and social care organisations to review a) the effectiveness of local systems to enable understanding and planning to meet the needs of people with learning disabilities and b) the capacity and capability of services to meet the complex needs of people with learning disabilities. *The Six Lives progress report* (2010) is a report by the Department of Health on progress made by NHS and social care organisations in implementing the recommendations of the Six Lives report.

Services for people with learning disability and challenging behaviour or mental health needs (The Mansell Report) (revised edition 2007) is an updated version of the guidance originally produced in 1993. This good practice guidance sets out the actions that should be taken in order to effectively meet the needs of people with challenging behaviour.

Valuing Employment Now (2009) sets out the Government's strategy to improve employment opportunities for people with learning disabilities.

Equal access? A practical guide for the NHS: creating a Single Equality Scheme that includes improving access for people with learning disabilities (2009) is a guide to support the NHS to include people with learning disabilities in their equality schemes, with practical examples of reasonable adjustments to achieve equality of access.

Improving the health and wellbeing of people with learning disabilities (2009) is a World Class Commissioning document that supports commissioners to meet the needs of people with learning disabilities, and ensure they are fulfilling their duty to promote equality.

The National report for commissioning services and support for people with learning disabilities and complex needs joint review (2009) published by The Healthcare Commission, Commission for Social Care Inspection and Mental Health Act Commission looked at nine areas of England to see how well people with learning disabilities and complex needs were being supported by local services. The report of the joint review gives key findings and recommendations, and some examples of good practice.

Raising our sights: services for adults with profound intellectual and multiple disabilities (2010) highlights the most important parts of planning and delivering support for people with the most complex needs.

The Learning Disability Observatory was established in 2010 and aims to provide better, easier to understand information on the health and wellbeing of people with learning disabilities. By collecting information from across England, it will help health and social care commissioners and providers to understand better the needs of people with learning disabilities, and their families and carers. It includes an annual report summarising the latest

evidence about the extent, nature and determinants of health inequalities experienced by people with learning disabilities in the UK.

Using Local Data to monitor the Health Needs of People with Learning Disabilities (2012) published by the Department of Health, provides information for commissioners about how to monitor the health of, and the healthcare received by this particularly vulnerable group.

The revised Department of Health *Learning Difficulties and Ethnicity: updating a framework for action* (2012) produced by The Foundation for People with Learning Disabilities to update the Framework for Action which was first published in 2004.

Reasonably Adjusted? Mental Health Services and Support for People with Autism and People with Learning Disabilities July 2012. The NHS Confederation commissioned NDTi (National Development Team for Inclusion) to write a report about the reasonable adjustments that should be made to mental health services to enable people with autism and people with learning disabilities to have equal access and effective treatment.

NDTi is also carrying out research into employment support for disabled people to identify value for money approaches.

Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs) (2012) was published by the Learning Disability Observatory to assist CCGs in developing local commissioning for people with learning disabilities.

Further key sources for information on effective interventions and evidence-based policy are highlighted on Bolton's Health Matters [by clicking here](#).

Community views and priorities

There is a need for more focused consultation with people with learning disabilities and their carers about health and wellbeing priorities in Bolton.

Some feedback from the statutory social care surveys with service users and carers has highlighted the following:

- There is a need to improve information and advice for people with learning disabilities and their carers:
 - *“My parents have had to fight for support and only found things out from word of mouth from other parents. (Adult Social Care Survey 2013)”*;
- Carers were more likely to feel that the process of arranging care for a person with learning disabilities was lengthy and difficult and did not give the person they care for a choice about how their needs were met;

- Direct Payments can have a very positive impact on the quality of life of a person with learning disabilities:
 - *“Direct payments have been life changing for our son who has severe learning difficulty. He is able to have a social life without us, his parents, being in attendance, he is able to meet new people and to keep in touch with his former school friends” (Adult Social Care Survey 2013);*
- There is inadequate disabled parking at the Bolton One health and leisure complex.

In addition, members of Bolton’s Disability Partnership have highlighted the need for improved employment support for people with learning disabilities in Bolton.

Equality impact assessments

No recent local equality impact assessments have been carried out that we are aware of. If you are aware of any such work locally please let us know at Bolton Health Matters.

Unmet needs and service gaps

Less than a fifth of the estimated population of adults with learning are recorded on the Quality and Outcomes Framework (QOF) learning disability registers at GP practices.

Some GP practices are carrying out bi-annual rather than annual health checks for people with learning disabilities.

National and international evidence suggests that people with learning disabilities have higher levels of unrecognised health needs than the general population. No information is currently available to highlight unrecognised health needs being identified through the annual health checks undertaken as part of the Direct Enhanced Service (DES) for adults with learning disabilities. When available this information will require monitoring, particularly in relation to newly-identified health needs being diagnosed in the local population.

There is currently a lack of information relating to the demographic profile, distribution, needs and service use for adults with mild learning disabilities.

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

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

There are low levels of employment among people with learning disabilities known to services and a lack of co-ordination of Employment Support services locally.

Recommendations for further needs assessment work

- Assessment of primary care data to further understanding of the health needs of adults with learning disabilities in particular in relation to lifestyle issues, immunisation rates, health screening and prevalence of chronic diseases.
- Further needs assessment on the needs of adults with learning disabilities from BME communities.
- Assessment of access to mental health services for people with learning disabilities in light of good practice.
- Consultation with people with learning disabilities and their carers to understand local priorities.

Key contacts

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