
Learning disabilities in adults in Lancashire

A JSNA report

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Intelligence for Healthy Lancashire (JSNA)

Working in partnership with:



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Introduction and methodology

Introduction

We know that people with a learning disability tend to have poorer health and often die younger than those who do not. This is a health inequality, since people with a learning disability should not have worse health than other people.

This report is a Joint Strategic Needs Assessment (JSNA) for adults with a learning disability in Lancashire. The report covers the Lancashire sub-region – the county of Lancashire plus Blackburn with Darwen and Blackpool.

This JSNA also includes information on people with autism, although people with autism do not always have a learning disability and people with a learning disability do not always have autism.

Definitions

Definition of learning disability

A definition of learning disability is a subjective area and there is no agreed national definition for the whole population. The definition of learning disabilities in adults focuses on clinical issues, whilst for children and young people the focus tends to be on any factors that impair the ability to learn. By nature this is a broader definition, which is understandable given the consequences that result from the inability to learn at the same level as other peers.

This section of the report outlines the different definitions used for both children and adults. The complexity of which explains why it has been agreed that this report should focus on adults only with a recommendation for a more detailed analysis of children and young people to be conducted separately. Although the needs of children and young people are not considered in this report, the numbers of those children with needs in line with the adult definition employed are included to support future service planning.

Adults and older people

For adults and older people (ages 18 to 80+), a definition of 'learning disability' will be based on that from Valuing People¹:

Learning disability includes the presence of:

¹ Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. HMSO.

- *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.*

Definition of autism

Adults with autism and higher level autistic spectrum disorders will be incorporated in this analysis, even though the definition of learning disability above does not include such groups. This will make the analysis more inclusive than had it simply used the Valuing People definition. This was agreed by the reference group.

Autism is:

"a behaviourally defined disorder, characterised by qualitative impairments in social communication, social interaction, and social imagination, with a restricted range of interests and often stereotyped repetitive behaviours and mannerisms²."

The definition of autism used by *Fulfilling and Rewarding Lives: the Strategy for Adults with Autism in England*³ will be adopted for this analysis:

autism is defined as a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. The three main areas of difficulty, which all people with autism share, are known as the 'triad of impairments'.

They are difficulties with:

- *social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice)*
- *social interaction (e.g. problems in recognising and understanding other people's feelings and managing their own)*
- *social imagination (e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine).*

² Baird et al (2003) *Diagnosis of Autism*. BMJ; 327 , pp488-493.

³ Department of Health (2010) *Fulfilling and Rewarding Lives: the Strategy for Adults with Autism in England*, p.10. Available online: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369 [accessed February 2012].

This definition uses 'autism' to cover terms such as 'autistic spectrum disorder,' 'autistic spectrum condition' and 'neuro-diversity' and includes Asperger's syndrome. This is in line with the terminology used by the National Autistic Society.

It should be emphasised that not all people with learning disabilities have autism, and not all people with autism have learning disabilities, although some people do have both diagnoses. Therefore this analysis will treat each condition separately in line with the recommendations of the project steering group. It is estimated that between 20% and 33% of people with learning disabilities also have autism, while approximately 55% of children and young people who have a diagnosis of autism also have a learning disability⁴.

Definition of multiple and complex needs

There are numerous formal definitions of multiple and/or complex needs. The definition proposed by Rankin and Regan will be used for this analysis, and they suggest complex needs imply⁵:

- *Breadth of needs – multiple needs (more than one) that are interrelated or interconnected.*
- *Depth of needs – profound, severe, serious or intense needs.*

Methodology

This report is based predominantly upon a wide range of secondary data sources including officially published datasets, locally available datasets and previous research conducted in the local area. The report aims to be systematic in the presentation of data to include:

- The current position in Lancashire, Blackpool and Blackburn with Darwen compared to the North West and England.
- The trend over time in Lancashire, Blackpool and Blackburn with Darwen as compared to the North West and England.
- Variations within the five primary care trust (PCT) areas and 12 districts in Lancashire and 2 unitary authorities at Blackpool and Blackburn with Darwen
- Variations within Lancashire by socio-demographic indicators.

⁴ Emerson, E et al (2011) *Health Inequalities and People with Learning Disabilities in the UK: 2011*. Available online: <http://www.improvinghealthandlives.org.uk/publications/978/> [accessed February 2012].

⁵ Rosengard, A et al (2007) *A Literature Review on Multiple and Complex Needs*. Available online: <http://www.scotland.gov.uk/Publications/2007/01/18133419/4> [Accessed February 2012].

It should be noted that not all datasets have this level of information so a systematic analysis is not always possible. The ambition has been to include data for the entire sub-region. Where this has not been possible within the timescale we have included data for the county of Lancashire.

Limitations

Every attempt has been made to ensure that the analysis is comprehensive. Despite this, we know that the data on learning disabilities is far from complete and not always available for all areas of Lancashire. Any gaps have been highlighted within the document and recommendations made to address these where appropriate or possible.

The analysis in the document is primarily based upon secondary data and it would be useful in the future to carry out some primary research to further understand the needs of people with learning disabilities.

Findings

Summary of key issues

The information in this report and in the full technical document that accompanies it will help us to make sure we provide services that people with a learning disability in Lancashire need, and improve their health. It will be used by learning disabilities service commissioners, autism partnership board, NHS service provider and Primary Care Trusts (until April 2013 and then Clinical Commissioning Groups and the Health and Wellbeing Boards), as well as local government and the third sector.

The analysis of learning disabilities in adults in Lancashire has highlighted a number of key issues:

- Nearly half of people experiencing a learning disability live in the most deprived areas of Lancashire.
- People with learning disabilities are much less likely to be in paid employment.
- People with learning disabilities are over-represented in prison populations.
- The changes to benefit allocation will also affect people with learning disabilities disproportionately.
- Housing needs of people with learning disabilities are considerable and will increase.
- People with learning disabilities experience much poorer health outcomes across a range of conditions.
- Prevalence and need is increasing whilst available budgets have been decreasing and are likely to continue to decrease.
- This has major implications for how services are delivered and will require a different approach to commissioning and developing co-produced services.

Poverty and deprivation

People with learning disabilities and autism are more likely to be living in poverty than the general population, partially because they are less likely to be in paid employment. Poverty is defined as

having less than 60% of the median national income (currently the median income is £406.40 per week so households living in poverty are those earning less than £243.84 a week⁶).

When people's resources are significantly below average, they are in effect excluded from normal living patterns, customs and activities. They are precluded from having a standard of living considered acceptable in the society in which they live. Because of their poverty they may experience multiple disadvantages through unemployment, low income and limited employment, poor housing, low educational attainment and health care issues. They can become marginalised and excluded from participating in activities (economic, social and cultural) that are the norm for other people.

Many people with moderate to severe learning disabilities receive benefits to support or supplement their income, such as disability living allowance and housing benefits and, for young people, employment support allowance in youth.

Many of these benefits are changing or being replaced altogether following the reforms to the benefits system. In particular, disability living allowance and many other benefits are being replaced with universal credit. It is anticipated that the additional payments for disability under universal credit will be lower than under the previous system, affecting individuals with disabilities, including learning disabilities. Additionally, housing benefits changes may adversely affect many people with learning disabilities who rely on this income. It is expected that £360million will be saved benefits and tax credits spending in Lancashire.

Personal budgets

1,022 people with learning disabilities in the county of Lancashire received a personal budget in 2009/10, and this increased to 1,825 in 2010/11 (Central, East and North Lancashire Learning Disability Partnership Board annual reports, 2011).

67 people with autism in the county of Lancashire receive a personal budget or direct pay.

Employment

Fewer than 15% of people with a learning disability across Lancashire are in employment. All areas have an employment strategy for people with learning disabilities in line with Valuing People Now: Real Jobs for People with Learning Disabilities.

⁶ Lancashire Profile: <http://www.lancashire.gov.uk/corporate/web/?siteid=6236&pageid=36487&e=e>

Data about the number of adults with autism in employment is not currently recorded. A subgroup of the Lancashire Autism Partnership Board is working to develop measures for the number of adults with autism in employment.

Crime, prison population and secure mental health services

Lancashire Probation Trust regularly assesses the education, training and employability status of offenders subject to supervision through completion of the offender assessment system (OASys). Data from a 'snapshot' of these assessments provides evidence that 4% of offenders in Lancashire have severe learning difficulties, with particular issues in the districts of West Lancashire and Lancaster (7%) and Burnley (5%). In such cases, offenders will have attended a special school for either behavioural or learning difficulties, or may have received a statement of educational needs. 10% of offenders assessed may have had problems at school or present evidence of difficulties coping in everyday situations. 23% of offenders under the supervision of Lancashire Probation Trust have no educational qualifications, with particular issues in Blackpool (29%), Lancaster (26%) and Preston and Burnley (24%).

People with learning disability and autism in secure mental health services and prison may not have been known previously to services, and those that are known may have demonstrated signs of pre-offending behaviour when they were younger.

Resources are needed to ensure that information about potential pre-offending behaviour is recorded and passed onto Adult Services through transitions, which would then enable earlier intervention. Also, factors that affect whether a person subsequently is admitted to secure provision or not need to be scoped, so that people at risk can be targeted and preventative strategies identified and developed.

Housing

Across the Lancashire county area over 1,800 people with a learning disability are estimated to have a housing need. It should be noted however that the methodology used to determine these estimates has been controversial, so are intended as indicative only.

Lancashire County Council currently support approximately 2,000 people committing £79 million within a range of 24 hour domiciliary support services, with each person having a tenancy agreement with a housing provider and support commissioned through the pooled budget. The schemes are referred to as 'supported living'.

Blackpool Council currently support approximately 115 people committing around £9 million within a range of 24 hour domiciliary support services, with each person having a tenancy agreement with

a housing provider and support commissioned through the social care budget . The schemes are referred to as 'supported living'.

Unfortunately, we were unable to obtain similar data for Blackburn with Darwen.

As at August 2011 there were 81 people with learning disabilities across the county of Lancashire who were in residential placements out of area as there is no suitable housing available in the area: 20 of these were in North Lancashire, 41 in Central Lancashire and 20 in East Lancashire.

Health outcomes

People with learning disabilities are at increased risk of early death and generally have a shorter life expectancy than the general population. Estimates at quantifying this additional risk suggest the all cause mortality rate for people with learning disabilities is three times higher than the general population⁷. However, life expectancy among people with learning disabilities is gradually increasing which will likely lead to increased demand for social care and health services as people with learning disabilities will begin to outlive their parents who currently provide the bulk of informal care⁸.

Since 2009 primary care trusts have been required to fund GP practices to carry out annual health checks for adults with learning disabilities through direct enhanced service (DES). The health check includes an assessment of physical and mental health; health promotion; review of chronic illness; a physical examination; review of epilepsy; review of behaviour and mental health; a syndrome specific check; review of prescribed medications; a review of co-ordination arrangements with secondary care; and a review of transition arrangements where appropriate⁹.

Around 60% of people in Lancashire with a learning disability received a health check in 2010-11; this varied from 45% in East Lancashire and Blackburn with Darwen to 79% in North Lancashire.

People with learning disabilities are at increased risk of many health conditions compared to the general population. Common problems include:

- **Respiratory disease** - the leading cause of death for people with learning disabilities (46%-52%¹⁰) and is much higher than for the general population (15-17%).

⁷ Ibid, p.2.

⁸ Emerson, E and Hatton, C (2008)

⁹ Emerson, E et al (2011b)

¹⁰ Carter and Jancar 1983, Hollins et al 1998, Puri et al 1995

- **Gastrointestinal cancer** - people with learning disabilities have proportionally higher rates compared to the general population (48%-58.5% vs 25% of cancer deaths)¹¹.
- **Long term conditions** - up to a third of people with a learning disability also have a physical disability, most often cerebral palsy which puts them at greater risk of associated health problems. The increased prevalence of **epilepsy** ranges from 10 - 20% in people with a mild learning disability up to 50% in those with profound learning disabilities. This is compared to 1% in the general population. Epilepsy is of a more complex nature with higher levels of poly pharmacy, complex seizure types and sudden unexplained death as a result of seizures¹².
- **Anxiety and depression** - particularly common among people with Downs' syndrome.
- **Schizophrenia** - limited evidence suggests prevalence is three times higher among people with learning disabilities than the general population (3% versus 1%)¹³.
- **Challenging behaviours** - such as aggression, destruction and self-injury are present in 10-15% of people with learning disabilities. This can result from pain associated with untreated medical disorders.
- **Dementia** - prevalence is higher amongst older people with learning disabilities (22%) compared to other older adults (6%). People with Downs' syndrome have a much higher risk of developing dementia than the general population, with onset often 30 to 40 years earlier.
- **Sensory impairment** - people with a mild learning disability (aged under 50 years) have 21% prevalence of hearing impairment compared to 0.2-1.9% in the general population. The prevalence is higher in people with profound and multiple disability. People with a mild learning disability (aged under 50 years) experience 4% prevalence of visual Impairment 4 compared to 2-7% in the general population. The results of an audit of people with learning disabilities in Preston showed that a third could not verbally communicate that they are in pain. Almost half use behaviour to communicate health needs and less than a fifth had access to Speech and Language Therapy.¹⁴

¹¹ Cooke 1997, Duff et al, 2001, Jancar 1990

¹² Sillanpaa et al 1999

¹³ Doody et al 1998

¹⁴ Valuing people now: delivery plan for Central Lancashire

- **Oral health** - 36.5% of adults with learning disabilities and 80% of adults with Down's syndrome have unhealthy teeth and gums¹⁵.
- **Dysphagia** - it is estimated that 8% of adults with learning disabilities known to services nationally are affected. Difficulties eating, drinking and swallowing have implications for health including poor nutrition, asphyxia and dehydration. Approximately 40% of adults with learning disabilities and dysphagia experience recurrent respiratory tract infections.
- **Diabetes** - international studies suggested adults with learning disabilities have increased rates of diabetes compared to the general population.
- **Gastro-Oesophageal Reflux Disease (GORD)** - in international studies, nearly 50% of institutionalised people with moderate and severe learning disabilities experienced GORD. Health problems associated with GORD include pain, sleep disturbance, anaemia, problem behaviour and increased risk of oesophageal cancer.
- **Osteoporosis** - international studies have suggested that people with learning disabilities may have increased prevalence of osteoporosis and lower bone density than the general population, and are exposed to greater risk factors than other people.
- **Injuries, accidents and falls** - adults with learning disabilities experience higher rates of injuries and falls when compared to the general population.

Please see our technical document for more detailed information on the needs of adults with learning disabilities in Lancashire.

¹⁵ Barr et al 1999

Recommendations

This analysis of learning disabilities in adults in Lancashire and their health needs provides strong evidence that there continues to be a poor health experience and early mortality of people with learning disabilities and autism. These inequalities should be acknowledged and urgently addressed. To this end, a number of recommendations have been identified by the reference group for this project:

- Appoint a public health champion (and Clinical Commissioning Group lead) for learning disability and autism - clear evidence of inequalities overall that cannot be ignored.
- Undertake a comprehensive needs assessment into the health and wellbeing of children and young people with learning disabilities and special educational needs.
- Develop a learning disability addressing inequalities strategy or delivery plan for Lancashire, drawing on all the information in this assessment to inform that process. This needs to be a joint initiative with a multi-agency working group, which should be separate to the 'Valuing People Now' Board. It is suggested that this should involve the Director of Public Health and Clinical Commissioning Groups via Health and Wellbeing Board.
- Develop and agree a set of principles or a charter for all organisations to work towards to address inequalities (related to strategy above).
- Utilise the population data from children and young people services to inform anticipated growth in adult population and inform commissioning and delivery – now and future.
- Develop health promotion and early intervention activity to prevent or mitigate future health problems.
- This could be supported by obtaining data from GPs from annual health checks – as yet there has been no outcome data available from the three years of checks. A good practice guide should be developed based on the outcome data research study on Central Lancashire, East Lancashire and Blackburn with Darwen.
- There was limited availability of data relating to learning disability and autism in Lancashire. It is recommended that action be taken to address data gaps by improving coding, recording and sharing of information.

- It is recommended that there should be contractual requirements to address the identified health needs. This could be via locally enhanced services and should be pursued via the appropriate channels such as the Health and Wellbeing Boards.
- A piece of work is required to identify action to help mitigate the pressures that will be caused by the increased demand on services as the population with a learning disability increases and life expectancy increases, the complexity of the presentation also increases, and the certainty of reducing resources.
- Expand knowledge and application of asset-based approaches – co-producing services and doing more with fewer resources. One example of this could be the joint commissioning of community equipment.
- Prevalence research relating to offending behaviour of people with a learning disability is highlighting that numbers within the Criminal Justice System is low, in comparison with those in the Bradley report¹⁶, although the levels of support required are complex.

¹⁶ The Bradley Report, 2009 [online] Available at: <http://www.rcpsych.ac.uk/pdf/Bradley%20Report11.pdf>