
Learning disabilities in adults in Lancashire

Technical document

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Working in partnership with:



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Executive summary

This report is a Joint Strategic Needs Assessment (JSNA) for people with a learning disability in Lancashire. The report covers the Lancashire sub-region – the county of Lancashire plus Blackburn with Darwen and Blackpool. 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 JSNA also includes information on people in Lancashire with autism, although people with autism do not always have a learning disability and people with a learning disability do not always have autism.

This is a technical report providing an overview of people with a learning disability in Lancashire, what services they need, what is provided or available, and how we'll fill this gap. This provides the detail that was produced in developing the learning disabilities JSNA analysis.

The information in this report 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.

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 report¹, although the levels of support required are complex.

¹ The Bradley Report, 2009 [online] Available at:
<http://www.rcpsych.ac.uk/pdf/Bradley%20Report11.pdf>

Introduction

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

Scope

This is a technical report providing an overview of people with a learning disability in Lancashire, what services they need, what is provided or available, how we'll fill this gap. This provides the detail that was produced in developing the Learning disabilities JSNA analysis.

It includes a range of information, including:

- A summary of what we know about people with a learning disability in Lancashire, including how many there are and in what areas they live
- Details of the services that are provided in Lancashire for people with a learning disability and how many people use these services
- What services and support people in Lancashire with a learning disability *need*
- The report mainly focuses on adults (aged 18+) with learning disabilities, but where relevant it includes information on children and young people as well. It also covers carers of people with learning disabilities and people with learning disabilities who are carers, and their needs
- It looks at risk factors associated with learning disability, and their status in Lancashire
- The report contains our recommendations to minimise any gaps between what we provide and what people with a learning disability need, including by how much

demand for these services is likely to increase in the future, and to address health inequalities

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

The report also looks at the potential support already with communities including the strengths and skills of people who have a learning disability.

This report was originally intended to provide a full population view of learning disabilities and autism across the life course. However, the needs of children and young people with learning disabilities (and indeed the definitions) are so different that it has been decided to focus this report on adults. Data is included on the numbers of children with learning disabilities using the adult definition as this intelligence will support future commissioning. It is recommended that a full needs assessment be conducted on children and young people with learning disabilities and special educational needs.

Project Team

The information within this document has been compiled by a large range of partners, who formed a sub-regional project team to undertake the work and were supported by a larger reference group, who all provided information and identified the key issues and recommendations. The project team enables us to consider how we develop and deliver services for people with a learning disability over the area as a whole and at local council level.

However, just as importantly, there is a need to ensure we build on this evidence base through talking to people with a learning disability and considering this feedback alongside the data and statistics.

Reference Group

At the start of this project a sub-regional reference group, made up of key stakeholders and commissioners from across the Lancashire sub-region, was assembled to scope out the project. The same group was kept informed of progress throughout and came together again at the end of the project to review the findings and compile a list of priorities and recommendations for learning disability in Lancashire.

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 People²:

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.*

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.

² Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. HMSO.

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 mannerisms³."

The definition of autism used by *Fulfilling and Rewarding Lives: the Strategy for Adults with Autism in England⁴* 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).*

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 disability⁵.

³ Baird et al (2003) *Diagnosis of Autism*. BMJ; 327 , pp488-493.

⁴ 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].

⁵ 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].

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 imply⁶:

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

⁶ 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].

Method

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.

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.

Report structure

This remainder of the report is structured as follows:

- A review of national and local policy around learning disabilities and autism.
- A profile of Lancashire, Blackpool and Blackburn with Darwen including population projections.

- A profile of people in Lancashire, Blackpool and Blackburn with Darwen with learning disabilities and autism.
- A review of the needs of people with learning disabilities and autism.
- Recommendations and conclusions for Lancashire, Blackpool and Blackburn with Darwen.

Policy context

Learning Disability

A number of key documents outline the national policy on learning disability, including:

- Equality Act (2010)
- Department of Health (2001) *Valuing People: A Strategy for Learning Disability in the 21st Century*.
- Department of Health (2008) *Valuing People Now*
- Department of Health (1993; revised edition 2007) *Services for People with Learning Disability and Challenging Behaviour or Mental Health Needs* (Mansell report).
- Department of Health (2009) *Valuing Employment Now - Real Jobs for People with Learning Disabilities*.
- NHS Ombudsman (2009) *Independent Enquiry Report into 'Death by Indifference.'*
- Department of Health (2009) *Commissioning Specialist Adult Learning Disability Health Services: Good Practice Guidance*.
- Department of Health (2009) *World Class Commissioning for the Health and Wellbeing of People with Learning Disabilities*.
- Commission for Social Care Inspection; Health Care Commission and Mental Health Act Commission (2009) *Commissioning Services and Support for People with Learning Disabilities and Complex Needs: National Report of Joint Review*.
- Children's Act 2004
- Department of Health (2007) *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*
- *Think Local, Act Personal: A Sector-Wide Commitment to Moving Forward with Personalisation and Community-Based Support* (2011)
- Department of Health (2007) *Putting People First: a shared vision and commitment to the transformation of adult social care*

- Housing Options (2011) *Planning and Commissioning Housing for People with Learning Disabilities – A Tool kit for Local Authorities*
- Improving Health and Lives (2010) *Health Inequalities and People Disabilities in the UK.*
- Department of Health (2010) *Rewarding and Fulfilling Lives*
- Mansell J (2010) *Raising our Sights: services for adults with profound intellectual and multiple disabilities*
- Department of Health (1993; revised edition 2007) *Services for people with learning disability and challenging behaviour or mental health needs (Mansell report)*
- Department of Health (2011) *Staying Positive: The Criminal Justice System and Learning Disabilities: Positive Practice, Positive Outcomes: A handbook for professional in the criminal justice system working with offenders with a learning disability*
- Department of Health (2009) *Lord Bradley's review of people with mental health problems or learning disabilities in the criminal justice system*
- NHS Ombudsman Independent Enquiry report (2009) *'Death by Indifference' – '6 lives'*
- Disability Rights Commission Formal Investigation (2006)
- Mencap (2007) *'Death by Indifference'*
- Healthcare Commission reports into Cornwall, Sutton & Merton and Bromley
- Healthcare Commission Audit of Specialist NHS Services
- The 'Healthcare for All' Independent Inquiry (2009)
- Department of Health (2009) *Commissioning Specialist Adult Learning Disability Health Services: Good Practice Guidance*
- Department of Health (2009) *World class commissioning for the health and wellbeing of people with learning disabilities*

- Commission for Social Care Inspection; Health care Commission and Mental Health Act Commission (2009) *Commissioning services and support for people with learning disabilities and complex needs: National report of joint review.*
- NHS Confederation (2009) *Commissioning healthcare for people with learning disabilities*, issue 174
- Department of Health (2007) *Good practice in learning disability nursing*
- Northway R; Hutchinson C and Kingdon A (2006) *Shaping the Future: A Vision for Learning Disability Nursing*
- British Psychological Society (2011) *Commissioning Clinical Psychology services for adults with LD*
- British Psychological Society and Royal College of Psychiatry (2007) *Challenging Behaviour a Unified Approach*
- British Psychological Society and Royal College of Psychiatry (2009) *Dementia and People with Learning Disabilities : Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia*
- Department of Health (2010) *Commissioning IAPT for the whole community: Improving Access to Psychological Therapies*
- Department of Health (2009) *IAPT Learning Disabilities Positive Practice Guide*
- Deb, S & Unwin G (2006) *Guide to Using Psychotropic Medication to Manage Behaviour Problems among Adults with Intellectual Disability*

Autism

The national autism strategy, *Fulfilling and Rewarding Lives: the Strategy for Adults with Autism in England* (Department of Health, 2010) provides a clear and measurable set of commissioning objectives and actions to improve the lives of adults with autism. The national autism strategy was the outcome of the 2009 Autism Act, which was the first ever piece of legislation to address the needs of one specific impairment group and was the result of a private members bill which was sponsored by Cheryl Gillan MP.

The delivery of the national strategy at a local level is supported by statutory guidance issued by the Department of Health which applies to local authorities and NHS

organisations, including those with Foundation Trust status. The national autism strategy outlined five key objectives which form the basis of the commissioning priorities for local authorities:

- 1) Increase awareness and understanding of autism among front line staff.
- 2) Develop a clear, consistent pathway for diagnosis of autism.
- 3) Improve access for adults with autism to the services and support they need to live independently.
- 4) Help adults with autism into work.
- 5) Enable local partners to develop services for adults with autism to meet identified needs and priorities.

Because not all people with autism have a learning disability, some local authorities have established an autism services partnership board. This is the route Lancashire County Council has taken, along with its neighbouring unitary councils Blackpool and Blackburn with Darwen who have joined the Lancashire autism partnership board. A commissioning project group has been established as a subgroup of the Lancashire autism partnership board and this analysis will be used to inform the autism commissioning plan to meet these five objectives.

A profile of Lancashire

Geography

The sub-region of Lancashire, incorporating the county of Lancashire, Blackburn with Darwen and Blackpool unitary authorities is currently administered for health and local government purposes by five primary care trusts (PCTs), three upper-tier local authorities and twelve district authorities. The NHS reforms will lead to the disestablishment of the five PCTs and in their place will be Clinical Commissioning Groups (CCGs) who will have the responsibility for commissioning most NHS services. The National Commissioning Board will be responsible for commissioning primary care services and specialist services that will be commissioned on a bigger footprint. In addition, the public health responsibilities of PCTs will transfer in part to the three upper tier local authorities and to the new Public Health England. Local Health and Wellbeing Boards, which operate at the upper tier local authority level, will be used to co-ordinate the commissioning of the various organisations that can contribute to health and wellbeing. This analysis will inform the Health and Wellbeing Strategy against which all organisations will align their commissioning plans.

County councils and unitary authorities – collectively referred to as ‘upper-tier’ authorities - have responsibility for social services. Twelve district councils and six CCGs operate in the Lancashire County Council area. Blackburn with Darwen CCG and Blackpool CCG share their boundaries with Blackburn with Darwen and Blackpool unitary authorities, respectively.

The geographical area administered by Lancashire County Council, the twelve district councils and six of the CCGs is referred to as the county of Lancashire or 'Lancashire-12' (referencing the number of district councils) in this report. The Lancashire sub-region (or Lancashire-14) is used to refer to the area administered by Lancashire County Council, Blackburn with Darwen and Blackpool unitary authorities.

The table overleaf illustrates the relationships between the various levels of local government and corresponding NHS organisations in Lancashire sub-region.

Table 1 - PCT and administrative areas in Lancashire

Upper tier local authority	Lower tier local authority	PCT	CCG
Lancashire County Council	Chorley	Central Lancashire PCT	Chorley and South Ribble CCG
	South Ribble		West Lancashire CCG
	West Lancashire		Greater Preston CCG (Preston and Longridge in Ribble Valley)
	Preston		East Lancashire CCG (All five districts without Longridge in Ribble Valley)
	Ribble Valley	East Lancashire PCT	
	Burnley		
	Hyndburn		
	Pendle		
	Rossendale		
	Fylde	North Lancashire PCT	Fylde and Wyre CCG (Fylde and Wyre without Garstang)
	Wyre		Lancashire North CCG (Lancaster and Garstang in Wyre)
	Lancaster		
Blackburn with Darwen Borough Council	Blackburn with Darwen Care Trust Plus	Blackburn with Darwen CCG	
Blackpool Council	Blackpool PCT	Blackpool CCG	

Map 1 - Lancashire sub-region local authorities



Population

The sub-region of Lancashire-14 is home to more than 1.4 million people, of whom 44% are aged 45 and over, compared with 42% nationally. Lancashire is an area of contrasts: some districts have particularly young populations, such as Burnley, Hyndburn, Pendle, Rossendale and Blackburn with Darwen, where around a fifth of the population are aged under 15 years; while other districts have much older populations, for example Fylde and Wyre where almost a quarter of the population are aged 65 and over, compared to just 17% nationally.

Table 2 - resident population by age group, 2010

		Age band:					Total
		0-14	15-24	25-44	45-64	65+	
Burnley	no.	16,300	11,700	20,900	22,500	14,100	85,300
	%	19.1	13.7	24.5	26.4	16.5	100
Chorley	no.	17,700	12,100	27,700	30,100	17,700	105,400
	%	16.8	11.5	26.3	28.6	16.8	100
Fylde	no.	10,900	7,800	16,900	22,700	18,400	76,600
	%	14.2	10.2	22.1	29.6	24	100
Hyndburn	no.	16,000	10,900	20,500	20,800	12,900	81,100
	%	19.7	13.4	25.3	25.6	15.9	100
Lancaster	no.	21,900	24,800	34,400	34,800	25,300	141,100
	%	15.5	17.6	24.4	24.7	17.9	100
Pendle	no.	17,000	11,600	22,100	24,000	14,500	89,300
	%	19	13	24.7	26.9	16.2	100
Preston	no.	23,700	23,800	37,300	31,000	19,100	135,100
	%	17.5	17.6	27.6	23	14.1	100
Ribble Valley	no.	9,700	6,400	12,900	17,300	11,400	58,000
	%	16.7	11	22.2	29.8	19.7	100
Rossendale	no.	12,600	8,600	17,100	18,900	10,200	67,400
	%	18.7	12.8	25.4	28	15.1	100
South Ribble	no.	18,400	12,900	27,900	30,200	19,300	108,300
	%	17	11.9	25.8	27.9	17.8	100
West Lancashire	no.	18,900	14,800	24,700	31,200	20,600	110,300
	%	17.1	13.4	22.4	28.3	18.7	100
Wyre	no.	16,700	12,700	24,200	31,200	26,600	111,100
	%	15	11.4	21.7	28	23.9	100
Lancashire-12	no.	200,00	158,300	286,600	314,300	210,200	1,169,300
	%	17.1	13.5	24.5	26.9	18	100
Blackburn with Darwen	no.	31,900	20,300	37,100	32,600	18,100	140,000
	%	22.8	14.5	26.5	23.3	12.9	100
Blackpool	no.	24,000	18,100	33,400	37,400	27,100	140,000
	%	17.1	12.9	23.9	26.7	19.4	100
Lancashire-14	no.	255,700	196,600	357,000	384,600	255,400	1,449,300
	%	17.6	13.6	24.6	26.5	17.6	100
North West	no.	1,214,300	957,100	1,805,700	1,799,300	1,159,500	6,935,700
	%	17.5	13.8	26	25.9	16.7	100
England and Wales	no.	9,662,300	7,284,000	15,092,200	14,037,400	9,164,400	55,240,500
	%	17.5	13.2	27.3	25.4	16.6	100
Some numbers do not sum exactly due to rounding.							
Sources: Lancashire Profile, ONS: Mid-year population estimates 2010							

Projected population increase

The total population is projected to increase but at a rate below both regional and national averages. Burnley, Blackburn with Darwen and Hyndburn are projected to experience a reduction or very low rates of population growth over the period 2008-2033, highlighting the continued loss of the population which stems from the decline of the manufacturing sector as a primary employer and the failure of the housing market. Conversely, areas on the M6 corridor are predicted to experience stronger population growth, highlighting the economic

growth experienced by the districts of Chorley, Lancaster, Preston and South Ribble in recent years. The table below summarises the projected population changes for each district for to 2033.

Table 3 - Population Projections, 2008 to 2033

	Projected population (thousands of people) in:						
	2008	2013	2018	2023	2028	2033	% change 2008-2033
Burnley	86	84.8	84.3	84.1	83.8	83.7	-2.7
Chorley	104.7	107.2	110	112.8	114.9	116.5	11.3
Fylde	76.1	76.9	78.2	80	81.7	83.1	9.2
Hyndburn	81.2	81.2	81.5	82.1	82.4	82.8	2
Lancaster	139.5	143.9	147.2	150.9	155.4	158.7	13.8
Pendle	89.1	90.1	91.5	92.8	93.8	94.6	6.2
Preston	135.3	138.9	141.1	143.1	145.6	147.6	9.1
Ribble Valley	57.8	59	60.4	61.9	63.1	64	10.7
Rosendale	66.7	67.7	69	70.5	71.7	72.6	8.8
South Ribble	107.5	110	113.1	116.1	118.4	120.2	11.8
West Lancashire	110.4	111.7	113	114.3	115.4	116	5.1
Wyre	110.8	113.7	116.8	120.1	123	125.3	13.1
Lancashire - 12	1,165.10	1,185.20	1,206.20	1,228.70	1,249.20	1,265.00	8.6
Blackburn with Darwen	139.4	140.8	142.5	144.3	145.4	146.5	5.1
Blackpool	140.6	140.2	140.8	142.1	143.7	145.5	3.5
Lancashire - 14	1,445.10	1,466.10	1,489.40	1,515.10	1,538.30	1,557.10	7.8

Source: Office for National Statistics

It is expected there will be large shifts in age structure by 2033, with a higher proportion of the population in older age groups and a reduction in the proportion of the population in younger age groups. The number of people aged 80 and over is projected to more than double over the period from 67,400 to 136,800.

Figure 1 - Population Pyramids, Lancashire (14 Authorities), 2008-2033



Table 4 - Population projections by age group (000s), Lancashire 14, 2008 to 2033

	2008	2013	2018	2023	2028	2033	% growth 2008 – 2018	% growth 2008 – 2033
0-4	85.4	87.9	86.9	86.2	84	82.8	1.8%	-3.0%
5-9	81.2	86.7	89.4	88.6	88.1	85.9	10.1%	5.8%
10-14	90.5	82.2	88.2	91	90.3	89.9	-2.5%	-0.7%
15-19	99.9	91.8	83.4	89.7	92.9	92.4	-16.5%	-7.5%
20-24	97.4	98	89.8	82.4	89.1	92.4	-7.8%	-5.1%
25-29	81.8	94.3	94.7	87.2	80.4	87	15.8%	6.4%
30-34	76.6	82.2	95	95.7	88.2	81.5	24.0%	6.4%
35-39	99.3	77.6	83.7	96.8	97.7	90.1	-15.7%	-9.3%
40-44	108.2	100.1	78.7	85.2	98.5	99.6	-27.3%	-7.9%
45-49	103.7	108.2	100	79	85.8	99.3	-3.6%	-4.2%
50-54	92.1	102.9	107.7	99.7	79	86	16.9%	-6.6%
55-59	90.2	90.3	101.1	106.3	98.4	78.3	12.1%	-13.2%
60-64	91.7	87	87.3	98.2	103.4	96	-4.8%	4.7%
65-69	70.3	86.6	82.5	83.3	94	99.4	17.4%	41.4%
70-74	60.8	64.4	80	76.9	77.9	88.5	31.6%	45.6%
75-79	49.1	52.7	57	71.6	69.3	70.7	16.1%	44.0%
80-84	35.7	38.2	43.1	47.6	60.7	59.2	20.7%	65.8%
85-89	22.2	22.8	26.2	31.4	35.9	46.7	18.0%	110.4%
90+	9.5	12.2	14.4	18.3	24.5	30.9	51.6%	225.3%
All ages	1445.1	1466.1	1489.5	1515.1	1538.3	1557	3.1%	7.7%

Source [Office for National Statistics](#); June 2010

Deprivation

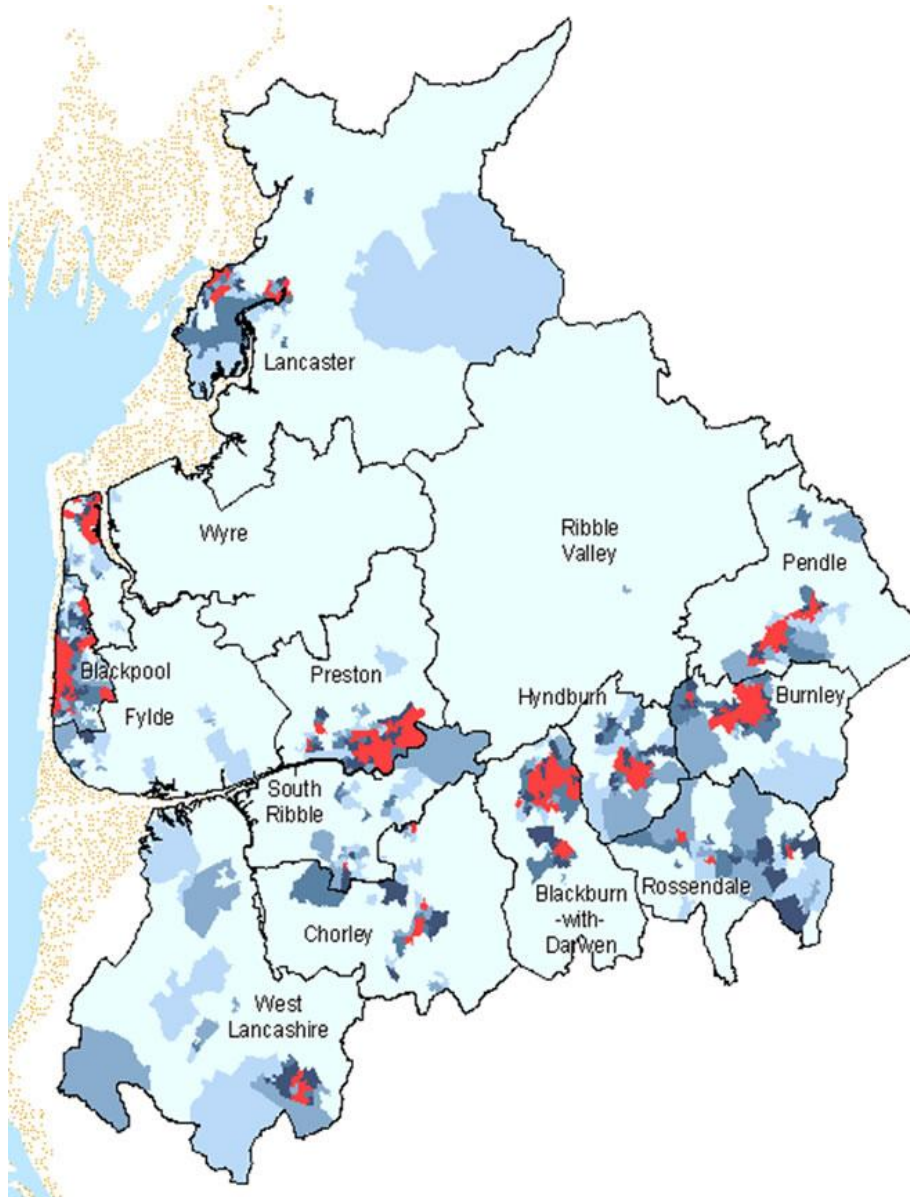
Lancashire has some of the most deprived parts of the country within its boundaries.

Blackpool, Burnley, Blackburn with Darwen, Hyndburn, Preston and Pendle are ranked as

being in the most deprived 50 local authorities nationally according to the 2010 Index of Multiple Deprivation (IMD).

The map below shows the national percentile ranking for the English Indices of Deprivation 2010 by lower level super output area (LSOA), where the red areas indicate the most deprived LSOAs. An LSOA is a statistical area and is made up of approximately 1,500 households, who should have similar demographics. The highest concentrations of LSOAs in the most deprived decile for this domain are found in Blackburn with Darwen (29 LSOAs), Blackpool (22), Burnley (18), Pendle (13) and Hyndburn (12).

Map 2 – Index of Multiple Deprivation in Lancashire, 2010



Source: Lancashire Profile; 2011

Ethnicity

Lancashire is less ethnically diverse than England overall. Higher ethnic diversity is found in the east Lancashire districts Pendle, Preston and Blackburn with Darwen. Conversely, there are 8 districts where more than 90% of the population are White British.

Table 5 - Population estimates by ethnic group, 2009

	Total number of people (1000s)	Percentage of total number of people in ethnic group:															
		White			Mixed				Asian or Asian British				Black or Black British			Chinese or Other	
		British	Irish	Other White	White and Black Caribbean	White and Black African	White and Asian	Other Mixed	Indian	Pakistani	Bangladeshi	Other Asian	Black Caribbean	Black African	Other Black	Chinese	Other
Burnley	85.6	86.6	0.9	1.4	0.3	0.1	0.5	0.2	0.9	6	1.6	0.6	0.2	0.4	0	0.2	0.2
Chorley	104.8	93.6	0.7	1.3	0.4	0.1	0.3	0.2	1	0.8	0.1	0.2	0.3	0.3	0.1	0.4	0.2
Fylde	76.3	92.6	0.8	2.3	0.3	0.1	0.3	0.2	1.2	0.8	0.1	0.2	0.2	0.3	0.1	0.3	0.3
Hyndburn	81.1	86.4	0.8	1.3	0.3	0.1	0.5	0.2	1.8	7	0.5	0.4	0.1	0.2	0	0.2	0.2
Lancaster	139.8	90.7	0.8	2.4	0.4	0.2	0.3	0.3	1.1	0.9	0.2	0.2	0.3	0.5	0.1	0.8	0.9
Pendle	89.3	81.4	0.6	1.1	0.2	0.1	0.6	0.2	1.1	12.3	0.9	0.4	0.2	0.3	0	0.2	0.2
Preston	134.6	81.6	0.9	1.9	0.8	0.2	0.5	0.3	6.8	3.1	0.6	0.6	0.6	0.5	0.1	0.9	0.7
Ribble Valley	57.7	91.8	0.7	1.8	0.2	0.1	0.3	0.2	1.4	1.9	0.2	0.3	0.2	0.3	0	0.3	0.3
Rosendale	67.1	90.6	1	1.3	0.3	0.1	0.3	0.2	1.3	2.2	1.4	0.4	0.2	0.3	0	0.3	0.2
South Ribble	108.2	93.2	0.8	1.2	0.4	0.1	0.4	0.2	1.7	0.6	0.1	0.2	0.2	0.2	0	0.4	0.3
West Lancs	110.2	94.9	0.6	1.4	0.3	0.1	0.3	0.2	0.6	0.4	0.1	0.2	0.1	0.3	0	0.3	0.2
Wyre	111.1	93.2	0.7	2	0.3	0.1	0.3	0.2	0.9	1	0.2	0.2	0.2	0.2	0	0.3	0.3
Lancs 12	1,165.80	89.6	0.8	1.7	0.4	0.1	0.4	0.2	1.8	2.9	0.5	0.3	0.2	0.3	0.1	0.4	0.4
Blackburn with Darwen	139.9	74.6	0.8	1.5	0.3	0.2	0.6	0.3	9.2	8.9	0.9	1	0.3	0.6	0.1	0.6	0.3
Blackpool	140	92.2	0.9	2.4	0.3	0.1	0.3	0.2	1	0.8	0.2	0.2	0.3	0.4	0.1	0.3	0.3
Lancs 14	1,445.70	88.4	0.8	1.7	0.3	0.1	0.4	0.2	2.4	3.2	0.5	0.4	0.2	0.4	0.1	0.4	0.4
North West	6,897.9	88.4	1	2.2	0.4	0.2	0.4	0.3	1.6	2.1	0.6	0.4	0.4	0.6	0.1	0.6	0.5
England	41,809.70	82.8	1.1	3.6	0.6	0.2	0.6	0.5	2.7	1.9	0.7	0.7	1.2	1.5	0.2	0.8	0.8

Sources: Lancashire Profile, ONS Population Estimates by Ethnic Group

A profile of people with Learning Disabilities and Autism in Lancashire

Estimated Prevalence

Learning Disability

The *Improving Health and Lives* learning disabilities observatory estimates that approximately 2% of the population have a learning disability, including mild, moderate and severe learning disabilities (Emerson & Hatton, 2004, p. 4).

The table below provides an estimate of the number of adults aged 18 and over with a learning disability by age band across Lancashire using the based on the estimated 2% prevalence and 2012 population estimates. It is estimated that there are over 27,000 adults aged 18 and over across Lancashire with a learning disability.

Table 6: Estimated number of adults aged 18 and over with a learning disability by age, 2012

Area	People aged 18-64 predicted to have a learning disability									Total pop (all ages)
	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total	
Burnley	219	261	255	277	233	168	94	42	1,549	85,700
Chorley	219	326	373	379	317	245	114	42	2,015	107,700
Fylde	133	189	228	279	245	213	131	55	1,473	77,700
Hyndburn	198	254	262	263	218	157	86	34	1,472	82,100
Lancaster	578	471	414	442	369	299	178	72	2,822	146,200
Pendle	219	291	277	293	263	176	98	38	1,656	91,300
Preston	544	543	424	409	320	225	138	44	2,646	139,700
Ribble Valley	106	125	191	221	179	146	80	27	1,074	58,700
Rosendale	155	197	230	242	199	133	66	27	1,248	68,600
South Ribble	236	334	368	384	313	247	134	45	2,060	110,600
West Lancashire	301	296	329	386	333	267	144	45	2,101	112,700
Wyre	222	274	311	382	344	313	193	70	2,110	112,200
Lancashire-12	3,139	3,558	3,668	3,958	3,334	2,591	1,459	542	22,249	1,193,200
Blackburn with Darwen	396	483	466	432	331	222	122	44	2,495	143,200
Blackpool	347	418	431	484	387	317	186	70	2,641	142,300
Lancashire-14	3,882	4,459	4,565	4,874	4,052	3,130	1,767	656	27,385	1,478,700

Source: PANSI and POPPI; ONS Sub-national population projections (2012); Emerson & Hatton (2004)

Autism

Various studies estimate the prevalence of autism among the general population to be between 0.9% and 1.1% (NHS Information Centre Community and Mental Health Team, 2012, p. 18). A prevalence rate of 1% is assumed in estimating the number of people with autism in the population, based on the estimates provided by PANSI (2012). However, it should be noted that there are wide confidence intervals associated with this estimate (95% confidence intervals are 0.3% - 1.9%). These estimates should only be treated as indicative. It is estimated that there are approximately 9,000 adults aged 18-64 across the Lancashire sub-region with autism.

Table 7: Estimated number of adults aged 18-64 with autism by age, 2012

Area	People aged 18-64 predicted to have autistic spectrum disorders						Total pop (all ages)
	18-24	25-34	35-44	45-54	55-64	Total for ages 18-64	
Burnley	82	104	101	115	102	504	85,700
Chorley	87	138	154	165	140	684	107,700
Fylde	51	83	92	120	108	454	77,700
Hyndburn	76	104	108	114	96	498	82,100
Lancaster	211	192	168	188	159	918	146,200
Pendle	82	118	114	124	118	556	91,300
Preston	200	229	177	178	142	926	139,700
Ribble Valley	40	50	75	96	80	340	58,700
Rossendale	58	77	93	106	86	419	68,600
South Ribble	89	135	149	163	137	673	110,600
West Lancashire	109	120	127	163	141	660	112,700
Wyre	87	115	123	163	147	635	112,200
Lancashire-12	1,169	1,464	1,477	1,689	1,454	7253	1,193,200
Blackburn with Darwen	151	197	192	182	146	868	143,200
Blackpool	131	173	174	208	172	858	142,300
Lancashire-14	1,451	1,834	1,843	2,079	1,772	8979	1,478,700

Source: PANSI; ONS Sub-national population projections (2012); Health and Social Care Information Centre (2009)

Projected Prevalence

With increased numbers of people with learning disabilities will most likely come increases in the need for social care and health services. Emerson and Hatton suggest we should expect "sustained growth in the need for social care services for adults with learning disabilities over the period 2009-2026. Average estimated *annual* increases varied from 1.04%... to 7.94% (2008, p. iii). This would equate to between 31,400 and 53,400 people with learning disabilities requiring support from services by 2018 (based on table above). These estimates assume a range of scenarios, including the provision of care services to people with critical, substantial and moderate needs or just those with critical and substantial needs (as defined in Department of Health, 2003 and 2010).

Learning Disabilities

By 2018 it is estimated that the population with learning disabilities in Lancashire will have grown to 29,800. This is based on the assumption that the percentage of people with learning disabilities in the population will remain unchanged at approximately 2%.

Table 8: Projected number of people with learning disabilities in 2018

District	Projected population (2018)	Nos. of people with learning disability
Burnley	84,300	1,686
Chorley	110,000	2,200
Fylde	78,200	1,564
Hyndburn	81,500	1,630
Lancaster	147,200	2,944
Pendle	91,500	1,830
Preston	141,100	2,822
Ribble Valley	60,400	1,208
Rossendale	69,000	1,380
South Ribble	113,100	2,262
West Lancashire	113,000	2,260
Wyre	116,800	2,336
Lancashire - 12	1,206,200	24,124
Blackburn with Darwen	142,500	2,850
Blackpool	140,800	2,816
Lancashire - 14	1,489,400	29,788

Source: Office for National Statistics; Table 3; Improving Health and Lives

Profound and Multiple Learning Disabilities

Table 9 shows the projected number of people by district with profound and multiple learning disabilities (PMLD) to 2020. Increased are expected in all districts over the next decade. Due to advances in medicine people are living longer with profound and multiple learning disabilities.

Table 9: Projected number of people with profound and multiple learning disabilities to 2020

Area	Estimate of people with PMLD									
	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
Burnley	27	28	28	29	29	30	30	31	31	32
Chorley	33	34	35	35	36	37	37	38	39	39
Fylde	24	24	25	25	25	26	26	27	27	28
Hyndburn	25	26	26	27	27	28	28	29	29	30
Lancaster	43	44	45	46	46	47	48	49	50	51
Pendle	28	28	29	29	30	31	31	32	32	33
Preston	44	45	45	46	47	48	49	50	50	51
Ribble Valley	18	18	18	19	19	19	20	20	21	21
Rossendale	21	22	22	22	23	23	24	24	24	25
South Ribble	34	35	35	36	37	37	38	39	39	40
West Lancashire	35	35	36	36	37	38	38	39	40	41
Wyre	34	34	35	35	36	37	37	38	39	39
Lancashire 12 districts	365	372	379	386	392	400	407	414	422	429
Blackburn with Darwen UA	46	47	48	49	49	50	51	52	53	54
Blackpool UA	44	45	46	47	48	48	49	50	51	52
Lancashire 14 authorities	456	464	472	481	490	498	507	516	526	535

Source: DH 2009 (Emerson E. e., 2009) and ONS (2011 Census).
Based on estimate of 78 per 250,000 population with a 1.8% annual increase.

Children and young people with learning disabilities

The data provided in this section treats children and young people as those of school age (4 – 18) unless otherwise indicated. The data in this section is based on the children living in Lancashire – not necessarily those attending school in Lancashire – although this is likely to be a small discrepancy. The figures here are not intended to provide a true picture of the level of learning disabilities, learning difficulties and special educational needs. The numbers here represent people who would be considered to have a learning disability

Year group

The following table summarises the number of children and young people with School Action or School Action Plus by year group with: autistic spectrum disorder (ASD); moderate learning difficulty (MLD); profound and multiple learning difficulty (PMLD); and severe learning difficulty (SLD).

Table 9: Number of children and young people aged 4 – 19 by year group with a learning disability, Lancashire 12

Year Group	ASD	MLD	PMLD	SLD	Totals
Early Years & Reception	94	65	36	62	257

Yr 1 - 6	578	2048	105	267	2,998
Yr 7 - 11	595	1592	69	197	2,453
Yr 12 - 14	76	92	31	112	311
Total	1,343	3,797	241	638	6,019

Source: January 2011 school census.
children and young people with School Action or School Action Plus by year group with: autistic spectrum disorder (ASD); moderate learning difficulty (MLD); profound and multiple learning difficulty (PMLD); and severe learning difficulty (SLD)

Table 9a: Number of children and young people aged 4 – 19 by year group with a learning disability, Blackburn with Darwen

Year Group	ASD	MLD	PMLD	SLD	Totals
Early Years & Reception	10	12	3	1	26
Yr 1 - 6	35	203	6	7	251
Yr 7 - 11	12	180	-	3	195
Yr 12 - 14	-	2	-	-	2
Total	57	397	9	11	474

Source: January 2011 school census.
children and young people with School Action or School Action Plus by year group with: autistic spectrum disorder (ASD); moderate learning difficulty (MLD); profound and multiple learning difficulty (PMLD); and severe learning difficulty (SLD)

Table 9b: Number of children and young people aged 4 – 19 by year group with a learning disability, Blackpool

Year Group	ASD	MLD	PMLD	SLD	Totals
Early Years & Reception	9	20	2	15	46
Yr 1 - 6	66	359	7	34	466
Yr 7 - 11	57	302	12	43	414
Yr 12 - 14	13	18	1	13	45
Total	145	699	22	105	971

Source: January 2011 school census.
children and young people with School Action or School Action Plus by year group with: autistic spectrum disorder (ASD); moderate learning difficulty (MLD); profound and multiple learning difficulty (PMLD); and severe learning difficulty (SLD)

Data for children and young people with learning disabilities younger than the age of 4 years is not generally available because a learning disability will not typically be apparent until the child is older, unless it is severe (Emerson E. e., 2011, p. 3), and this can be seen by the relatively low numbers of children at this age observed with a learning disability or autism.

It is likely that the sudden decrease in numbers of young people with a learning disability from year 11 (ages 15-16) to year 12 (ages 16-17) in the preceding tables is due to these young people not continuing into further education, rather than an actual decrease in the prevalence of learning disability or ASD at this age.

Geography

The table below shows the number of children and young people with statements, school action or school action plus by district:

Table 10: Number of children and young people aged 4-19 by district with a learning disability in Lancashire

District	Statements					School Action & Action Plus				
	ASD	MLD	PMLD	SLD	Total	ASD	MLD	PMLD	SLD	Total
Burnley	65	115	9	42	231	111	457	20	59	647
Chorley	100	94	1	54	249	118	323	28	46	515
Fylde	59	34	4	49	146	66	116	8	44	234
Hyndburn	69	138	13	42	262	76	444	26	20	566
Lancaster	168	135	20	92	415	203	362	26	101	692
Pendle	61	127	13	56	257	106	441	25	55	627
Preston	138	167	4	82	391	132	482	34	86	734
Ribble Valley	18	19	4	9	50	45	102	10	11	168
Rossendale	70	76	7	26	179	82	232	16	22	352
South Ribble	136	88	4	56	284	160	261	25	44	490
West Lancs	153	95	3	61	312	144	314	15	68	541
Wyre	84	70	1	77	232	100	262	8	82	452
Not Known	3	9	0	2	14	0	1	0	0	1
Total (Lancs-12)	1124	1167	83	648	3022	1343	3797	241	638	6019
Blackburn with Darwen	62	100	44	66	272	57	397	9	11	474
Blackpool	*	*	*	*	*	145	699	22	105	971
Total (Lancs-14)						1545	4893	272	754	7464

Source: January 2011 school census
 children and young people with School Action or School Action Plus by year group with: autistic spectrum disorder (ASD); moderate learning difficulty (MLD); profound and multiple learning difficulty (PMLD); and severe learning difficulty (SLD)
 *Data not available/obtainable

Autism

It is estimated that by 2018 there will be 14,900 people aged 18 to 64 with autism in Lancashire, based on a continued 1% prevalence.

Table 11: Projected number of adults aged 18 to 64 with autism in 2018

District	Projected population (2018)	Estimated number of people with autism
Burnley	84,300	843
Chorley	110,000	1,100
Fylde	78,200	782
Hyndburn	81,500	815
Lancaster	147,200	1,472
Pendle	91,500	915
Preston	141,100	1,411
Ribble Valley	60,400	604
Rossendale	69,000	690
South Ribble	113,100	1,131

Learning disabilities in adults in Lancashire

West Lancashire	113,000	1,130
Wyre	116,800	11,68
Lancashire - 12	1,206,200	12,062
Blackburn with Darwen	142,500	1,425
Blackpool	140,800	1,408
Lancashire - 14	1,489,400	14,894
Source: Office for National Statistics; Table 3; PANSI.org.uk		

Needs of people with Learning Disabilities and Autism

For this report, the needs and support received by people with learning disabilities and autism have been broadly grouped into two categories: social support needs and health needs. Social support needs include, for example, help with day-to-day living, accommodation, income and social needs. Health needs relate specifically to the poorer health outcomes experienced by people with learning disabilities and autism and the additional health care they require to address this health inequality.

Social support needs

Relationships and social capital

Good relationships and social capital are important to an individual's mental health and wellbeing and physical health⁷. There is evidence of the need to support people with learning disabilities to form and maintain relationships.

There is evidence that people with learning disabilities do not enjoy social relationships equal to people who do not have a learning disability, so supporting people with learning disabilities to form and maintain good relationships will significantly improve their health outcomes.

Employment

The table below shows the number of adults with a learning disability in employment in the Lancashire County area.

Table 12: Percentage of adults with a learning disability in employment

	Percentage in part-time employment	Percentage in full-time employment	Percentage in employment
Blackburn with Darwen	*	*	*
Blackpool	4.6%	*	4.6%
Central Lancashire	6%	8.4%	14.4%
East Lancashire	2.3%	3.1%	5.4%
North Lancashire	2.9%	3.3%	11.3% ⁸
Source: Central, East and North Lancashire Learning Disability Partnership Board annual reports 2011			
*Data not available/obtainable			

All areas have an employment strategy for people with learning disabilities in line with Valuing People Now: Real Jobs for People with Learning Disabilities.

⁷ Umberson, D and Montez, J (2010) 'Social Relationships and Health: A Flashpoint for Health Policy' in Journal of Health and Social Behaviour, vol. 51, no. 1. Available online: http://hsb.sagepub.com/content/51/1_suppl/S54.full [accessed April 2012].

⁸ Includes 65 people with learning disabilities in voluntary placements.

Similar 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.

The table below shows the total local authority spend in the county of Lancashire on supported employment for adults with a learning disability:

Table 13: Local authority spend on support employment for adults with a learning disability

Area	Budget for Supported Employment
Blackburn with Darwen	*
Blackpool	£117,000
Central Lancashire	£77,007
East Lancashire	£189,037
North Lancashire	£107,781
Source: Central, East and North Lancashire Learning Disability Partnership Board annual reports 2011	
*Data not available/obtainable	

Fylde Community Link has set up its own recycling and gardening projects based in the local community. The groups operate on charitable donations and income from what they sell on. The recycling team won prizes at the Lancashire Red Rose Recycling Network Awards, where they achieved Best Newcomer Award 2008 and Best Voluntary Community Project Award 2009. Both groups are self sufficient, and give adults with learning disabilities the opportunity to learn new skills, gain work experience, develop friendships and feel valued.

Vedas' TEAM (Together Everyone Achieves More) project operates in East Lancashire aims to improve the employability and motivation to work of people with a Learning Disability. As well as giving people new knowledge and skills to compete in the labour market, the project also matches their new skills to an employer's needs.

The course includes series of Neuro Linguistic Programming workshops (NLP is the practice of understanding how people organise their thinking, feeling, language and behaviour to produce the results they do.) This plays a large part in transforming the experience of jobseekers that have had little or no paid work experience. The emphasis is on positive mindset, regularly reinforced through discussion and exercises. It uses techniques that provide help to rebuild the client's self-belief, showing how behaviour can affect the results they obtain. These self-development sessions are combined with individual life coaching sessions, if required.

The programme provides work experience placements for individuals and supports them to look for paid employment.

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 week⁹).

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.

Mosaic¹⁰ analysis of data from the 2012 school census suggest that types 44, 69 and 42¹¹ are the top three groups that have higher than expected numbers of people with a learning disability or autism, suggesting a link between the prevalence of learning disabilities and autism and deprivation. This might be because people with learning disabilities are excluded from opportunities such as higher income employment and therefore can only afford housing in more deprived areas with cheaper, and usually poorer quality, housing.

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

⁹ Lancashire Profile: <http://www.lancashire.gov.uk/corporate/web/?siteid=6236&pageid=36487&e=e>

¹⁰ Mosaic is a tool used by the public sector to provide a demographic profile of the population.

¹¹ Mosaic type definitions: low income families occupying poor quality older terraces (44); vulnerable young parents needing substantial state support (69); and south-Asian communities experiencing social deprivation (42).

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.

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.

Housing

Much has happened since the publication of *A Model District Service* (1983) almost 30 years ago, the long stay institutions have been closed and people who lived in them moved to ordinary housing mostly in the areas that they originally lived in. New services have developed to provide for people who at one time would have gone to live away from home in a large institution. Many of the principles identified are valid and inform service design today. However within such a positive picture there were and continue to be some problems:

- Some learning disabled people complained about a lack of control over what happened in their homes
- Limited or no choice regarding co tenants
- Lack of involvement in domestic tasks and routines
- Staff controlled their money
- A lack of day time support opportunities.
- Overreliance on formal support

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'

The schemes and model sprung from the resettlement of people from long stay hospitals. This has been the traditional model of support for many people with a learning disability not just in the county of Lancashire, but right across the country. It is acknowledged that the model enabled many people living in institutional care achieve better lives. However the model has limitations particularly in light self directed support.

There are very few alternatives for people who may need to move or choose to move when their individual service is reviewed.

The model also is based on the premise of traditional contracting arrangements, there may be some local differences; however it is still on the premise that a set number of people are required to live under the same roof to share support. In Lancashire we work with:

- Private landlords (approximately 10%)
- Registered social landlords (75%)
- Non-registered social landlords (15%, although this figure is reducing)
- Owner/Occupiers (< 1%)

In 2010 agreement was reached between the Leaders of Lancashire County Council and the twelve district councils within the county boundaries on a number of issues in relation to Supported Living Schemes for people with learning disability. The commitments were:

- To work with each district partner to map existing schemes to ensure there is a full baseline of activity and share potential future need and associated cost for 12-18 month timeframe.
- To work with Strategic Housing Officers in each district to ensure that the needs of vulnerable adults who may require specialist supported living arrangements are included within current locality focus groups within North, East and Central Lancashire.
- All new proposals for specialist housing schemes will be fully discussed with local Housing Benefit Managers to ensure a joint and collaborative approach to meeting needs. This will cross reference with meetings when predictions will be shared and an agreement that any changes will be updated on a quarterly

- To commission with registered social landlords and other preferred housing providers (as advised by the district councils) unless there are agreed extenuating circumstances that would place citizens at risk or challenge respective organisations duty of care.
- To work collaboratively through the regular meetings and strategic planning
- Strategic planning and future predictions would be formalised with meetings of the Strategic Housing, Housing Benefit Managers and ACS Commissioning Team. Medium term communication and engagement would take place on a quarterly basis and in the event of a short term crisis; officers would engage the appropriate district partners immediately they were aware of the situation.
- Lancashire County Council commissioning team will work with other colleagues to ensure that individual citizens with specialist housing needs register those needs with the appropriate district partner and also gave a commitment to explore other models of specialist housing such as, medium to small extra care schemes that would enable people to enjoy the benefits of having an assured tenancy whilst maintaining within a reasonable rent level.

However, there are a number of risks to the model:

- Likely increase in health issues.
- Issues about the suitability of existing accommodation for an older population.
- Personal budgets being spent on shared supports, for example sleep-ins or background support, and not on individual support plans.
- 100% of personal budget spent with one provider.
- High number of support voids in existing schemes.
- High number of safeguarding issues in supported living settings.
- Lack of choice of accommodation.
- Over reliance on formal support.
- Limited use of assistive technology.

- People's needs change and can become more complex.

The Valuing People Now outcomes remain key priorities and key indicators for measuring our progress. We are developing a plan to:

- Support the wider use of self directed supports, managing the challenges involved when pooling resources.
- Creating a wider range of accommodation and support options to improve opportunities for tenants to move on and choose alternative housing and support options.
- Extending the range of accommodation and support options is intended to minimise the individual safeguarding issues created by tenant compatibility where people share a household.
- The current accommodation and support options can create dependencies and over support as people have been offered what is available.
- Develop the information available in the Joint Strategic Needs Assessment and available on the JSNA web platform to inform the commissioning cycle.

The table below shows the percentage of overall learning disability social care spend by Lancashire County Council allocated to residential and nursing home placements.

Table 14: Percentage of overall learning disability social care spend allocated to residential and nursing home placements, Lancashire county

	2009/10	2010/11	2011/12 (projected)
Blackburn with Darwen	*	*	*
Blackpool	16.3%	15.6%	16.7%
Central Lancashire	11.9%	12.8%	14.5%
East Lancashire	15.1%	15.1%	16.5%
North Lancashire	16%	16%	14%
Source: Central, East and North Lancashire Learning Disability Partnership Board annual reports 2011			
*Data not available/obtainable			

The following table shows the estimated number of people with learning disability with a housing need in the county of Lancashire. It should be noted that the methodology used to determine these estimates has been controversial, so are intended as indicative only.

Table 15: Estimated number of people with a learning disability with a housing need, in Lancashire

District	Number of people with a learning disability with a housing need
Burnley	134
Chorley	167
Fylde	113
Hyndburn	126
Lancaster	241
Pendle	139
Preston	215
Ribble Valley	90
Rossendale	105
South Ribble	167
West Lancashire	164
Wyre	164
Lancashire 12 total	1,825
Blackburn with Darwen	*
Blackpool	*
Lancashire-14 total	
Source: 4NW Regional Supported Housing Needs Analysis 2009	
*Data not available/obtainable	

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.

A toolkit for assessing the housing needs of people with a learning disability is summarised in The Housing and Support Partnership (2011) *Housing Options: Planning and Commissioning Housing for People with Learning Disabilities, A Tool Kit for Local Authorities*.

Valuing People Now sets an objective that all people with learning disabilities and their families have the opportunity to make an informed choice about where, and with whom, they live. The following extract is taken from the Valuing People Now report:

Many people with learning disabilities – unlike the rest of the population – do not choose where they live or with whom. More than half live with their families, and most of the remainder live in residential care. Whilst undoubtedly both these options suit some people, many others are denied the opportunities and choices that are theirs by right. Residential care should continue to be available for those who actively choose it, but more emphasis needs to be placed on alternative ways of providing the housing that people want, and the support they need to live in it.

Table 16: Housing of people with learning disabilities compared to the general population

People with learning disabilities	General population
50–55% live in the family home 30% live in residential care 15% rent their own home	70% own their own home 29% rent their own home

People with learning disabilities and their families need to consider how to match their aspirations, both in the long and short terms, with the different sorts of housing and support that can be made available. At the same time, those who plan and commission services should consider how they could develop creative solutions to meeting those aspirations. Possibilities include people with learning disabilities being supported to live in their own home as owners or tenants; being supported to share with a group of friends; or living in residential care.

Home ownership and assured tenancies have to be matched and coordinated with a package of care specifically designed to support the particular individual in the home of their choice. Independent supported living can be enjoyed by people with very high or complex needs as well as those with fewer needs, because the support is tailored to their particular requirements. This was identified in the evaluation of dh’s extra care housing pilot programme for people with learning disabilities, *A Measure of Success* (CSip, 2008)

Housing related support, through the Supporting people programme, already helps many people with learning disabilities to live in their own home through the provision of housing related support services. People with learning disabilities will continue to benefit from locally planned and delivered housing related support to help individuals live as independently as possible. The Supporting people outcomes set is a measurement tool designed to test the effectiveness of housing related support services.

Making it happen locally and regionally – key recommended actions

- Joint Strategic needs assessments to identify the housing needs of people with learning disabilities to inform strategic planning, including the number of people with learning disabilities living with family carers over 70 and those with complex needs.
- Local authorities to facilitate people’s access to housing of their choice including: more people receiving personal budgets and direct payments to increase their choice and control over where they live and with whom;
- Local authority care managers to have an increased focus on home ownership and assured tenancies as a model for housing and support; and

- Through person centred planning, work with people still living with families to establish if that is the person's preferred option and to instigate plans accordingly.
- All local authorities are already required to produce a housing strategy reflecting local population housing needs, including those of people with learning disabilities. government offices to ensure that all local authorities have an appropriate housing strategy.
- Wherever possible, transition plans and year 9 reviews to address future accommodation choices.

Case study

The Shared Lives Service offers people aged 18+ (currently people with a learning disability and older adults) the opportunity to live an ordinary life as part of the Shared Lives Placement Carers family. This can be on a long term, short term or respite basis, but the principle of 'normal life' remains the same, and is highly flexible to meet the needs of the individual within the carers own home. The matching of needs and interests between individuals and carer households is crucial in establishing a placement.

Carers are assessed and trained by the Shared Lives Placement Service which is registered with the Care Quality Commission (CQC). They are able to offer services within the remit of the Scheme registration, to persons with a Disability. The quality of the service offered is monitored and compared with the National Minimum Standards introduced by the Government.

Hate crime and discrimination

The number of incidents of hate crime against people with a learning disability is not known as incidents are coded as a general disability. For the year 2010/11, 53 incidents of hate crime and a further 35 hate incidents were recorded¹². However, it is not known how many of these refer specifically to learning disability, and it is believed these figures are under-reported and the actual incidence is much higher.

Accurate recording of hate crime and hate incidents for learning disability separately is a priority.

¹² Lancashire Constabulary: <http://www.lancashire.police.uk/about-us/corporate-information/equality-act-data-publication/protecting-people>

Hate crime case study

The Lancashire Against Hate Crime Action Plan has been developed with a keen group of 10 self advocates who have a learning disability working with professionals to combat Hate Crime. Initiatives include information workshops for self advocates on staying safe in your community, explaining how to report hate crime and taking part in the Lancashire Against Hate video and national campaign. We are also developing work with schools and colleges raising awareness of what hate crime is and how it affects people.

Comments from adults with a learning disability involved in the project include Jane saying that she wanted to help people with something that she found interesting and Julie who said she wanted to help people have a better understanding of what hate crime is.

Julie said she feels better knowing more about Hate crime and if others were subjected to hate crime she said she would help them.

Jane said, "hate crime is people picking on you and calling you names" and that she would now know to report it. Jane was asked her if she would now be able to help others too and Jane said, "I would talk to others and support them to report hate crime at a local police station."

People with learning disabilities committing crimes

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%).

The table below shows the number of offenders who have a learning disability. A score of 2 means the offender is considered to have a severe learning disability, and may have a statement of educational needs; a score of 1 means the offender is considered to have mild

learning disabilities; and a score of 0 + N/A means there is no evidence the offender has a learning disability.

Table 17: Number of offenders with a learning disability

District	0 + NA	1	2	Total	% Severe
Burnley	307	20	18	345	5%
Chorley	170	16	6	192	3%
Fylde	129	3	3	135	2%
Hyndburn	278	16	7	301	2%
Lancaster	290	22	24	336	7%
Pendle	216	9	4	229	2%
Preston	418	36	14	468	3%
Ribble Valley	50	5	5	60	8%
Rossendale	102	4	6	112	5%
South Ribble	175	8	3	186	2%
West Lancashire	160	15	14	189	7%
Wyre	205	14	7	226	3%
Lancashire-12	2500	168	111	2779	4%
Blackburn	587	31	27	645	4%
Blackpool	683	61	32	776	4%
Lancashire-14	3770	260	170	4200	4%

Source: OASys 2012

Ten percent of offenders have significant problems reading, 12% have significant problems writing, and 8% have significant numeracy skill problems. From the sample of offenders, reading was a particular issue in the districts of Blackburn, Hyndburn, Lancaster and Ribble Valley with 13% of offenders having problems reading. Poor writing skills is a significant issue among offenders in the districts of Burnley, Hyndburn, Lancaster and Ribble Valley, with 15% of offenders showing problems writing. In Hyndburn (11%) and Lancaster and Burnley (10%) offenders had problems with numeracy skills.

Managing arrangements through which offenders can access learning and employment opportunities remains a key priority for Lancashire Probation Trust. The European Social Fund (ESF) programme 'Achieve' aims to remove the barriers for those offenders furthest away from the job market and offers practical advice and assistance around issues such as childcare, disclosure and preparation for interviews. Close working relationships with Lancashire Adult Learning and Blackpool and Fylde College has improved the offer for offenders in approved premises and undertaking unpaid work. Offenders on unpaid work are also able to benefit from an accredited health and safety programme, including the delivery of Ascentis, Edexcel and British Safety Council accredited units.

Offenders in approved premises undertake a structured regime of learning activities to address offending pathways and increase their opportunities for successful resettlement. Literacy, numeracy, skills for self employment, increasing self esteem, interview skills, jobsearch and gardening are some examples of the provision available via Lancashire Adult Learning.

All offenders have access to Next Step (information, advice and guidance) within probation offices, improving their chances of gaining employment and reducing their risk of re-offending. Close working arrangements exist with JobCentre Plus and work programme providers to ensure that offenders are able to access provision and support to move into employment.

Further information on the health needs of offenders with learning disabilities are available from:

- Department of Health (2011) *Staying Positive: The Criminal Justice System and Learning Disabilities* (easy read information for people with learning disabilities and learning difficulties).
- Department of Health (2009) *Lord Bradley's Review of People with Mental Health Problems or Learning Disabilities in the Criminal Justice System*.
- Department of Health (2011) *Positive Practice, Positive Outcomes: A Handbook for Professionals in the Criminal Justice System Working with Offenders with a Learning Disability*.

Civil & legal rights

Human Rights Act

Human Rights were incorporated into UK domestic law through the Human Rights Act 1998 and apply to people with learning disabilities and autism. The specific needs of people with learning disabilities and autism are recognised, e.g.

- The Report An Evaluation of the Human Rights Based Approach to risk assessment and management in a Learning Disabilities Service¹³
- Human rights training materials and human rights resources for people with learning disabilities.¹⁴
- Autism Europe which advocates for the full recognition of the rights of people with autism at European and national level.¹⁵

¹³http://www.advancingqualityalliance.nhs.uk/document_uploads/Case_Studies/An%20Evaluation%20of%20the%20Human%20Rights%20Based%20Approach%20to%20Risk%20Assessment%20and%20Management%20in%20LDS.pdf

People with LD and autism are less likely to be aware of their human rights. Resources are needed locally to ensure roll out and implementation of human rights in practice.

Mental Capacity Act 2005

The Mental Capacity Act applies mostly to people aged 16 and over, and incorporates compliance with Human Rights.

About 2 million people in England and Wales are thought to lack capacity to make some decisions for themselves. They are cared for by around 6 million people, including a broad range of health and social care staff, plus unpaid carers.¹⁶

Having a learning disability and / or autism can impair capacity, and people with PMLD are likely to lack capacity in many or even all areas of their life. Everyone including professionals, care providers, family and unpaid carers, must be able to apply the Mental Capacity Act in practice so that people:

- are supported to make their own decisions
- if they lack capacity, have decisions made in their best interests
- have an Independent Mental Capacity Advocate (IMCA) to support them for specified decisions
- are safeguarded under the Deprivation of Liberty Safeguards (MCA DoLS) in a hospital or care home (an amendment to the Act which was introduced in 2009)
- have their case heard by the Court of Protection under some circumstances

People with LD and autism are more likely to need extra support to make their own decisions, and/ or to need the involvement of qualified / specialist staff in the best interests decision-making process, especially around life - changing and major decisions.

Applications to the Court of Protection are needed particularly in relation to tenancy agreements, deprivation of liberty and contact (safeguarding). Resources are needed locally to ensure the continued roll out and implementation of the Mental Capacity Act in practice.

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http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_115174

¹⁵ <http://www.autismeurope.org/publications/rights-and-autism-2/>

¹⁶ *SCIE At a glance 5 - Mental Capacity Act*

<http://www.scie.org.uk/publications/ataglance/ataglance05.pdf>

IMCA and DoLS activity are good indicators of MCA implementation as they rely on health and social care referrals. The statistics below suggest more resources are needed to fully implement MCA.

IMCA Activity

The Department of Health's original assumptions about IMCA activity were that for every 100,000 population there would be the following numbers of instructions per year.¹⁷

- 19 accommodation decisions
- 19 care reviews
- 12 serious medical treatment decisions
- 8 safeguarding adults.

In addition there will be instructions associated with the DoLS.

For an adult (16+) population of 100,000 this equates to 68 IMCA instructions per annum.¹⁸

Table 18: IMCA Learning Disability Cases 2011-12 in Lancashire

Lancashire county IMCA Learning Disability Cases 2011-12 (all decisions including DoLS)	
North Lancs	20
East Lancs	26
Central Lancs	52
Lancashire-12 TOTAL	108
Blackburn with Darwen	*
Blackpool	3
Lancashire-14 TOTAL	*
*Data not available/obtainable	

Figures for people with Autism are not available.

DoLS Activity

Of the total DoLS applications completed nationally in quarters 2 to 4 in 2010/11, 14% were for people with learning disabilities¹⁹, compared to 6% for Lancashire County Council and Blackpool unitary authority, and 9% for the 3 Lancs PCTs for 2010/11.

¹⁷ Good practice guidance for the commissioning and monitoring of Independent Mental Capacity Advocate services SCIE Guide 31
<http://www.scie.org.uk/publications/guides/guide31/files/guide31.pdf>

Table 19: DoLS applications 2010/11 to 2011/12, Lancashire-12

2010 -11	All completed	LD completed	All granted	LD granted	All not granted	LD not granted
North Lancs PCT	8	0	4	0	4	0
Central Lancs PCT	11	3	7	1	4	2
East Lancs PCT	14	0	5	0	9	0
YEAR 2 TOTALS FOR PCTS	33	3 (9% of total)	16	1	17	2
YEAR 2 TOTALS LANCASHIRE COUNTY COUNCIL	186	11 (6% of total)	106	6	80	5
Blackburn with Darwen	*	*	*	*	*	*
Blackpool	33	2 (6% of total)	13	1	20	1
2011 -12	All completed	LD completed	All granted	LD granted	All not granted	LD not granted
North Lancs PCT	25	2	12	0	13	2
Central Lancs PCT	20	3	9	2	11	1
East Lancs PCT	23	1	13	0	10	1
YEAR 3 TOTALS FOR PCTS	68	6 (9% of total)	34	2	34	4
YEAR 3 TOTALS LANCASHIRE COUNTY COUNCIL	231	22 (10% of total)	114	14	117	8
Blackburn with Darwen	*	*	*	*	*	*
Blackpool	29	3 (10% of total)	9	1	20	2

*Data not available/obtainable

Figures for people with autism are not available.

Compared to many other areas, Lancashire County has more people with learning disabilities living in supported living and fewer in care homes, which may account for the lower percentage figure. Therefore resources are needed to ensure that people with learning disabilities in supported living who lack capacity to consent to their care arrangements are not being deprived of liberty, and that they are being managed in the least restrictive way possible. Resources are also needed to ensure that if people lack capacity to sign their own tenancy agreements, a deputy or declaration from the Court of Protection is sought.

¹⁸ Source: *Explanatory memorandum to the Mental Capacity Act 2005 (Independent Mental Capacity Advocates) (expansion of role) regulations 2006.*

http://www.legislation.gov.uk/uksi/2006/2883/pdfs/uksem_20062883_en.pdf

¹⁹ *Mental Capacity Act 2005*

Mental Health Act

CQC has found that the assessing and recording of capacity and consent of people detained under the Mental Health Act was an area that needed significant improvement and that in some cases doctors appeared to assume too readily that patients had the capacity to give their consent.²⁰

People with learning disabilities and autism detained under the Mental Health Act may therefore be more disadvantaged compared with others so need additional support to understand their rights. Anyone detained under the Act has a right to access an Independent Mental Health Advocate (IMHA). However CQC has found that detained patients had regular access to an IMHA on only 65% of wards they visited, and that problems continued with commissioning arrangements for some IMHA services, particularly for patients placed out of the area. They also found that some staff were ignorant of the IMHA service even though they should have been fulfilling the detaining authority's legal duty to provide information.

Resources are needed to ensure that people with Learning Disability and autism who are more likely to be placed out of area when detained under the Mental Health Act, have accessible information on all aspects of their care including access to IMHA.

Safeguarding Adults

Safeguarding policies and procedures are essential to ensure that people's Human Rights are upheld, particularly their rights to life and not to be subjected to inhuman and degrading treatment. People with a learning disability need access to independent advocacy to support them through safeguarding procedures, whether as victims or perpetrators. Significant numbers of people with learning disability are subject to abuse. Figures for people with autism are not available.

²⁰ CQC Monitoring the Mental Health Act in 2010/11
http://www.cqc.org.uk/sites/default/files/media/documents/cqc_mha_report_2011_summary_final.pdf
Easy Read version
http://www.cqc.org.uk/sites/default/files/media/documents/20111207__mha_summary_report_final_low_res_er_0.pdf

Table 20: Safeguarding referrals by client type and age group in England, 2010-11²¹

Primary Client Type	Age group				Gender		Total	Client Type Percentage Distribution
	18-64	65-74	75-84	85 and over	M	F		
Physical Disability	18	13	30	39	34	66	46,720	49
Mental Health	36	13	26	24	35	65	22,030	23
Learning Disability	93	5	2	0	52	48	19,465	20
Substance misuse	87	9	3	1	50	50	915	1
Other Vulnerable People	35	14	25	26	38	62	5,930	6
Total	39	12	23	27	38	62	95,065	
Figures may not add up to 100 per cent due to rounding								
Based on information provided by 152 councils								

Table 21: Completed safeguarding referrals by client type and age group in England, 2010-11

Primary Client Type	Age Group				Gender		Total	Client Type Percentage Distribution
	18-64	65-74	75-84	85 and over	Male	Female		
Physical Disability	17	13	30	39	34	66	37,55	50
Mental Health	34	13	27	26	34	66	16,720	22
Learning Disability	93	5	2	0	52	48	15,520	21
Substance Misuse	87	8	3	2	49	51	685	1
Other Vulnerable People	35	13	25	27	36	64	4,530	6
Total	38	12	23	27	38	62	75,405	
Figures may not add up to 100 per cent due to rounding.								

In the county of Lancashire there were 671 safeguarding alerts during 2010-11, accounting for more than 20% of the total. 200 of these proceeded to investigation, making up almost one in four of all investigations. The numbers of alerts for people with learning disabilities remained reasonably constant during 2011-12 (693 alerts), but the number of those which proceeded to investigation fell. The proportion of alerts as a proportion of the total for people with learning disabilities has reduced between the two years. This might reflect success in increasing the numbers of overall numbers through safeguarding promotions.

In Blackpool during 2010-11, there were 59 alerts for people with a learning disability, making up almost 13% of the total. More than one in four of these proceeded to investigation (50 alerts). In 2011-12 the number of alerts dropped to 36, as did the proportion of these that

²¹ Abuse of Vulnerable Adults in England 2010-11: Experimental Statistics - Final Report NHS Info Centre <http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care->

proceeded to investigation (25% compared to 30% the previous year). Figures for Blackburn with Darwen were not obtainable.

Table 22: Safeguarding alerts received and proceeding to investigation, 2010-11 and 2011-12, Lancashire 12

	Age group				Gender		
	18-64	65 - 74	75 - 84	85+	F	M	Total
Learning Disability	620	36	11	4	266	405	671
All Service Users	1203	392	704	849	1870	1278	3148
% Learning Disability							21.3
The number that proceeded to investigation							
Learning Disability	188	10	1	1	78	122	200
All Service Users	283	94	189	257	508	315	823
% Learning Disability							24.3
The number of safeguarding alerts received between 1/4/2011 and 31/3/2012							
Learning Disability	635	51	4	3	280	413	693
All Service Users	1455	533	961	1,018	2,421	1,546	3967
% Learning Disability							17.5
The number that proceeded to investigation							
Learning Disability	159	14	1		66	108	174
All Service Users	300	118	214	272	556	348	904
% Learning Disability							19.3

Table 22b: Safeguarding alerts received and proceeding to investigation, 2010-11 and 2011-12, Blackpool

	Age group				Gender		
	18-64	65 - 74	75 - 84	85+	F	M	Total
Learning Disability	55	3	1	0	28	31	59
All Service Users	154	78	105	133	286	184	470
% Learning Disability	35.7	3.8	1.0	0	9.8	16.8	12.6
The number that proceeded to investigation							
Learning Disability	46	3	1	0	23	27	50
All Service Users	80	19	39	49	107	80	187
% Learning Disability	57.5	15.8	2.6	0	21.5	33.8	26.7
The number of safeguarding alerts received between 1/4/2011 and 31/3/2012							
Learning Disability	32	2	1	1	18	18	36
All Service Users	136	75	125	116	280	172	452
% Learning Disability	23.5	2.7	0.8	0.9	6.4	10.5	8.0
The number that proceeded to investigation							
Learning Disability	22	2	0	1	13	12	25
All Service Users	91	45	80	68	167	117	284

% Learning Disability	24.2	4.4	0	1.5	7.8	10.3	8.8
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More resources are needed to ensure that people with learning disabilities can report abuse and that they are adequately protected and supported through Adult Safeguarding Procedures.

Preventing offending behaviour & reducing numbers of people with LD in prison population and secure mental health services

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.

Health needs

People with learning disabilities experience poorer health than the general population and these constitute health inequalities since many of these poorer outcomes are unnecessary and avoidable²².

It has been very difficult to obtain data on the health needs of people in Lancashire and it is recommended that better data collection should be a priority. The following sections summarise the poorer health outcomes people with learning disabilities are known to experience, based on a range of sources including the Valuing People Now deliver plan for addressing health inequalities in Central Lancashire²³, a confidential enquiry on deaths of people with learning disabilities and research by the Improving Health and Lives learning disability observatory²⁴.

²² Emerson, E. (2011)

²³ <http://www.centrallancashire.nhs.uk/your-health/Learning-disabilities/Learning-disabilities.aspx>, accessed July 2012

²⁴ Ibid, p. 2-6.

Confidential inquiry into the deaths of people with learning disabilities

Extract taken from the executive summary of the confidential inquiry:

Following the Michael Report in 2008, the Secretary of State for Health invited tenders for a Learning Disabilities Public Health Observatory and Confidential Inquiry into the deaths of people with learning disabilities. A team based at the Norah Fry Research Centre, University of Bristol, was subsequently asked to undertake a time-limited Confidential Inquiry into premature deaths in people with learning difficulties to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention.

The CI team started work in March 2010 and reported to the Government with an Interim Report in January 2011. The purpose of this report is to update the Government on the progress of the CI, and its emerging issues, to the end of January 2012.

The report has been produced to fulfil contractual obligations, and findings are based on a number of completed investigations which may not reflect those when the study is complete.

Preliminary Findings

Preliminary findings based on a review of the deaths of people with learning disabilities from five PCT areas (Bristol, Bath and NE Somerset, North Somerset, South Gloucestershire and Gloucestershire) over a one year period suggest that:

- *The death rate of 7.1 per 100,000 of the population in the CI study area is two to three times higher than expected. There is clearly a need for mortality data to be collected within defined geographical areas over a period of at least a year's duration in order to provide further national estimates of the mortality of people with learning disabilities.*
- *Over a half of all deaths have been from cardio-respiratory causes.*
- *In all, half (49.5%) of the deaths were unexpected.*
- *35% of people with learning disabilities in the CI were under the age of 55 when they died compared with approximately 10% of the general population.*
- *The median age at death for people with mild learning disabilities was 67; it was 62.5 for people with moderate learning disabilities; 53.5 for people with severe learning disabilities; and 46 for people with profound/multiple learning disabilities.*
- *A larger proportion of people with learning disabilities were either more underweight or overweight/obese than would be expected in the general population.*
- *Of the 116 people who had died in the first year of the CI, a third (32%) had severe or profound/multiple learning disabilities.*
- *For each case, a Local Review Panel meeting is held to which those professionals who have been involved in supporting the individual are invited. Their decisions are reviewed by an independent Overview Panel, comprising a range of expert*

professionals not connected with the case. Of the 93 completed cases reviewed by the Overview Panel, agreement with the Local Review Panel as to whether a death should be considered premature or not was generally good (86%). In 10 cases (11%) the Overview Panel considered the death to be premature whilst the Local Review Panel did not. This re-affirms our belief that Overview Panels are essential in maintaining consistency of assessment across the inquiry.

- Over a half (56%) of the cases reviewed by the Overview Panel were considered to be premature deaths. This was not so much based on age, but whether the timeliness of their death was considered reasonable, given the specific circumstances of each death.
- It is not clear whether the issues identified, or the contributory factors are exclusive to the deaths of people with learning disabilities or more generic to premature deaths in the wider population. The CI has started investigating the deaths of a Comparator Group of people without learning disabilities. They have been purposively sampled from GP death registers and matched to people with learning disabilities whose deaths have been investigated by the CI on the grounds of age at death, cause of death, geographical area and gender. This will help put the findings in context and identify modifiable factors specific to people with learning disabilities. The analysis of data pertaining to the deaths of the comparator group of people without learning disabilities, and how the circumstances of their deaths compare to those of people with learning disabilities will be detailed in our Final Report to be presented to Ministers in March 2013.
- The CI has involved over 500 interviews with professionals who have supported a person with learning disabilities who has died. This has provided them with a valuable opportunity to reflect on their practice and consider their own role as part of a team supporting an individual. The CI also discusses with agencies who are involved with a number of deaths and with Safeguarding Leads at each of the hospitals in the CI area relevant findings of investigations pertaining to their clients. This occurs on a routine basis every six months and during the interim if a case gives rise for concern. We have found that professionals have, in the main, benefited from this aspect of the CI.

Mortality

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 population²⁵. 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 care²⁶.

Health checks

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 appropriate²⁷.

The following table summarised the percentage of adults with a learning disability in Lancashire who received a health check in 2010-11.

Table 23: Percentage of adults with a learning disability receiving a health check

Primary Care Trust	Percentage receiving health check
Central Lancashire	66%
East Lancashire	45%
North Lancashire	79%
Blackburn with Darwen	45%
Blackpool	60%
Source: Improving Health and Lives 2012	

North Lancashire and Central Lancashire PCTs were among the 20% top performing primary care trusts in the North West and nationally.

Number of people with a learning disability who received a health check

Table 24: Number of adults with a learning disability who received a health check

	2009/10	2010/11
Central Lancashire	1,051	1,386
East Lancashire	-	-
North Lancashire	201	551
Blackburn with Darwen	*	*
Blackpool	184	269
Source: Central, East and North Lancashire Learning Disability Partnership Board annual reports 2011		
*Data not available		

²⁵ Ibid, p.2.

²⁶ Emerson, E and Hatton, C (2008)

²⁷ Emerson, E et al (2011b)

General health status

Health screening of adults with learning disabilities "reveals high levels of unmet physical and mental health needs"²⁸.

The Anticipatory Care Calendar (ACC) is a simple tool to improve the daily surveillance of health for adults with learning disabilities. It overcomes some of the barriers that can prevent people with learning disabilities accessing health services and addresses health inequalities²⁹

Data collected from Living in Lancashire suggest that people with a long-standing disability, including a learning disability, have poorer self reported health than the general population. The following table summarises respondents' self-reported health status:

Table 25: Self-reported general health, Lancashire-12

	Do you have any long-standing illness, disability or infirmity?		
	Yes, affecting something else ³⁰	All respondents	
How is your health in general?	Very good	5%	27%
	Good	30%	40%
	Fair	42%	24%
	Bad	18%	7%
	Very bad	2%	2%
	Don't know	2%	0%
	Total (count)	167	1,400
Total (unweighted count)	264	1,948	

Source: Lancashire County Council Living in Lancashire survey 2012

Life style risk factors

National evidence shows that people with learning disabilities are much more likely to be either underweight or obese than the general population³¹. Results from audits of people with learning disabilities in Preston and Chorley and South Ribble found that 17% of those living at home in Preston were obese, 21% living in commissioned services in Preston were obese and in Chorley the overall obesity rate as 21%. These figures are in line with the general population.

²⁸ Ibid, p. 2.

²⁹ <http://www.cancerlancashire.org.uk/your-network/about-network/network-projects/the-anticipatory-care-pathway.php>

³⁰ Possible responses are 'Yes – affecting my hearing,' 'Yes – affecting my ability to move around,' 'Yes – affecting my sight,' 'Yes – affecting something else,' and 'no.'

³¹ Bell and Bhate 1992, Messent et al 1998, Robertson et al 2000, Wood 1994

Nationally, less than 10% of adults with learning disabilities eat a balanced diet, with an insufficient intake of fruit and vegetables and a lack of knowledge and choice about healthy eating³². In Preston, less than 5% of people with learning disabilities ate the recommended '5 a day', compared with 21% of the general population. More than half ate heavily processed foods once or twice a week.

Over 80% of adults with learning disabilities engage in levels of physical activity below the minimum recommended by the Department of Health, a much lower level of physical activity than the general population (53%-64%)³³, with people of lower ability in more restrictive environments at increased risk of inactivity³⁴.

Cancer

Overall the proportion of people with learning disabilities who die from cancer is lower than the general population. Gastric-oesophageal cancer is responsible for more deaths than other cancers for people with a learning disability.

People with learning disabilities have proportionally higher rates of gastrointestinal cancer than the general population (48%-58.5% vs 25% of cancer deaths)³⁵. Women with learning disabilities are much less likely to undergo cervical screening tests than the general population (19% vs 77%³⁶; 24% vs 82%)³⁷. An audit was conducted in Blackpool in 2009 to gauge the proportion of women with a learning disability covered for breast and cervical screening. An estimated coverage for breast screening of eligible women with a learning disability was 47% compared with an overall 72.8% coverage in Blackpool, 75.8% in the North West and 76.5% in England. An estimated 34% of eligible women with learning disabilities had received cervical screening compared with an overall 75.2% coverage in Blackpool, 78.5% in the North West and 78.9% in England. The Cancer Awareness Toolkit is a resource that supports front line staff to promote awareness of cancer and the importance of early detection.³⁸ It was developed as a result of a man with a learning disability developing symptoms of cancer that were undetected until it was too late.

³² Robertson et al 2000, Rodgers 1998

³³ Messent et al 1998, Robertson et al 2000

³⁴ Robertson et al 2000

³⁵ Cooke 1997, Duff et al, 2001, Jancar 1990

³⁶ Djuretic et al, 1999

³⁷ Pearson et al 1998

³⁸ <http://cancerawarenesstoolkit.com/about>

Coronary heart disease

Approximately a fifth of people with a learning disability die from coronary heart disease and this is expected to increase due to increased life expectancy. The lack of empirical data to support analysis of coronary heart disease among people with a learning disability is highlighted as a healthcare data gap by the *Improving Health and Lives* observatory, who recommend additional national data collection³⁹.

Respiratory disease

Respiratory disease is the leading cause of death for people with learning disabilities (46%-52%⁴⁰) and is much higher than for the general population (15-17%).

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 seizures⁴¹.

Mental Health

Many people with a learning disability have additional mental health needs, including:

- Anxiety and depression are particularly common among people with Downs' syndrome.
- People with learning disabilities who live with their families more likely to have anxiety disorders.
- Limited evidence suggests the prevalence of schizophrenia is three times higher among people with learning disabilities than the general population (3% versus 1%)⁴².

³⁹ Glover, G et al (2011).

⁴⁰ Carter and Jancar 1983, Hollins et al 1998, Puri et al 1995

⁴¹ Sillanpaa et al 1999

⁴² Doody et al 1998

- People with learning disabilities who live independently of their family are more likely to have a personality disorder.

Challenging behaviour

- 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.
- Adults with learning disability who have ADHD are more severely affected by mental health problems and less likely to improve over time than others with ADHD.

Dementia

The prevalence of dementia is higher amongst older people with learning disabilities (22%) compared to other older adults (6%). People with Down's syndrome have a much higher risk of developing dementia than the general population, with onset often 30 to 40 years earlier.

Sensory Impairments and communication

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.⁴³

Oral Health

36.5% of adults with learning disabilities and 80% of adults with Down's syndrome have unhealthy teeth and gums⁴⁴, with adults living with families having more untreated decay and poorer oral hygiene and adults living in residential services having more missing teeth⁴⁵.

⁴³ Valuing people now: delivery plan for Central Lancashire

⁴⁴ Barr et al 1999

⁴⁵ Tiller et al 2001

Dysphagia

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. It is estimated that 8% of adults with learning disabilities known to services nationally are affected by dysphagia.

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. Such risk factors include lack of weight-bearing exercise, delayed puberty, earlier average age for menopause in women, poorer nutrition, increased risk of being underweight, and use of anti-epilepsy medication. As a result of osteoporosis fractures can occur more easily and can be more numerous.

Injuries, accidents and falls

Adults with learning disabilities experience higher rates of injuries and falls when compared to the general population, and in some international studies accidents are a more common cause of death among people with learning disabilities than in the general population.

Women's health

There is no or little difference in the number of women with learning disabilities experiencing problems with menstruation compared to other women, but these problems may not be recognised by carers and may be experienced more negatively by women with learning disabilities.

Parents and carers may feel that women with learning disabilities may not cope well with menstruation so seek medical support to suppress or eliminate periods. These can result in negative side effects including reduction in bone mineral density, weight gain, increased risk of thromboembolism, breast or cervical cancer, infection, sterility and the need for invasive surgery. Many authors state this is unnecessary as women with learning disabilities can manage their own care with appropriate support and education.

End of life care

The Department of Health has identified high incidences of inappropriate admissions to hospital at the end of life and highlighted a need for end of life care training for care home staff through the 6 Steps to Success programme.⁴⁶ *This approach needs to be adapted for people with learning disabilities who are more likely to be in supported living and resources are needed to roll out this approach as well as the ACC and Cancer Awareness Toolkit.*

Reasonable adjustments

People with learning disabilities and autism – along with other disabled groups – are legally entitled to have equal access to information and services. This is outlined in the Disability Discrimination Act and the Equality Act and, for people with autism, reinforced in the *Fulfilling and Rewarding Lives* strategy⁴⁷ and specifically mentioned in the 2010/11 NHS Standard Contract for Mental Health and Learning Disability Services. Public services must make their services accessible for people with disabilities, including policies, procedures and staff training, and these must be 'anticipatory,' that is, they must think about and implement changes before people with learning disabilities attempt to use the service⁴⁸.

The *Improving Health and Lives* learning disability observatory have published recent guidance on implementing reasonable adjustments⁴⁹. They recommend the following adjustments for people with learning disabilities:

1. Provide information in an accessible format – ensure there is a strategy in place to provide accessible, easy read information, rectify gaps in provision, and ensure people with learning disabilities and their carers can obtain and use this information.

⁴⁶ http://www.endoflifecumbriaandlancashire.org.uk/six_steps.php

⁴⁷

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

⁴⁸ Hatton, C et al (2011).

⁴⁹ Turner, S and Robinson, C (2011)

2. Work in partnership with families and carers – recognise carers and family members should be involved appropriately in care decisions (as long as the individual consents) to achieve the best care outcome.
3. Ensure staff comply with the law regarding capacity, consent and best interest decision making – ensure policies on the Mental Capacity Act and Deprivation of Liberty are readily available, provide adequate training and audit decisions to ensure compliance. People with learning disabilities and their families and carers should be aware of their rights under the Mental Capacity Act.
4. Support people with learning disabilities to attend appointments – this can include easy read appointment letters, reminder phone calls or text messages, appointments at specific times and longer appointments and regular health checks.
5. Diagnosis – it can be more difficult to diagnose people with learning disabilities and signs or symptoms might be ascribed to the person's learning disability rather than the actual cause. Staff should ensure they get the best quality information about the individual from their health passport or hospital book or, where these are not possible, from families, carers or others who know the individual well.
6. Discharge arrangements – plan for discharge early, ensure arrangements are in place for home support arrangements.
7. Monitoring and reporting mechanisms – ensure people with learning disabilities are identifiable in information systems by agreeing clinical codes with other local services. Consider use of a flagging system and use health passports and health action plans appropriately.
8. Involvement – service evaluations and reviews should be accessible for people with learning disabilities and their families and carers so they can give their views on the services they receive. Complaints procedures must be accessible.
9. Employment – include an accessible application process in line with national good practice relating to learning disabilities. Ensure people with learning disabilities have the same access to training and development opportunities.
10. Equality Impact Assessments should be carried out by people with a range of needs, including those with learning disabilities.

Good practice case studies

Health case study

The Learning Disability Partnership in North Lancashire held a Health Day which was billed as a 'Fun Café'. Over 200 people attended, with a large number participating in taster sessions including healthy eating, watching your weight, cycling, dancing, drumming, judo, and relaxation techniques.

The event was successful because it was person-centred involving service users in designing the event. It was an engaging partnership event with all parties creatively contributing. Marketing was crucial. It was well timed and carefully thought out. Partnership contacts were essential. We used the day to get information from people with a learning disability which would help us plan future services. It was cost effective.

Annual health checks

Lancaster District Case Study

The invitation for the appointment came in easy read format with symbols. It gave an option of which surgery to attend – one was more accessible than the other.

The appointment has been with a named nurse in attendance who is aware of the individual's needs and background. The assessment was very good. The nurse was very patient and understanding. This has helped the service user when the second assessment was due as they knew what to expect.

Fylde District Case Study

We had excellent support from the Doctors at the surgery. They called all the service users registered with them to annual health checks immediately and gave additional time to ensure that the individual and the staff have chance to discuss their issues and concerns. As a result many people have been referred for additional screening and diagnostic tests.

Hospital case study North Lancashire

All the staff were made welcome to come and support the service user at anytime. Even when we were with him, the staff would always speak to him first, only have us as his support staff to re-emphasise what was said to him. The one factor that did impress me was that all the staff were aware that he had a Hospital Passport which highlighted any information, from medical to general regarding who he is as a person. This also stated his likes and dislikes and forms of appropriate communication. Each time I asked if the staff

were aware of this, they said they were and that was evident from the positive treatment he received.

From his first appointment to the actual operation, his family and support staff felt that he was treated in a dignified and respectful way. All appointments were kept, staff were obliging and respectful to his needs, his Hospital Passport was always evident in his file and where humanly possible, information was passed on in a manner to either his family, support staff and more importantly, to the gentleman himself.

Case Study

Audit of uptake of breast and cervical screening amongst women with learning disabilities in Blackpool

Women with learning disabilities are less likely to attend for cervical screening compared to the general population. A baseline audit was undertaken in Blackpool to ascertain the uptake of breast and cervical screening amongst women registered with learning disabilities in the town. This work found that the participation on breast and cervical screening was lower amongst women on the register compared with women overall in the town. An estimated that 47% of eligible women on the learning disabilities register had received breast screening compared with 72.8% of all eligible women in the town. For cervical screening the coverage of women with learning disabilities was 34% compared with 75.2% of eligible women in Blackpool overall. The results of the baseline audit were discussed at Blackpool Cervical Screening Programme Board, an action plan was developed. The results of the audit were presented to cervical screening sample takers as part of their regular update training and information about the support available from Learning Disabilities Team has been included in Cervical Screening Resource Packs for GPs, practice nurses and community clinics.

Carers

As healthcare improvements lead to increased life expectancy for people with complex health needs the population of significant learning disabilities also increases. More children who historically would have died during childhood are now living into adulthood. The aging profile of people with learning disability is also increasing as healthcare improves and as such some people with learning disability are outliving their family carers, who are often their parents.

The role as main care giver can vary considerable depending upon the needs of the person with a learning disability. Where the person with learning disability is more capable of independent life the impact of caring can be emotionally draining as the ability to protect the person from exploitation and other risks is difficult in community settings. Where the person with a learning disability is wholly dependent on others for daily living tasks there is both emotional and physical impact.

Whatever the level of support need the person with a learning disability has, it is clear that the health and wellbeing of carers is impacted by the responsibilities they carry each day for many years. Carers develop their own health and social care needs, particularly those who are older in age.

Within each of the localities family carers networks have been established to help support family carers and enable their access to support services. Carers are entitled to a carer's assessment and GPs add information onto people's health records where they have a caring role for others so that this can be taken into account when they provide assessment and health services to the carer.

As healthcare improvements lead to increased life expectancy for people with significant learning disabilities or autism they are beginning to outlive their carers, who are often their parents, or their parents and families are no longer able to provide care due to old age. There may also be increases in the number of people with a learning disability or autism providing informal care for their own elderly parents.

The carers subgroup of the autism board are currently collating a variety of information for carers of people with autism and for people with autism who themselves provide care. Currently this information is not collected and an important recommendation for this analysis is to encourage and support the development of mature, Lancashire-wide data collection of carers and people with learning disabilities or autism.

Case study

The North Lancashire Family Carers Network has a bi-monthly family carer's bulletin with local, regional and national news and chance to give views and share information. One family carer noted that this information was a "life-saver". It reaches over 200 families by email or post.

Carers groups meet in Lancaster and in Wyre monthly or bi-monthly. The Network also has an annual Family Carers Network Day giving carers the opportunity to share news and

problems and learn about ideas like person centred approaches and dealing with conflict. The carers enjoy receiving lots of different information and meeting a range of people.

They find the workshops very interesting and like the way the speakers are able to change the content to cater for individual needs. Some family carers feel able to talk about very personal issues and gather support and ideas from each other.

Services for people with learning disabilities and autism

Please contact Adult and Community Services to seek advice on the most up to date services and details.

Budget for people with learning disabilities

The following table outlines the budget available for social care and health care services for adults and older people with learning disabilities:

Table 26: Budget available for services for people with a learning disability in Lancashire-12

	Social Care		Health Care		Joint		Total	
	2010/11	2011/12	2010/11	2011/12	2010/11	2011/12	2010/11	2011/12
Central Lancashire	£49,976,973	£48,672,409	£4,552,423	£4,552,513	*	*	£54,529,396	£53,224,922
East Lancashire	£41,151,521	£37,698,650	£2,422,775	£2,429,270	*	*	£43,574,296	£40,127,920
North Lancashire	£32,087,132	£31,121,073	£5,285,298	£5,285,298	*	*	£37,372,430	£36,406,371
Lancashire 12 Total	£123,215,626	£117,492,132	£12,260,496	£12,267,081	*	*	£135,476,122	£129,759,213
Blackburn with Darwen	*	*	*	*	*	*	*	*
Blackpool	£16,116,000	£16,623,000	£1,329,739	£1,329,739	*	*	*	*
Lancashire 14 total	*	*	*	*	*	*	*	*
Source: Central, East and North Lancashire Learning Disability Partnership Board annual report 2011								
*Data not available/obtainable								

Table 27: Local authority spend on day services, Lancashire-12

Area	Budget
Central Lancashire	£6,662,740
East Lancashire	£4,209,600
North Lancashire	£2,483,075
Blackburn with Darwen	*
Blackpool	£1,161,525
Source: Central, East and North Lancashire Learning Disability Partnership Board annual report 2011	
*Data not available/obtainable	

Some of the changes to budgets can be attributed to a review of arrangements and changes commissioning supports that provide better value for money for individuals. This is helping us to meet the needs of more people with less available money. In addition, some families and individuals are choosing direct payments and to spend their budgets differently, more people are making better use of universal services or primary care (and therefore mainstream, rather than specialist, budgets).

In addition to this specific/ring fenced budget for adults with learning disabilities in table 26 within healthcare there is the opportunity to access universal and mainstream finance from Continuing Healthcare; Free Nursing Care and Complex Packages of Care budgets. It is recognised that generally people with learning disability struggle to access finance from these mainstream budgets and therefore it is recommended that the situation be considered in more depth to determine whether any discrimination or inequality exists with actions being identified to rectify this.

In both health and social care there will be reductions in the available budgets as the governments required cost improvement and cost savings schemes are implemented locally. Actions should be identified to mitigate this

Known service users

This section presents a summary of people in Lancashire sub-region with a learning disability who currently are known to services or who receive some form of support. These figures are likely to be much lower than the estimated prevalence because the estimates of prevalence (1% and 2% for autism and learning disabilities respectively) include people who:

- May only need limited support which they receive through universal services, or who do not need additional support at all.

- Have mild or less severe forms of learning disability or autism, whereas people who access specialised services – and are therefore recorded – tend to have more significant forms of autism and higher support needs.

The data provided in this section treats adults as those aged 18 to 64 years, and older people as those aged 65 years and older.

Age

The table below shows the number of people in Lancashire who are receiving support from Lancashire County Council's adult social services for a learning disability.

Table 28: Numbers of adults aged 18+ with a learning disability in receipt of social care support by age group

Age	Number of people with a learning disability		
	Lancashire 12	Blackburn with Darwen	Blackpool
18 - 49	3,257	*	414 (18-64)**
50 - 64	974	*	
65 - 74	359	*	43 (65+)**
75 - 84	123	*	
85+	43	*	
Total	4,756	*	457

Source: Lancashire County Council Adult and Community Services
 *Data not available/obtainable
 **Data not available by more specific age groups

The numbers for people receiving support for autism is likely to be under-reported, since this information is not always coded correctly. The data is for a secondary category of autism, as there were no cases of autism as a primary category. Data for people with autism should be accurately recorded on the Lancashire County Council system (ISSIS).

Table 29: Numbers of adults aged 18+ with autism in receipt of social care support by age group

Age Band	Number of people		
	Lancashire 12	Blackburn with Darwen	Blackpool
18 - 64	166	*	*
65+	-	*	*

Source: Lancashire County Council Adult and Community Services
 - Fewer than 5 cases suppressed
 *Data not available/obtainable

Geography

The table below shows the number of adults and older people Lancashire with a learning disability who are obtaining services provided by their local council.

Table 30: Numbers of adults aged 18+ with a learning disability in receipt of social care support by district

District	Number of adults and older people with a learning disability
Burnley	472
Chorley	415
Fylde	256
Hyndburn	393
Lancaster	669
Pendle	279
Preston	612
Ribble Valley	194
Rossendale	237
South Ribble	398
West Lancs	475
Wyre	355
Not Known	1
Lancashire 12 Total	4,756
Blackburn with Darwen	*
Blackpool	449
Lancashire 14 Total	*

Source: Lancashire County Council Adult and Community Services 2012
 *Data not available/obtainable

The table below shows the number of people with autism receiving services for autism by district from Lancashire County Council.

Table 31: Numbers of adults aged 18+ with autism in receipt of social care support by district

District	Number ASD	Percentage
Burnley	25	15%
Chorley	16	9%
Fylde	17	10%
Hyndburn	7	4%
Lancaster	36	21%
Pendle	5	3%
Preston	6	4%
Ribble Valley	4	2%
Rossendale	13	8%
South Ribble	21	12%
West Lancashire	2	1%
Wyre	17	10%
Lancashire 12 Total	169	*
Blackburn with Darwen	*	*
Blackpool	52	*
Lancashire 14 Total	*	*

Source: Lancashire County Council Adult and Community Services 2012
 *Data not available/obtainable

Sex

The table below summarises the number of males and females receiving support for learning disability in Lancashire-12.

Table 32: Numbers of adults aged 18+ with a learning disability in receipt of social care support by sex

Sex	Number of people with a learning disability					
	Lancashire 12		Blackburn with Darwen		Blackpool	
	Nos.	%	Nos.	%	Nos.	%
Male	2,835	59.6%	*	*	239	53%
Female	1,921	40.4%	*	*	210	47%
Total	4,756		*		449	

Source: Lancashire County Council Adult and Community Services 2012
*Data not available/obtainable

The table below shows the number of males and females receiving support for autism in Lancashire-12.

Table 33: Numbers of adults aged 18+ with autism in receipt of social care support by sex

Sex	Lancashire 14		Blackburn with Darwen		Blackpool	
	Number	%	Number	%	Number	%
Male	130	77%	*	*	*	*
Female	39	23%	*	*	*	*
Total	169		*		*	

Source: Lancashire County Council Adult and Community Services 2012
*Data not available/obtainable

Ethnicity

The number of people receiving support from Lancashire County Council for a learning disability by ethnic group is provided in the table below. Numbers less than five have been suppressed to maintain anonymity of the service users.

Table 34: Numbers of adults aged 18+ with a learning disability in receipt of social care support by ethnic group

Ethnicity Group	Ethnicity	Number of people with a learning disability		
		Lancashire 12	Blackburn with Darwen	Blackpool
Asian or Asian British	Bangladeshi	8	*	*
	Indian	51	*	*
	Other Asian background	17	*	*
	Pakistani	117	*	*
Black or Black British	Caribbean	7	*	*
	Other Black background	9	*	*
	Any other ethnic group	5	*	*
Chinese or other ethnic	Chinese	<5	*	*
Mixed	Other mixed background	14	*	*
	White and Asian	10	*	*
	White and Black African	<5	*	*
	White and Black Caribbean	6	*	*
Unknown	Unknown	160	*	8
White	Other White background	26	*	*
	Traveller: Irish Heritage	<5	*	*
	White British	4,300	*	441
	White Irish	19	*	*
Total		4,756	*	449

Source: Lancashire County Council Adult and Community Services 2012. Cases fewer than 5 suppressed.
*Data not available/obtainable

The following table shows the ethnic breakdown for people receiving services for autism.

Table 35: Numbers of adults aged 18+ with autism in receipt of social care support by ethnic group

Ethnicity	Lancashire 12	Blackburn with Darwen	Blackpool
White British	164	*	*
Pakistani	-	*	*
Other mixed background	-	*	*
Not known	-	*	*
Other Asian background	-	*	*

Source: Lancashire County Council Adult and Community Services 2012
- Fewer than 5 cases suppressed
*Data not available/obtainable

GP learning disabilities registers

The table below shows the number of adults aged 18 and over registered with a GP practice and on the learning disabilities register. There are 5,544 people with a learning disability registered with a GP practice in Lancashire sub-region, suggesting that only one in five people with a learning disability is accessing the full range of support offered by their GP.

Table 36: People registered with a GP and on the learning disability register

	No. of practices	List Sizes (total registered pop.)	Estimated pop. 18+	Learning Disabilities (ages 18+)	
				No.	%
CENTRAL LANCS PCT	85	468,879	370,609	1,705	0.5%
EAST LANCS PCT	67	388,324	303,111	1,412	0.5%
NORTH LANCS PCT	37	339,272	275,771	1,130	0.4%
BLACKBURN WITH DARWEN PCT	30	167,693	126,077	619	0.5%
BLACKPOOL PCT	21	150,532	120,626	678	0.6%
Burnley	16	97,106	75,719	426	0.6%
Chorley	19	100,912	80,270	386	0.5%
Fylde	9	71,184	58,911	242	0.4%
Hyndburn	19	79,713	61,405	367	0.6%
Lancaster	11	142,337	113,567	548	0.5%
Pendle	17	89,361	69,128	296	0.4%
Preston	26	131,883	101,896	533	0.5%
Ribble Valley	6	53,789	43,024	131	0.3%
Rosendale	9	68,355	53,835	192	0.4%
South Ribble	17	124,456	99,733	395	0.4%
West Lancashire	23	111,628	88,710	391	0.4%
Wyre	17	125,751	103,293	340	0.3%
Lancashire 12	189	1,196,475	949,491	4,247	0.4%
Blackburn-with-Darwen	30	167,693	126,077	619	0.5%
Blackpool	21	150,532	120,626	678	0.6%
Lancashire 14	240	1,514,700	1,196,194	5,544	0.4%
North West SHA	1,273	7,381,814	5,824,700	26,858	0.5%
England				188,819	0.4%
Source: NHS Information Centre QOF; QMAS Database, July 2011					

Unfortunately this information is not available for people with autism as there is no autism register.

Key issues

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

- Nearly half of people experiencing a learning disability live in the most deprived areas of Lancashire sub-region.
- 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.

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 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 H & WB 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 3 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 and 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, and 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 report, although the levels of support required are complex.

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