



**Liverpool
Public Health
Observatory**

**Learning disabilities and autism:
A health needs assessment for children and adults
in Merseyside and North Cheshire**

FULL REPORT

**Janet Ubido, Sharon McAteer, Sophie Kelly,
Cath Lewis, Alex Scott-Samuel**

**Liverpool Public Health Observatory
Report series number 94, September 2013**

PROVIDING INTELLIGENCE FOR THE PUBLIC HEALTH

Link to Summary Report and (from October) Easy read version:

http://www.liv.ac.uk/PublicHealth/obs/publications/report/obs_report.htm

Glossary

ASCOF: Adult Social Care Outcomes Framework data

ASC-CAR: Adult Social Care Combined Activity Returns data

CCG: Clinical Commissioning Group

CSU: Commissioning Support Unit

IAPT: Improving Access to Psychological Therapies

IHAL: Improving Health and Lives. The Learning Disability Observatory.

Modelled data: By combining available evidence from different sources, modelling enables predictions of future outcomes (Jacobs-van der Bruggen et al, 2009)

NHS IC: National Health Service Information Centre

PANSI: Projecting Adult Needs and Service Information System

PCT: Primary Care Trust (now replaced by CCGs)

QOF: Quality and Outcomes Framework (QOF) GP dataset.

Reasonable adjustments: All public sector services have a legal duty to provide reasonable adjustments for people with learning disabilities in order to ensure equal access to services. These may include additional support to make a service accessible, such as the provision of easy read information.

SAF: health self-assessment framework for learning disability services: involves specialist healthcare professionals as well as people with learning disabilities and family carers in assessing local services.

School Action Plus: when the school is required to monitor the different or additional needs of a pupil.

School statement: used if the child's needs are not met by the school action plus



**Liverpool
Public Health
Observatory**

Liverpool Public Health Observatory was founded in 1990 as a research centre providing intelligence for public health across Merseyside. It receives core funding from local authorities in Halton, Knowsley, Liverpool, Sefton, St. Helens and Wirral.

The Observatory is situated within the University of Liverpool's Department of Public Health and Policy, with access to academic support and materials. It is an independent unit. It is not part of the network of regional public health observatories that were established ten years later, in 2000.

Contact email: obs@liv.ac.uk

Contents

Summary and recommendations	i
Full Report	1
1. Background.....	1
1.1 Project Vision.....	1
1.2 Definitions	2
Health Needs Assessment	2
Learning disability.....	3
Autistic Spectrum Disorder (ASD).....	4
1.3 National policy	4
1.4 Health inequalities amongst people with learning disabilities.....	7
2. Demography of learning disability and autism in Merseyside and North Cheshire.....	9
2.1 Estimated prevalence and projections: learning disability	9
Projections.....	15
Moderate and Severe Learning Disability	16
Profound and multiple learning disability	17
2.2 Known prevalence (local authority data): learning disability.....	22
2.3 Known prevalence aged 18+ (GP data): learning disability.....	26
2.4 Autistic Spectrum Disorder (ASD).....	29
Asperger’s syndrome.....	34
3. Health Profile.....	36
3.1 Disease prevalence and access to care	36
3.2 Health checks.....	40
3.3 Screening	43
3.4 Contraception and sex education.....	46
3.5 Lifestyle.....	49
3.6 Hospital admissions.....	51
3.7 Mental Health.....	59
3.8 Challenging behaviour	63
3.9 Mortality and age at death.....	68
4. Social profile	72
4.1 Housing.....	72
4.2 Community care	81
4.3 Violence/ keeping safe/ social isolation	81

4.4 People with learning disabilities in the criminal justice system.....	84
4.5 People with learning disability who are parents.....	88
4.6 Employment and benefits	92
Employment	92
Benefits.....	98
4.7 Transport	98
5. User perspectives	101
6. Recommendations.....	106
References.....	110
Appendices	117
Acknowledgements and author details.....	128

Summary and recommendations

People with learning disabilities and autism are a very diverse population, with differing needs and are one of the most vulnerable groups in society, experiencing health inequalities, social exclusion and stigmatisation.

Amongst those with more severe learning disabilities, there have been considerable life changes for many, with the closure of learning disability hospitals (IHAL, 2012). Following the enquiry and reports after the closure of Winterbourne View Hospital (DH, 2012) and the development of the government's 'Valuing People Now' strategy (DH 2009), there are now clear guidelines in place covering all aspects of the health needs of people with learning disabilities. Under the Disability and Equality Act (2010), 'reasonable adjustments' are required in all practices and procedures to ensure that discrimination against people with learning disabilities does not occur.

This health needs assessment for learning disabilities and autism amongst adults and children covers Halton, Knowsley, Liverpool, Sefton, St Helens, Warrington and Wirral (Merseyside and North Cheshire). It tries to determine the health and wellbeing needs of people with learning disabilities and autism living in Merseyside and North Cheshire. The findings have been used to develop a set of recommendations for local commissioners. This report represents the findings of the project working group. An easy read version has been circulated to user and carer groups for feedback and will be available by October 2013.

Due to the availability of data, the health and social profile sections of this report have focussed more on learning disability than autism.

How many people have learning disabilities and autism across Merseyside and North Cheshire?

It is important to consider the hidden population with learning disability – those not using services with potentially unmet needs. This is because although about 4.6 people per 1,000 in the population are known to have a learning disability, research suggests there may actually be around 20 people in every 1,000 with a learning disability.

There is no routinely collected data on the number of children with learning disabilities. We do know how many children locally have been identified as having a learning difficulty. It has been estimated that just over three and a half children in every 1,000 has a severe learning difficulty. Those classified as having a severe learning difficulty may well have a learning disability but we cannot say this for certain. The number of adults with learning disabilities GPs know about is about the same as the numbers local authorities have on their registers. However, there is a lot of variation in GP figures. Also, there are far fewer people known to these services than we estimate live in our local communities. This means significant numbers are not receiving any help. In Merseyside and North Cheshire, there are an estimated 33,579 people with a learning disability aged 18 and over, but there are only 5,325 who are known to services (2011/12).

There are an estimated 436 adults with profound and multiple learning disability (PMLD) in Merseyside and North Cheshire. There is no data available on the numbers actually known to have PMLD. We estimate there are about 3,732 children and 10,500 adults in Merseyside and North

Cheshire with autism. We do not know how many of these have Asperger's syndrome, although the Liverpool Asperger's team had 245 referrals in 2012. Most of these were people living in Liverpool, with 35 being from neighbouring areas.

Health of people with learning disabilities and autism

People with learning disabilities face a number of challenges in using health services. These include understanding literature they have been given, keeping appointments and following treatment regimes. It is important that people who provide healthcare can identify when a person has a learning disability or autism so they can make 'reasonable adjustments' to their care.

People with learning disabilities tend to be less physically active and a higher proportion of them are obese compared to the general population. Local information on this is very limited but it does seem to show this is the case. This, and other factors, results in people having higher levels of certain diseases. Information was only available for a few areas, but it showed that, compared to the general population, people with a learning disability:

- are twice as likely to have asthma
- are 25 times more likely to have epilepsy
- have higher levels of mental health problems
- die earlier, with death rates three times as high as the general population and a median age at death of between 55 to 60 in Merseyside and North Cheshire.

In addition, people with learning disabilities are more likely to be admitted to hospital as an emergency case, compared to those with no learning disability:- 59% of all admissions for those with learning disability are emergencies, compared to 37% of admissions for those with no learning disability in 2012/13. It is likely that this difference is due to problems in accessing care and lack of advance planning.

People with learning disabilities are also more likely to be admitted for digestive symptoms than those with no learning disability (18% vs. 12%) and injury and poisoning, (12% vs. 6%) (2012/13).

As well as lifestyles, another major reason for this poor health experience is poorer access to health promotion and early treatment. The health checks that are available either help to prevent people from developing illnesses or treat them early to make it easier and more likely to recover. Local data was only available from a few areas. It shows a similar pattern to national research including:

- High rates of people with learning disability refuse or do not attend cancer screening appointments
- Less than half of people with learning disabilities who have diabetes get an annual review to help manage their condition in the best way possible.
- Advice on sex and relationships and help with contraception is poor.

Social issues for people with learning disabilities and autism

People with learning disabilities do not just face challenges with healthcare. Many live in poverty and are unable to secure employment. National research suggests only 15% of people with autism

are in full-time employment and only 7.1% of people with a learning disability are in either part-time or full-time employment. Locally, all areas apart from Liverpool and Halton, have below the national average levels of employment for people with learning disabilities. The wide variation locally also suggests there may be different definitions of work being used and even disincentives to count people as having jobs as they would be removed from local authority registers if this was the case.

National research has shown many local authorities believe the type of housing people with learning disability and autism are in does not meet their needs. Although the levels in 'settled accommodation', across Merseyside and North Cheshire, generally are high, this does not tell us about the quality and suitability of their accommodation.

National research also shows that people with learning disabilities and autism are at increased risk of becoming victims of violence and abuse. Local data shows the number of people with learning disability referred to social services safeguarding teams is higher than the regional and national average in some areas.

The estimated proportion of people in prison who have learning disabilities or learning difficulties that interfere with their ability to cope with the criminal justice system is around 20-30%. Many are unidentified.

Many people with learning disabilities and autism have little or no contact with friends. One research study found that 31% of adults with a learning disability having no contact with friends, compared to 3% of adults without a learning disability.

Six out of 10 women with learning disabilities who become a parent have their children taken in to care. Numbers of parents are small in each local authority, between 11-16 in each area. However, they are likely to have complex and on-going support needs.

People with learning disabilities rely heavily on public transport. This is an important issue locally. Other issues identified by local people with learning disability include employment and educational opportunities, hate crime, benefits changes as well as housing and support needs.

Recommendations

Recommendations resulting from the findings of this report and relevant identified guidelines are presented here. All the recommendations are aimed at ensuring that reasonable adjustments for people with learning disabilities and autism are carried in order to ensure equal access to services, as required by the Disability and Equality Act 2010:

1. Actions for both health and social care services

Joint working

1.1 Ensure partnership working arrangements are in place, with Clinical Commissioning Groups (CCGs) taking lead responsibility for the commissioning of specialist and general health services for people with learning disabilities and autism. Local authorities will be responsible for services relating to personal care and the wider determinants of health and wellbeing, such as housing, discrimination, unemployment and social exclusion.

1.2 Demonstrate that people with learning disabilities and autism, families and carers are involved in the process of planning and decision making, so that their needs, choices and preferences are understood, and services are available to reflect individual choice (IHAL, 2012).

1.3 Ensure that each local authority and CCG circulates the report (including the 'easy read' version) widely amongst user and carer groups and that feedback is obtained.

1.4 *Challenging behaviour:*

1.4.1 Agree on a standard definition across the region and maintain a register of those with challenging behaviour (DH, 2012). Use the register to enable the development of appropriate jointly commissioned local services for people who challenge.

1.4.2 Enable the pooling of resources to support and assist people held in secure accommodation to return back to community placements (where appropriate) in their home borough.

Access/support

1.5 Introduce accessible information and offer support to ensure equal access to all health and social services. Remove physical barriers to access and make whatever alterations are necessary to policies, procedures, staff training and service delivery to ensure that they work equally well for people with learning disabilities, including:

1.5.1 Make all self-help and service information 'easy to read'.

1.5.2 Ensure support is available where required, for example in housing application processes.

1.5.3 Provide appropriate staff awareness training across all services. This will help to tackle the issues around reasons for high refusal and non-attendance (DNA) rates for example in screening.

1.5.4 Include an exemption clause in DNA (did not attend) policies for people with learning disabilities and autism.

Data

1.6 Ensure that collection of all health and social care data relating to learning disability and autism becomes more co-ordinated and systematic.

1.6.1 Ensure that local authority and GP information systems allow for the collection of data separately on numbers with learning disability, autism and Asperger's syndrome and profound and multiple learning disability (PMLD), for age groups under 18, 18-64 and 65 plus, and by ethnic group and gender.

1.6.2 Develop the use of GP clinical systems so that data on lifestyle, screening and disease management for those with learning disability and autism can be monitored and compared across each area and with the general population.

1.6.3 The needs of people with learning disabilities and autism should be reflected in JSNAs (Joint Strategic Needs Assessments).

1.7 Collect information on numbers of children with a learning disability, with added details on issues such as numbers in foster care, or on short breaks. Liverpool City Council's work on producing a single dataset for children and young people will assist in this and should be in place by 2014/15.

1.8 Ensure that health service agreements (school nurses and health visitors) on identifying those with learning disability and autism are built into tendering arrangements with schools and colleges.

1.9 Collect and use data on numbers of parents and prospective parents with learning disabilities and autism, so that their needs can be catered for, involving joint working between maternity units and health and social care services.

1.10 Further investigate the needs of people with autism as data collection improves (due to the availability of data, the health and social profile sections of this report have focussed more on learning disability than autism).

2. Local authorities

(recommendations in addition to those for joint action in section 1 above)

Housing

2.1 Include specific plans for improving the housing situation of people with learning disability and autism in local housing strategies. An action plan designed around promoting independent living should accompany any such plans (Mencap, 2012), with housing and social care working together.

2.2 Ensure the accommodation status of all those with learning disabilities and autism is recorded by all local authorities.

Assistive technology

2.3 Ensure care managers and commissioners of packages of support consider what assistive technology and telecare (AT&T) can do as part of a package of support (Beyer et al, 2008).

Parents

2.4 Where a parent has learning disability or autism, enable children to live with their parents (if this is consistent with their welfare) by providing the support that they and their families need (DH and DfES, 2007). This would include ensuring equal access to services, such as parenting support and information services and support through any court processes.

Sex and relationships education

2.5 Consider developing sex and relationships policies in schools and services for children and adults with learning disabilities and autism, to include staff training. This needs to be collaborative with CCGs so healthcare staff can raise the issue and support people with appropriate contraceptive and sexual health advice.

Violence and stigma

2.6 Explore the possibility of using newly available disability hate crime statistics to help to identify problems relating to this issue (from the Merseyside Police SIGMA unit).

Employment

2.7 Improve employer awareness to support people with learning disability and autism in the workplace. Use simple adjustments like making job interviews more accessible and providing assistance to understand the 'unwritten rules' of the workplace (Broad, 2007).

2.8 Across all local authorities, ensure consistency of definitions and recording of numbers of people with learning disability and autism in employment.

Transport

2.9 Provide better transport solutions for people with learning disabilities and autism, organized by councils, charities and communities in partnership. To include:

- increasing public and driver awareness of learning disabilities and autism and improving acceptance of disabled people on public transport.
- working with Merseytravel to consider extending the Transport Community Card taxi scheme in St. Helens to the whole of Merseyside.

3. Clinical Commissioning Groups (CCGs) (recommendations in addition to those for joint action in section 1 above)

Psychological Therapies

3.1 Ensure that the needs of people with learning disabilities and autism are reflected in contracting for Improving Access to Psychological Therapies (IAPT). 'Reasonable adjustments' would include the provision of longer sessions than usual, to take account of the person's varying levels of understanding and need (DH, 2009a).

3.2 Make data available on numbers of people with learning disability and autism accessing psychological therapies, so that access can be monitored.

Health checks

3.3 Continue to promote annual health checks for people with learning disability, with a 90% uptake rate target (IHAL, 2012).

Screening

3.4 CCGs should work with Public Health England to ensure appropriate support is offered to individuals with a learning disability and/or autism to improve access to screening programmes. This should tackle issues around reasons for high refusal and non-attendance (DNA) rates and would include the provision of 'easy read' materials

Sexual health

3.5 Ensure healthcare staff are trained to raise sexual health issues with people who have learning disabilities and autism and to support them with appropriate contraceptive and sexual health advice (see 2.5 above).

Hospital admissions

3.6 Ensure that the performance of each acute provider Trust is monitored against quality indicators which relate to the needs and experiences of patients with learning disabilities and autism.

3.7 Monitor action taken by provider Trusts to ensure that reasonable adjustments are carried out, as identified in recommendations 4.1 to 4.3 below.

3.8 Carry out local monitoring to identify potentially avoidable hospital admissions amongst those with learning disabilities and autism.

Avoidable deaths

3.9 Focus prevention strategies on areas where deaths are more avoidable, such as aspirational pneumonia, seizures, heart disease and accidental deaths (Tyler and McGrother, 2009).

4. Hospital Trusts

4.1 Ensure the identification and coding of people with learning disabilities and autism and the ability to track episodes of care and an individual's movement within a hospital trust, including which specialities/departments have been required.

4.2 Ensure there is a senior person identified in each acute hospital Trust with responsibility for patients with learning disabilities and autism (possibly an acute liaison nurse) and that this individual puts in place reasonable adjustments to meet the specific needs of such patients.

4.3 Notify the GP and the community learning disabilities team when a patient with learning disabilities or autism is discharged after having being admitted with an Ambulatory Care Sensitive Condition (i.e. a condition which shouldn't need hospital care).

5. Criminal Justice System

5.1. Address the under-reporting of learning disability and autism for people in the Criminal Justice System and the need for improved identification at the point of first contact. This will include those in custody, also offenders serving community sentences and those on probation.

1. Background

People with learning disabilities and autism are one of the most vulnerable groups in society, experiencing health inequalities, social exclusion and stigmatisation. In general, those with learning disabilities have greater and more complex health needs than the general population, and often these needs are not identified or treated (Weston et al, 2012).

Life expectancy of those with learning disability is shorter than the general population, though this has increased recently (Emerson et al, 2012). In addition a number of national reports have highlighted that adults with learning disabilities often experience barriers to accessing healthcare services, and poor levels of care. Adults with learning disabilities are more likely to die from a preventable cause than the general population (Tyrer and McGrother, 2009).

Patterns of health needs amongst those with a learning disability are different to the general population, and therefore current programmes that target health inequalities may exclude this population group (Emerson et al, 2012).

Liverpool Public Health Observatory was commissioned to deliver this health needs assessment for learning disabilities and autism amongst adults and children, to cover Halton, Knowsley, Liverpool, Sefton, St Helens, Warrington and Wirral (Merseyside and North Cheshire). Map 1 in the Appendix shows the area covered by the needs assessment.

A working group was established to oversee the project, consisting of representatives from each area, a mix of public health, Clinical Commissioning Group and local authority staff, covering child and adult learning disability and autism commissioning. This report represents the findings of the working group. An easy read version has been circulated to user and carer groups for feedback and will be available by October 2013

1.1 Project Vision

The needs assessment should inform each area's Joint Strategic Needs Assessment and the future commissioning priorities and intentions for local authorities and NHS Commissioners with regard to people with learning disabilities and people with autism. It will also provide some of the data and evidence needed by Clinical Commissioning Groups and local authorities for completing their submissions for the 2013 Learning Disabilities Joint Health & Social Care Self Assessment Framework.

In addition to the standard Health Needs Assessment format, the report therefore needed to ensure that it enabled local areas to complete as many relevant lines of enquiry within the self-assessment frameworks as possible.

Aims

- To determine the health and wellbeing needs of people with learning disabilities and autism living in Merseyside and North Cheshire

- To provide accurate data to help inform local JSNA's (Joint Strategic Needs Assessments) and the Learning Disabilities Self-Assessment framework
- To make a set of evidence-based recommendations for local commissioners, within the framework provided by a recent Commissioning Guide (IHAL, 2012).

Objectives

- Assess existing evidence on the health and wellbeing needs of people with learning disabilities and/or autism.
- Analyse quantitative data from available sources relevant to the health and wellbeing needs of people with learning disabilities and autism health in Merseyside and North Cheshire.
- Describe key characteristics of the population with learning disabilities and autism in Merseyside and North Cheshire relevant to commissioning health and social care services.
- Detail available qualitative information from local stakeholders, service users and their carers on the quality of services, user perspective of service provision and gaps.
- Identify priority health, care and wellbeing issues, barriers to accessing services and barriers to delivering services for people with learning disabilities and autism in Merseyside and North Cheshire.
- Make recommendations for better addressing the health, care and wellbeing needs of people with learning disabilities and autism across Merseyside and North Cheshire, within the framework provided by the Commissioning Guide – but also highlighting areas that exceed the guidance (i.e. best practice).

Methods

For this needs assessment, estimates of the expected number of people with learning disability and autism have been taken from the Learning Disability Observatory 'Improving Health and Lives' website (IHAL) and the PANSI website (Projecting Adult Needs and Service Information system). Data on those known to services, where available, has been taken from the NHS Information Centre (numbers reported by social services), GP QOF data and directly from each local authority.

1.2 Definitions

Health Needs Assessment

As described in the NHS Merseyside Guide (McAteer and Du Plessis, 2012), health needs assessment (HNA) is a systematic method for reviewing the health needs and issues facing a given population, leading to agreed needs (priorities) for that population. HNA is a more in depth analysis of need than that provided by Joint Strategic Needs Assessments. The starting point in HNA is a defined population. This population can be defined in a number of ways, which in this case is the experience of learning disability or autism. This HNA will use an epidemiological approach, which includes an examination of available information on incidence and prevalence in order to assess need.

Learning disability

For the purposes of this needs assessment, the definition of learning disability will be that used in the white paper 'Valuing People Now: A New Strategy for Learning Disability for the 21st Century' (DH, 2001). This white paper formed the basis of the recent government paper 'Valuing People Now: A new three-year strategy for people with learning disabilities' (DH, 2009). In the 'Valuing People' definition, the term '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.

The definition covers people with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average or even above average intelligence. 'Learning disability' does not include all those who have a 'learning difficulty' which is more broadly defined in education legislation.

Learning disabilities are usually detected from childhood and can result from a number of causes such as genetics, chromosomal abnormalities or environmental factors. Sometimes there is no known cause for a learning disability (About Learning Disabilities, online A).

Learning disabilities are different to learning 'difficulties' like dyslexia, which do not affect intellectual ability (NICE, 2013). However, the report of the first national survey of adults with learning disabilities in England (Emerson et al, 2005) used the term 'learning difficulties' rather than 'learning disabilities'. This was because these are the words that the people themselves said they prefer. It was used throughout the research as meaning people who since they were a child had a real difficulty in learning many things. It did not include people who just have a specific difficulty in learning, for example dyslexia.

Coding in datasets

Learning disability is divided into four main categories: mild, moderate, severe and profound. The World Health Organisation International Classification of Diseases (ICD) for learning disability is shown in Table 1.

Table 1
Learning disability classification

	IQ Levels	ICD Code
Mild	50-69	F70
Moderate	35-49	F71
Severe	20-34	F72
Profound	<20	F73

source: DWP website

<http://www.dwp.gov.uk/publications/specialist-guides/medical-conditions/a-z-of-medical-conditions/learning-disability/classification-ld.shtml>

Additional ICD categories are 'other' (F78) and 'unspecified' (F79), characterised with reference to IQ levels, mental ages and broad descriptive characteristics. An additional qualifier is also available to indicate the presence or absence of 'impairment of behaviour requiring attention or treatment' (Glover and Emerson, 2012). The ICD 10 F70-79 group of conditions is termed 'mental retardation', which is considered outdated and offensive. Proposed revisions are outlined by Glover and Emerson (2012).

Since March 2011, new minimum datasets from the NHS Data Standards Board have included a question about the presence of disability. Glover and Emerson (2012) note that the disability question was included in the dataset for the new Improving Access to Psychological Therapy (IAPT) services.

Glover and Emerson (2012) point out two defects in the disability question:

- It does not identify whether individuals have a continuing impairment in the way that the definition of disability in the Disability and Equality Act (2010) requires.
- It provides a classification in which neither learning disability nor autism can be satisfactorily identified as discrete categories.

At present the disability question and the ICD are the only two approaches to recording disability statistically for which the NHS has standardised methods (Glover and Emerson, 2012).

Autistic Spectrum Disorder (ASD)

Autistic spectrum disorder (ASD) is a lifelong condition characterised by impairments in three main areas: social interaction, communication and the presence of repetitive behaviours (known as the triad of impairments). The term "spectrum" is used due to the significant variations between individual cases, including severity and presentation of the triad of impairments; differing IQ levels; and general functional abilities. Autistic Disorder, Asperger's Syndrome and High Functioning Autism are all types of Autistic Spectrum Conditions (National Autistic Society, 2013).

1.3 National policy

There have been a number of recent developments in policies relating to people with learning disabilities. The most important of these, with related literature, are listed as follows (Bean, 2012):

Disability and Equality Act 2010 and Reasonable Adjustments

Since the Disability and Equality Act 2010, disabled people have important rights of access to everyday services (Directgov). Service providers are now obliged to make reasonable adjustments to premises or to the way they provide services. Access to services is not only about physical access, it is about making services easier to use for everybody, for example longer appointment times and more accessible health promotion information.

Valuing People

The 'Valuing People' white paper (DH, 2001) formed the basis of the recent government paper 'Valuing People Now: A new three-year strategy for people with learning disabilities' (DH, 2009).

Valuing People recognises that people with a learning disability are amongst the most vulnerable and socially excluded in our society. The strategy set out new opportunities for children and adults

with a learning disability and their families and called for action to reduce health inequalities and discrimination. It has six priority areas:

- Disabled children and young people
- More choice and control for people with a learning disability
- Supporting carers
- Improving health for people with a learning disability
- Housing, fulfilling lives and employment
- Quality services

Valuing People Now (DH, 2009) set out the Government's strategy for people with learning disabilities. It also responds to the main recommendations in 'Healthcare for All (DH, 2008), which was an independent inquiry set up after the publication of 'Death by Indifference' (Mencap 2007).

A number of high profile reports have been published in relation to the health of people with learning disabilities:

Mansell Report and Transforming Care (challenging behaviour and autism)

The '*Mansell Report*' *Services for people with learning disabilities and challenging behaviour or mental health needs* (DH, 2007a) set out the Department of Health's recommendations for designing effective services to support people with challenging behaviour and/or autism. It concluded: 'specialist multi-disciplinary support teams focussed on challenging behaviour are an essential component of modern provision'.

The wellbeing of people with learning disabilities who show challenging behaviours has attracted increasing attention following the investigation of serious abuse at Winterbourne View. The resulting government report, 'Transforming Care', set out a programme of action to transform services, so that vulnerable people no longer live inappropriately in hospitals and are cared for in line with best practice (DH, 2012b).

Six Lives

Six Lives: the provision of public services to people with learning disabilities – the Health Service Ombudsman and Local Government Ombudsman (2009) published a joint report, based on findings from their investigations in response to complaints brought by Mencap following publication in October 2007 of their report *Death by Indifference* (Mencap, 2007). This report outlined case studies of six people with learning disabilities who Mencap believed died unnecessarily as a result of receiving a lower standard of healthcare than afforded to the general public. The report prompted an independent inquiry into access to healthcare for people with learning disabilities, '*Healthcare for All*' which reported in July 2008 (DH, 2008).

Strategic plan 2010-2015

The *Strategic plan 2010-2015 – position statement and action plan for learning disabilities*, CQC (Care Quality Commission, 2009) sets out early thoughts of the CQC about an approach to ensure not only that services for people with learning disabilities reach basic standards of quality and safety, but also improve. It provides some priority actions for CQC to take to ensure that, working with others, they can make a difference to services for people with learning disabilities.

The report outlines three key areas for improvement, which are:

- Ensuring that the care of people with learning disabilities becomes more person-centred, including a greater focus on person-centred plans.
- Ensuring that people with learning disabilities receive care that is safe.
- Improving the commissioning of services for people with learning disabilities.

National study – Specialist inpatient learning disability services

National study – Specialist inpatient learning disability services – Follow-up audit of services 2008/09 (Care Quality Commission, 2009a) sets out the findings and subsequent recommendations from an audit of 43 services across 37 organisations between September 2008 and January 2009 – which was a follow-up to the audit conducted in 2007. The inspections conducted with the 43 services found ‘...that the quality of specialist healthcare services for people with learning disabilities is at best inconsistent and at worst damaging...’.

Commissioning Specialist Adult Learning Disability Health Services

Commissioning Specialist Adult Learning Disability Health Services (DH, 2007) details good practice guidance on the commissioning of specialist learning disability health services for adults, in particular to assist in responding to shortcomings identified in these services in recent Healthcare Commission reports including those into abuse in Cornwall and Merton and Sutton. It included recommendations relating to offenders with learning disabilities, in particular to carry out health screening to identify those in prison who have learning disabilities and the health needs they may have and to provide links to community learning disability teams.

Commissioning guidance

The recently published commissioning guidance for Clinical Commissioning Groups (IHAL, 2012) has been written for CCGs to assist them to:

- Commission high quality, cost effective general and specialist health services for people with learning disabilities;
- Jointly commission services for people who challenge services and those with complex needs;
- Work with Local Authorities and others to address the social factors which adversely affect the health of people with learning disabilities.

Fulfilling and rewarding lives

Fulfilling and rewarding lives (DH, 2010) is Statutory Guidance that focuses on the seven areas required by the Autism Act 2009, in each case identifying what health and social services bodies are already expected to do, and then setting out any additional requirements introduced by the strategy. The additional requirements are focused on achieving two key outcomes:

- improving the way health and social care services identify the needs of adults with autism, and
- ensuring identified needs are met more effectively to improve the health and wellbeing of adults with autism.

Raising our sights

In the consultation for ‘Valuing people now’, concerns were raised that needs were not sufficiently being addressed for adults with profound intellectual and multiple disabilities. *‘Raising our sights:*

services for adults with profound intellectual and multiple disabilities, by Professor Jim Mansell (DH, 2010a) responded to these concerns. The report called for the wider development of personalised services for people with profound and multiple learning disabilities (PMLD).

Equal Treatment Closing the Gap

The Disability Rights Commission publication *'Equal Treatment Closing the Gap'* (DRC, 2006) is based on an investigation which established that people with learning disabilities are less likely to receive some of the expected evidence-based checks and treatments.

A Directed Enhanced Service (DES) is currently in place to support the provision of health checks. The DES only includes those known to social services, but some areas have offered health checks to everyone on the Quality Outcomes Framework (QOF) register (NHS England, 2013).

1.4 Health inequalities amongst people with learning disabilities

Health inequalities are differences in health status between different groups of the population. A report by IHAL¹ on health inequalities noted that the poorer health status of people with learning disabilities compared to the general population has been widely recognised (Emerson et al, 2012). These differences in health status are acknowledged to be often avoidable, representing health inequalities, which those with learning disability face from an early age. The inequalities often result from barriers faced in accessing health care. Patterns of healthcare provision for people with learning disabilities are likely to be in contravention of legal requirements under various acts of parliament, including the Disability and Equality Act 2010 (Emerson et al, 2012).

Mortality

A study by Tyrer and McGrother (2009) found mortality rates amongst people with moderate to severe learning disabilities to be almost three times higher than in the general population. They noted that it is not possible to say how many of these deaths would be unexpected, as people with learning disabilities often have significant comorbidity, such as physical impairments, congenital heart malformations and mental disorders, which all incur a greater risk of death. However, this would not explain all the difference.

Morbidity

A report by Emerson et al (2012) summarised the literature on inequalities in health status faced by those with learning disabilities. Some examples are as follows:

- Amongst children with learning disabilities, 36% have psychiatric disorders, compared to 8% amongst children with no learning disability.

¹ IHAL: Improving Health and Lives; Learning Disabilities Observatory

- Between 10%-15% of people with learning disabilities have challenging behaviours (including aggression, destruction and self-injury).
- The risk of epilepsy is at least 20 times higher amongst those with learning disabilities than for the general population. The NHS Information Centre study into access to healthcare found that, of all people with epilepsy, those with learning disability had higher rates of seizures (NHS IC, 2010). It was noted that patients with learning disability and epilepsy often have many different seizure types, which may be more difficult to treat.

Social determinants and individual lifestyle factors

The Marmot review recognised that health inequalities are the result of an interaction of a range of different factors, including housing, poverty, employment, education, social isolation and disability, all of which are strongly affected by economic and social status (Marmot, 2010). These social determinants of health can influence lifestyle factors (for example leading to poor diet) and are related to other factors such as stigma and bullying, all of which can have a negative impact on health and wellbeing. People with learning disabilities are at increased risk of disadvantage relating to the social determinants of health.

Across England, there are significant variations in total NHS expenditure and expenditure per person on specialist services for those with learning disabilities, indicating health care inequalities between areas (Emerson et al, 2012).

Further details relating to health and social inequalities for those with learning disabilities can be found in Section 3 (Health Profile) and Section 4 (Social Profile) of this report.

2. Demography of learning disability and autism in Merseyside and North Cheshire

Age, sex, deprivation and ethnic group

Learning disability and autism have some associations with age, gender, ethnicity and deprivation, identified by Emerson and Baines (2010) as follows:

- *Age*: Due to the reduced life expectancy of people with learning disabilities, learning disabilities are significantly more prevalent in younger adult age groups. As a result, areas with younger demographic profiles would be expected to have increased number of adults with learning disabilities and autism.
- *Gender*: Of those known to services, learning disability appears to be more prevalent amongst men. The rate of autism among men (1.8%) is higher than that among women (0.2%) (HSCIC, 2009).
- *Ethnicity*: Severe learning disabilities are more common among Pakistani and Bangladeshi children. As a result, areas with higher proportions of young Pakistani and Bangladeshi adults would be expected to have an increased number of adults with learning disabilities and autism.
- *Deprivation*: Learning disabilities are more common in poorer households and less severe learning disabilities are also more common in poorer communities. As a result, more socially deprived areas would be expected to have an increased number of adults with learning disabilities and autism. However, this effect may not be particularly pronounced as autism is less common among people with less severe learning disabilities.

Difference between known and true prevalence (i.e. met and unmet need)

Amongst children, although having a moderate or severe learning 'difficulty' does not always imply a learning 'disability', the likelihood is that for the majority, this will be the case. Nationally, there is a large difference between the estimated prevalence of moderate or more severe learning difficulties in schools (around 24.5 per 1,000) and those adults estimated by GPs and adult social services to have learning disability (4.3 per 1,000). This would suggest that for those recognised in schools as having a moderate or severe learning difficulty, many will develop into adults with a learning disability that is unknown to their GP and will not be known by the hospital if the individual requires a hospital visit (Emerson and Baines, 2010). There is further discussion of this issue in Section 2.2.

Collection of ward level data was considered, but this would probably only reveal the location of supported living units and would not help identify unmet need, so it was decided not to pursue this line of enquiry.

2.1 Estimated prevalence and projections: learning disability

It is important to consider the hidden population with learning disability – those not using services (Emerson, 2011). Emerson and Hatton (2004) noted that research indicates that people with learning disabilities who are not known to specialist services may still have some significant support needs, being significantly more likely than their peers to be still living with their parents, be unemployed, have literacy and numeracy problems and to experience high levels of psychological distress.

Emerson and Hatton (2004) suggested that roughly 20 people in every 1,000 have a learning disability, but only 4.6 per 1,000 of these are likely to be known to local health and social services. These numbers vary with age. Emerson and Hatton estimated the numbers known to services (administrative prevalence) for each local authority for 5 year age bands up to 80+. Estimates were based on a sample of local authority learning disability registers combined with census population data. They added estimates of 'hidden' numbers with learning disabilities (mainly mild) to calculate estimates of true prevalence.

Table 2 below shows the estimated true prevalence for each age group and sex. The national estimates in Table 2 are adjusted to take into account variations relating to ethnicity (i.e. the increased prevalence of learning disabilities in South Asian communities) and mortality (i.e. both increased survival rates of young people with severe and complex disabilities and reduced mortality among older adults with learning disabilities).

Table 2
Estimated True Prevalence of Learning Disabilities

Age	Male	Female	Total
0-4	0.19%	0.11%	0.15%
5-9	1.21%	0.72%	0.97%
10-14	2.76%	1.73%	2.26%
15-19	3.22%	2.10%	2.67%
20-24	3.09%	2.11%	2.60%
25-29	2.84%	1.98%	2.40%
30-34	2.87%	1.97%	2.41%
35-39	2.82%	1.95%	2.38%
40-44	2.86%	1.95%	2.40%
45-49	2.66%	1.84%	2.25%
50-54	2.51%	1.74%	2.12%
55-59	2.44%	1.74%	2.09%
60-64	2.34%	1.62%	1.97%
65-69	2.17%	1.46%	1.80%
70-74	2.08%	1.42%	1.72%
75-79	1.89%	1.25%	1.52%
80+	1.86%	1.23%	1.43%
Total	2.41%	1.62%	2.00%

Source: Emerson and Hatton (2004)

Children

In the absence of any other data on disabilities, the data on learning difficulties from *Improving Health and Lives: The Learning Disabilities Observatory (IHAL)* is a proxy indicator of the prevalence of learning disabilities amongst children.

IHAL considers that children with learning difficulties at 'school action plus' level or above have a learning disability. '**School action plus**' requires teachers to monitor the different or additional needs of the pupil, and put into place any short term targets and observe what they achieve. 'School action plus' is where school action has not helped the pupil to make adequate progress in their education. School action plus seeks advice from the Local Education Authority's support services, from health and social work professionals, giving recommendations on how to work more effectively with the child in class. A **statement of special educational needs** will be used if the child's needs are not met by the school action plus (IHAL, online)².

The Learning Disabilities Observatory (IHAL) use the Department of Education categories for classifying the different levels of learning difficulties, as follows:

1. Moderate learning difficulties: Quite often children with moderate learning difficulties find it hard to attempt new tasks alone and require individual pupil support, this is a result of low levels of self-esteem and low confidence in their own abilities to complete the task.

2. Severe learning difficulties: School children with severe learning difficulties experience significant intellectual cognitive impairments which require a high level of support in school.

3. Profound and multiple learning difficulties: School children with profound and multiple learning difficulties can often have more than one disability. These disabilities can be physical and sensory, but they will also have significant problems with learning. Most parents of children with profound and multiple learning difficulties find that residential schools offer the best support.

4. Autistic spectrum disorder: School children with Autistic Spectrum Disorders can find changes to routine very unsettling. Pupils need to be informed and prepared in advance of any changes. Some get special support in mainstream school, and some attend specialist schools. Only certain levels of the Autistic Spectrum are given Statements of Special Needs.

IHAL estimates that:

- 21 children in every 1000 have a moderate learning difficulties
- Just over three and a half have severe learning difficulties
- Just over one has profound and multiple learning difficulties

Data on learning difficulties has been used here as a proxy indicator of the prevalence of learning disabilities amongst children. IHAL took numbers of schoolchildren reported as having 'learning difficulties' in the 2010 and 2011 annual school censuses. They used modelling techniques to make allowance for differences in the way different local authorities code learning difficulties. Some seem to have higher and some lower thresholds. Their modelled data show how many schoolchildren

² SEN Statements and Learning Difficulty Assessments are soon to be replaced by the 0 – 25 integrated Education, Health and Care Plan (EHC Plan) for individual children and young people with special educational needs and disabilities (DfE, 2013)

aged 7-15 with learning difficulties can be expected to live in each region, local authority and ward in England.

Table 3 gives estimates of numbers aged 7-15 expected to have different levels of learning difficulties in each local authority in Merseyside and North Cheshire, excluding those with a mild learning difficulty.

Table 3
Number of children aged 7-15 expected to have learning difficulties, 2010

LA	All pupils	Severe learning difficulties	Profound and multiple learning difficulties	Moderate learning difficulties	Autism spectrum disorder
Halton	13,553	45	16	656	132
Knowsley	16,917	64	23	886	140
Liverpool	42,951	160	57	2224	384
Sefton	26,641	88	31	920	261
St Helens	18,049	66	73	753	177
Warrington	21,145	62	22	604	212
Wirral	33,016	104	38	1352	329
Total Merseyside and North Cheshire	172,272	589	260	7,395	1,635

Source: IHAL website, accessed May 2013, from 2010 school census

<http://www.improvinghealthandlives.org.uk/projects/howmanyhavelearningdisabilities/numbers/index.php?LA=00BX>

The severe learning difficulty category will not capture all those with learning disability. The moderate learning difficulty category is broad and will include many children with no learning disability. There is a need for data on the numbers of children with a learning disability.

Adults

The Learning Disability Observatory at IHAL have used Emerson and Hatton's (2004) paper to calculate estimated known and true prevalence of learning disability amongst adults for each local authority. Estimates for Merseyside and North Cheshire are shown in Figure 1. Estimates relate to total learning disabilities (including mild, moderate and severe). The total numbers for Merseyside and North Cheshire are 33,579 (estimated true prevalence) and 7,595 (number probably known to services) aged 18 plus.

The estimates do not take into account local variations, so that there will be an over-estimate in communities with a low South Asian community, and an under-estimate in communities with a high South Asian community (Emerson and Hatton, 2004). In Merseyside and North Cheshire, there are relatively low proportions of people of South Asian origin.

Figure 1
(Note: includes those aged 65+)

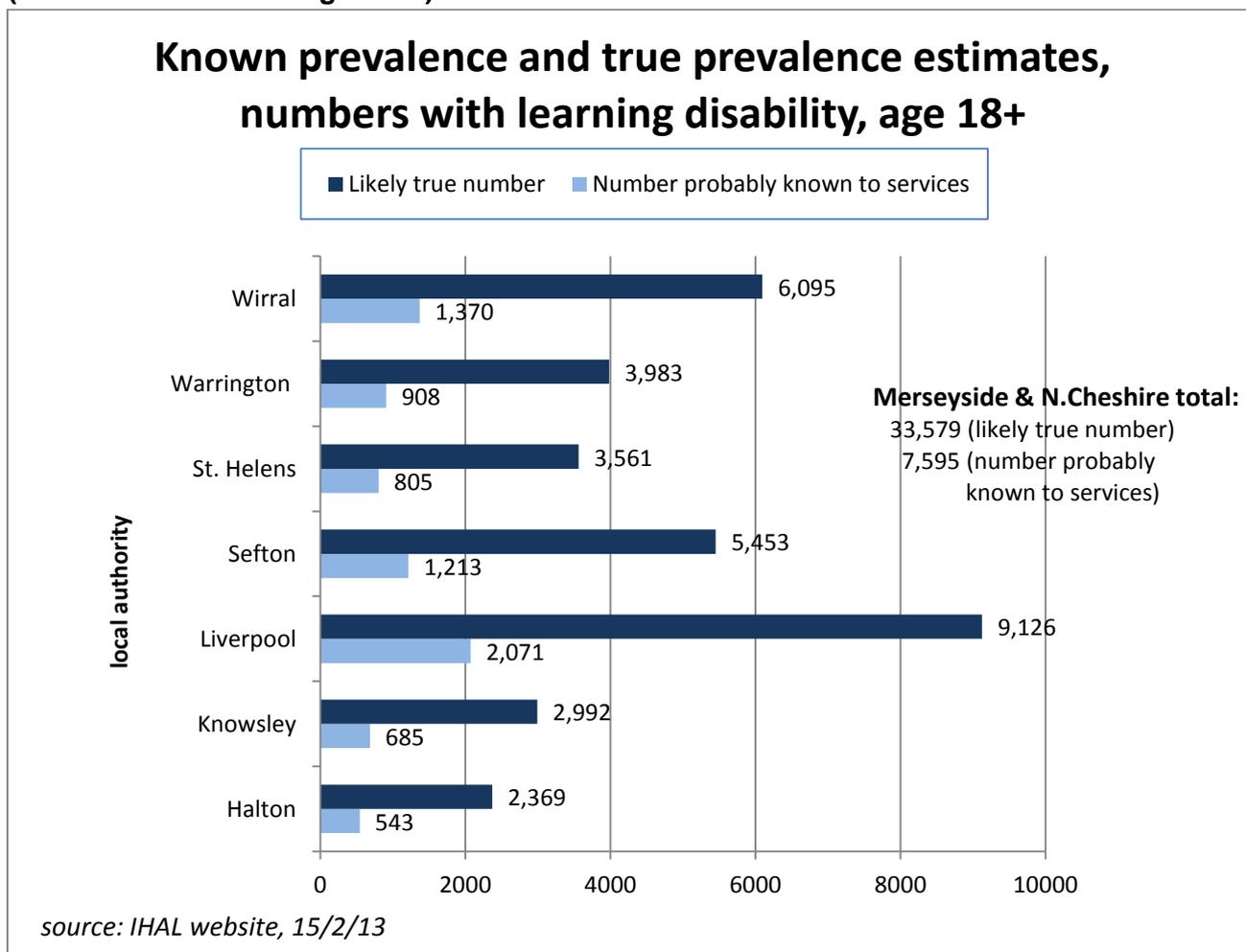
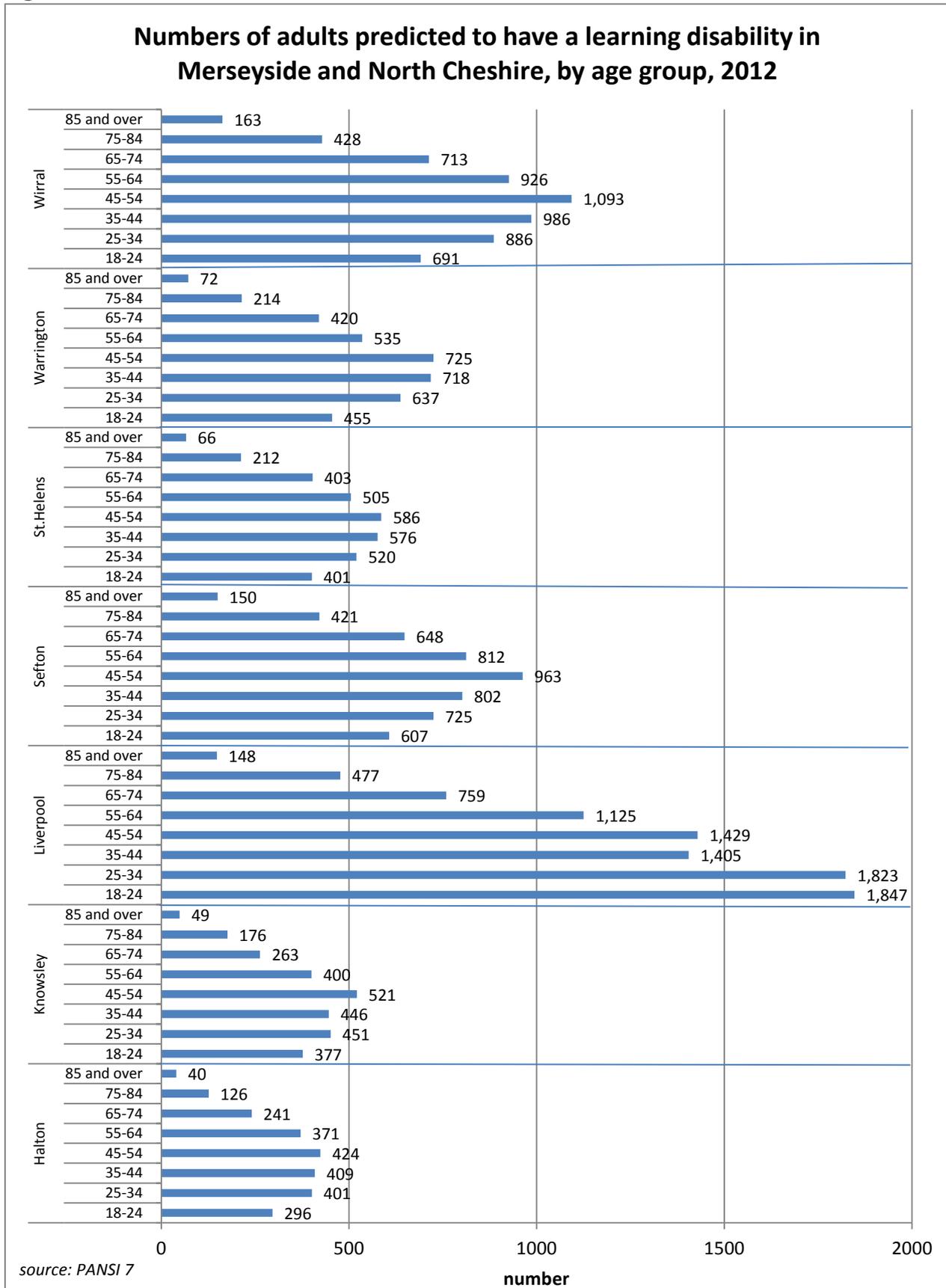


Figure 2 shows the prevalence across Merseyside and North Cheshire by 10 year age bands. In Liverpool, the proportion of people aged 25 and under estimated to have learning disabilities is relatively high. This reflects the high proportion in this age group amongst the general population in Liverpool.

In each local authority, totals taken from the PANSI (Projecting Adult Needs and Service Information) database were slightly less than the totals taken from the IHAL website (shown above in Figure 1). This could be because the IHAL data was based on an earlier version of PANSI (version 6).

Note: data are taken from PANSI version 7 which is an update to version 6 and is based on ONS 2011, with projections up to 2020 (not 2030, as in version 6).

Figure 2



Projections

Projections of future numbers of people with learning disability are presented in the PANSI database. They are based on the prevalence rates in the report by Emerson and Hatton (2004) (see Table 2 above). Amongst those aged 18-64, numbers are expected to decrease slightly between 2012 and 2020 in each local authority except Warrington (Figure 3). Although numbers are much smaller amongst those aged 65+, they are expected to increase steadily in each local authority (Figure 4).

Figure 3

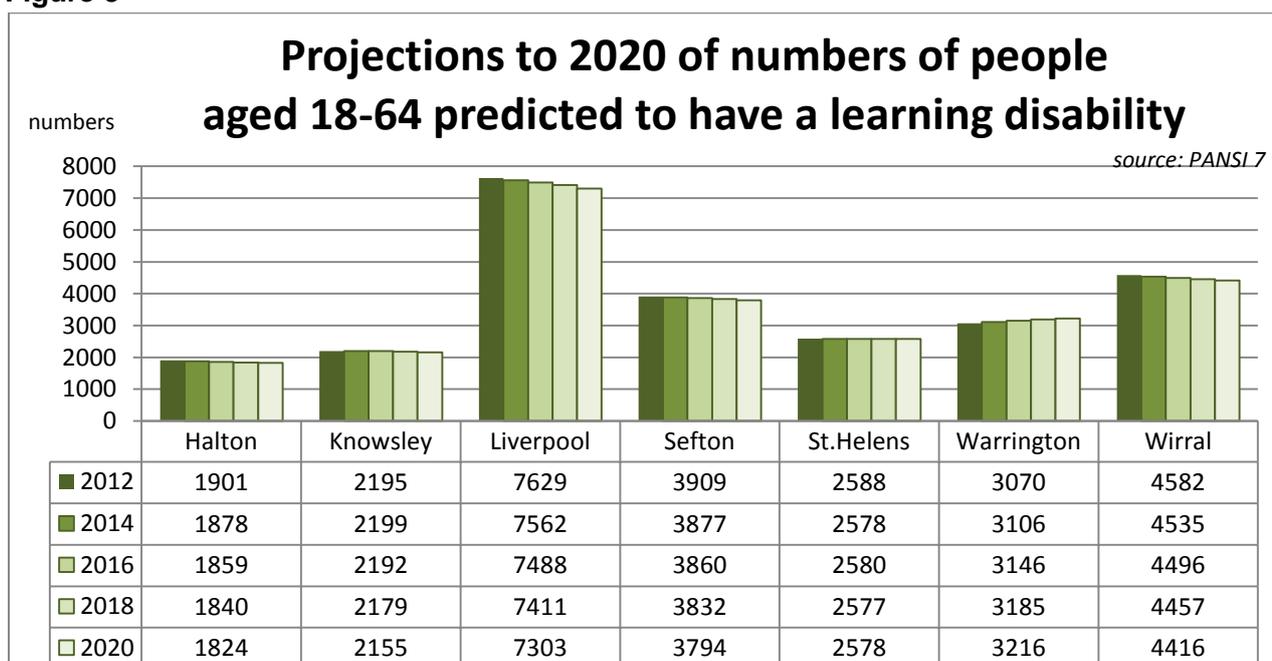
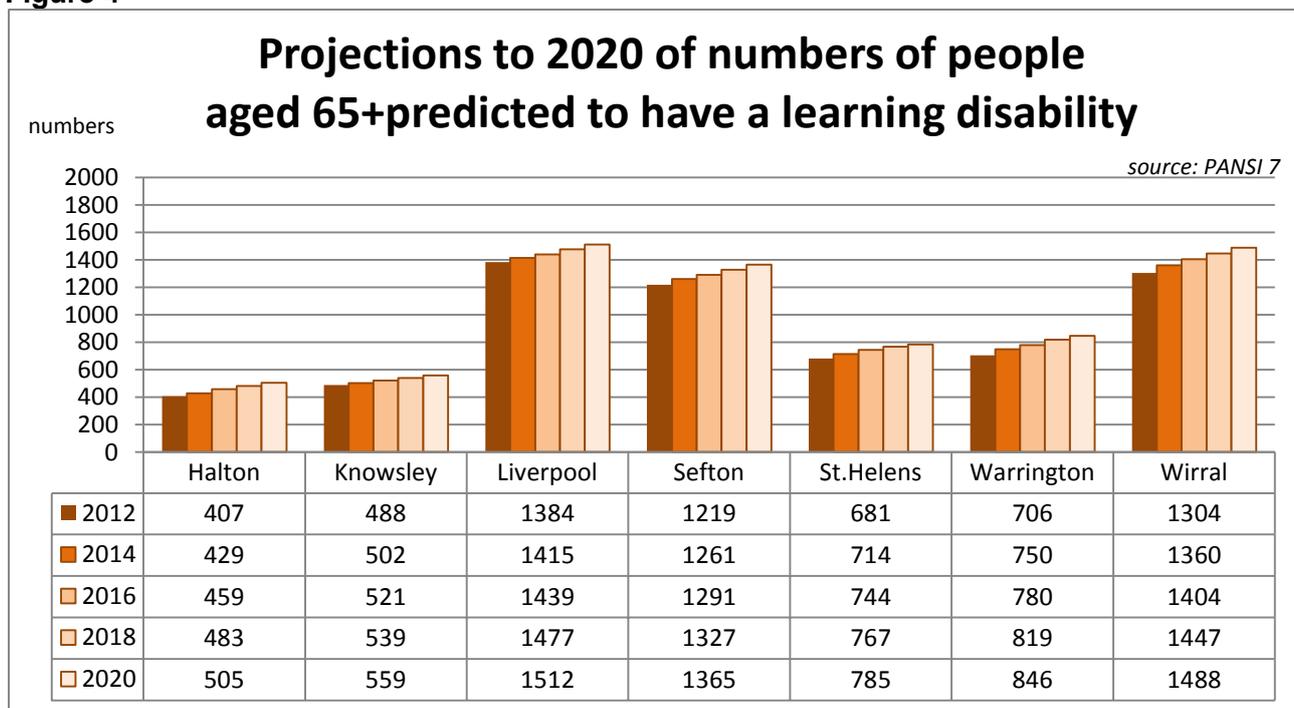


Figure 4



Moderate and Severe Learning Disability

PANSI data estimates are also available for two sub-categories of learning disability: 'moderate and severe' and 'severe' learning disability. These are the groups of people most likely to be in receipt of services and numbers should therefore correspond to the 'known' or 'administrative' prevalence of learning disability.

Merseyside and North Cheshire

Table 4 shows numbers with moderate or severe learning disability for each local authority in Merseyside and North Cheshire. Numbers are slightly different to the known prevalence data shown in Table 5 (also see Figure 5 in Section 2.2 below). There were estimated to be 6,641 people with moderate and severe learning disability in Merseyside and North Cheshire in 2012. Four out of five (80.2%) of this number were actually known to services (5,325). In Warrington there were far fewer people known to services than would be expected from the estimated numbers (only 57.7%). Known numbers are also less than expected in each of the other local authorities except Knowsley, where there are more known to services than predicted to have moderate or severe learning disability (see last column, Table 5).

Table 4
Numbers predicted to have a moderate or severe learning disability aged 18-64

	2012	2014	2016	2018	2020
Halton	482	482	483	483	484
Knowsley	558	561	564	564	563
Liverpool	1,892	1,887	1,881	1,874	1,861
Sefton	1,040	1,040	1,042	1,041	1,040
St. Helens	675	679	684	687	691
Warrington	789	804	818	833	846
Wirral	1,205	1,204	1,204	1,201	1,200
Total Merseyside and North Cheshire	6641	6657	6676	6683	6685

Source: PANSI 7

Table 5
Numbers with learning disability known to local authorities, 18-64

	2011/12	Known as % of predicted (2012, table 4)
Halton	395	82.0%
Knowsley	670	120.1%
Liverpool	1,445	76.4%
Sefton	795	76.4%
St. Helens	545	80.7%
Warrington	455	57.7%
Wirral	1,020	84.6%
Total Merseyside and North Cheshire	5325	80.2%

Source: NHS IC ASCCAR L2 (1st data column)

Table 6 shows future predicted numbers of those with severe learning disability. Between 2012 and 2020, numbers are expected to fall or remain constant in each local authority, with the exception of Warrington, where numbers are likely to rise from 183 in 2012 to 191 in 2020.

Table 6
Numbers predicted to have a severe learning disability
aged 18-64

	2012	2014	2016	2018	2020
Halton	113	111	110	109	109
Knowsley	130	131	130	130	129
Liverpool	466	462	459	455	450
Sefton	230	228	227	226	225
St. Helens	154	153	153	153	153
Warrington	183	184	187	189	191
Wirral	271	268	265	263	262

Source: PANSI 7

Numbers of those with profound multiple learning disabilities are smaller than those with severe learning disability. This group of people has particular needs and numbers are presented next.

Profound and multiple learning disability

Definition: An individual with an IQ of less than 20 has a profound learning disability (ICD classification, see Table 1 above). People with profound and multiple learning disability (PMLD) have more than one disability, the most significant of which is a profound learning disability. They have great difficulty communicating and need high levels of support with most aspects of daily life. Many people will have additional sensory or physical disabilities, complex health needs or mental health difficulties. The combination of these needs and/or the lack of the right support may also affect behaviour. Some other people, such as those with autism and Down's syndrome may also have profound and multiple learning disabilities (Mencap, 2010 and PMLD network).

People with PMLD are a separate group from those with 'complex' or 'high support' needs, because in addition, they have a learning disability. For example, someone with a physical disability and communication impairment but high intellectual ability may be described as having complex needs or high support needs (PMLD network).

There are about 16,000 adults with PMLD in England (Mencap, 2010). At present, there is a lack of data on numbers of people with PMLD known to local authorities.

Mencap highlighted the key issues relating to PMLD:

- People with PMLD are frequently excluded and remain some of the most disadvantaged people within our society. For this to change there needs to be better understanding of their distinctive needs. The numbers and needs of people with PMLD also need to be understood so that there can be better planning of services. This was also emphasised in 'Raising our Sights (see Box 1).

- People with PMLD have specific communication needs and many have complex health needs. We need to meet these needs if people with PMLD are to be included like everyone else. This requires investment in services and training for professionals working with people with PMLD, such as training in how to communicate with people with PMLD.
- People with PMLD are not properly represented in self-advocacy groups and groups involved in policy-making. It is important that the needs of people with PMLD are represented in these groups so that decision makers understand what their needs are and plan appropriate services.

(Mencap 2013)

Box 1

The need for local data on PMLD

‘Local authority social care services, together with their education and health partners, should keep up-to-date information about the number, needs and circumstances of people with profound intellectual and multiple disabilities in their area currently and projected future to enable effective planning of services’

Raising Our Sights, DH, 2010a

Merseyside and North Cheshire

There is no local data available on known numbers of adults and children with PMLD (only on children with profound and multiple learning *difficulty*). Estimates are presented as follows:

Children

There is some school census data on children with profound and multiple *difficulties*, but this is likely to be different to the number with *disabilities* (see discussion in Section 1.2 and start of Section 2). Table 7 (an extract from Table 3 above), shows the numbers of children aged between 7 to 15 expected to have profound and multiple learning difficulties in Merseyside and North Cheshire (total 260). This is modelled data, calculated by IHAL, based partly on the 2010 school census. As the educational needs of these children are unlikely to be met in mainstream schools, the variation in numbers is possibly due to the existence of special schools in some areas – although IHAL may have taken this into account when they calculated their estimates. Numbers in St. Helens appear to be very high, at more than double the rate in other local authorities in Merseyside and North Cheshire. If the school census counts which school the child attends, rather than where the child lives, this could be explained by children crossing boroughs to go to special schools.

Table 7

Number of children aged 7-15 expected to have profound and multiple learning difficulties, 2010

LA	Number of pupils	Number with profound and multiple learning difficulties	Rate per 1,000*
Halton	13,553	16	1.2
Knowsley	16,917	23	1.4
Liverpool	42,951	57	1.3
Sefton	26,641	31	1.2
St Helens	18,049	73	4.0
Warrington	21,145	22	1.0
Wirral	33,016	38	1.2
Total Merseyside and N.Cheshire	172,272	260	1.5

Source: IHAL website, accessed May 2013

*rates calculated from their data

<http://www.improvinghealthandlives.org.uk/projects/howmanyhavelearningdisabilities/numbers/index.php?LA=00BX>

Data from the annual school census, made available by Liverpool for 2012 and Wirral for 2013, shows that there are more children with profound and multiple learning difficulties than predicted in the IHAL estimates (Table 8). The IHAL data was based partly on the school census (see previous paragraph).

Table 8

School Census data

Pupils with Statements and School Action Plus

	Profound & Multiple Learning Difficulty
Liverpool, Jan 2012	76
Wirral, Jan 2013	62

Adults

Despite the Department of Health call for local data (see Box 1 on previous page), local authority registers of learning disability do not have a category indicating PMLD. Emerson (2009) produced a paper estimating the future numbers of adults with PMLD in England. He suggests that there will be a sustained and accelerated growth in numbers of adults with PMLD, with an annual percent increase of 1.8%. There will be a corresponding increase in need and demand for health and social care services for adults with PMLD.

This increase is due to a combination of factors, including changes in: birth rates; rates of incidence of children being born with or acquiring of PMLD; and changes in mortality amongst infants, children and adults with PMLD (Emerson, 2009).

In an average area in England with a population of 250,000, Emerson predicted that there would be around 78 adults with PMLD in 2009, rising to 105 in 2026. The number of young people with PMLD becoming adults (i.e.18) in any given year will rise from 3 in 2009 to 5 in 2026 (per 250,000). (N.B. the population of Liverpool is very close to Emerson’s ‘average area population’ of 250,000).

Rates would be higher in communities that have a younger demographic profile and in those that contain a greater proportion of people of Pakistani or Bangladeshi origin. Emerson’s estimates allow for demographic changes and the increased mortality of people with PMLD.

Emerson’s PMLD estimates have been applied to Merseyside and North Cheshire population estimates. Numbers across Merseyside and North Cheshire will rise from 436 in 2013 to 489 in 2021. Table 9 gives numbers expected in each local authority.

All those with profound and multiple learning disability are likely to be known to services, but attempts to identify numbers were challenging due to no specific register being kept. As a proxy measure, it was assumed that residents with learning disability who meet the Fair Access to Care Services banding definition of critical and received services during 2012/13, are likely to have a profound level of disability. However, this is likely to provide an overestimate, as there are a number of reasons a person may be assessed as critical which may not be related directly to level of disability. As an example, an individual may be banded ‘critical’ due to carer circumstances not being optimally configured to ensure the safety of the individual. Table 10 shows that where this data was available, totals were at least twice as high as Emerson’s estimates (Table 9). There is a need for accurate locally available data on numbers with PLMD.

Table 9
Estimated number of adults (18+) with profound and multiple learning disability, 2013 to 2021

	2013	2014	2015	2016	2017	2018	2019	2020	2021
Halton	31	32	32	33	33	34	34	35	35
Knowsley	43	44	45	46	47	48	49	50	51
Liverpool	79	80	81	82	82	83	84	85	86
St. Helens	83	84	85	86	87	88	89	90	91
Sefton	56	57	58	59	60	61	62	63	64
Warrington	63	64	65	66	67	68	70	71	72
Wirral	81	82	83	84	85	86	88	89	90
Merseyside and North Cheshire	436	443	450	456	462	468	476	483	489

Source: Based on estimate of 78 per 250,000 in 2009 (Emerson 2009) and annual % change estimates, applied to Merseyside and North Cheshire population estimates (ONS interim 2011-based, released Sept 2012).

Table 10
Learning disability residents meeting the ‘Critical’ eligibility threshold, receiving social services, 2012/13

	female	male	Total
Liverpool	62	79	141
St. Helens			304

Source: Liverpool and St. Helens local authorities, Intelligence Analysis, Adult Social Care & Health

Guidelines: people with profound and multiple learning disabilities

Guidelines on the care and management of people with PMLD are summarised in the Appendix.

Example of local delivery: estimating the prevalence of PMLD

Lambeth: Estimating numbers with PMLD

The Lambeth PMLD project, led by Mencap, explored the numbers and needs of people with PMLD in Lambeth (Lambeth Mencap, 2010). Local authority registers of learning disability do not have a category indicating PMLD. In Lambeth, they developed criteria which, when applied to the learning disability register database information, would identify people with the health and social care needs and skills associated with people with PMLD. These were people who:

- had a severe learning disability (there is no ‘profound’ category so they had to look at the wider ‘severe’ category)
- needed full-time support
- used speech and signing ‘sometimes’ or ‘never’ (most people with PMLD will use little or no formal communication)
- were not able to read or write at all
- were not able to cook alone
- needed support when using the toilet.

The estimate of 81 people in Lambeth identified as likely to have PMLD fitted with the estimate given in Emerson's report ‘Estimating future numbers of people with profound and multiple learning disabilities in England.’

Of the 81 adults with learning disability, 34 (42%) lived in the family home. A priority issue to come out of the project was to ensure family carers who are caring for someone with PMLD in the family home get the support they need - help from support staff with the right skills, reliable, high quality respite, better information and advice about local services and how to manage direct payments and individual budgets.

Findings also indicate that people with PMLD living in the family were less likely to have a person-centred plan or health action plan which suggests family carers need more support with these.

http://www.mencap.org.uk/sites/default/files/documents/2010-10/Lambeth%20PMLD%20report%20-%20FINAL_v4.pdf

2.2 Known prevalence (local authority data): learning disability

Children

Local authorities are not required to maintain registers of children with learning disabilities. As a proxy, some local authorities have looked at data on children with statements of educational need (SEN) and learning difficulties. However, this does not reflect the spectrum of disability and is only a weak proxy measure for severity (St. Helens JSNA, 2012). It is also likely that there are different definitions of each level of learning difficulty used by each school.

Table 11 below shows data provided by representatives on the project working group on numbers of schoolchildren in Liverpool and Wirral who have either Statements of Educational Need or School Action Plus status for learning difficulty. Children with learning difficulties who leave school at 16 will not be captured. Wirral noted that the school census is the only regularly updated source of data on learning difficulty in school-aged children that the local authority have.

Wirral data is for January 2013 and represents the known prevalence of learning difficulty. Although taken from the same school census, numbers are quite different to the true prevalence estimates calculated by IHAL in Table 3 above (although they are for a later time period and slightly broader age range). For each category, numbers from the school census are much higher than the estimates in the IHAL calculations, with the exception of 'moderate learning difficulty', where there are fewer (841 in the census, compared to 1,352 in IHAL). The school census has an extra 'specific learning difficulty' category, which is not included in the IHAL calculations. IHAL did note that there are differences in the way different local authorities' code learning difficulties, and their calculations made allowances for these differences.

Numbers in Liverpool follow the same pattern (Table 11), with numbers in the school census much higher than those in the IHAL estimated prevalence of learning difficulty (Table 3), with the exception of moderate learning difficulty.

Table 12 shows schoolchildren in Warrington who have Statements of Educational Need for learning difficulty (but not those with School Action Plus status). The number of those with severe learning difficulty (62) is the same as the number estimated by IHAL (Table 3). Numbers in the other categories are lower, with numbers with moderate learning difficulty much lower (240, compared to 604 in the IHAL estimates).

Table 11
Pupils with Statements and School Action Plus

SEN Need Type	Moderate Learning Difficulty	Profound & Multiple Learning Difficulty	Severe Learning Difficulty	Specific Learning Difficulty
Liverpool, Jan 2012	1,529	76	389	1,068
Wirral, Jan 2013	841	62	348	1,207

Source: Liverpool City Council and Wirral Borough Council, School census

Table 12
Pupils with Statements

SEN Need Type	Moderate Learning Difficulty	Profound & Multiple Learning Difficulty	Severe Learning Difficulty	Specific Learning Difficulty
Warrington May 2013	240	11	62	88

Source: Warrington Borough Council

There is limited data available on learning disability amongst children in some local authorities:

- In Sefton, the local authorities Local Partnership Board Annual Self-Assessment submission 2011/12 reported that there were 282 males and 69 females (total 351) aged 14-17 with a learning disability. Four of these individuals belonged to an ethnic minority group.
- Data supplied by Knowsley in April 2013 indicated that there were 53 children with learning disability known to services. This is a lot less than the estimate of learning difficulties calculated by IHAL in Table 3 above, where there were expected to be 64 children with severe, 23 with profound and 886 with moderate learning difficulty (Section 2.1).
- In Wirral, GP data was made available for children with learning disabilities (see table 14 in next Section, 2.3). In 2012/13, there were 91 children aged 0-13 and 126 aged 14-18 on the GP learning disability register (total 217 aged 0-18). This compares to the IHAL estimates of 104 with severe, 38 profound and 1352 moderate learning difficulty (Table 3, Section 2.1).

Single dataset for children and young people:

Liverpool City Council (Adults & Children's Social Care & Education) is working in partnership with Mersey Care, CCGs and external service providers such as Connexions towards producing a single dataset for children and young people. It is intended the single dataset will providing clear and comprehensive information on the needs and trends of children and young people with Special Educational Needs and Disability across services in Liverpool. To facilitate this a scoping exercise is underway to identify what datasets already exist, who they are being held by and in what system. Preliminary discussions are taking place with stakeholders to determine what information sharing agreements are in place and to identify any gaps. It is expected that the dataset will be in place in 2014/15 subject to data governance issues being met.

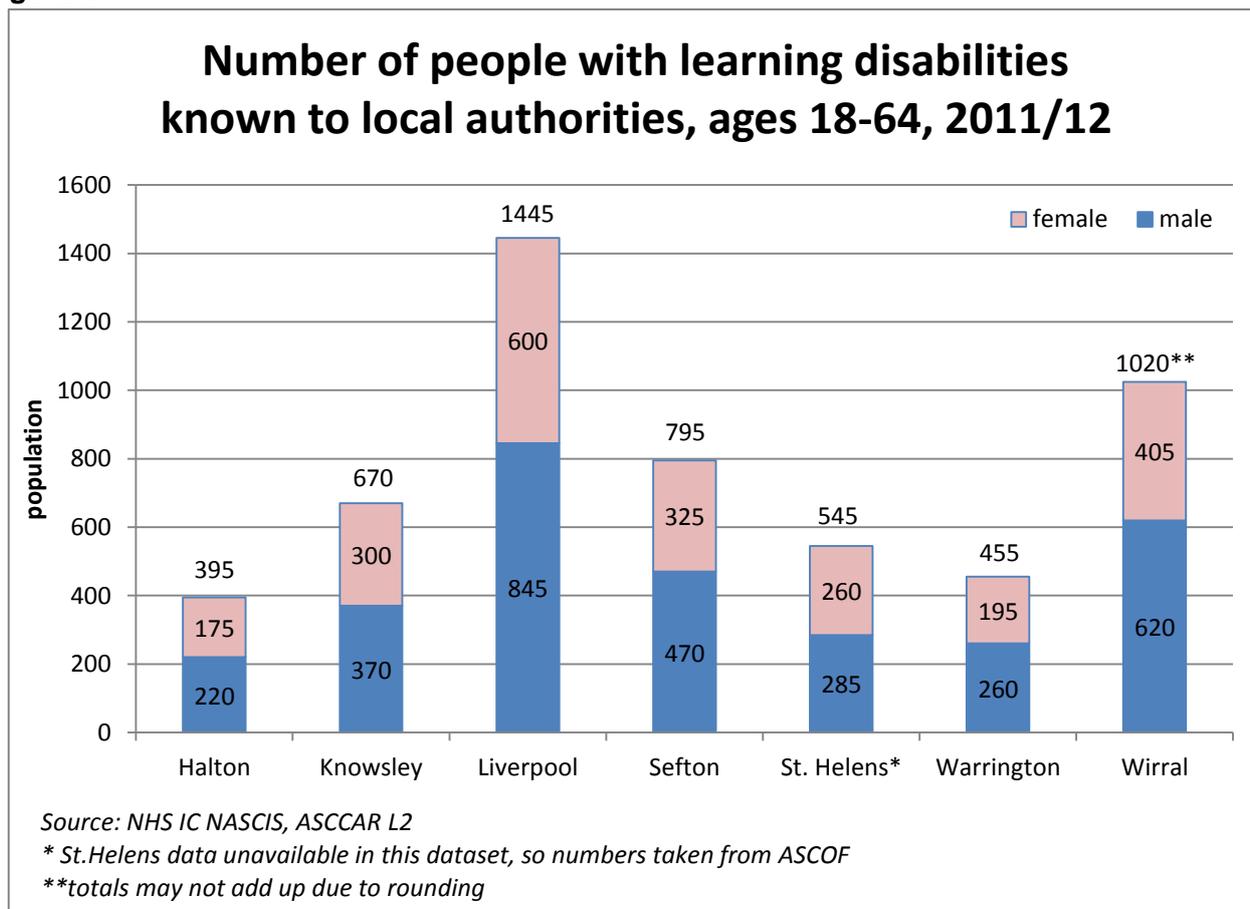
2013 Children and Families Bill

SEN Statements and Learning Difficulty Assessments are soon to be replaced by the 0 – 25 integrated Education, Health and Care Plan (EHC Plan) for individual children and young people with special educational needs and disabilities. This is outlined in the 2013 Children and Families Bill currently going through Parliament (DfE, 2013). The new arrangement should assist in ensuring that health service agreements (involving school nurses and health visitors) on identifying those with learning disability and autism are built into tendering arrangements with schools and colleges.

Adults 18-64

Known prevalence data for ages 18-64 was obtained from the Adult Social Care Combined Activity Returns (ASCCAR, NHS Information Centre). The numbers of people with learning disability known to local authorities in Merseyside and North Cheshire is shown in Figure 5 below, with a total 5,325 across the whole area (3,070 males and 2,260 females). The data relates to people of working age (18-64) and is broken down by sex. Figure 6 shows the prevalence in each local authority as a percentage of the general population. Rates of learning disability are highest in Knowsley, at 0.70% and lowest in Warrington, at 0.36%.

Figure 5



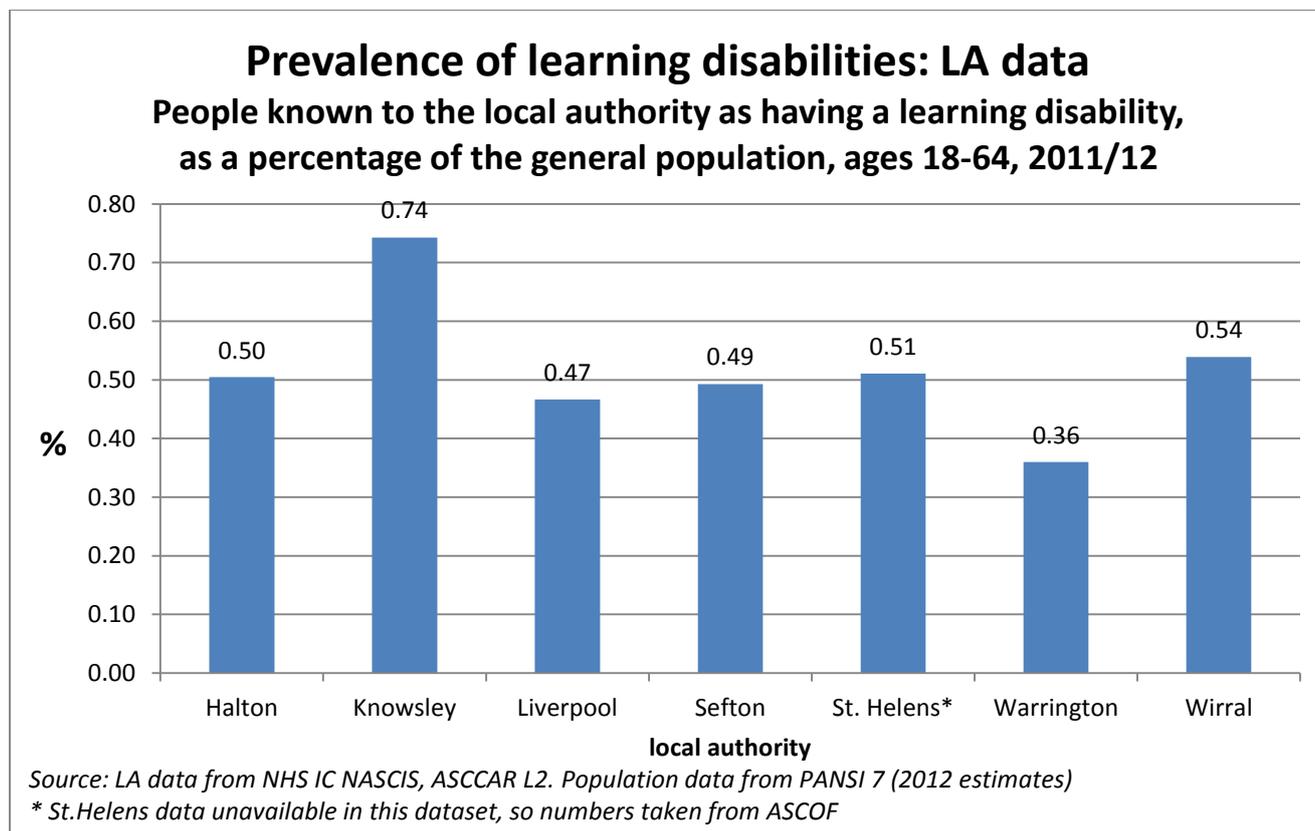
Percentages	Halton	Knowsley	Liverpool	Sefton	St Helens	Warrington	Wirral	Mside & N Cheshire	North West	England
% women	44.3	44.8	41.5	40.9	47.7	42.9	39.5	42.4	41.3	42.2
% men	55.7	55.2	58.5	59.1	52.3	57.1	60.5	57.6	58.7	57.8
	100	100	100	100	100	100	100	100	100	100

Gender

Of those known to services, learning disability appears to be more prevalent amongst men. Across Merseyside and North Cheshire, the proportion of those with learning disability who are men ranges

from 52.3% in St. Helens to 60% in Wirral (Figure 5). In 2011, there were more females than males in the general population of each local authority, which means that if rates of learning disability by sex were calculated, rates for males would be considerably higher than for females. This could be partly accounted for by the much higher prevalence of autism amongst males (HSCIC, 2009). Autistic spectrum disorders are shown by between 20%-33% of people with learning disabilities known to the local authorities (Emerson et al, 2012) (see section 2.4 for more details of autism).

Figure 6



Data provided directly from Wirral Borough Council, taken from their information system in April 2013, indicated that there were 1,563 people aged 18-64 with learning disabilities. This is higher than the 1,020 known to social services reported to the NHS Information Centre (ASCCAR) in 2011/12 (see Figure 5 above). This difference could possibly be due to numbers rising over time, but the difference is very large and requires further investigation.

Data provided by Knowsley Borough Council in April 2013 reported that there were 722 people aged 18-64 with learning disability known to services. Again, this figure is higher than the 670 reported to the NHS Information Centre 2011/12.

Warrington provided data for 2012/13 which showed that there were 451 people classified as having a learning disability, which is similar to the 455 figure reported to the NHS Information Centre in 2011/12 (Figure 5 above).

Data provided directly from Sefton had the same totals as those shown in Figure 5.

Ages 65+

Data for those aged 65 and over with learning disability is not available from the Adult Social Care Combined Activity Returns (ASCCAR, NHS Information Centre). There is no readily available data on numbers known to services aged 65+ with learning disability.

There is some data available from the local authorities Local Partnership Board Annual Self-Assessment submission. This reported that in **Sefton**, there were **41 males** and **55 females** aged 65+ with a learning disability in 2011/12.

Data from the **Wirral** indicated that there were **215** people aged 65+ with learning disabilities (data accessed April 2013).

Data provided in April 2013 by **Knowsley** reported that there were **32** people aged 65+ with a learning disability who were known to services.

In **Warrington**, there were **46** people aged 65+ recorded as having learning disability as a primary classification, 2012/13.

In **Liverpool** in 2012/13, there were a total of 110 people with learning disability known to social services aged 65+ (71 male and 39 female). Of these, 83 were community based, 19 in residential care and 3 in nursing care.

2.3 Known prevalence aged 18+ (GP data): learning disability

The Directed Enhanced Service (DES) for learning disabilities was set up in 2008 to provide primary care practices with funding to set up learning disability registers and provide health checks for people on that register. The GP Learning Disability Register is part of the Quality and Outcomes Framework (QOF) dataset. This data is only available for ages 18 plus and is not available by age group. (Although in Wirral, 2011/12 data is available this way). Wirral have recently begun to collect data on the numbers of children with learning disability. At 217 aged under 19, numbers are less than would be expected compared to Wirral schools data of 348 with severe learning difficulty.

The definition of learning disability used in primary care is based on the World Health Organisation ICD classification, using IQs (see table 1 in Section 1.2 above). However, Weston et al (2012) point out that IQ scores may not be readily available in primary care, so that in practice, the definition of learning disability tends to be based on the one used in Valuing People (DH, 2001) (see Section 1.2 above).

Merseyside and North Cheshire

Since the reorganisation of the NHS in April 2013, with Clinical Commissioning Groups (CCGs) replacing PCTs, some of the old PCTs are now served by more than one CCG. This is the case in the old Halton and St. Helens PCT, which is now replaced by Halton CCG and St. Helens CCG. Sefton PCT has been replaced by South Sefton CCG and Southport and Formby CCG.

For the purposes of this needs assessment, learning disability register data for the old PCTs has been separated into the new CCGs using practice codes.

Table 13 shows that across Merseyside and North Cheshire in 2011-12, levels of learning disability recorded in general practice were higher than the national average of 0.45% in all areas except Warrington. Levels were highest in Knowsley, at 0.70% of the total practice population aged 18 plus.

As would be expected, levels and patterns are similar to local authority learning disability register data, where percentages were highest in Knowsley (0.70%) and lowest in Warrington (0.36%) (see Section 2.2, Figure 6).

Table 13 also includes numbers on the register and practice level variation in prevalence. Variations between practices are most notable in Southport & Formby, where the percentage of the practice population aged 18 plus on the learning disability register is as high as 4.17% in one practice. In the other 20 practices, the proportion on the register varies from 0.13% to 1.28%. In the Wirral, the prevalence in one practice was 2.34%, with the rest ranging from 0.14 to 1.66.

Table 13
Number and percentage on the GP Learning Disability Register,
and range of learning disability (LD) prevalence across practices, 2011-12, ages 18+

CCG	Estimated practice population 18+	number on LD register 18+	LD prevalence (%)	Range of LD prevalence between practices in each CCG	
				lowest (%)	highest (%)
Halton*	100296	665	0.66%	0.21%	1.15%
Knowsley	124,093	863	0.70%	0.00%	1.15%
Liverpool	391,554	1,959	0.50%	0.06%	1.67%
Sefton*	126456	610	0.48%	0.05%	0.97%
St. Helens*	154012	792	0.51%	0.15%	1.33%
Southport/Formby*	99915	680	0.68%	0.13%	1.28%
Warrington	164,713	636	0.39%	0.08%	0.77%
Wirral	264,099	1,574	0.60%	0.14%	2.34%
North West			0.45%		
England			0.48%		

Source: NHS IC QOF

Note: data was for PCTs. *Practice codes have been used to separate data into CCGs

Actual numbers on the GP learning disability register are higher than numbers recorded by local authorities in Section 2.2 above. This is partly because GP data counts all those aged 18+, and data readily available from local authorities is for ages 18-64 only.

However, some of the differences appear to be larger than would be expected, for example in Halton, where there were 395 people aged 18-64 recorded by the local authority, and as many as 665 on the GP learning disability register aged 18+.

Also, on the Wirral, GP data was obtained for 2012/13 by age group, which indicated that there were 1,386 aged 19-64 and 128 aged 65+ (total 1514, see table 14 below). This compares to only

1,020 recorded as known to the local authority (2011/12) (see Section 2.2 above). (Although numbers 65+ were higher in local authority records, at 215).

These differences could be partly due to the fact that GP registers are capturing more people with learning disabilities, as they will include those not necessarily known to local authority services. They could also be due to the fact that data is not directly comparable, because GP registered populations are different to local authority resident populations. In Halton GP registered population is higher than local authority resident population. It is not possible to determine with accuracy if this is the sole reason for the difference and further investigation may be required.

GP data was obtained for Wirral for 2012/13 which includes ethnic group. There were 19 people on the GP learning disability register from minority ethnic groups. This dataset also included numbers with learning disability by age groups 0-13; 14-18; 19-25; 26-64 and 65+. This data is available because Wirral has recently set up a service level agreement (SLA) to reward GPs for improved recording of learning disability. It has had the effect of increasing figures on GP databases and has the potential to capture those not currently receiving services from the local authority.

Table 14

Wirral: Numbers on the GP learning disability register by age group, 2012/13

Age group	Number with learning disability
Children aged 0 - 13	91
Children aged 14 - 18	126
Young people aged 19 - 25	244
Adults aged 26 - 64	1142
Older people aged 65+	128
Total	1731

Guidelines: GP learning disability registers

- In order to be effective, primary care services need to ensure that learning disability QOF registers reflect local prevalence data.
- The registers should be validated at least on a yearly basis. This will enable reasonable adjustments to be made, reducing the inequalities in access to and provision of care for people with learning disabilities.

from the learning disability commissioning guide for Clinical Commissioning Groups (CCGs) (IHAL, 2012), quoting Health Self-Assessment (SAF) indicators.

2.4 Autistic Spectrum Disorder (ASD)

Autistic Spectrum Disorder (ASD) has been defined in Section 1.2. ASD has been found to have some associations with gender, age, ethnicity and socio-economic status, identified by Emerson and Baines (2010) for IHAL (see Section 2 above).

The rate of ASD among men (1.8%) is higher than that among women (0.2%) (HSCIC, 2009). The National Autistic Society noted the need for further exploration of how autism affects males and females differently. Their survey of around 3,000 people with autism and 5,500 carers found that it was harder for females to get a diagnosis and that they were more likely to be mis-diagnosed (Bancroft et al 2013). Only one-fifth of females with Asperger's syndrome or higher functioning autism had been diagnosed by the age of eleven, compared to half of males. This is possibly because autism is often seen as a male condition.

The survey found a lack of awareness amongst those making diagnostic referrals (GPs and health visitors), leading to autism being overlooked and not recognised. Fifty five per cent of people with autism said it took too long to get a diagnosis. The authors highlight the official guidelines for diagnosis (NICE, 2011 and 2012).

The National Autistic Society survey also revealed that over two thirds (38%) of adults with autism still lived at home with their parents. Of this group, around half (48%) said they would like to live in their own home, with or without support (Bancroft et al, 2013).

The survey also found that 27% of people with autism have been excluded from school, compared to 4% of children without autism.

Learning disability and autism

Autistic spectrum disorders are shown by between 20%-33% of people with learning disabilities known to the local authorities (Emerson et al, 2012).

There is even more variation in estimates of the proportion of people with ASD who have a learning disability. Emerson and Baines (2010) suggested that the estimate amongst children was somewhere between 40% and 67%. The National Autistic Society discussed possible reasons for the different estimates. They noted that some very able people with ASD may never come to the attention of services as having special needs, because they have learned strategies to overcome any difficulties with communication and social interaction and found fulfilling employment that suits their particular talents. Other people with ASD may be able intellectually, but have need of support from services, because the degree of impairment they have relating to social interaction hampers their chances of employment and achieving independence (National Autistic Society, 2013).

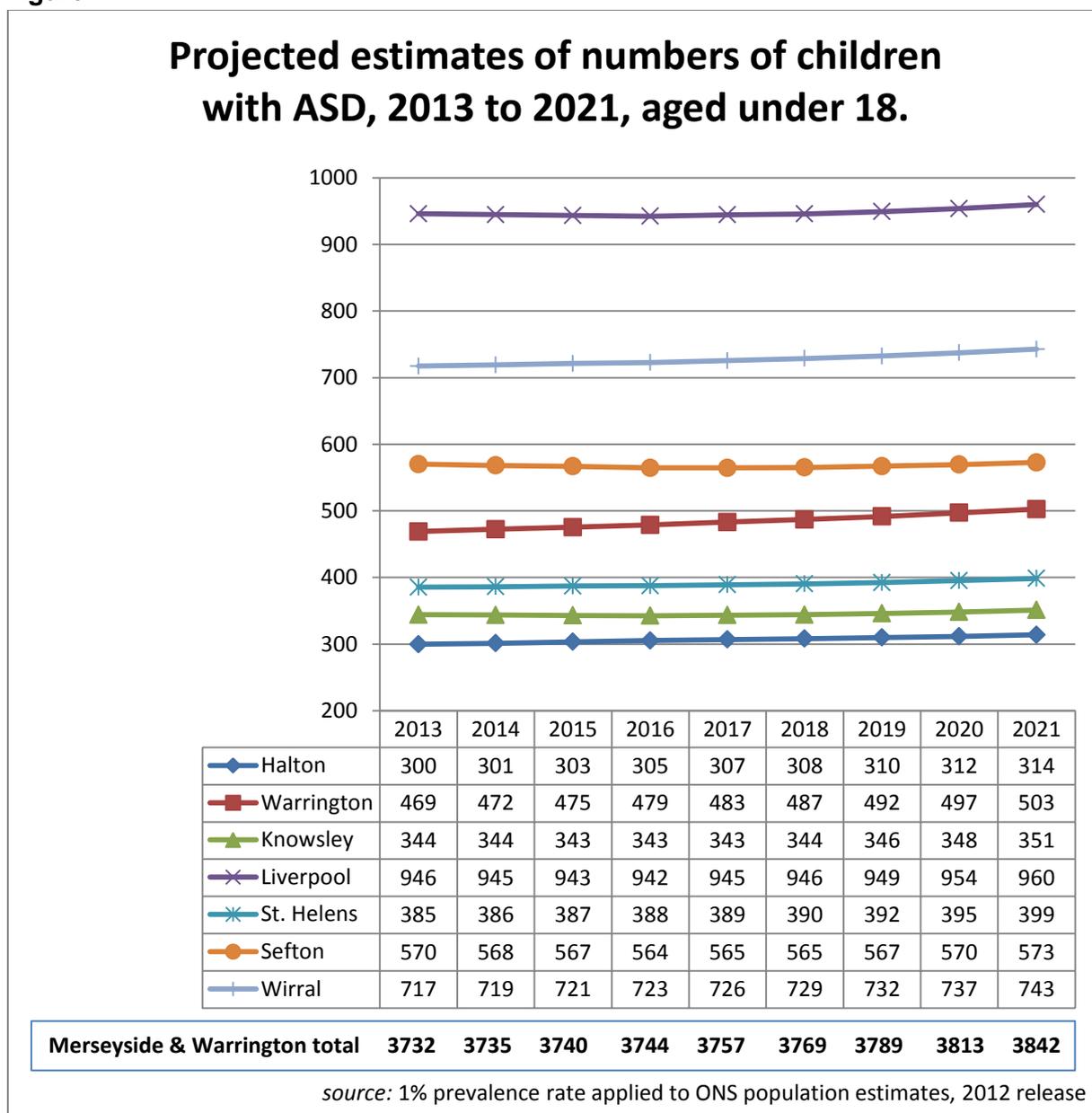
The European Commission (2005) highlights the problems associated with establishing prevalence rates for ASDs. These include inconsistencies of definition over time and between locations. Unlike learning disabilities, there is no register held by general practice. However, using data from prevalence studies, it is possible to estimate numbers.

ASD in children

Expected numbers of children with ASD have been estimated by applying the prevalence rate of 1% reported by the National Autistic Society (2013) to local populations.

Figure 7 shows the numbers of children aged under 18 estimated to have autism across Merseyside and North Cheshire, projected to 2021. Numbers are set to rise slightly in each local authority across the region. By 2021, projections indicate that there will be 3,842 children with ASD across Merseyside and North Cheshire, which is 121 more than the estimated 3,732 in 2013.

Figure 7



Emerson and Baines (2010) reviewed the most recent prevalence studies and concluded that it is likely that the prevalence of learning disability amongst children with autism is somewhere between 40% and 67%. The average prevalence across the studies reviewed by Emerson & Baines was around half (52.6%). This means that at least half of those children with autism should have come to the attention of schools as having special educational needs.

However, as noted under 'Prevalence' above in this Section, even those with autism who are intellectually able may still require support to help them to overcome communication difficulties.

Known prevalence: In practice, it would appear that numbers of those with autism recognised by the school as having special educational needs are around half of the predicted population prevalence of autism. For example in Liverpool, there were 946 children predicted to have autism in 2013 (Figure 7 above). and the school census revealed that there were 552 at statement or school action plus level for autism in 2011 (Table 15).

The first column of Table 15 shows data supplied by local authorities on numbers of school children with autism in 2013. Data obtained directly from each local authority is not comparable, as slightly different definitions have been used.

The next two columns show data from the 2011 school census, collected centrally by IHAL. They show numbers and rates of pupils with a school action plus or statement for ASD. Rates are highest in St. Helens, at 10.9 per 1,000 pupils. This is higher than the national average of 7.6. They are also higher than the national average in Sefton, Wirral and Liverpool. Halton and Knowsley have levels below the national average. These middle columns may be the most accurate to use as an indicator of levels of autism known to local authorities, as some schools may use 'school action plus' instead of statements, and these columns combine the two measures (see Section 2.1 'Children' for a definition of these terms).

The final column shows rates with a statement only for ASD. As with the previous two columns, rates are highest in Sefton, Liverpool, Wirral and St. Helens.

Table 15
Known numbers of primary and secondary schoolchildren with ASD

	*Number of children with ASD 2013 data supplied directly from local authorities NOTE: these are not directly comparable - some may include all with ASD and others only those stated	**Number with school action plus or statement for ASD, 2011	**Rate with school action plus or statement for ASD per 1,000, 2011	*** Rate with statements for ASD per 1,000 2012
Halton	167 (plus 22 with Asperger's) at school action plus enhanced	117	6.4	4.1
Knowsley	52 on statement for autism	144	6.6	4.6
Liverpool	601 (365 school action plus and 236 on statement, 2012)	552	8.0	6.6
Sefton		393	8.9	7.0
St. Helens	333 (120 primary, 213 secondary)	286	10.9	6.2
Warrington	182 on statement for autism	229	7.3	4.9
Wirral	478 on statement or school action plus	438	8.6	6.5
England			7.6	

Sources:

*LA representatives on project working group, 2013 data

** IHAL data from 2011 school census

*** CHIMAT service snapshots, accessed 18/4/13. Based on DfE data, 2012, with reference to Statements of Special Educational Need (SEN). <http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=41&geoTypeId=2>

GP data from Wirral for 2012/13 showed that there were 30 children and young people aged 0-17 with learning disability who also have autism known to general practice.

ASD in adults:

An assessment of the issues arising from completion of the local authority autism self-assessment framework in 2011 was undertaken (Roberts et al, 2012a). Issues included the identification of a major gap in local information about people with autism, such as the number of people with autism, and what services they use.

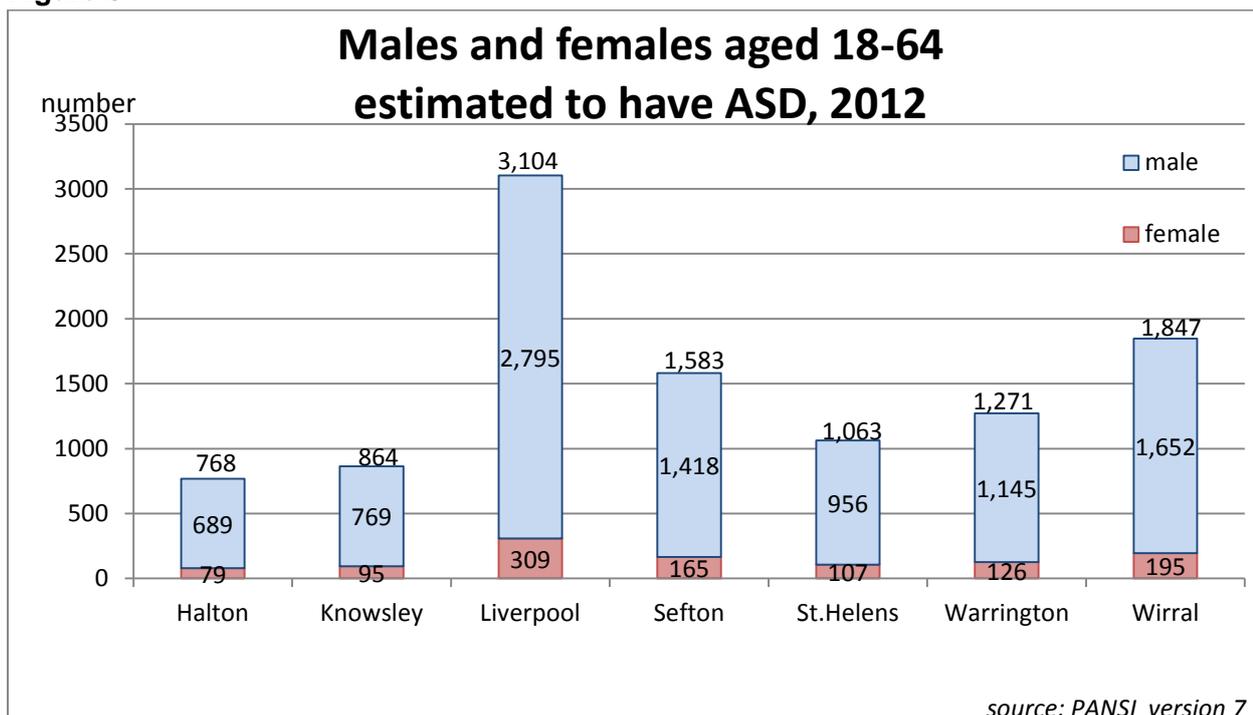
In the absence of known numbers, estimates can be calculated using the national morbidity survey on autism in adults. This survey found the prevalence of ASD to be 1.0% of the adult population (HSCIC, 2009). The rate among men (1.8%) was higher than that among women (0.2%), which fits with the profile found in childhood population studies, according to the HSCIC.

In the PANSI database, these prevalence rates have been applied to ONS population estimates of the 18 to 64 male and female population to give expected numbers predicted to have autistic spectrum disorder.

Figure 8 shows the expected prevalence of ASD amongst adults aged 18-64 across Merseyside and North Cheshire, with 1,076 females and 9,424 males (10,500 total). There are around nine times more males than females expected to have autism. This is much higher than in learning disability as a whole, where expected prevalence rates amongst males are only slightly higher than amongst females (Table 2 above).

On the whole, numbers with ASD are expected to remain fairly constant or slightly decrease between 2012 and 2020. The exceptions are Liverpool, where there will be a more marked decrease in numbers, and Warrington, where numbers will increase slightly (see Figure A1 and A2 in Appendix).

Figure 8



Local authority data on known prevalence

Data obtained directly from some local authorities was not always consistent. Where data was available, some data systems do not distinguish between learning disability and autism. Also, it was not common practice to specify separate numbers with Asperger's syndrome.

In **Knowsley** in 2013, there were reported to be **56** adults known to services aged **18-64** with autism and **4** aged **65+**.

Data obtained for **Warrington** for 2012/13 indicated that there were **97** people with an autism classification known to services aged **18-64** and only **1** aged **65+**.

Current **Wirral** local authority data systems and registers of learning disability do not distinguish between learning disability and autism. There was therefore no readily available data on numbers known to have autism.

However, in 2011, the Wirral Self-Assessment Framework for autism (SAF) did state there were 192 individuals with autism (including Asperger's) known to the local authority. Of these, 154 lived with their family or in their own home, 17 lived in residential care within the local authority and 2 outside the area.

http://www.improvinghealthandlives.org.uk/uploads/doc/vid_16524_Wirral%202011%20Autism%20SAF%20report.09.08.2012.pdf

GP data from Wirral for 2012/13 indicated that there were 259 adults aged 18+ with learning disability who also had autism and were known to general practice.

In **Halton**, the 2011 Self-Assessment Framework for autism (SAF) stated that there were 82 individuals with autism (including Asperger's) known to the local authority. Of these, 59 lived with their family or in their own home, and 4 lived in residential care outside the local authority. 13 were receiving care from specialist mental health services.

http://www.improvinghealthandlives.org.uk/uploads/doc/vid_16509_Halton%202011%20Autism%20SAF%20report.08.08.2012.pdf

The 2011 SAF returns for Liverpool, Sefton, Warrington and St. Helens did not include numbers with autism.

Amongst children with autism, it is expected that at least half will have a learning disability that would lead to them being identified by the authorities (see text following Figure 7 above). Numbers of adults with autism who are known to services (where available) are far smaller than the estimated prevalence of autism shown in Figure 8 above. For example, there are 56 adults with autism known to services in Knowsley, where there are an estimated 864 people with autism. This would suggest that there are a large number of adults with autism unknown to the local authorities who may be in need of additional support.

Autism and learning disability

Sefton provided GP data showing the numbers of individuals having both learning disability and autism (Table 16). Amongst adults with learning disabilities, 1 in 10 (10.6%) also had an autistic spectrum disorder.

Table 16
Sefton: Numbers of adults with autism known to GPs
Learning Disabilities data from 41 GP practices, 2012

	number	%
Number of adults (18+) with learning disabilities (LD)	1113	
LD with Autism/Autistic Spectrum Disorder/ Asperger's Syndrome under 18	14	
LD with Autism/Autistic Spectrum Disorder/ Asperger's Syndrome aged 18-64	118	10.6% of all adults with LD
LD with Autism/Autistic Spectrum Disorder/ Asperger's Syndrome aged 64+	0	

Source: Sefton Public Health Team, Learning Disabilities Return Sheet, 26/3/13

Asperger's syndrome

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language. (Source: The National Autistic Society, www.autism.org.uk).

Proposed changes in the diagnosis of Asperger's disorder involve collapsing the condition into the general spectrum of autism. In an analysis of online discussions about this proposal, Giles (2013) found that many members of the online Asperger's community welcome the notion of the spectrum. Others, however, are suspicious of the motives behind the absorption of Asperger's disorder, and potential threats to the benefits it brings (mainly access to mental health and other services).

There is a need to know more about the numbers and needs of people with High Functioning Autism and Asperger syndrome, in order to support them better, particularly as they are unlikely to meet stringent eligibility criteria for social care services (Roberts et al, 2012a). Higher level autistic spectrum disorders are excluded from the definition of learning disability in Valuing People. This would include some people with Asperger's syndrome (DH, 2001).

Local data

There is no readily available data on numbers of people with Asperger's. The autism Self-Assessment Framework (SAF) counts total numbers with autism and Asperger's (this was the case in 2011). GP data is coded for Asperger's but this data is not readily available.

In the Merseyside and North Cheshire area, there is a specialist Asperger/High Functioning Autism team based in Liverpool. Many other local authorities in the country do not have such support available. They do not deal with people who have Asperger's with a learning disability – such people would be the responsibility of the learning disability team.

In 2012, the Liverpool Asperger Team had 210 referrals from Liverpool, with a further 35 from outside areas including Sefton, Warrington, Knowsley, Halton, St. Helens and Wirral. This does not give a true figure of people with Asperger's on Merseyside, as there are far more people out there than are known to the service.

Guidelines: Autism

NICE guidance on the diagnosis and management of people with autism is summarised in the Appendix.

3. Health Profile

The hidden prevalence of the majority of learning disabilities and autism has been described in Section 2.1. This means that for most people with a learning disability, their disability is unknown to their GP. Glover and Emerson (2012) point out that even if referrals between GPs and specialist services are working well, many people with learning disability, when referred to hospital, will arrive with no advance warning. The group most likely to be missed will be those with mild to moderate learning disability (using the healthcare term - moderate learning difficulties using the education term) and possibly even some with severe learning difficulties. This group are unlikely to be able to understand more than very simple written literature, may struggle with written correspondence, have difficulty at keeping appointments, and need particular help with explanations for purposes of consent or after care. They are likely to have particular difficulties with treatment regimes, such as for diabetes, requiring a degree of understanding of how their body works (Glover and Emerson, 2012).

Specialist providers need to be able to identify people with learning disabilities and autism for themselves. As pointed out by Glover and Emerson (2012), learning disability is always relevant when caring for someone in hospital, so when present, should always be recorded as a co-morbid condition. However, in practice, although the full extent of missing data is unclear, it is known to be substantial (Glover and Emerson, 2012).

3.1 Disease prevalence and access to care

The report by Emerson et al (2012) summarised the literature on inequalities in health status faced by those with learning disabilities. Key facts include the following:

- Amongst those aged 65+, the prevalence of dementia is higher amongst those with learning disabilities (22%) compared to the general population (6%). Amongst those with Down's syndrome, the risk of dementia is high and the age of onset is 30-40 years younger than the general population.
- The risk of epilepsy is at least 20 times higher amongst those with learning disabilities than for the general population. The NHS Information Centre study into access to healthcare found that, of all people with epilepsy, those with learning disability had higher rates of seizures (NHS IC, 2010). It was noted that patients with learning disability and epilepsy often have many different seizure types, which may be more difficult to treat.
- Around 40% of people with learning disabilities have a hearing impairment (47% of those with Down's syndrome).
- Visual impairments are between 8 to 200 times more likely amongst those with learning disabilities compared to the general population.
- Pain was reported by 67% of people with learning disabilities when asked about their health and 18% said they did not tell people when they were in pain.

- The estimated prevalence rates of sleep problems in adults with learning disabilities range from 9% to 34%, (9% for significant sleep problems).

Inequalities in access to care:

Inequalities in cancer care mean that those with learning disabilities are less likely to be told their diagnosis, to be given pain relief and to be involved in decisions about their care (Emerson et al 2012).

Amongst those with learning disability, lower rates of same-day antibiotic prescribing for patients diagnosed with urinary tract infection were found in the NHS Information Centre study into access to healthcare (NHS IC, 2010).

Other examples of inequalities in care are discussed relating to screening and contraception in Section 3.3 below. There are more details and further health inequalities listed in Weston et al 2012 (p.25 to 41).

Merseyside and North Cheshire data on disease prevalence in primary care

Data on co-morbidities amongst people with learning disabilities and autism is not routinely available, apart from the annual health checks required as part of the QOF GP Learning Disability Register (see section 3.2). However, local interrogation of GP systems does demonstrate some consistency with the findings of national research described above.

Sefton

Sefton provided GP data on the prevalence of certain diseases/conditions amongst those identified as having a learning disability. Data was obtained from 41 general practices for 2012. Results are presented in Table 16.

For four disease categories, it was possible to compare prevalence of disease amongst people with learning disability to the general population of Sefton. The prevalence of asthma was twice as high amongst those with learning disabilities and epilepsy was 25 times more likely to occur, being present in around 1 in 4 (24.9%) of all adults with a learning disability, compared to only 1% of the general population. This corresponds with the literature on epilepsy quoted above (at the start of Section 3.1) with Emerson et al (2012) reporting that epilepsy is at least 20 times higher amongst those with learning disability.

Diabetes prevalence was slightly higher, and heart disease was slightly lower amongst those with learning disability.

Table 16

Sefton: Learning Disabilities (LD) and diseases data from 41 GP Practices, 2011-12

	% of Sefton general population	% of Sefton learning disability population	number with LD in Sefton
Asthma	6.2%*	12.7%	141
CHD	4.5%*	3.1%	35
Diabetes	6.0%*	7.9%	88
Epilepsy	1.0%*	24.9%	277
At risk of dysphagia		2.3	26
Assessed as having dysphagia, screened and have a care plan in place		34.6% (of those at risk of dysphagia)	9
Abdominal Aortic Aneurysm (AAA) (any age)		0.2	2
LD with Autism/Autistic Spectrum Disorder/ Asperger's Syndrome under 18		n/a	14
LD with Autism/Autistic Spectrum Disorder/ Asperger's Syndrome aged 18-64		10.6	118
LD with Autism/Autistic Spectrum Disorder/ Asperger's Syndrome aged 64+		n/a	0
Total number of adults (18+) with learning disabilities			1113

Source: Sefton Public Health Team, Learning Disabilities Return Sheet, 26/3/13

*from Sefton's QOF estimates 11-12 long term health conditions gen pop 2012

Of the 35 adults identified with heart disease and learning disability in Sefton, only 4 (11.4%) had a review between 1/5/11 and 31/7/12.

Reviews were more likely for those with diabetes. Of the 88 adults identified with diabetes and learning disability, 50 (56.8%) had a review between 1/5/11 and 31/7/12 and 53 (60.2%) had retinal screening.

Wirral

Wirral did collect numbers screened for different conditions in general practice, but not presented as percentages compared to the general population as yet.

Knowsley

In Knowsley, a health needs assessment was carried out for adults aged over 18 years with a learning disability registered with general practice on 31st December 2008. For the 21 practices with 'In Practice System (INPS)', data was collected electronically. For the remaining 8 practices, data was extracted manually.

The needs assessment reported that adults with learning disability in Knowsley had higher rates of epilepsy, asthma, and hypothyroidism than the rest of the Knowsley population. They had similar levels of circulatory diseases to the rest of the population. The prevalence of type 2 diabetes was

slightly higher in adults with learning disabilities; which may be due to the higher levels of obesity in this group (Oyinloye and Lee, 2010).

The needs assessment also found that those with learning disability have visual and hearing impairments missed and that they have higher rates of difficulty in swallowing than the rest of the population.

Guidelines: Access to care

Health Action Planning and Health Facilitation for people with learning disabilities: good practice guidance (DH, 2008a), describes and clarifies good practice in relation to health facilitation and health action planning – how people can be supported to access the health care they need from primary care and other NHS services. It supports localities to make progress on this and on reducing health inequalities experienced by people with learning disabilities.

The commissioning guide for Clinical Commissioning Groups (CCGs) note that the Health and Social Care Act 2012 contains the first ever specific legal duties on health inequalities (IHAL, 2012). Under the Act, CCGs have a duty to have regard to the need to reduce inequalities in access to health services and the outcomes achieved for patients. They have further duties around integration of health services with social care and other health related services where they consider this would reduce inequalities.

The Commissioning Guide sets out the reasonable adjustments needed to improve access to care for those with learning disabilities (IHAL, 2012). It is noted that reasonable adjustments include removing physical barriers to access but importantly also include making whatever alterations are necessary to policies, procedures, staff training and service delivery to ensure that they work equally well for people with learning disabilities. Links are provided to accessible information on health at www.easyhealth.org and www.apictureofhealth.southwest.nhs.uk. The authors emphasise that commissioners should ensure providers implement reasonable adjustments including the use of accessible information in all health services (IHAL, 2012).

Guidelines on improving access to health checks and screening in primary care are described on the following pages in Sections 3.2 and 3.3. The Commissioning Guide mentions other primary care services where action is needed, noting that CCGs should ensure that the needs of people with learning disabilities are reflected in contracting for Improving Access to Psychological Therapies (IAPT) and community podiatry services (IHAL, 2012).

NHS England is responsible for the commissioning of other primary care services such as GP out of hours services, primary dental services, community pharmacy, primary ophthalmic services and audiology, although IHAL note that specialist learning disability services often play a role in enabling people to access these services (IHAL, 2012). IHAL provide a link to an eye care pathway for adults and young people with learning disabilities, available at: www.locsu.co.uk/enhanced-services-pathways/community-eye-care-pathway-for-adults-and-young-pe

Other considerations summarised in the Commissioning Guide included ensuring access to:

- *Integrated continence services.*
- *Dysphagia services.*
- *End of life care.*

- *Wheelchair services.*
- *Pain recognition and management.* Social and health care commissioners can ensure that joint commissioning allows for support workers to be trained to recognise potential problems and take action.
- *Postural care.* It should not be assumed that changes in body shape are inevitable for people who have movement difficulties. They need access to services, equipment and training to support the long term management of their body shape.
- *Medication reviews.* The need for regular medication reviews was highlighted. This would result in important cost savings, as well as being beneficial to the individuals concerned. People with learning disabilities are often on a large amount of medication which may not always be effective.

(IHAL, 2012)

Guidelines: tackling the determinants of health inequalities

Potential solutions can be identified by examining the determinants of health inequalities, to which people with learning disabilities are more likely to be exposed. These have been identified by Emerson et al (2012) as follows:

- Reduce the exposure to social determinants of poor health, including poverty, poor housing, unemployment, social isolation and discrimination;
- Improve early identification of illness, for example by improving the uptake of health checks and screening;
- Improve the health literacy of people with learning disability and their carers;
- Enhance the knowledge and skills of healthcare workers in working with people with learning disabilities.
- Make 'reasonable adjustments' wherever possible, for example longer appointment times and more accessible health promotion information.
- Monitor progress towards eliminating inequalities faced by those with learning disabilities.

3.2 Health checks

As detailed in Section 3.1 above, people with learning disabilities have significantly poorer health than their non-disabled peers. This is partly due to difficulties in identifying ill health among people with learning disabilities and problems with access to services (Glover et al, 2012).

The Disability Rights Commission published 'Equal Treatment Closing the Gap' (DRC, 2006) which is based on an investigation which established that people with learning disabilities are less likely to receive some of the expected evidence-based health checks and treatments.

In 2006, the Disability Rights Commission recommended the introduction of annual health checks for those with learning disability, to help to improve the identification of illness amongst this group. GP practices in England can now provide health checks for adults with learning disabilities as part of a Directed Enhanced Service scheme. Originally agreed for two years (2008-9 and 2009-10), this scheme has been extended, most recently to 2012/13 (Glover et al, 2012).

A Directed Enhanced Service (DES) is currently in place to support the provision of health checks. The DES only includes those known to social services, but some areas have offered health checks to everyone on the QOF register (NHS England, 2013).

The introduction of health checks in 2008/09 has been one of the most important 'reasonable adjustments' made by primary health care services in an attempt to address the health inequalities faced by people with learning disabilities and detect unmet health need. They are a start in meeting the requirements of the Disability and Equality Act 2010 (IHAL, 2012 commissioning guide). However, although there has been an increase in uptake over time, the latest figures for 2011/12 show that there were still only just over half (52.8%) of those eligible receiving the checks (Emerson et al, 2012).

Local data

Nationally, of those known to either the GP or social services as having a learning disability, just over half (52.8%) had a health check during 2011-12 (Figure 9 and Table 17). In Merseyside and North Cheshire, Halton & St. Helens, Liverpool and Sefton had levels below the national average, with only 1 in 3 (32.8%) of those with a learning disability in Halton & St. Helens receiving a health check. In Sefton and Halton & St. Helens, levels had been higher than the national average in 2009-10, but then fell in subsequent years. In contrast in Knowsley, over two-thirds of those known to have a learning disability consistently received a health check between 2008-09 and 2011-12. In 2011-12, levels were also higher than the national average in Wirral and Warrington (Figure 9 and Table 17).

There are obstacles to the uptake of health checks, notably the fact that there are estimated to be a large number people with learning disabilities who are not known to the authorities and do not appear on any registers (see Section 2.1). Communication difficulties are another obstacle.

Nevertheless, the IHAL stated that the provision of health checks is probably the most important Reasonable Adjustment that can be made by PCTs (now CCGs) through GPs, to ensure that people with learning disabilities receive a reasonable acceptable standard of primary medical care (Glover et al, 2012). While 52.8% national coverage represents an improvement on the figure for 2010/11, nationally only 12 PCTs attained 75% coverage, a level of performance which according to Glover et al (2012), could reasonably be considered a minimum standard for satisfactory performance in such a critically important area. None of the areas in Merseyside and North Cheshire achieved this level, although Knowsley and Wirral came fairly close, at around 70%.

Figure 9

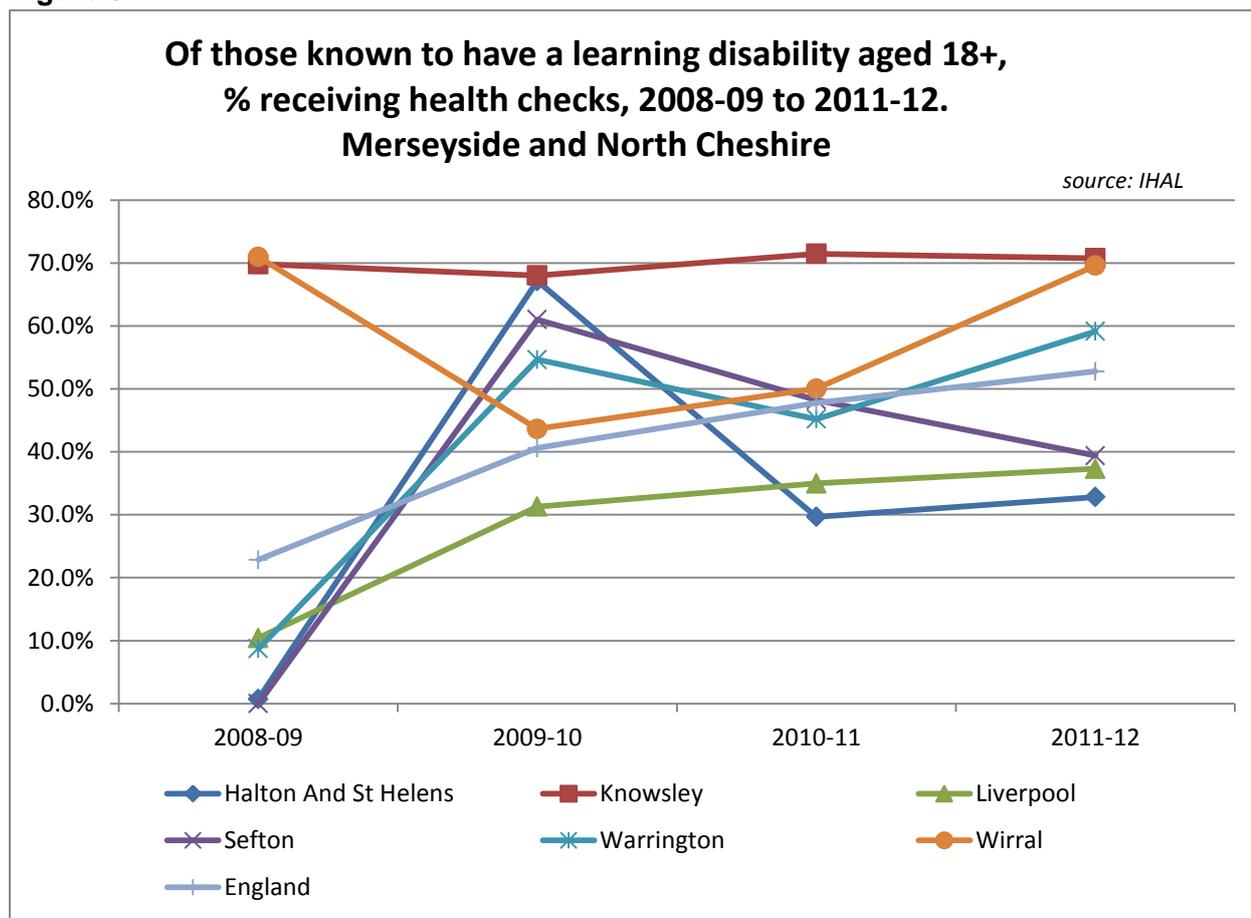


Table 17

Numbers and percentages of those known to have a learning disability who received health checks, aged 18+, 2008-09 to 2011-12.

	2008-09		2009-10		2010-11		2011-12	
	Number	%	Number	%	Number	%	Number	%
Halton and St Helens	7	0.7%	194	67.1%	423	29.7%	524	32.8%
Knowsley	537	69.8%	547	68.0%	584	71.5%	610	70.8%
Liverpool	100	10.4%	412	31.3%	476	35.0%	731	37.3%
Sefton	0	0.0%	382	61.0%	371	48.2%	303	39.4%
Warrington	42	8.7%	205	54.7%	236	45.2%	310	59.2%
Wirral	577	71.0%	565	43.7%	459	50.1%	703	69.6%
England		22.8%		40.6%		47.8%		52.8%
North West		20.5%		43.4%		47.1%		53.9%

Source: IHAL (HSCIC directs to IHAL website for this data)

N.B. data provided directly from Sefton CCG was slightly different, with 56% in 2010/11 and 43% in 2011/12. Sefton said this may be due to differing dates for collection and submission of information.

Guidelines: Health checks

Annual health checks for people with learning disability should be promoted, with a target of a 90% uptake rate.

from the learning disability commissioning guide for Clinical Commissioning Groups (CCGs) (IHAL, 2012), quoting Health Self-Assessment (SAF) indicators.

3.3 Screening

Access to health screening and health promotion may be significantly poorer for those with learning disabilities, especially amongst those with more severe learning disabilities (e.g. in residential care) and for those who do not use learning disability services. For example, lower rates of breast self-examinations, mammography, assessments for vision and hearing impairments and routine dental care amongst people with learning disabilities have been reported (Emerson et al 2012).

A health needs assessment in Lincolnshire looked at GP data on the uptake of cervical screening, health checks, and diabetes check (HbA1c). Proportions who declined cervical screening were four times higher amongst those with learning disability. The uptake of cervical screening was 71% in the general population, compared to 28% amongst those with LD (Weston et al, 2012).

Local data examples: screening

Some recent local screening data was obtained for Liverpool and Sefton:

Liverpool

The Liverpool Learning Disabilities Performance and Self Assessment Framework, North West Pilot 2012 included screening uptake data showing that people with learning disabilities are much less likely to have been screened than the general population:

- **Cervical** – 33.1% of people with learning disabilities were screened in the last 5 years, compared to 81.4%, in 2011, aged 25-64 in the Liverpool population as a whole. 82.9% in the North West and 78.6% of the population of England as a whole had been screened in the last 5 years.
- **Breast** – 64.2% of people with learning disabilities were screened in the last 5 years, compared to 71.6% in 2011 of people aged 53-70 in the Liverpool population as a whole and 75% in the North West.
- **Bowel** – 59.5% of people with learning disabilities were screened in the last 5 years. Figures for those undertaking bowel screening in Liverpool were not available from this report.

Percentages given for people with learning disabilities are for people screened in the last 5 years. Figures given for the PCT population as a whole are for 2011.

Sefton

Sefton provided GP data on screening and disease management for people with learning disabilities from 41 general practices for 2012. Results are shown in Table 18. Of the 332 females with learning disability eligible for cervical screening in Sefton (i.e. those aged 24-65), only around two-thirds were offered screening (37.7%). Only just over 1 in 4 of those eligible actually received the screening (28%). Around one-third of those eligible (36.2%) either refused screening or did not attend (Table 18).

Only 1 in 10 (11.4%) of those with heart disease and learning disabilities had a review in the 14 month period May 2011 to July 2012. Reviews were much more common for those with diabetes, however there were still just under half of those with diabetes and learning disability who did not have a review in the 14 month period (43.2%. 56.8% had a review) (Table 18).

Table 18
Sefton: Learning Disabilities (LD) screening and disease management
data from 41 GP Practices, 2011-12

	Description	Number	%	notes
	Number of adults (18+) with learning disabilities	1113		
Of those with Learning Disabilities				
Cervical Screening (1/7/07 to 31/7/12)	Eligible for cervical screening (females aged 24-65)	332		
	Offered cervical screening	125	37.7%	of those eligible, % offered
	Received cervical screening	93	28.0%	of those eligible, % received
	DNA cervical screening	44	13.3%	of those eligible, % DNA
	Refused cervical screening	76	22.9%	of those eligible, %refused (36.2% DNA or refused)
Breast Screening (1/7/11 to 31/7/12)	Offered breast screening	3		How many eligible N/A
	Seen for breast screening	22		
	DNA breast screening	33		
	Refused breast screening	5		
Bowel Screening (1/7/11 to 31/7/12)	Seen for bowel screening	35		How many eligible N/A
	DNA bowel screening	23		
	Refused bowel screening	11		
Prostate Screening (1/7/11 to 31/7/12)	Seen for prostate screening	16		How many eligible N/A
Obesity advice	Showing obesity (BMI) and offered dietary advice	136	12.2%	% of all adults with LD (no numbers on how many showed obesity)

Diabetes care	Diabetes Mellitus: had review 1/5/11 to 31/7/12	50	56.8%	% of all those with LD and diabetes
	Diabetes Mellitus: received retinal screening	53	60.2%	% of all those with LD and diabetes
Heart disease care	Heart Disease: had review 1/5/11 to 31/7/12	4	11.4%	% of all those with LD and heart disease

Source: Sefton Public Health Team, Learning Disabilities Return Sheet, 26/3/13

More recently, a learning disability screening audit in Sefton (Reed, 2013) found that for cervical screening, the number of individuals ceased from the programme had more than doubled by September 2012 (96) compared to August 2011 (41).

There were 100 adults with learning disability eligible for bowel screening in a two year period from July 2010 to July 2012. All were invited for screening and 18 (18%) were adequately screened. In the general population in Sefton, a far higher proportion (53.8%) were screened for bowel cancer in the one year period from July 2011 to July 2012.

Wirral

Wirral provided data from 2012/13 on numbers screened, but their data has not as yet been presented as uptake percentages to be compared with the general population.

Knowsley

An earlier health needs assessment in Knowsley found similar results. It reported that adults with learning disability known to general practice were less likely to have breast and cervical screening (33% compared to 70.6% for the Knowsley general population) (31st December 2008) (Oyinloye and Lee, 2010).

Guidelines: screening

The guide for Clinical Commissioning Groups (IHAL, 2012) notes that with the right support, most people with learning disabilities can access health screening services that are available to the general population. While NHS England will be commissioning screening services, CCGs will commission specialist learning disability services which often provide support both to people with learning disabilities and screening/health promotion services to enable access. Reasonable adjustments regarding the three national cancer screening programmes have been collated by IHAL and are available at:

www.improvinghealthandlives.org.uk/publications/1126/Making_Reasonable_Adjustments_to_Cancer_Screening

CCGs should ensure that data on access to disease prevention and screening by people with learning disabilities compared to the general population is collected (IHAL, 2012 - quoting Health Self-Assessment [SAF] indicators).

Recommendation from this report: Develop access to GP clinical systems so that GP data on screening and disease management for those with learning disability can be compared and monitored across each CCG.

Locally prepared 'easy read' materials on issues such as breast screening should be widely available. These will be available in Liverpool in the near future.

3.4 Contraception and sex education

Contraception

As with cervical and other types of screening (discussed in the previous section), lower rates of contraceptive advice and smear tests amongst those with learning disabilities have been reported in the NHS Information Centre study into access to healthcare (NHS IC, 2010). The NHS IC suggested that this is possibly due to an assumption that patients with learning disability are not likely to be sexually active; or that they are not able to make choices relating to contraception; or GPs may not feel able to raise sexual health issues with patients who have learning disabilities.

Contraceptive use for women with learning disabilities involves much greater use of long term methods such as depot injection, oral contraceptive, intrauterine device or sterilisation and significantly less use of barrier methods compared to the general population. They may be prescribed contraception or even sterilised even when they are not sexually active or are past child bearing age (Emerson et al, 2012).

Sex and relationships education:

The University of Ulster and Family Planning Association (2006) noted that a lack of acknowledgement of the sexuality of people with learning disabilities means their needs are being fundamentally ignored. The importance of addressing the sex education needs of young people with learning disabilities was highlighted by an NSPCC study which revealed a higher level of sexual abuse and exploitation among children and young people with learning disabilities (NSPCC, 2006).

A children's learning disability nursing team in Leeds audited the amount of referrals for "inappropriate sexual behaviour" (Simpson et al, 2010). The results highlighted that in most cases, children with learning disabilities received little or no sex and relationships education or support. The audit also showed that approaches are usually reactive rather than proactive. The team liaised with professionals in education, public health and healthy schools advisers, and discovered that few staff were addressing the sexual health needs of this group. The majority of staff envisaged great difficulties in addressing these needs. Some of the available teaching resources were outdated and staff did not have the time, commitment or confidence to deliver them. The team developed a resource to support professionals in delivering sex and relationship education (NHS Leeds, 2009).

A three year research project undertaken by the University of Leeds looked at relationships and sexuality for young people with learning disabilities (University of Leeds, 2009). Their findings included:

- Everybody felt sex education should be better. Sex education often only talks about what sex is, rather than having sex in a relationship, or to feel good.
- Most people did not know much about puberty and pregnancy.
- It was difficult to get accessible information. No parents had been given information without asking for it. They “had to fight for it”. Parents and teachers said young people really need accessible information that they could take away.
- Some young people with learning disabilities think talking about relationships and sex could get them into trouble. Some parents and professionals think young people with learning disabilities shouldn’t have relationships or sex. Parents said some people think young people with learning disabilities don’t need information.
- Many teachers said that sex education doesn’t always get taught in special schools. Focus groups with teachers found that sex education in schools is often done on an ‘as-and-when-needed’ basis with individuals, rather than structured classes or programmes. They said that sex education needs to be treated more importantly by schools and by the Government.

There is an obvious need for relationships education and contraceptive advice, but this need is hard to meet, often due to resistance from parents. Some areas have considered developing a ‘relationships policy’.

Examples of local delivery: Sex and relationships education

Bluebell Park, Knowsley

Bluebell Park is a 185 place school providing primary, secondary and post 16 facilities for students with special educational needs. The school has a sex education policy developed in consultation with parents and teaches sex education as part of their PHSE curriculum.

Contact: Stuart.Sheridan@knowsley.gov.uk

Sex Education Courses, Sefton

Mersey Care NHS Trust run a ten week Health and Sex Education course, as well as Body Awareness course, for people with learning disabilities in Sefton. The courses are interactive, involving role play, games and quizzes, as well as arts and crafts, and all participants receive a certificate. These courses started in Knowsley and have also taken place in Wirral.

Contact : amanda.fitzsimmons@merseycare.nhs.uk

Adult social care users, sexual health needs policy, Halton

In 2012, Halton formulated a policy covering the sexual health needs of adult social care service users, including those with learning disabilities.

The policy is a statement of what the Communities Directorate (who commission and provide adult social care) plans to do, to carry out its responsibilities in relation to the sexual health of service users and safeguarding vulnerable adults from abuse, including sexual, physical and emotional abuse, domestic abuse, discrimination and exploitation. It details procedure and practice.

It uses the World Health Organisation's definition of sexual health, which goes beyond the medical model, taking a respectful approach to sexuality and sexual relationships, including the possibility of having pleasurable and safe sexual experiences.

It covers a wide range of issues including sexually transmitted infections, contraception, pregnancy, adoption, abortion, masturbation, pornography, same sex relationships and others.

For more information, contact: Sharon.mcateer@halton.gov.uk

London: The Good Sexual Health Project was commissioned by NHS Westminster and Westminster City Council for people with learning disabilities in Westminster. It commenced in April 2009 and was a 2 year project that funded a full-time Personal Relationship Facilitator from the Family Planning Association. It provides:

- Sex and relationships education for people with learning disabilities through individual or group work.
- Sexual health training for staff working with/supporting people with learning disabilities.
- Support work with parents and carers of people with learning disabilities.
- Opportunities for people with learning disabilities to access support around sex, sexual health and relationships.
- The project group has developed a policy on sexual health and relationships for care staff. This policy is also available in an easy read format.

Taken from the IHAL website

<http://www.improvinghealthandlives.org.uk/search.php?q=GOOD+PRACTICE&f=21>

Leeds: Puberty & Sexuality for children and young people with a learning disability is an award winning teaching pack, developed for use with learning disabled children and young people between the ages of 9-18 years old. The pack has been produced as a supporting document for National Curriculum objectives. It has been designed to include the needs of children and young people with severe learning disability to deliver extensive knowledge appropriate to this group but equally comparable to their mainstream peers (NHS Leeds, 2009).

3.5 Lifestyle

Emerson et al (2012) carried out analysis of the Millennium cohort study, which tracks children born between 2000 and 2002. They found that more than half of seven year olds with learning disability (56%) never do sport/exercise, compared to a quarter (25%) of those with no learning disability.

Amongst adults with learning disability, a literature review by Emerson et al (2012) reported that some risk-taking behaviour has been found to be lower amongst adults with learning disability, such as smoking and drinking alcohol (Emerson et al, 2012). However, they found that:

- rates of smoking are considerably higher among adolescents with mild learning disabilities.
- obesity rates tend to be higher amongst those with learning disabilities. The NHS Information Centre study into access to healthcare also noted that people with learning disability have been found to have higher rates of obesity, possibly associated with relative under activity and poor diet, (NHS IC, 2010).
- 4 in 5 adults with learning disability (80%) have lower levels of physical activity than recommended, compared to 53-64% amongst the general population.

Local data

In Knowsley, a health needs assessment was carried out for adults aged over 18 years with a learning disability registered with general practice on 31st December 2008 (Oyinloye and Lee, 2010). It reported that:

- one in ten adults with learning disability use tobacco. This is less than the Knowsley average of one in four adults and is consistent with other research findings.
- those with learning disability were more likely to be obese (BMI>30) than the total Knowsley population (40.5% compared to 20%)
- they were also more likely to be underweight (BMI<20) than the total Knowsley population (8.7% compared to 2%).

Guidelines: Lifestyle

'*Eating well: children and adults with learning disabilities*' is a set of guidelines summarising the current evidence on the nutritional needs of children, young people and adults with learning disabilities in the UK. They consider issues around nutritional health, food choice and eating well

and provide both nutritional and practical guidelines to promote eating well amongst people with learning disabilities (Caroline Walker Trust, 2007).

Examples of local delivery: lifestyle

Westminster: lifestyle

'Choosing the chance to change' is a healthy living project for people with learning disability commissioned by NHS Westminster which commenced in 2008.

In Westminster at least 65% of people with learning disabilities are overweight or obese. The project was developed as part of the NHS Westminster Obesity Strategy and included the development of;

- A health action planning DVD
- An eight week health and physical activity promotion course for people with learning disabilities. The course is delivered by the mainstream vulnerable adults dietician and exercise co-coordinator with support from the learning disability service
- Education sessions for carers and support staff on supporting people with learning disabilities around healthy eating and physical activity.

Taken from the IHAL website <http://www.improvinghealthandlives.org.uk/search.php?q=GOOD+PRACTICE&f=21>

Westminster: oral health

'The Good Oral Health Project' was commissioned by NHS Westminster and run in partnership with Westminster Learning Disability (WLDP) and the Central London Community Healthcare Community Dental Service (CDS). The aim of the project was to develop a better dental service in the Westminster area for adults with Learning Disabilities.

There were two phases to the project. The first phase was a baseline assessment of dental preventive, clinical, educational and service needs among the client group. The second phase involved a proactive approach to bring the most appropriate educational, preventive and treatment services to the clients.

- Of 411 people on the learning disability register: 318 were contacted, and 269 have been seen. Only 30 had their own 'high street' dentist
- Findings: 28% had dental decay, 11% had no teeth
- All service users seen were offered an oral health action plan.

As a result of this project the number of people receiving treatment within the Community Dental Service has almost doubled. Oral health awareness is much higher now in carers and support workers. The secret of their success was described as access to good data, a commitment from mainstream primary care services and commissioning and good Partnership working between services.

Taken from the IHAL website <http://www.improvinghealthandlives.org.uk/search.php?q=GOOD+PRACTICE&f=21>

3.6 Hospital admissions

People with learning disabilities have different patterns of hospital admissions compared to the general population. The proportion of admissions to general hospital which happen as an emergency are substantially larger than for people who do not have learning disabilities (50.0% vs. 31.1%) (IHAL, 2013).

In Lincolnshire, an analysis of service activity data confirmed that emergency admissions to hospital and A&E attendance in adults with learning disabilities were greater than the Lincolnshire average, whilst elective admissions were lower (Weston et al, 2012). They found higher levels of admission amongst people with learning disabilities for some conditions, for example diseases of the digestive system resulted in 14% of admissions for the general population and 18% for people with a learning disability' (Weston et al, 2012).

The authors felt that these differences may be explained by the identified barriers to services, diagnostic overshadowing, low rate of annual health checks in primary care, and other factors which combine to increase the burden of disease in this vulnerable population.

Once people with learning disabilities access the hospital care system, they face inequalities in their care. As mentioned in Section 1.3 above, Mencap's *Death by Indifference* report outlined six case studies of people with learning disabilities who were believed to have died unnecessarily as a result of receiving a lower standard of healthcare than afforded to the general public (Mencap, 2007). Issues requiring attention included lack of basic care, poor communication and failure to recognise pain. The report prompted an independent inquiry into access to healthcare for people with learning disabilities, '*Healthcare for All*', which reported in July 2008 (DH, 2008).

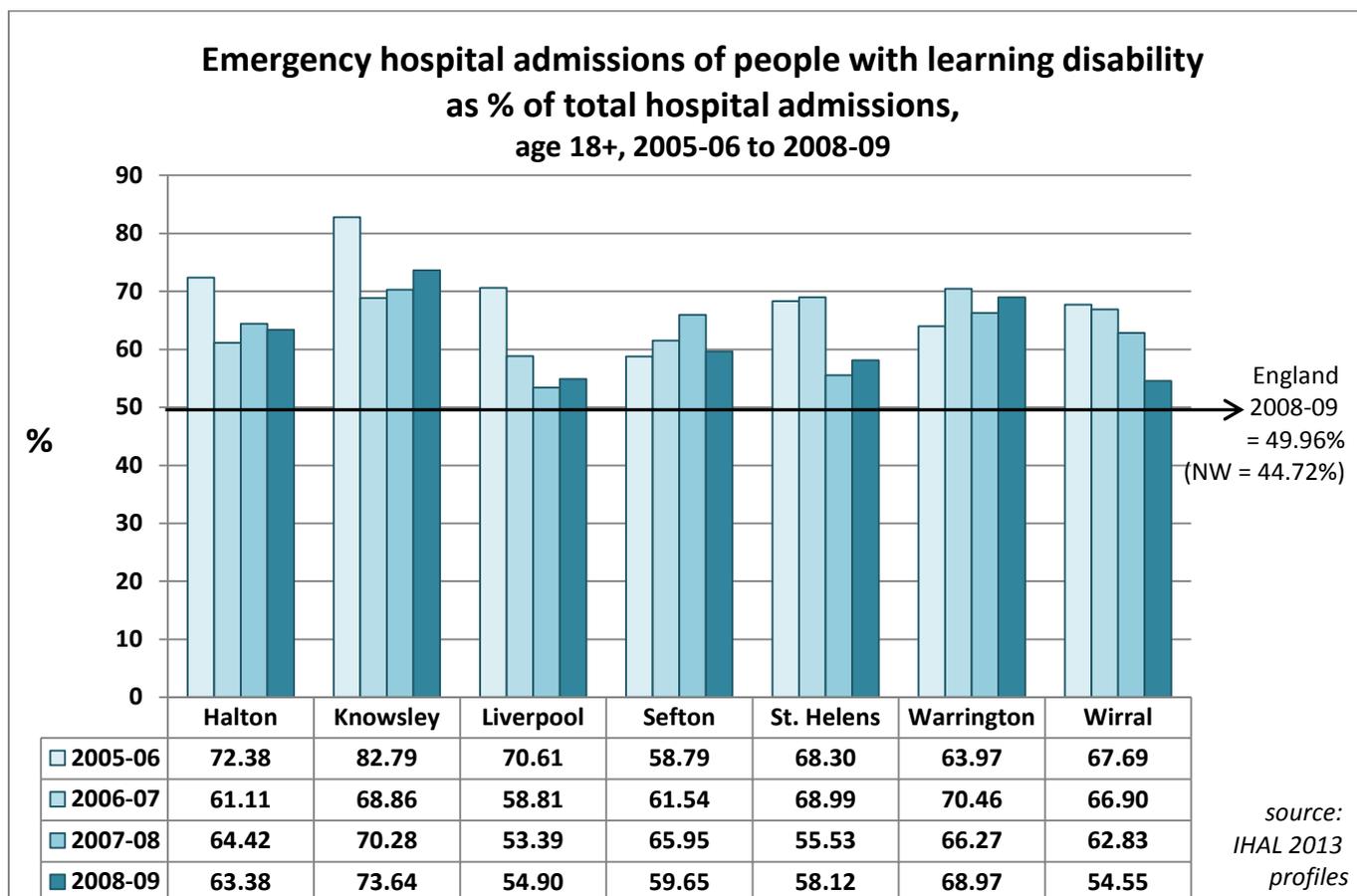
Hospital admissions that should not happen

Ambulatory care sensitive conditions (ACSCs) have been defined as conditions which can usually be looked after without needing people to go into hospital (Glover and Evison, 2013). IHAL carried out a study of hospital admissions of people with learning disabilities for these conditions. The study found that about 8% of hospital admissions for people with learning disabilities are emergencies that might be preventable, compared to around 5% for those without learning disabilities. The commonest cause for people with learning disabilities is convulsions and epilepsy. Other common causes for those with learning disability included diabetes, constipation and influenza/pneumonia (Glover and Evison, 2013).

Merseyside and North Cheshire

Centrally collected data showed that across Merseyside and North Cheshire, in 2008-09, there were 3,779 hospital admissions of people known to have learning disabilities. Of these, 2,231 (59%) were emergency admissions (IHAL Online. 2012 and 2013 profiles). Figure 10 shows trends over time in each local authority from 2005-06 to 2008-09. In 2008-09, the proportion of hospital admissions that were emergencies amongst those with learning disability was higher than the national average of 49.96% in each local authority. Levels were highest in Knowsley (73.64%) and lowest in Wirral (54.55%). The average for the North West (44.72%) was lower than the national average.

Figure 10



Further data by local authority on various other types of hospital admission for people with learning disability can be found on the IHAL website: <http://www.improvinghealthandlives.org.uk/profiles/>

Locally collected data

Merseyside hospital admissions (elective and non-elective) in 2012/13³

Data collected for this needs assessment show that in 2012/13 there were approximately 1,750 admissions (elective and non-elective) among the learning disability population in Merseyside and North Cheshire⁴. Children and young people under 18 years of age accounted for just over one third

³ Hospital admissions with a primary or secondary diagnosis of learning disability or autism ICD10 codes F70-F79 and F840-F849 and excluding ICD10 code Z755 Holiday relief care.

⁴ These results are not comparable to those in the IHAL profiles (reported on the previous page) which use a different methodological approach towards identifying admissions for patients with learning disability.

of admissions whilst almost two-thirds were among males. Rates of hospital admission among the adult learning disabilities population were calculated using numbers of persons aged 18 and over on GP practice lists with a learning disability as the denominator, of which there were 5,569 people in Merseyside and North Cheshire (QOF, 2011/12). The results showed South Sefton CCG has the lowest rates of admission among adults with learning disabilities whilst St. Helens CCG has the highest (Figure 11).

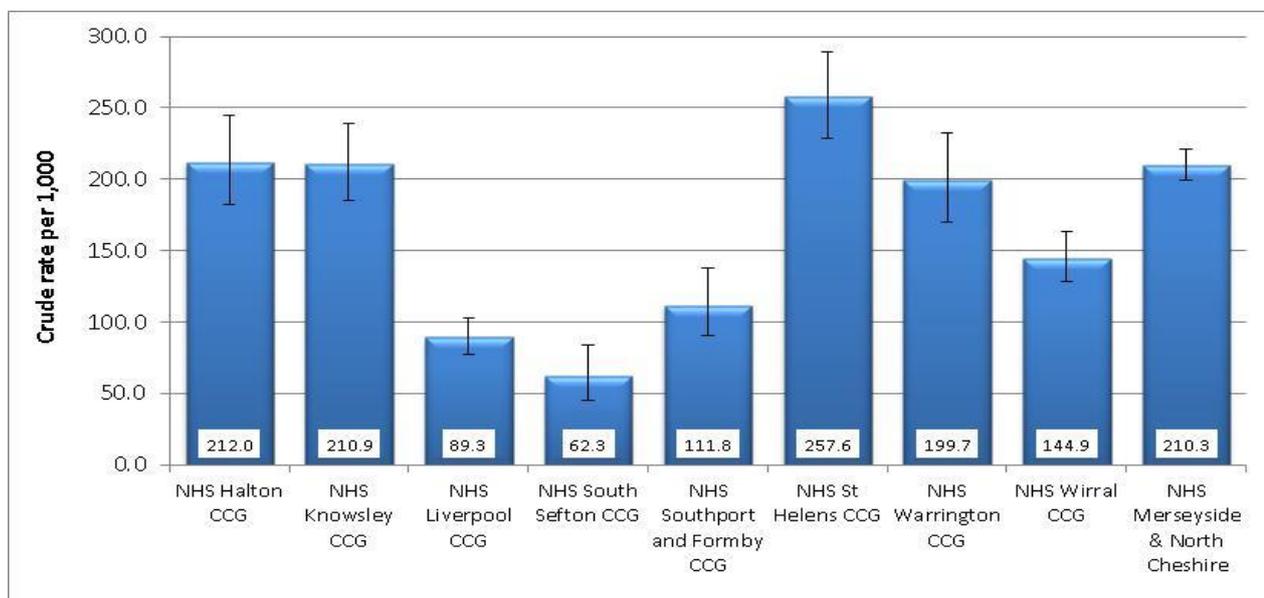
The term learning disability used in this hospital admissions analysis refers to patients with a primary or secondary diagnosis of learning disability and/or autism. There is a limitation in the denominator used to calculate the CCG rates because although it includes people with autism who also have a learning disability, people with higher level autistic spectrum disorder will not be included.

Further caution is advised in interpreting these results, as it is known that people with a learning disability are not routinely identified on admission to acute hospitals and low rates may simply reflect lower rates of identification and recording of people with learning disability, and vice versa. Also, GP learning disability registers used to calculate rates will not include people with higher level autistic spectrum disorders.

The high rates in St.Helens could be partly due to the accuracy of recording for learning disability in Whiston Hospital (see Whiston local examples box at the end of this section).

Liverpool CCG raised the issue of short term holiday relief breaks being coded as emergency admissions, therefore artificially inflating the figures for Liverpool. Holiday relief care admissions were therefore removed from the analysis (ICD 10 code Z755).

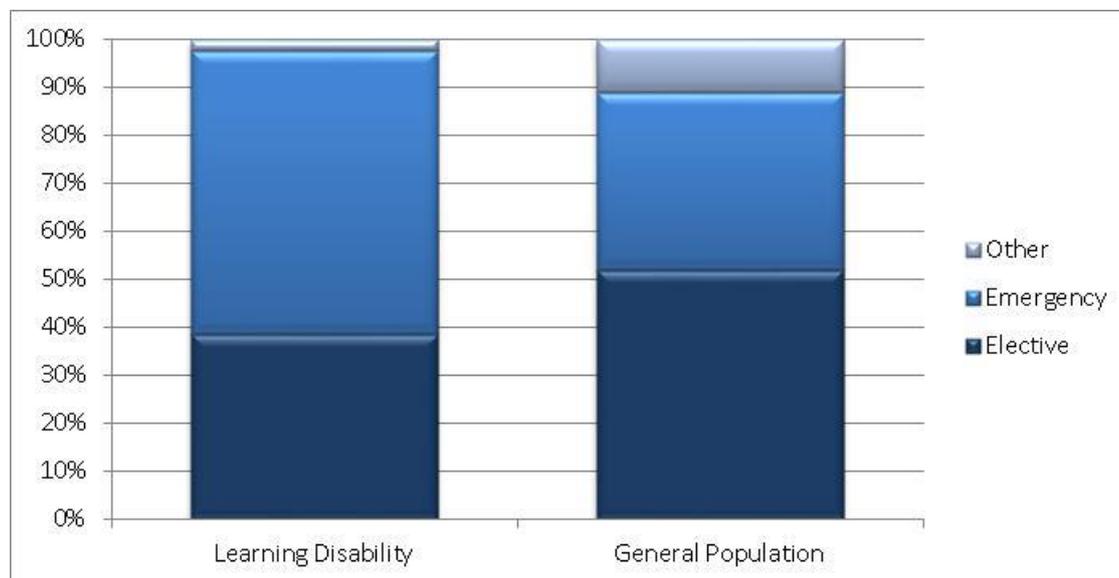
Figure 11 Rates of hospital admission per 1,000 among the learning disability population ages 18 and over, 2012/13



Source: SUS/Cheshire & Merseyside Commissioning Support Unit

In 2012/13 59% of admissions among the learning disability population on Merseyside and North Cheshire were for an emergency admission compared to 37% among the general population (Figure 12).

Fig 12. Merseyside and North Cheshire admissions by method of admission 2012/13 (all ages)



Source: SUS/Cheshire & Merseyside Commissioning Support Unit

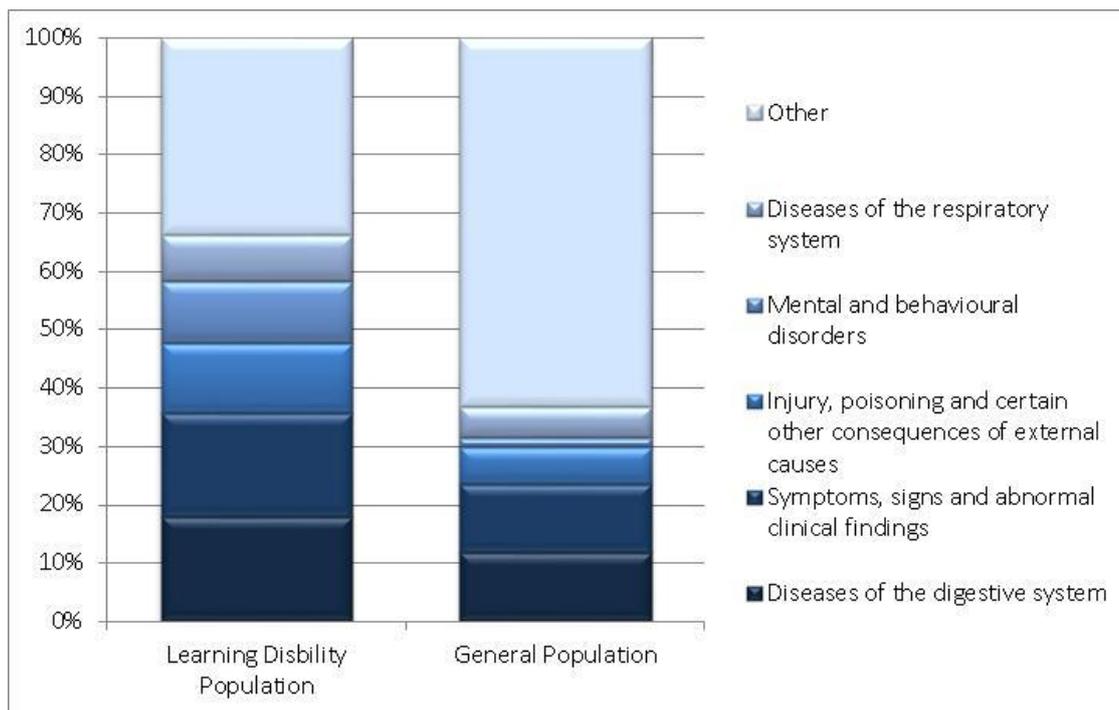
Hospital admissions (elective and non-elective) among people with a learning disability in Merseyside and North Cheshire in 2012/13 were categorised by ICD10 Disease Chapter (i.e. groups of diseases) (Figure 13). The top presenting conditions were Symptoms, signs and abnormal clinical findings (R00-R99), Mental and behavioural disorders (F00-F99) and Diseases of the Digestive System (K00-K93) which each accounted for 16% of total admissions.

Examining these admissions further by the primary diagnosis of the admission, Dental caries unspecified, Epilepsy unspecified and Urinary tract infection site not specified were among the top presenting conditions for the learning disability population on Merseyside and North Cheshire:-

- Dental caries, unspecified (K02.9) accounted for 7% of total admissions and 16% of elective admissions. This was the main cause of an admission and the main cause of an elective admission among the learning disability population.
- Epilepsy, unspecified (G40.9) accounted for 3% of total admissions and 4% of emergency admissions in the learning disability population. This was the main cause of an emergency admission in the learning disability population.
- The second main cause of an emergency admission was Urinary tract infection, site not specified (N39.0) which accounted for almost 3% of the emergency admissions among the learning disability population whilst the third main reason was lobar pneumonia unspecified organism (J18.1) which accounted for 2% of emergency admissions.

Comparing admissions (elective and non-elective) in 2012/13 among the learning disability population in Merseyside to those among the general population, the top presenting conditions categorised by ICD10 Disease Chapter were Diseases of the Digestive System (K00-K93), Symptoms, signs and abnormal clinical findings (R00-R99) and Injury, poisoning and certain other consequences of external causes (S00-T98). North Cheshire was not included in this analysis as comparative data for the general population was not available.

Figure 13. Hospital admissions by top presenting conditions (ICD10 Disease Chapter) in 2012/13 (all ages)



Source: SUS/Cheshire & Merseyside Commissioning Support Unit

□ Diseases of the digestive system (K00-K93) accounted for 18% of admissions in the learning disability population in Merseyside compared to 12% among the general population. This was the main cause of an elective admission among the learning disability population.

□ Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99) likewise accounted for 18% of admissions compared to 12% among the general population. This was the main cause of an emergency admission among the learning disability population in Merseyside.

□ Injury, poisoning and certain other consequences of external causes (S00-T98) accounted for 12% of admissions among the learning disability population in Merseyside compared to 6% of admissions among the general population. This was the second main cause of an emergency admission in the learning disability population.

These findings replicate the literature on hospital admissions mentioned at the start of this section, with admissions more likely to be for emergency and for digestive symptoms and injury and poisoning than in the general population.

Whiston and Southport & Ormskirk Hospitals

The 'best practice' boxes at the end of this section detail audits of learning disability patients carried out at Whiston Hospital and Southport and Ormskirk NHS Trust.

Guidelines: secondary care

The CCG Commissioning Guide notes that CCGs should ensure that healthcare providers have put in place systems to regularly assess and monitor the quality of the service they provide (IHAL, 2012). Amongst other things, they need to avoid unlawful discrimination through making reasonable adjustments where applicable. Requirements would include ensuring that the following are in place:

- A named Board level Executive Lead with responsibility for learning disabilities;
- An acute liaison nurse function;
- A 'care pathway' for people with learning disabilities which includes pre-admission and discharge planning, a risk assessment and use of a 'Patient Passport' (e.g. see Brodrick et al, 2011);
- Use of a recognised pain identification tool (<http://www.disdat.co.uk/>);
- Care co-ordinator arrangements, so that the individual and their family have an identified person they can talk to;
- A learning disability resource pack and communication aids available on each ward;
- Learning disability awareness training and Mental Capacity Act training in place for all appropriate staff;
- An exemption clause in Trust DNA policies for people with learning disabilities as they are vulnerable patients, and there may be good reasons why they do not attend appointments;
- Access to Paediatric Neuro-disability specialist care for children with profound and multiple learning disabilities;
- Changing places toilets;
- The use of Summary Care Records (SCR) to ensure that records are available to out of hours services and acute hospital trusts.

(see p. 22, IHAL, 2012, for full list)

Based on recommendations in *Healthcare for All* (DH, 2008), Monitor's Compliance Framework set out six criteria for meeting the needs of people with learning disability:

1. Mechanism in place to identify and flag patients with learning disabilities, and protocols that ensure pathways of care are reasonably adjusted to meet their health needs.
2. Readily available and comprehensible information to patients with learning disabilities about treatment options, complaints procedures and appointments.
3. Protocols in place to provide suitable support to family carers.
4. Protocols in place to routinely include training on providing healthcare to patients with

learning disabilities for all staff.

5. Protocols in place to encourage representation of people with learning disabilities and their family carers.
6. Protocols in place to regularly audit practices for patients with learning disabilities and to demonstrate the findings in routine public reports.

(Monitor, 2013; IHAL, 2012, p. 25)

Glover and Evison identified four key messages from their report into ambulatory care sensitive conditions (ACSCs) as follows:

1. The study suggested weaknesses in primary care for people with learning disabilities. CCGs need to act to check whether and to what extent this is a problem in their area and to take necessary action to meet their statutory obligations to address it.
2. The NHS Information Centre could produce annotated hospital episode and mortality data sources, using GP learning disability register data to report how often people with learning disabilities go into hospital. This would allow national benchmarks to be produced.
3. In addition to monitoring, remedial action is needed. At the least, every in-patient unit caring for NHS patients should establish a routine Emergency ACSC notification to go with every discharge of a patient with learning disabilities admitted this way. This would advise the GP and the community learning disabilities team that a patient had been discharged with a condition suggestive of a requirement for review of their Health Action Plan.
4. In the specific situation of patients with learning disabilities and convulsions, emergency admissions should be seen as a danger warning signal. This event should trigger a review of the long term care of their epilepsy by a specialist neurologist.

(Glover and Evison, 2013)

Further guidelines on the care of people with learning disability in general hospital settings can be found in a report from Northern Ireland (GAIN, 2010)

There are several guidelines relating to learning disability nursing, including:

- *Good practice in learning disability nursing*, provides good practice guidance to support learning disability nurses to make a major contribution to the health and wellbeing of people with a learning disability in the future.
http://www.hscbusiness.hscni.net/pdf/DH_Good_practice_in_learning_disability_nursing-2007_pdf.pdf
- *Learning from the past – setting out the future: Developing learning disability nursing in the United Kingdom* (RCN, 2011), sets out the College's position to people with learning disabilities.
- In 2011, the RCN produced a report aiming to support nurses in primary and secondary care, who are trained in fields other than learning disabilities, to deliver high quality health care to people with learning disabilities. It highlights the specific health needs of people with learning disabilities and supports staff in making their services more accessible.
Meeting the health needs of people with learning disabilities (RCN, 2011).

Examples of local delivery: secondary care

Patient Passport: Cheshire and Wirral Partnership NHS Foundation Trust

A one-page patient passport has been developed, designed to provide individualised information about the person for doctors, nurses and administrative staff. The results from a pilot evaluation indicate that the tool promotes high levels of support for people with learning disabilities on admission to and during their stay in hospital (Brodrick et al, 2011).

Further details: <http://nursingstandard.rcnpublishing.co.uk/archive/article-one-page-patient-passport-for-people-with-learning-disabilities>

Developing an LD flagging system as a reasonable adjustment

Whiston Hospital is developing a system for tracking and flagging patients with learning disability. They want to know how many learning disability patients go through the hospital system each year and who they are. At present, it is not possible for the hospital to access GP or local authority learning disability registers.

To check coding procedures, safeguarding data was used to identify around 40 people with learning disability who had been inpatients. The hospital clinical coding team was asked to check these known learning disability patients against their ICD codings. Of the 40 admitted patients known to have learning disability, they had coded within F70 –F79 a total of 35 times (these are the ICD codes covering learning disability). Two patients were coded F83 (a code which is considered to be inaccurate and misleading) and a further two were not coded (a double check revealed that this may have been because their learning disability was very mild). It was concluded that Whiston coders are 90% accurate in their use of the F70 – 79 codes.

The next stage involved finding out how many patients in one calendar year (1/11/11 – 31/10/12) had been coded F70 -79. Results showed a total of 336 adult attendances involving 242 patients and 30 paediatric attendances involving 26 patients identified. The next stage was to carry out an audit of this data, to include Date, Ward Area, Consultant, Length of Stay, Locality and GP. This revealed that the vast majority of adult attendances were to Accident and Emergency, Medical and Surgical Assessment Units, 3A (Plastics), 2C (Respiratory) and Endoscopy Unit. The average number of attendances was 28 per month. Out of the 242 patients audited, 6 maternity patients were identified who gave birth across the period. Whiston Hospital now has the best data it has ever had on the number of people with a learning disability accessing inpatient care. They are now working with their partners to establish alerts on each of these patients.

Such identification of patients with learning disability is the first stage in a process of reasonable adjustments for those with learning disabilities. Future plans include using the same model on other patient populations.

Contact: Philip.Dearden@sthk.nhs.uk & Diane.Gould@sthk.nhs.uk

Sefton: Audit of patients admitted with a learning disability

Southport and Ormskirk NHS Trust carried out an audit to identify how many patients with learning disability were admitted to the Trust. The audit identified patients flagged for learning disability and admitted between January 2011 to August 2011. There were 99 admissions (43 patients).

Epilepsy was by far the most common reason for admission.

Recommended actions included working with community learning disability teams to review current provision for epilepsy review for service users.

The audit suggested that a consideration of the nutritional status and feeding ability should have been documented (highlighted in 8 admissions).

Work is now under way to work with community teams to understand why a large number of patients are admitted a number of times to the Trust.

Now it has been set up, the data search can be run as often as necessary and reports easily generated.

Contacts: Bridget Lees Matron SDGH [bridgetlees@nhs.net]; Sue Johnson Matron SDGH [s.johnson12@nhs.net]; Carol Fowler Matron SDGH [carol.fowler@nhs.net]

3.7 Mental Health

Between 25 and 40% of people with learning disabilities also suffer from mental health problems. Amongst children with learning disabilities, 36% have psychiatric disorders, compared to 8% amongst children with no learning disability (Emerson et al, 2012, literature review and Foundation for People with Learning Disabilities [online]). Of children with autism, 71% have at least one co-occurring mental health problem, while 40% have two or more (National Autistic Society 2011).

As noted by the Foundation for People with Learning Disabilities (online), children and young people with learning disabilities are much more likely than others to live in poverty, to have few friends and to have additional long term health problems and disabilities such as epilepsy and sensory impairments. These factors are all associated with mental health problems and have been discussed in the relevant sections of this report.

The Foundation for People with Learning Disabilities summarised the statistics available relating to learning disability and mental health as follows:

- People with learning disabilities demonstrate the complete spectrum of mental health problems, with higher prevalence than found in those without learning disabilities;
- The prevalence of dementia is much higher amongst older adults with learning disabilities compared to the general population (21.6% vs 5.7% aged 65+);
- Prevalence rates for schizophrenia in people with learning disabilities are approximately three times greater than for the general population (3% vs 1%);

- Reported prevalence rates for anxiety and depression amongst people with learning disabilities vary widely, but are generally reported to be at least as prevalent as the general population;
- Challenging behaviours (aggression, destruction, self-injury and others) are shown by 10%-15% of people with learning disabilities, with age-specific prevalence peaking between ages 20 and 49 (see next section on 'Challenging behaviour').

(Foundation for People with Learning Disabilities [online])

Of adults with autism in England, nearly two-thirds do not have enough support to meet their needs. At least one in three adults with autism experience severe mental health difficulties due to a lack of support (National Autistic Society, 2013).

Access to care: A person with a learning disability who has a mental illness should be able to access services and be treated in the same way as anyone else, with reasonable adjustments being made in accordance with the Disability Discrimination Act (2005), the Disability Equality Duty (2006) (DH, 2009a) and more recently, the Disability and Equality Act 2010.

However, it can be difficult to identify the prevalence of depression and anxiety among people with learning disabilities. Many people with learning disabilities are not able to express their feelings easily in words, which can mask the clinical presentation of a mental health problem and cause difficulty in making an accurate diagnosis (DH, 2009a). The Department of Health note that over recent years, more mainstream assessment tools for mental health have been adapted for people with a learning disability and specialist tools have also been developed.

The Green Light Toolkit was developed to help mental health services to assess the standard of accessibility of services to people with learning disabilities (Foundation for People with Learning Disabilities, 2004).

The Department of Health produced a positive practice guide for Improving Access to Psychological Therapies (IAPT) (DH, 2009a). They noted that commissioners of mental health services need to work with commissioners of learning disability services to ensure that the development of joint local protocols is an accepted requirement and that cohesion across IAPT services exists. Several 'reasonable adjustments' necessary to make IAPT accessible to those with learning disabilities were highlighted, including the provision of longer sessions than usual, to take account of the person's varying levels of understanding and need (DH, 2009a). There is a need to make data available on numbers accessing psychological therapies (IAPT) for people with learning disabilities.

Self-help: A series of very accessible, easy read information for people with mental health problems and learning disabilities has been produced by the Royal College of Psychiatrists' Faculty of the Psychiatry of Learning Disability and the Leicestershire Partnership NHS Trust (RCPsych, 2010a). There is a separate guide for each mental health condition (anxiety, depression, etc.).

Children/CAMHS

For young people with learning disabilities and mental health problems, services may be commissioned as part of the general Child and Adolescent Mental Health Services (CAMHS) (IHAL, 2012). It is possible that CAMHS does not cater for people with learning disability unless the

individual also has a mental health condition. There is a need to find out about CAMHS commissioning through CCGs, to identify what services are defined across CAMHS for learning disabilities in each area.

Local data: Snapshot data for 8th May 2013 was provided for St. Helens children and adolescents who use CAMHS. Of 374 cases known to CAMHS, 18% (67) had either ASD or learning disability. There were 52 with ASD and 27 with a learning disability (12 individuals had a dual diagnosis). Of the 67 children and adolescents, 76% were male and 24% female. All were aged over 7. (Data from project working group, St.Helens children's rep.)

Adults

Data obtained in May 2013 for the Wirral showed that there were 67 people with a learning disability currently known to social services who had ever had a mental health problem. In Liverpool, there were 68 mental health clients who were also identified as having a learning disability at their last review (2012/13). Data systems do not record the type of mental health problem.

Data from the community learning disability team from 5 Boroughs Partnership NHS Trust on numbers accessing community mental health services is shown in Table 19 below. This data was obtained near the project completion date and requires further exploration in future, including how many contacts are for IAPT. Comparative data from MerseyCare NHS Trust is needed to give a more complete picture of access across Merseyside and to enable the calculation of rates.

Table 19
Learning Disability (LD) Community Service at 5 Boroughs Partnership NHS Trust, Contacts, April 2013.

Service	St. Helens	Halton	Knowsley	Warrington	Liverpool
LD Community	457	290	359	457	16
Outpatients	279	218	60	279	4

Source: St. Helens CCG contact

Guidelines: mental health

The commissioning guide for Clinical Commissioning Groups (IHAL, 2012) states that the full range of mental health services should be accessible to people with learning disabilities and mental health problems. Mental health and learning disability services should work together to ensure that there is a single point of access and robust local pathways for people with overlapping needs that are delivered in the least restrictive way possible. IHAL note that the JSNA (Joint Strategic Needs Assessments) should include information about the needs of people with learning disabilities and mental health problems, and Health and Wellbeing Boards should facilitate joint working. The Department of Health interim report on Winterbourne View included an action to 'build understanding of the reasonable adjustments needed for people with learning disabilities who have a mental health problem so that they can make use of local generic mental health beds' (DH, 2012a).

The Joint Commissioning Panel for Mental Health are writing good practice guidance on the commissioning of mental health services for people with learning disabilities (mentioned in IHAL 2012).

The Foundation for People with Learning Disabilities has produced a '*Green light pack*' which is a framework and self audit toolkit for improving mental health support services for people with learning disabilities. It provides a picture of what services should be aiming to achieve, including:

- making information 'easy to read'.
- helping young people who have mental health problems and learning disabilities to get the support they need.
- having some beds in the local mental health unit that are just for people with mental health problems who have learning disabilities.
- supporting people with mental health problems who have learning disabilities to use the local mental health drop-in service.
- having a local house where people can go to stay if they need a break away from home because of their mental health problems, with support from staff who know the best ways to help them.

There are more examples in Sections 3 and 4 of the green light pack (Foundation for People with Learning Disabilities, 2004).

Improving Access to Psychological Therapies (IAPT): Commissioners of mental health services need to work with commissioners of learning disability services to ensure that the development of joint local protocols is an accepted requirement and that cohesion across IAPT services exists (DH, 2009a). Necessary 'reasonable adjustments' were highlighted.

For children and young people, there are two publications that deal with service requirements for those with learning disability and mental health problems:

- A set of standards for measuring the delivery of Tier 3 Learning Disability CAMH services by QUINMAC (Quality Improvement Network for Multi-Agency CAMHS). The QINMAC and QINMAC-LD networks were merged in 2010, and both sets of standards were integrated into a single edition. The revised standards highlight the expectation that services for vulnerable groups, such as children with a learning disability, should now be part of all mainstream CAMHS: These standards describe the quality of care that young people with learning disabilities and autistic spectrum disorders should receive whether or not they are referred to a specialist LD CAMHS team (RCPsych 2010).
- A Toolkit for Clinicians developing Mental Health Services for Children and Adolescents with Learning Disabilities in collaboration with the National CAMHS Support Service (RCPsych, 2009):

The NICE autism report (NICE, 2012) also provides guidance on interventions for coexisting mental disorders (<http://publications.nice.org.uk/autism-recognition-referral-diagnosis-and-management-of-adults-on-the-autism-spectrum-cg142/guidance#interventions-for-autism>)

NICE guidance on 'mental health problems in people with learning disability' is in development, with an expected publication date of 2016.

Recommendations from this report:

Monitor the numbers of people with learning disability admitted to hospital for mental health problems. Data on those seeing their GP for mental health problems should be available through annual health check data. Data on numbers, what type of mental health problem and access to treatments such as IAPT should be available from community learning disability teams.

3.8 Challenging behaviour

Challenging behaviour is sometimes displayed by people with learning disabilities. This behaviour is not a health condition and often results from an interaction of individual and environmental factors. NICE have recently produced a scoping document on challenging behaviour and learning disability. They note that challenging behaviour can include anger, aggression, self-injury, stereotypic behaviour (e.g. rocking, hand flapping) and disruptive or destructive behaviour (NICE, 2013).

The Mansell Report on challenging behaviour (see Section 1.3 above, DH 2007a) used the definition developed by Emerson (1995):

“The phrase “challenging behaviour” is therefore used in this report to include people whose behaviour presents a significant challenge to services, whatever the presumed cause of the problem. Wherever it is used, it includes behaviour which is attributable to mental health problems. As a working definition, that proposed by Emerson (1995) has been used:

“Severely challenging behaviour refers to behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities.”’

This is also the definition used in the NICE scoping document (NICE, 2013).

Local definitions:

Each CCG is now expected to have a register of people with learning disabilities who have challenging behaviour, so definitions are important (p.22, DH, 2012b). However in practice, challenging behaviour is not always clearly defined, so that different areas may be dealing with it differently according to the definition they use. The Mansell definition above (i.e. from Emerson 1995) is the one adopted by Knowsley, Sefton, Warrington and Liverpool.

Wirral stated that for children, the definition would be based on the standard disability recorded for the CIN Census identifying behaviour as an issue. DASS who deal with adults stated that they were not aware of any widely used standard definition for adults.

Prevalence

Between 10%-15% of people with learning disabilities have challenging behaviours (including aggression, destruction and self-injury), with age-specific prevalence peaking between ages 20 and

49 (Emerson et al, 2012 literature review). The prevalence is much higher amongst those in hospital (NICE, 2013).

People with learning disability and challenging behaviour are part of a group with complex needs. To inform commissioning, there is a need for information on how they are managed, with data on inpatient use and outpatient out of area use. The NICE scoping document on challenging behaviour and learning disability (NICE, 2013) noted that the transition from child to adult services is often badly managed, and that services for adults with a mild learning disability who may have significant challenging behaviour but are otherwise relatively able are often poorly organised.

If challenging behaviour is not dealt with properly, it can result in high costs, with some individuals for example having to be cared for in secure units. Early identification and intervention and the provision of adequate services to meet individual needs is crucial. Inappropriate or inadequate care can result in escalating the challenging behaviour. In children, individuals might be flagged as '*had contact with the police*' or '*had an ASBO (anti-social behaviour order)*'. It is necessary to consider how these individuals can be targeted for the support they need.

Providing the right support for people held in secure commissioning to return back to community placements (where appropriate) in their home borough is important. Although numbers may be small, the cost to the NHS is huge. Recent changes to the way that secure placements are funded have made this transition more difficult. The cost of community placements would need to be borne by local authorities and CCGs rather than NHS England who fund specialist commissioning. The effect of this financial disincentive needs to be monitored closely to ensure that people do not remain in secure settings for longer than is necessary.

Local data

There was limited data available on numbers with challenging behaviour. It was noted that identifying numbers of those with challenging behaviour may not be possible, as it is a transitory condition, and can change according to how the individual is being managed.

As most individuals with challenging behaviour would be referred to the Positive Behaviour Support Service (PBSS) or its equivalent, the best way of collecting data may be to count how many behaviour related referrals there are. In Knowsley, there were 7 referrals to PBSS in 2012/13. In 2012/13, the Liverpool Community Learning Disability Team received 85 referrals that might initially indicate challenging behaviour. There will be many more who subsequently become identified as such. (There is no Positive Behaviour Support Service available in Liverpool).

Extreme forms of challenging behaviour can result in an individual being detained in a secure Assessment and Treatment Unit (ATU). Data on numbers of individuals with learning disability detained in ATUs was obtained for some areas within Merseyside and North Cheshire (Liverpool 14, Sefton 11, St. Helens 4 and Knowsley 6, 2012/13).

Preliminary investigations in Knowsley suggested that of those in ATUs who had referrals to the Positive Behaviour Support Service, readmission was less likely.

Guidelines: challenging behaviour

NICE have recently released a scoping document for a piece of guidance they are starting to produce on managing challenging behaviour amongst people with learning disabilities (NICE, 2013). The Mansell Report on challenging behaviour (DH 2007) concluded that 'specialist multi-disciplinary support teams focussed on challenging behaviour are an essential component of modern provision'. Guidelines for CCGs relating to challenging behaviour suggest that they work with social care commissioners to develop strategies for partnership working to prevent problems arising in the first place and to manage them when they do (IHAL, 2012). Further information on working with providers can be found in the following documents:

- *Guide for commissioners of services for people with learning disabilities who challenge services*, (National Development Team for Inclusion, 2010)
- *Developing better commissioning for individuals with behaviour that challenges services: a scoping exercise*, (Challenging Behaviour Foundation, 2010)
- *Commissioning person-centred, cost-effective, local support for people with learning difficulties*, (Emerson and Robertson, 2008)

The wellbeing of people with learning disabilities who show challenging behaviours attracted increasing attention following the investigation of serious abuse at Winterbourne View (see Appendix 6 for an account of events relating to Winterbourne View). 'Transforming Care' (DH, 2012b) was the government response to what had happened at Winterbourne View. It set out a programme of action to transform services, so that vulnerable people showing challenging behaviour no longer live inappropriately in hospitals and are cared for in line with best practice, as follows:

- All current placements for people with learning disabilities should be reviewed by 1 June 2013, and everyone inappropriately in hospital will move to community-based support as quickly as possible, and no later than 1 June 2014.
- By April 2014, each area will have a locally agreed joint plan to ensure high quality care and support services for all children, young people and adults with learning disabilities or autism and mental health conditions or behaviour described as challenging. As a consequence, there is expected to be a dramatic reduction in hospital placements for this group of people and the closure of large hospitals.
- A new NHS and local government-led joint improvement team, with funding from the Department of Health, will be created to lead and support this transformation. Where someone is admitted to hospital the priority from the start should be rehabilitation and returning home. This requires a strong and continuing relationship between local commissioners and service providers and the hospital, focused on the individual patient's care plan, and a real effort to maintain links with their family and the home community. It also means for example, maintaining the person's tenancy of their home where relevant unless and until a more appropriate home in the community is found.
- Most of all, it is vital that families are involved in decision-making.

NHS England will; ensure by 1 April 2013 that all Primary Care Trusts develop local registers of all people with challenging behaviour in NHS-funded care, and set up reviews of care. Where responsibility transfers from the NHS to local government, councils should not be financially

disadvantaged. The NHS should agree locally how any new burden on local authorities will be met, whether through a transfer of funding or as part of a pooled budget arrangement (DH, 2012b)

Transition

The University of Birmingham published guidelines aimed at young people with learning difficulties/disabilities with mental health problems and behaviour problems/challenging behaviour (University of Birmingham. 2006).

The CCG Commissioning Guide noted that transition planning starts at the year 9 review (age 13/14), should be person centred, and should include health, independent living, employment and social inclusion (IHAL, 2012). Well planned, person centred transition is important. Poor transition can lead to serious health outcomes following disengagement with health services and subsequent costs to health services. Identifying a care coordinator or navigator is important, and is valued by families and young people (IHAL, 2012). Examples of person centred commissioning are provided in the learning disability support guide produced by the Improvement and Development Agency (IDeA, 2008).

Early identification and links with CAMHS

Links with child and adolescent mental health services (CAMHS) are important: If the needs of those with learning disability are not met early enough, some may develop additional mental health problems and challenging behaviour as adults (see mental health, Section 3.5). There needs to be an understanding of what services are defined across CAMHS for learning disability in each area.

The NICE autism report (NICE, 2012) includes guidance on interventions for challenging behaviour.

Guidelines for those working directly with challenging behaviour include the following:

- *Challenging behaviour: a unified approach* (RCPsych et al, 2007) offers best practice in working with people whose behaviour is described as challenging and has been developed by a number of professional bodies
- The RCN produced a report aimed at those in health and social care who might work with adults with learning disabilities: *Mental health nursing of adults with learning disabilities* (RCN, 2010). The report gives guidance on working with people with learning disabilities who have challenging behaviour. It notes that person-centred active support (PCAS) is the best way to achieve long-lasting positive behavioural change. The PCAS model focuses on helping people engage in meaningful activities and relationships throughout the day.

Examples of local delivery: Challenging behaviour

Sefton local authority and NHS: Joint Funding

A project in Sefton provides people with learning disabilities who display severe challenging behaviour with an integrated package of care, based on a long term supported tenancy model, to allow them to remain within community based settings, as opposed to having to access out of area specialist care. The process has been in operation since 1997. A joint funding process between NHS Sefton and Sefton Social Services, alongside integrated working and the development of a joint funded post to co-ordinate and monitor individual care packages, allows the project to run effectively. Tailor made care packages are designed to meet the specific needs of individuals with learning disabilities and complex challenging behaviour.

Individuals remain living within their local community within Sefton, as opposed to out of area; and access good local services provided by the local authority, NHS Health services and from the community learning disability team (CLDT) i.e. training staff teams who support individuals with complex challenging behaviours/autism. Family carers and people with learning disabilities are involved in the process of interviewing for their own staff team. Family carers are involved within the tender process for provider agencies, and people with learning disabilities are enabled and supported to maintain and personalise their own tenancies/homes and access local services; and therefore develop a presence and participation within the community.

Project details were submitted for inclusion in the Department of Health GOOD PRACTICE PROJECT: 'WHAT DOES GOOD LOOK LIKE?' [Sefton joint funding.doc](#)

Contact– sue.crump@sefton.nhs.uk Senior Pathway Development Manager

Response to Winterbourne: Merseyside and North Cheshire

Local authorities on Merseyside and North Cheshire have acted on the government response to the practices revealed at Winterbourne View. They have put in place resources so that people with learning disabilities who display challenging behaviour can be kept in community placements, as in the model of care set out in a report with the title: '*A Concurrent Rapid Health Impact Assessment for the Redesigning of In-patient and Community Health Services for Adults with Learning Disabilities for Halton & St Helens, Knowsley, and Warrington Primary Care Trusts*' (Grinnell, 2012)

<http://www.apho.org.uk/resource/item.aspx?RID=116992>

Positive Behaviour Support Service: Halton, Knowsley and St Helens

The service exists to support mainstream services working with people with learning disabilities, whose behaviour is a significant challenge. It works directly with people whose behaviour presents the greatest level of challenge. The service is available to service users of all ages and there is a specialist children's arm and a specialist adult's arm of the service. Halton Borough Council is the service provider. By developing a Positive Behaviour Support Service locally it provides a unique support service to those service users presenting with behaviour that challenges services in Halton, Knowsley or St Helens and reduces the financial constraints of seeking out of borough placements in the future. The service works collaboratively with the service user and their families, front line staff and other professionals to achieve the service's overall aims. It contributes to the multidisciplinary assessment process.

Further details:

<http://councillors.halton.gov.uk/documents/s24914/Positive%20Behaviour%20Support%20Service%20PPPP.doc.pdf>

Short break service, Ealing

Ealing services for children with additional needs set up "The Intensive Therapeutic & Short Break Service (ITSBS). The service provides a viable model for significantly reducing challenging behaviour and securing home placement stability for a small but significant number of children and young people whose challenging behaviour would otherwise most likely result in a move to residential placements. Residential placement was avoided for all five young people who had been offered the service between 2008 and 2010. Residential placement has also been avoided for six out of the seven young people who were first offered the service between 2010 and 2011.

Although this service does require additional staff resources and financial support, this is considerably less than the cost of a residential placement (costings are listed on p.26).

From: Winterbourne View Review: Good Practice Examples

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127314/good-practice-examples.pdf.pdf

3.9 Mortality and age at death.

A study published in 2009 by Tyrer and McGrother found mortality rates amongst people with moderate to severe learning disabilities to be almost three times higher than in the general population. Mortality was especially high in young adults, women and people with Down's syndrome, although the life expectancy of those with Down's syndrome has increased more rapidly recently, compared to those with other types of learning disability (Emerson et al, 2012).

It was not possible for the authors to say how many of these deaths would be unexpected, as they noted that people with learning disabilities often have significant co morbidity, such as physical impairments, congenital heart malformations and mental disorders, which all incur a greater risk of death. However, this would not explain all the difference (Tyrer and McGrother 2009).

The four conditions or diseases where people with a learning disability were at greatest risk of death were:

- deaths caused by congenital abnormalities (SMR = 8560),
- diseases of the nervous system and sense organs (SMR = 1630),
- mental disorders (other than dementia) (SMR = 1141) and
- bronchopneumonia (SMR = 647).

Excess deaths were also seen for diseases of the genitourinary system or digestive system, cerebrovascular disease, other respiratory infections, dementia (in men only), other circulatory system diseases (in women only) and accidental deaths (in women only) (Tyrer and McGrother, 2009).

Emerson et al noted that overall, the proportion of people with learning disabilities who die from cancer in the UK is lower than the general population (12%-18% compared to 26%), although people with learning disabilities have proportionally higher rates of gastrointestinal cancer (48%-59%, compared to 25% of cancer deaths in the general population) (Emerson et al, 2012).

Details on further disease categories can be found in the reports by Weston et al (2012) and Emerson et al (2012) on health inequalities relating to those with learning disabilities.

The *Six Lives* report outlined the cases of six people with learning disabilities who were thought to have died unnecessarily as a result of problems with accessing healthcare (Health Service Ombudsman and Local Government Ombudsman, 2009).

Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) 2013

Following the *Six Lives* report, a confidential inquiry was set up. The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) produced a report in 2013 (CIPOLD, 2013). The inquiry aimed to investigate the extent of premature death in people with learning disabilities and to offer guidance on prevention. The findings confirmed that people with learning disabilities are more likely to have a premature death than those in the general population. Researchers found that men with learning disabilities died, on average, 13 years sooner than men in the general population. Women with learning disabilities died, on average, 20 years sooner than women in the general population. Overall, 22 per cent of the people with learning disabilities were under the age of 50 when they died, compared with just nine per cent of people in the general population.

The inquiry found that the cause of premature deaths amongst people with learning disability is not, like many in the general population, due to lifestyle-related illnesses. The cause of their premature deaths appears to be because the NHS is not being provided equitably to everyone based on need. People with learning disabilities were significantly more likely than the general population to die prematurely because there had been delays or problems with investigating, diagnosing and treating their illnesses. They were also more likely to have problems in having their needs identified and appropriate care being provided in relation to their changing needs. Their families or carers had more problems in getting their views heard and listened to.

The inquiry concluded that premature deaths amongst those with learning disabilities could be avoided by improving the quality of the healthcare that they receive. The recommendations of the inquiry are summarised at the end of this section.

Merseyside and North Cheshire

The Learning Disability Observatory (IHAL) examined mortality data for the period 2006 to 2010 and calculated the median age at death of people with learning disability (i.e. the midpoint of the ages of all the people who have died). IHAL noted that data may be incomplete because often, doctors do not record learning disabilities on death certificates if they consider it had no relationship to the person's death.

Results for four of the local authorities in Merseyside and North Cheshire are shown in Table 20. Values were only recorded where the number of deaths is greater than 10, which is probably why data for Halton, St. Helens and Warrington was unavailable.

In Liverpool, the median age at death was the same as the national and North West figure of 55 and in Wirral, it was just under, at 54. In Knowsley and Sefton, people with learning disability lived longer, with a median age at death of 60.5 (although differences to the national figure were not significant).

Table 20
Median age at death for people with learning disabilities, 2006-2010.

	Age at death	Number of deaths
Knowsley	60.5	16
Liverpool	55.0	51
Sefton	60.5	40
Wirral	54.0	29
North West	55.0	610
England	55.0	4,667

Source: IHAL profiles. Data for Halton, St. Helens and Warrington was unavailable.

Guidelines: avoidable deaths

Recommendations from CIPOLD

The key recommendations from the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD 2013) include:

- The need to identify people with learning disabilities in healthcare settings, and to record, implement and audit the provision of 'reasonable adjustments'² to avoid their serious disadvantage.
- A named health professional to co-ordinate the care of those with multiple health conditions, aided by the routine use of portable patient or carer-held health records and the continuing involvement of specialist healthcare staff, who can work with the individual on a long-term basis.
- The identification of effective advocates to help people with learning disabilities access healthcare services.
- Proactive planning for the future and anticipating needs, rather than responding in a crisis.
- Standardisation of Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans.
- Better adherence to the protection of the Mental Capacity Act. There is a need for greater awareness of professional responsibility and further work at national and local levels to support conformity to its requirements.

- Adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems.
- Guidelines for orders not to attempt cardiopulmonary resuscitation on a person to be revised and clarified.
- The routine collection of data that provides information about the age and cause of death of people with learning disabilities at national level.
- The establishment of a National Learning Disability Mortality Review Body to take forward the reviews of deaths of people with learning disabilities.

In a response to the confidential inquiry, Mencap have launched a charter to eliminate health inequalities in the NHS:

http://www.learningdisabilitytoday.co.uk/mencap_launches_charter_to_eliminate_health_inequalities_in_the_nhs.aspx

In addition, prevention strategies should focus on those areas where deaths are potentially avoidable, such as

- aspirational pneumonia
- seizures

(both relatively common and affect most groups of people with learning disability – Emerson et al, 2012)

- cardiovascular disease
- diseases of the genitourinary system and digestive system
- accidental deaths

(Tyrrer and McGrother, 2009)

People with learning disability who are most at risk should be targeted, such as those with hypertension or obesity (Tyrrer and McGrother, 2009).

² Reasonable adjustments: *All public sector services now have a legal duty to provide reasonable adjustments for people with learning disabilities in order to ensure equal access to services. These may include additional support to make a service accessible, such as the provision of easy read information (CIPOLD).*

4. Social profile

The Marmot review recognised that health inequalities are the result of an interaction of a range of different factors, including housing, poverty, employment, education, social isolation and disability, all of which are strongly affected by economic and social status (Marmot, 2010). These social determinants of health can influence lifestyle factors (for example leading to poor diet) and are related to other factors such as stigma and bullying, all of which can have a negative impact on health and wellbeing.

Poverty: At the age of seven, significantly more children with learning disabilities live in a poor household (44%) when compared to those with no learning disability (20%) (Emerson et al, 2012, in an analysis of the Millennium cohort study, which tracks children born between 2000 and 2002).

4.1 Housing

A recent Mencap Housing Report (Mencap, 2012) noted that the demand for services is set to rise steeply. In 2011, there was a 3% increase in the number of people with a learning disability known to local authorities who needed housing with support. A further 5.7% increase is expected over the next two years. Mencap quoted research showing that to meet demand from the growing number of people with a learning disability, there would have to be an additional 1,324 registered care home places and 941 supported living places created every year until 2026.

Mencap (2012) found that nearly 20% of people with a learning disability known to local authorities live in accommodation that needs improvement. This includes one in three people living in registered care homes and one in four people living with family and friends.

An important barrier to independence for people with learning disabilities is a lack of appropriate housing. Mencap reported that almost two-thirds (61%) of local authorities believe that local housing arrangements do not meet the needs of people with a learning disability. This has led to long waiting lists, large numbers of people living far away from family and friends, and a high number of people living in arrangements that do not promote independent living (Mencap, 2012).

Benefits reforms have introduced another barrier. Mencap note that changes to the benefits system under the Welfare Reform Act 2012 change the way many housing options are funded, which will affect the ability of local authorities to support independent living for people with a learning disability. With only 6.6% of people with a learning disability in paid employment (see 'employment', Section 4.6), there is widespread reliance on benefits to support living arrangements. Changes in the Act place a greater focus on those with high-level needs, reducing the availability of benefits for those with low and moderate needs (Mencap, 2012).

The majority of people with learning disabilities live in the family home, many with ageing parents. Some people live in residential care, others in their own home with support coming in. Housing and support needs can change as people age. The British Institute of Learning Disabilities (BILD) note that some people want to 'age in place,' that is stay in their home with adaptations and physical changes to their home depending on their needs. Others are happy to consider different housing options as their needs change. There are a range of different housing options for older people and with the growing use of technology people can be well supported to stay in their own home (BILD, 2013).

Assistive technology and telecare (AT&T)

The introduction of assistive technology and telecare (AT&T) into people's lives should help to advance the goals of increasing choice, independence/autonomy and inclusion for those with learning disabilities. It has the potential to help people with learning disabilities to become more independent while keeping them safe and reducing staff input. Devices such as finger-print operated door and room locks, tracking systems and epilepsy and enuresis sensors have created the potential for vulnerable people to be monitored remotely and supported as needs arise rather than having to be supported by staff directly and irrespective of immediate need (Beyer et al, 2008).

Increased social isolation may be a potential consequence of AT&T in a certain situations. This needs to be monitored and consideration given to compensatory strategies where necessary, such as fostering relations with neighbours, or exploring more leisure activities with social contact in mind.

AT&T can also enhance the employability of people with learning disabilities, as demonstrated by the TATE (Through Assistive Technology to Employment) project (see 'Employment', Section 4.6).

Types of accommodation

Local authority social service departments often become involved in helping people with learning disabilities to arrange where they live. Types of accommodation can be divided into settled accommodation, where the person can reasonably expect to stay as long as they want and unsettled accommodation which is either unsatisfactory or, where, as in residential care homes, residents do not have security of tenure (IHAL 2013). Examples of each of these are given in Table 21.

Severely unsatisfactory accommodation: Some non-settled accommodation could be seen as involving serious emergency situations for people with learning disability. IHAL (2013) noted that these situations are undesirable for anybody, but for people particularly likely to be vulnerable to abuse or exploitation, or in need of particular support, they are especially serious. These severely unsatisfactory types of accommodation are the non-settled categories marked * in Table 21.

Accommodation unknown: Looking at local authority figures for types of accommodation for working age adults with learning disability, it is apparent that social services departments do not know about everyone. The indicator 'accommodation unknown' shows the percentage of adults (aged 18 to 64) with learning disability known to the local authority for whom no information about accommodation is available (IHAL, 2013). This is calculated as the difference between 'total service users' and the sum of the indicators 'living in settled accommodation' and 'living in non-settled accommodation' (as instructed in IHAL 2013).

Table 21
Categories of ‘settled’ and ‘non-settled’ accommodation lived in by people with learning disability

Settled accommodation	Non-settled accommodation
<ul style="list-style-type: none"> • Owner Occupier/Shared ownership scheme • Tenant - Local Authority/Arm’s Length Management Organisation/Registered Social Landlord/Housing Association • Tenant - Private Landlord • Settled mainstream housing with family/friends (including flat-sharing) • Supported accommodation/Supported lodgings/Supported group • Adult placement scheme • Approved premises for offenders released from prison or under probation supervision • Sheltered Housing/Extra care sheltered housing/Other sheltered housing • Mobile accommodation for Gypsy/Roma and Traveller community 	<ul style="list-style-type: none"> • *Rough sleeper/Squatting • *Night shelter/emergency hostel/direct access hostel • *Refuge • *Placed in temporary accommodation by Local Authority e.g., Bed and Breakfast • Staying with family/friends as a short term guest • Acute/long stay healthcare residential facility or hospital • Registered Care Home • Registered Nursing Home • Prison/Young Offenders Institution/Detention Centre • Other temporary accommodation <p><i>*= severely unsatisfactory accommodation</i></p>

Source: IHAL (2013)

Merseyside and North Cheshire

Table 22 shows the number of adults (aged 18 to 64) with learning disability, known to local authorities, who the local authorities report are living in any one of these types of accommodation – either unsettled, settled or accommodation unknown.

Settled

The majority of people with learning disabilities live in settled accommodation, either in their own home or with family. In 2011/12, there were 3,070 male and 2,260 female adults with learning disability of working age in Merseyside and North Cheshire who were known to social services. Of these, three quarters (75.0%) were recorded as living in their own homes or with their family (i.e. in ‘settled accommodation’). This is higher than the national average of 70.0%, and slightly lower than the North West average of 77.8% (see Appendix Figure A3 and Table A1).

Table 22 shows the differences in proportions in settled and non-settled accommodation across Merseyside and North Cheshire. Proportions in settled accommodation are especially high in Knowsley (more than 9 in 10, or 90.6%). Wirral is the only local authority to fall below the national average of 70.0%, with only 1 in 3 (33.2%) of those with learning disability recorded as living in settled accommodation.

Table 22 show that some of this variation can be explained by the fact that in some areas, there are large proportions of people with learning disability whose accommodation status is unknown, especially in Wirral.

Gender

Differences between the sexes in type of accommodation were very small (see Figure A3 and Table A1 in Appendix for further breakdown by sex).

Table 22
Accommodation status of people with learning disabilities (LD) aged 18-64, 2011/12

	Non-settled accommodation		Settled accommodation		Accommodation unknown**		Total service users	
	number of service users	% of all with LD	number of service users	% of all with LD	number of service users	% of all with LD	number	%
Halton	25	6.4%	305	77.2%	65	16.5%	395	100%
Knowsley	65	9.4%	610	90.6%	*	-0.8%*	670	100%
Liverpool	200	13.7%	1245	86.3%	0	0.0%	1445	100%
Sefton	140	17.5%	655	82.5%	0	0.0%	795	100%
St. Helens	440
Warrington	55	12.0%	400	88.0%	0	0.0%	455	100%
Wirral	45	4.5%	340	33.2%	635	62.3%	1020	100%
North West	1850	9.3%	15475	77.8%	2575	12.9%	19900	100%
England	31255	22.5%	97360	70.0%	10475	7.5%	139090	100%

Source: NHS IC, ASCCAR L2

.. St. Helens: data was incomplete - see note with Table A3 in Appendix

*in Knowsley, figures for 'non-settled' plus 'settled' added up to more than 'total with LD'.

Merseyside totals have not been included, due to the missing S.Helens data

**'Accommodation unknown' is calculated as calculated as the difference between 'total service users' and the sum of the indicators 'living in settled accommodation' and 'living in non-settled accommodation' (as instructed in IHAL 2013)

Non-Settled

Nationally, more than 1 in 5 (22.5%) adults with learning disability age 18-64 live in non-settled accommodation. In Merseyside and North Cheshire, the situation is much more favourable, but there are still five local authorities where the level is above the North West average of around 1 in 10 (9.3%). Levels are highest in Sefton (17.5%), Liverpool (13.7%) and Warrington (12.0%) (see Table 22).

Living in permanent residential and nursing care homes

The NHS IC term 'unsettled accommodation' includes those living in residential care homes. Their Adult Social Care Outcomes Framework data for 2011/12 includes permanent admissions to residential and nursing care of younger adults with learning disability.

Table 23 gives the rate of admission per 100,000 of the general population for each local authority in Merseyside and North Cheshire. Rates are lower than the national and regional average in each local authority except Wirral and Warrington.

Actual numbers of permanent admissions are very small. In 2011/12, across Merseyside and North Cheshire, there were only 30 such admissions amongst people with learning disability aged 18-64.

As the term 'unsettled accommodation' includes those living in residential care homes, it is possible that in Warrington, the higher levels of unsettled accommodation for those with learning disability (see table 22 above) could possibly be partly explained by the high levels of care home admissions in the borough.

Table 23
Permanent admissions of younger adults (aged 18 to 64) with learning disabilities (LD) to residential and nursing care homes, per 100,000 population (adjusted), 20011/12

Local authority	Number of council-supported permanent admissions to residential and nursing care, ages 18-64 with LD	Total population aged 18-64 in each area	Rate of admissions per 100,000 of the general population aged 18-64
Halton	*	78,890	*
Knowsley	*	90,130	*
Liverpool	5	311,135	2.2
Sefton	5	162,410	3.7
St. Helens	*	107,375	0.9
Warrington	5	126,210	5.5
Wirral	15	190,830	6.8
Merseyside & North Cheshire	30		
North West	172	4,376,031	3.9
England	1,470	33,036,751	4.4

Source: NHS Information Centre, Adult Social Care Outcomes Framework for 2011/12. Adults with learning disabilities known to Councils with Adult Social Services Responsibilities (CASSRs). Final report, Feb. 15th 2013. Excludes transfers between residential and nursing care. Based on ONS 2011 mid-year population estimates.

**= numbers too small to include*

NHS IC note: The data used in this measure was collected in previous years from the ASC-CAR return. However, the NHS IC expect the data behind the measure in 2011-12 to be higher as responsibility for some learning disability services has been transferred from the NHS to local authorities. In 2011-12 these service users were treated as new admissions.

Severely unsatisfactory

IHAL (2013) report that numbers for this indicator are fortunately low and in most cases where the figure is not zero the exact number is not known (because rounding is introduced into the statistics for confidentiality reasons). They add that in any case, it is likely that numbers reported are out of date by the time tables are published.

In Merseyside and North Cheshire, Liverpool was the only local authority in which adults with learning disability were recorded as living in severely unsatisfactory accommodation. There were 10 such people in Liverpool in 2011/12, with 35 in the whole of the North West, and 260 nationally. All 10 in Liverpool were in the category '*night shelter/emergency hostel/direct access hostel (temporary accommodation accepting self referrals)*' (see Table 21 above). Of these, 5 were male and 5 female.

Unknown

Table 22 shows that some of the variation in levels of settled and unsettled accommodation can be explained by the fact that in some areas, there are large proportions of people with learning disability whose accommodation status is unknown to the local authority (as mentioned in the text preceding Table 22 above).

In Wirral, the accommodation status of around two-thirds (62.3%) of adults with learning disability was unknown in 2011/12. Levels were also higher than the national average of 7.5% in Halton (16.5%). The North West average for unknown accommodation status was 13.0%.

Gender

Overall, there was not a great deal of difference between the sexes in accommodation status across Merseyside and North Cheshire and nationally. However, there were noticeable differences in 3 local authorities:

- In Sefton and Wirral, females with learning disability were more likely to live in unsettled accommodation than males:
 - although numbers were small, on Wirral, females were twice as likely to live in unsettled accommodation (6.2%) compared to males (3.2%). This could be partly explained by the fact that the accommodation status of males was more likely to have been unknown
 - in Sefton, the accommodation status of all those with learning disability had been recorded. There were 1 in 5 (21.5%) females in unsettled accommodation, a figure similar to the high national rate of 21.9%. The rate for males was still high compared to the rest of Merseyside and North Cheshire, at 13.8%

A more detailed breakdown of the data according to sex can be found in the Appendix (Figures A4 and A5).

Guidelines: Housing

Social determinants of health: The CCG Commissioning Guide noted that CCGs will need to work with Local Authorities and public health to tackle the social determinants of poorer health, such as housing, discrimination, unemployment and social exclusion (IHAL, 2012). Commissioning responsibility for these issues sits with Local Authorities.

The Mencap (2012) housing report called for the development of a national strategy on housing for people with a learning disability. This will pull together learning across local authorities and identify what action needs to be taken at the national level.

Mencap also recommend that all local authorities include specific plans for improving the housing situation of people with a learning disability in local housing strategies. As local authorities will face growing pressures from increasing local need, planning for the future is crucial. An action plan designed around promoting independent living should accompany any such plans.

Assistive technology: Care managers and commissioners of packages of support will increasingly require assistive technology and telecare (AT&T) to be part of the services provided by support organisations. They need to consider what AT&T can do as part of a package of support (Beyer et al, 2008). Beyer et al set out steps for assessing the AT&T needs of people with learning disabilities. Arrangements need to be made for increasing awareness of AT&T and its use among staff, person centred planners, service users and commissioners.

Examples of local delivery: Housing

Wirral: Lee Court

Lee Court is a scheme in Hoylake for young disabled people, some with learning disabilities and others with physical disabilities, who all wanted to live together, but independently from parents. The issue of young disabled people still living 'at home' with increasingly elderly parents was one that needed to be addressed. Wirral Council and the RSL (Wirral Methodist Housing Association) made a successful bid to the Government's Homes and Communities Agency for £529,000, and the scheme cost £3.2 million in total. 11 flats for clients with learning difficulties were built, as well as two bungalows in small group settings for the disabled, and eight two bedroom flats for the active elderly. Wirral Department of Adult Social Services provide a care and support package to assist the residents in maintaining their tenancies, with 24 hour coverage and targeted interventions contracted out to Wirral Independent Living and Learning.

Contact: Sarah Kinsella [sarahkinsella@wirral.gov.uk]

'My Housing Plan', Wirral.

Wirral has a specific Learning Disability Housing Plan, which has been developed as an action from the Learning Disability Housing Strategy and is available in EasyRead for LD clients. In turn, this has led to the development of a 'My Housing Plan' document which has been designed to capture needs and aspirations, provide an evidence base of future housing needs for clients with a learning disability, show current and future housing needs, and inform future commissioning for housing and services.

The aim is to enable people with learning disabilities to have the same choice and options about where they live as the rest of the population. The My Housing Plan will be completed at a clients review with all clients (even if they have no wish to currently move).

Partnership working between local housing authorities, social services, health and other local agencies will be required in order to accomplish the plan.

Contact: Sarah Kinsella [sarahkinsella@wirral.gov.uk]

London: Settled accommodation

In London, a number of boroughs took part in an initiative to increase the number of people with learning disabilities in settled accommodation. This included:

- person-centred reviewing to support adults with a learning disability to achieve their aspirations;
- engagement and negotiation with providers to reduce costs;

The initiative delivered:

- significant efficiency savings in expenditure on learning disability services;
- quality outcomes for adults with learning disabilities;
- improvements in the balance between supported living and residential care;
- an increase in the number of adults living in settled accommodation.

IHAL, 2012. Further information: www.evidence.nhs.uk/qipp

'What Lies Ahead' Project
Whitfield Lodge, Family led housing scheme, St. Helens

Whitfield Lodge in the Clock Face area of St Helens is a 'Your Housing Group' supported living environment for 10 people with learning disabilities. The Care Provider is Creative Support. It was commissioned by a group of parents who were looking for long term solutions for their sons and daughters as they aged. The group wanted to have more involvement in the planning process of care, rather than wait until a crisis occurred.

Over many months the parents, on behalf of their families, worked closely with St Helens Council and Arena Housing Association and in 2002 a plot of land had been negotiated and design options for the housing scheme had been finalised. The new accommodation was to consist of 10 individually designed apartments all under one roof (similar to a sheltered housing complex). The concept behind the scheme was that the adult tenants should be able to live as independently as possible within the confines of their individual disabilities. During the build the families worked with an independent Brokerage Organisation and Social Services to finalise the care packages for each person.

The Housing Association decided to procure the project using the PPC 2000 Partnering Form of contract, which meant that all partners could participate in the briefing process right the way through the project from inception to completion.

Work on the site began in February 2003 and handover of the project took place in November the same year. During this time the Housing Association also arranged monthly meetings with the parents so that everyone was kept up to date on progress which proved invaluable when it came to tendering for the Care provider and the eventual transitional process of their sons' and daughters' into their new homes. Arena Housing Group have now merged with Harvest Housing Group to form Your Housing Group

St. Helens council was breaking new ground by working with a group of parents on this project, with the Assistant Director of Social Services telling the carers and clients that they would be in the driving seat from the outset, which they felt they have been. They hope it has paved an easier path for those families who will follow on when their time comes.

Contacts:

Carolann Bowers, Carers Support Group, St. Helens carolann1945@live.co.uk

*Colin.Croxton@yourhousinggroup.co.uk Agency Services Manager
www.yourhousinggroup.co.uk*

Extra Care Housing Scheme

A mother in her 80s and daughter with Down syndrome in her 50s had been separated for the first time in their lives through illness; the mother was temporarily in a care home. They were able to move into a one bedroom flat together in an extra care housing scheme: in their previous housing they had always shared the same bedroom. Within a year the mother died, but the daughter was able to remain in the flat. She received sensitive and appropriate support from staff and other tenants who already knew her, she continues to thrive.

Housing Learning and Improvement Network (2006), quoted on BILD website (BILD is the British Institute of Learning Disabilities)

<http://www.bild.org.uk/information/ageingwell/housing/>

4.2 Community care

Table 24 below shows the extent to which local authorities are providing community services for people with learning disabilities known to them. Nationally, three quarters (75%) of those with learning disability were receiving community services amongst those aged 18-64 in 2011/12. Across Merseyside and North Cheshire, rates were higher than the national average of 75%, with the exception of Wirral, where just over two-thirds (68.1%) received community services.

Table 24
Community Based Services received by those with learning disabilities,
aged 18 to 64, 2011/12

	Numbers receiving learning disability community services	Total population with learning disability known to the local authority aged 18-64, 2011/12	% of all learning disability clients receiving community services
Halton	310	395	78.5
Knowsley	575	670	85.8
Liverpool	1255	1445	86.9
Sefton	655	795	82.4
St. Helens	425	545	78.0
Warrington	400	455	87.9
Wirral	695	1020	68.1
North West	16810	19900	84.5
England	104315	139085	75.0

Source: NHS IC NASCIS, RAP P1 (P1 data also includes numbers in residential and nursing care. IHAL didn't include this in their profiles – see social care NASCIS.xls, 3rd tab. Larger numbers than in Table A1 in Appendix – [permanent admissions to res & nursing care].

Note from IHAL: in 2011/12, the denominator was changed from those who had a review to those eligible for a review

4.3 Violence/ keeping safe/ social isolation

A vulnerable adult is someone who is aged over 18, but may not have the ability to not only look after themselves, but may also be at risk because they can't protect themselves from harm or exploitation (About Learning Disabilities, online B). People with learning disabilities may be classed as vulnerable. They may be at risk in their own homes, in their local communities or whilst using public transport. They are at increased risk of becoming victims of sexual abuse, bullying, and are less able to defend themselves against violence.

Factors which place people with disabilities at higher risk of violence include stigma, discrimination, and ignorance about disability, as well as a lack of social support for those who care for them. Placement of people with disabilities in institutions also increases their vulnerability to violence (WHO, online).

Violence

A review on the prevalence and risk of violence against children with disabilities found that overall children with disabilities are almost four times more likely to experience violence than non-disabled children. Children with mental or intellectual impairments appear to be among the most vulnerable, with 4.6 times the risk of sexual violence than their non-disabled peers (Jones et al, 2012). A separate review on adults found that those with 'intellectual impairments' were 1.6 times more likely to be a victim of violence than those without a disability (Hughes et al, 2012).

It has been recognised that the sex education needs of young people with learning disabilities are not being met (Simpson et al, 2010) (see Section 3.4). The importance of addressing these needs was highlighted by an NSPCC study which revealed a higher level of sexual abuse and exploitation among children and young people with learning disabilities (NSPCC, 2006).

Bullying

At the age of seven, significantly more children with learning disabilities report being bullied more than once or twice at school (14%) when compared to those with no learning disability (6%) (Emerson et al, 2012, analysis of the Millennium cohort study, which tracks children born between 2000 and 2002).

In a recent survey of people with autism, 63% of young people reported having been bullied at school, rising to 75% in secondary school and as many as 82% of those with high functioning autism or Asperger's syndrome (Bancroft et al, 2013).

Social isolation

Isolation can make people more vulnerable. The report of the first national survey of adults with learning disabilities in England (Emerson et al, 2005) found evidence of social exclusion and stigma amongst the 2,898 participants:

- 58% of adults with learning disability had infrequent contact with their families (compared to 9% of those with no learning disability)
- 31% of adults with learning disability had no contact with friends (compared to 3% of adults without learning disability)
- Nearly one in three people (32%) said someone had been rude or offensive to them in the last year because they have learning difficulties

The survey found that barriers to social contact for those with learning disability included living too far away; no time; no money; unable to get out; or afraid of going out (Emerson 2005).

In the 2012 survey of people with autism, 22% of young people said they had no friends at all and half said they would like more friends (Bancroft et al, 2013). Amongst adults, 1 in 4 (24%) said they had no friends, with 66% saying that their main friend was a family member or their carer and 65% saying they would like more friends. For those adults with autism who also had a learning disability, the proportion who said they had no friends was higher, at one-third.

The survey found that the support that people with autism most want is to help them to socialise and become less isolated.

Merseyside and North Cheshire

Table 25 shows local statistics relating to the abuse of vulnerable adults with learning disabilities across Merseyside and North Cheshire in 2011/12. It lists numbers and rates per 10,000 of referrals of adults with learning disabilities to the social service safeguarding teams.

Table 25

Abuse of Vulnerable Adults:

Number of completed referrals to Social Care Adult Safeguarding Teams by age of alleged victim with learning disabilities, 2011/12

	Age 18 to 64		Age 65 to 74		Age 75 to 84	Age 85 and over	Total aged 18+
	Number of completed referrals	Rate per 10,000 Population	Number of completed referrals	Rate per 10,000 Population	Number of completed referrals	Number of completed referrals	Number of completed referrals
Halton	40	5	0	0	0	0	40
Knowsley	40	5	5	5	0	0	45
Liverpool	180	5	20	5	5	0	205
Sefton	125	10	15	5	0	0	140
St Helens	170	15	10	5	0	0	180
Warrington	110	10	20	10	0	0	130
Wirral	185	10	10	5	5	0	200
North West	2100	5	170	5	45	15	2330
Total	15580	5	1060	0	320	125	17085

Source: NHS IC NASCIS, AVA, Table 1 Completed Referrals

Amongst those aged 18-64, referral rates were higher than the North West and national average of 5 per 10,000 in four of the seven local authorities in Merseyside and North Cheshire. They were highest in St. Helens, where there were 170 referrals of people with learning disability (15 per 10,000) during 2011/12. Rates in Halton, Knowsley and Liverpool were the same as the North West and national average.

For those aged 65-74, only Warrington had a higher rate of referrals than the North West average of 5 per 10,000. Numbers of referrals amongst those aged 65+ were very small. For those aged 75 plus, numbers were too small to calculate meaningful rates. There were 5 referrals in Liverpool, 5 in Wirral and none elsewhere.

There was not a great deal of difference between the sexes in numbers of vulnerable adults with learning disability who were referred to social services in 2011/12.

Hate crime: Hate Crime is any offence or incident committed against individuals, groups and communities because of who they are. It is an act motivated by someone's prejudice towards another person because of his or her age, disability, gender identity, race, religion or belief or sexuality (Safer St.Helens online). Hate crime was one of the main issues identified by people with learning disabilities in a consultation exercise in Sefton (see Section 5). In future, it may be possible to obtain figures on disability hate crime from Merseyside Police's SIGMA unit. SIGMA is a dedicated Hate Crime Investigation Unit, (the name is taken from a character in the Greek alphabet).

Guidelines: vulnerable people and isolation, stigma and violence

The government has published a booklet for vulnerable people and their carers entitled 'Keep Safe'. It advises ways in which vulnerable people, including learning disabled, can help to reinforce their personal safety, whether in their homes, entering into their local communities or travelling around (About Learning disabilities, online B).

The National Autistic Society runs social groups, where people with autism can get together and socialise with their peers. 82% of those attending Scottish social groups said that they had learnt new skills as a result of attending, with 72% saying that thanks to attending the group they now had sufficient confidence to socialise outside of it Bancroft et al, 2013).

Guidance produced by the Child and Maternal Health Intelligence Network (CHIMAT) provides advice on dealing with bullying involving children with special educational needs (SEN) and disabilities (CHIMAT, 2008).

Social determinants of health: The CCG Commissioning Guide noted that CCGs will need to work with Local Authorities and public health to tackle the social determinants of poorer health, such as housing, discrimination, unemployment and social exclusion (IHAL, 2012). Commissioning responsibility for these issues sits with Local Authorities.

Recommendation from this project working group: In future, it may be possible to obtain figures on disability hate crime from Merseyside Police SIGMA (hate crime) unit.

4.4 People with learning disabilities in the criminal justice system

The Bradley Report (DH Bradley Report, 2009) highlighted the disproportionately high number of people with learning disabilities and mental health problems in the criminal justice system (CJS - a term used to mean the police, courts, prison and probation). It has been estimated that the proportion of people in prison who have learning disabilities or learning difficulties that interfere with their ability to cope with the criminal justice system is around 20-30% (Loucks, 2007, Talbot, 2008). There are high numbers of offenders with unidentified learning difficulties or learning disabilities.

The Prison Reform Trust (2012a) found that information accompanying people into prison is unlikely to show that the presence of learning disabilities or difficulties had been identified prior to their arrival.

Young people with learning disabilities are over-represented in the youth justice system (YJS), which is the system for dealing with offending by those aged 10-18. It is estimated that 25 to 30 per cent of children and young people in the YJS (i.e. not necessarily in custody) have learning disabilities, and that around 50 per cent of those in custody have learning difficulties (HM Government, 2009). (see Section 1.2 for a discussion of the distinctions between the term 'learning disability' and 'learning difficulty'). A report carried out on behalf of the Youth Justice Board (Harrington and Bailey, 2005) found that almost a quarter of young offenders had learning difficulties (IQ<70), while a further third had borderline learning difficulties, with an IQ of between 70 and 80.

There are large numbers of people with learning disabilities being dealt with by the criminal courts on a daily basis, with the actual numbers unknown (Prison Reform Trust, 2012a). The Prison Reform Trust (PRT) called for reasonable adjustments to be made, so that the ordinary trial process is adapted so far as is necessary to assist vulnerable defendants to understand and to participate in proceedings. They noted that at present, vulnerable defendants don't have the same statutory protection to support, in law, as vulnerable witnesses do. However, under the Disability and Equality Act (2010), 'reasonable adjustments' should be made to ensure that discrimination against people with disabilities does not occur. The government has committed to liaison and diversion services in every police custody suite and criminal court by 2014 (NLDDN, online). As pointed out by the PRT, these will only work if local learning disability service providers work collaboratively to ensure the most appropriate outcome for the individual concerned. Learning disability services need to work with criminal justice staff to identify when people might have a learning disability and to ensure that the necessary support is put in place (Prison Reform Trust, 2012a).

The Bromley Briefings (Prison Reform Trust, 2012b) provided evidence that people with learning disabilities may serve longer custodial sentences than others convicted of comparable crimes (see Box 2). Many miss out on interventions they needed to secure their release. Offending behaviour programmes are not generally accessible for offenders with an IQ below 80.

There are difficulties in accessing prison information; with four-fifths of prisoners with learning disabilities having problems reading prison information. This means that they often miss out on things such as family visits and going to the gym, or getting the wrong things delivered such as canteen goods. Prisoners with learning

disabilities or difficulties are the most likely to spend time on their own and have fewer things to do. They are also five times as likely as prisoners without such impairments to have been subject to control and restraint techniques and more than three times as likely to have spent time in segregation (Prison Reform Trust, 2012b).

Box 2
Inequalities in access to
offending behaviour programmes

In February 2010 a prisoner with learning disabilities, who had served over twice his tariff, was awarded a case for breach of the Disability Discrimination Act and for breach by the Secretary of State for Justice for failing in his duties to take steps to enable the prisoner in question to undertake some type of offending behaviour work.

The Prison Reform Trust, 2012b

Research by Talbot found that over half of prison staff believe that prisoners with learning disabilities or difficulties are more likely to be victimised and bullied than other prisoners. Over half of such prisoners say they had been scared while in prison and almost half say they had been bullied or that people had been nasty to them (Talbot, 2008).

Merseyside and North Cheshire

For those aged under 18, Hindley is where the majority of male young offenders from the Merseyside area are sent to if they are sentenced to custody. There are no YOI institutions in Merseyside. Female offenders are sent elsewhere in the country, and are likely to be held further from home. There is one secure children's home for offenders in St Helens (Red Bank). There are no secure training centres.

For over 18s – there are no female prisons on Merseyside. There are 3 male prisons on Merseyside – HMP Liverpool, Altcourse, HMP Kennet. Female offenders from the Merseyside area are sent to HMP Styal in Cheshire.

As with other agencies, young people with learning disabilities are considered to be young people until the age of 25 years. Most youth offending teams will assess young people at 18, and make a decision as to their suitability for transfer and ability to cope with the adult system (Lewis and Scott-Samuel, 2013).

Local data: The Adult Social Care Combined Activity Returns (ASCCAR) from the NHS Information Centre include information on accommodation type for those people with learning disability who are known to local authorities. This includes:

- numbers in custody (prison/young offenders institution/detention centres), and also
- numbers in approved premises for offenders released from prison or under probation supervision (e.g., probation hostel)

In the whole of the North West, there were only 5 people known to have learning disability recorded as being in custody and another 5 in approved premises in the community in 2011/12. None were recorded in Merseyside and Warrington (Source: NHS IC, ASCCAR L2 – see Glossary). This illustrates the under-reporting of learning disability for people in the criminal justice system and the need for improved screening at the point of first contact.

A health needs assessment for young offenders across the youth justice system on Merseyside has recently been completed (Lewis and Scott-Samuel, 2013). The needs assessment found that at HMYOI Hindley, in a 4 month period (1st August to 30th November 2011), there were 56 referrals to the learning disability service. It is not known what proportion of these referrals were of people from the Merseyside area. At the time of the needs assessment, there were two full-time learning disability nurses employed at Hindley.

There was found to be no direct provision for young offenders with learning disabilities at Red Bank home in St. Helens.

Guidelines: criminal justice system

'Commissioning Specialist Adult Learning Disability Health Services' (DH, 2007) details good practice guidance, including recommendations relating to offenders with learning disabilities. In particular, it was recommended that health screening should be carried out to identify those in prison who have learning disabilities and the health needs they may have and to provide links to community learning disability teams.

Lord Bradley was asked to look at diverting people with mental health problems and learning disabilities away from the CJS. The main findings of the report included interventions to help vulnerable people as soon as possible in the criminal justice system. It also called for a separate review, looking at prevention and intervention for options for children and young people who are at risk of offending. In terms of prison health care, the report calls for appropriate community alternatives for vulnerable offenders, saving up to 2,000 prison places per year. The report reiterated the need for better screening for learning disabilities and mental health problems when people arrive at prison. It also called for greater continuity of care when people enter and leave prison (DH Bradley Report, 2009).

The recommendation for offender health screening programmes to identify learning disability also featured in the interim report published in response to Winterbourne View (DH, 2012a). This report also recommended that social care services should work closely with prison and secure services to ensure person centred planning and health action planning and to plan for appropriate provision when people move on from prison or secure services.

'Positive Practice, Positive Outcomes 2011' (DH, 2011a), has been written for staff working in the Criminal Justice System. It gives staff information about learning disabilities and learning difficulties, outlines the laws that protect people with learning disabilities and learning difficulties in the Criminal Justice System, and gives examples of good practice from around the country. The Government have also produced an Easy Read booklet for people with a learning disability who find themselves in contact with the Criminal Justice System.

The NCB are now responsible for the commissioning of all health services for people in prisons and other custodial settings (adult prisons, young offender institutions, juvenile prisons, secure children's homes, secure training centres, immigration removal centres, police custody suites) and this will include people with learning disabilities. Health services for adults and young offenders serving community sentences and those on probation are within the responsibility of Clinical Commissioning Groups.

The CCGs have an important role in collaborating with NHS England to ensure there is a joined up pathway between services for offenders with learning disabilities (IHAL, 2012). There need to be good links between forensic services and other services such as mental health services, social care and the Criminal Justice System (CJS), and the involvement of agencies such as housing, employment and education, to help to find pathways away from the CJS. CCGs should check that Joint Strategic Needs Assessment (JSNAs) include information about people with learning disabilities at risk of offending/reoffending. Health and Wellbeing Boards should facilitate integrated working to reduce the likelihood of individuals coming into contact with the CJS (IHAL, 2012).

In the court system, reasonable adjustments are required, including the establishment of Liaison and Diversion Development services, which require collaborative working between learning disability services and criminal justice staff (Prison Reform Trust, 2012a).

Examples of local delivery: Criminal Justice System

Joint working in Sefton

The Criminal Justice liaison system is in place between the Courts and MerseyCare NHS Trust to enable vulnerable adults including those with ASC (autism spectrum condition) to receive appropriate NHS interventions. Joint planning with health partners is in place. The MARAC process is well established with all criminal justice agencies for vulnerable adults.

Sefton Autism Self Assessment, 2012

Hindley

Case Study 'We supported a young person who had a significant learning disability and an attachment disorder. It was quite quickly apparent that he was struggling to cope with prison life. He was on the Disruptive Prisoner Protocol but it was believed that moving him to another prison could make his attachment disorder worse. After the multi-disciplinary team assessed his degree of 'mental disorder' and his level of vulnerability and risk in prison, it was agreed that treatment in hospital was the more appropriate option. He received the formal psychiatric assessments required for a transfer under the Mental Health Act. We then made sure that he was appropriately supported in prison until he could be transferred'.

*Learning Disability Lead, HMYOI Hindley
(Department of Health, 2011)*

4.5 People with learning disability who are parents

Estimates of the total number of parents with learning disabilities in the United Kingdom vary widely, from 23,000 to 250,000. There are increasing numbers of parents with learning disabilities in contact with services (DH & DfES, 2007).

There are varying estimates of the proportion of parents with learning disabilities whose children are removed from their care. It is likely that about 40% of parents are not living with their children. Fathers are more likely to be living with their children than mothers. Six out of ten mothers (60%) who live either on their own or with a partner, are not living with their children aged under 18 (DH & DfES, 2007).

Research by Cleaver and Nicholson (2008) compared the needs of 76 children from 10 different local authorities living with a parent who had learning disabilities, with a group of 152 children where

neither parent had a learning disability. The researchers found that parents with learning disabilities rarely approached children's services for help – practitioners were more likely to seek help on their behalf. Most parents who had a learning disability also had or had experienced: poor mental and physical health, domestic violence, childhood abuse, growing up in care, or substance misuse. Many parents were also bringing up children with learning disabilities, some of whom also had physical disabilities. The researchers found that removing children from their parents was a 'last resort', and the decision to place children away from home was taken after substantial input of services had been tried. They found little evidence of collaborative working between adult and children's services, despite collaborative working being recommended by Government guidance.

Involvement of services tended to be time-limited. Three years after referral, 78.8% of cases were closed to children's social care services and to learning disability teams within adult services. However, this resulted in cyclical crisis episodes for families – over half the cases that were closed to children's social care services were re-referred, at least once, over three years, for example. The authors conclude that short-term, targeted interventions by statutory agencies are insufficient – families need continued formal and informal support, and contingency planning. Resources will often need to be committed for the whole of a young person's childhood.

Merseyside and North Cheshire

There is a lack of readily available data on numbers of people with learning disabilities who are parents. Sefton provided information that in 2009/10, there were 16 people with learning disabilities identified as parents within the local authority (Sefton LD Partnership Board Self-Assessment report). As at July 2013, there were 16 adults with a learning disability recorded to have a child in St. Helens and 11 in Halton.

In Knowsley, 16 parents with learning disability have been supported with accessible information through the 'Parents Together' scheme (see best practice box below for more details).

An audit of patients with learning disability carried out at Whiston Hospital revealed that there were 6 maternity patients who gave birth during a 12 month period (from St. Helens and Knowsley, November 2011 to October 2012) (see Whiston 'Local examples' box at the end of Section 3.6)

Guidelines: parents with a learning disability

The government has produced guidelines on working with parents who have a learning disability (DH and DfES, 2007). They stated that the general aims of good practice in supporting parents with learning disabilities are to:

- Improve the wellbeing of children, to enable them to be healthy, stay safe, achieve, make a positive contribution and achieve economic wellbeing.
- Enable children to live with their parents (is this is consistent with their welfare) by providing the support that they and their families need.

Good practice is underpinned by legislation and guidance that sets out the responsibilities of children's and adult services (listed in Appendix B, DH & DfES, 2007). Legislation and associated guidance says that;

- Children have a right to be protected from harm
- In family court proceedings, children's interests are paramount
- Children's needs are usually best met by supporting their parents to look after them.

- Parents with learning disabilities have the right to an assessment of their needs for support in their daily lives, which should include any assistance needed with parenting roles. Parents should have their assessed needs met, considering available resources, in line with Fair Access to Care Services (DH, 2002). Assessments should only be done with informed consent, unless required by the Courts.
- Parents with learning disabilities are entitled to equal access to services, including parenting support and information services.
- Public bodies have a duty to actively promote equality of opportunity for people with learning disabilities.
- Good practice is also underpinned by an approach to parenting and learning disability which addresses needs relating to both impairment, and also the barriers of unequal access.

Key features of good practice

The government guidance set out five key features of good practice in working with parents with learning disabilities;

1. Accessible information and communication

- All services for parents and children should make information and communication accessible for people with learning disabilities (example in Box 3). Information should be in formats suitable for people with learning disabilities, such as Easy Read, information on CD/DVD, and fully accessible websites.
- People with learning disabilities need to hear the message that it is not unusual to need support with parenting.
- Professionals should avoid using jargon.

Box 3

Communication with schools is particularly important

'The school put their letters on tape. And they gave me stickers to put in each of my children's homework book which I used to say when homework had been done, so I didn't need to sign it'.

(from consultation with parents for DH & DfES, 2007)

2. Clear and co-ordinated referral and assessment procedures and processes, eligibility criteria and care pathways

- Eligibility criteria and care pathways should prevent avoidable difficulties from arising by recognising low levels of need, which are likely to undermine children's welfare if unaddressed.
- Adult and children's services, and health and social care, should jointly agree local protocols for referrals, assessments and care pathways, to prevent adults and children from falling between services. Attention should be paid to promoting good communication between different agencies. This may be achieved through liaison posts, joint training or joint network, for example. Local protocols should clearly specify responsibilities for assessment and care planning.

3. Support designed to meet the needs of parents and children based on assessments of their needs and strengths

- A range of services are required. All families are different and at different stages of their life cycle families require different types of support. For example, if parents with learning disabilities are to benefit from parenting education programmes – whether run in a mainstream or specialist setting – such programmes will need to be adapted to meet the particular learning needs of the parents concerned (this is a requirement under the Disability

and Equality Act, 2010).

Long-term support where necessary

- Some parents with learning disabilities will only need short-term support, such as help with looking after a new baby or learning about child development and childcare tasks. Others, however, will need on-going support.

Access to independent advocacy

- Advocacy and self-advocacy should be made available to help parents access and engage with services. Independent advocacy should always be provided where children are the subject of a child protection plan and/or care proceedings instituted.

(DH and DfES, 2007)

Good practice where safeguarding procedures are necessary

Parents have a right to a private and family life, but children have a right to protection from harm. The interests of the children should be paramount. They also have the right to receive the necessary support to remain living with their parents wherever possible.

- Local authorities have a duty, under the Children Act 1989, to ascertain the wishes of children when conducting assessments and making decisions about service provision. Children have the right to information at all stages of the safeguarding process. Children have the right to participate in child protection conferences, subject to their age and understanding.
- When a key worker is appointed for a child who has a learning disability, the key worker should have experience of learning disability, or access to expertise in the area.
- Where children are subject to a child protection plan, it is good practice to appoint a key worker for the parent with learning disabilities, as well as for the children.
- Local authorities should promote contact with family members for children who are the subjects of care orders, unless the court have given them permission to refuse contact.
- Where necessary, placement with extended family members should be considered.
-

Good practice in commissioning

- It is important that adult and children's services take joint responsibility for commissioning services that meet the needs of parents with learning disabilities and their children. It is good practice to have formal joint commissioning arrangements which are underpinned by the pooling of budgets.
- Service user perspectives should inform the development of mainstream and specialist services.

(DH and DfES, 2007)

The CCG Commissioning Guide (IHAL, 2012) added that people with learning disabilities need appropriate contraceptive advice to avoid unwanted pregnancies (see Section 3.3).

Example of local delivery: Parents with learning disabilities

Parents together, Knowsley

Knowsley Parents Together is run by Knowsley Disability Concern (KDC), which is an independent charity. Knowsley Parents Together believes that everyone has a right to be a parent. For some this is challenging. Knowsley Parents Together supports parents with learning support needs to overcome the barriers they face. The charity provides peer support groups across Knowsley where parents can come together and share their experiences of the barriers they face as parents over a cup of tea. Staff help them to find solutions and to support each other. Parents themselves decide what the group should talk about. The groups are held in Surestart Children's Centres in Halewood, Huyton, Kirkby and Whiston. There is an open invitation and everyone is welcome. Parents Together also works alongside KDC's Citizens Advocacy service and can arrange an independent person to help parents have their voices heard. Knowsley Parents Together can provide training for parents to learn about how to support each other, and training that is tailored for particular organisations, for example, the Equality Act and Making Information Easy to Read.

Contact: phone: 0151 480 4090 for more details

4.6 Employment and benefits

Employment

Levels of employment amongst people with learning disabilities are generally a lot lower than amongst the general population. In 2010/11, only 6.6% of working age adults with learning disabilities were in any form of paid employment, part time or full time. As few as 1.6% men and 0.4% women with learning disability worked for 30 or more hours per week (Emerson et al 2012, literature review).

The National Autistic Society survey found that only 15% of adults with autism were in full-time paid employment. Of those aged 16-24, one third were not in education, employment or training (NEET). Of those aged over 55, 41% had spent ten years or more with no paid job and 43% had left or lost a job because of their condition. Only 10% received employment support, whereas 53% would like such support (Bancroft et al, 2013).

The survey's authors recommended that simple adjustments like making job interviews more accessible and assistance to understand the 'unwritten rules' of the workplace would help. Under the Disability Discrimination Act (and now, the Disability and Equality Act, 2010), employers are obliged to make adjustments in the workplace for staff if they are disadvantaged, including recruitment procedures and employment policies (Broad, 2007). A survey carried out by Broad (2007) for 'Community Care' found that 77% of firms used normal recruitment methods when handling applications by people with learning disabilities, as opposed to the specialist services that exist. If more employers had specialist recruitment schemes that made it easier for people with learning disabilities to apply for jobs then a lot more would be in work.

Assistive technology and telecare (AT&T) can enhance the employability of people with learning disabilities, as demonstrated by the TATE (Through Assistive Technology to Employment) project. The project was a consortium of 18 partners from commercial, voluntary and public sectors, who worked together to identify the benefits of providing assistive technology and telecare to people with a learning disability and those who support them (Beyer et al, 2008). (See Housing, Section 4.1 for more details on assistive technology).

Approaches to employment for those with learning disability need to be reviewed. Recent changes to the benefits system (see 'Benefits' heading below), mean that individuals may not always be better off in work. The paid employment landscape has become much more challenging and appears less willing to fit in with the requirements of different individuals, but there is currently more pressure than ever on people to look for work. Some people with learning disability will be employed or supported to be long term volunteers on council sponsored schemes. However, a lot of these and other jobs are not 'for life'. Casual work is problematic, as individuals may be taken off ESA (employment support allowance) or other disability related benefits to take a casual job. They may then be unable to access the same benefits when the job finishes. It is perhaps time for a different emphasis on employment/occupation for those with learning disability, with a consideration that volunteer positions, which can potentially offer some of the same social and psychological benefits as paid employment, may realistically be the best solution in many cases.

Local data

Any paid employment (up to or more than 16 hours per week)

Figure 14 shows levels of paid employment amongst those of working age (18-64) who have a learning disability and who are known to social services. A paid employee will be earning at or above the minimum wage. For this dataset, being in paid employment is measured using the following two categories:

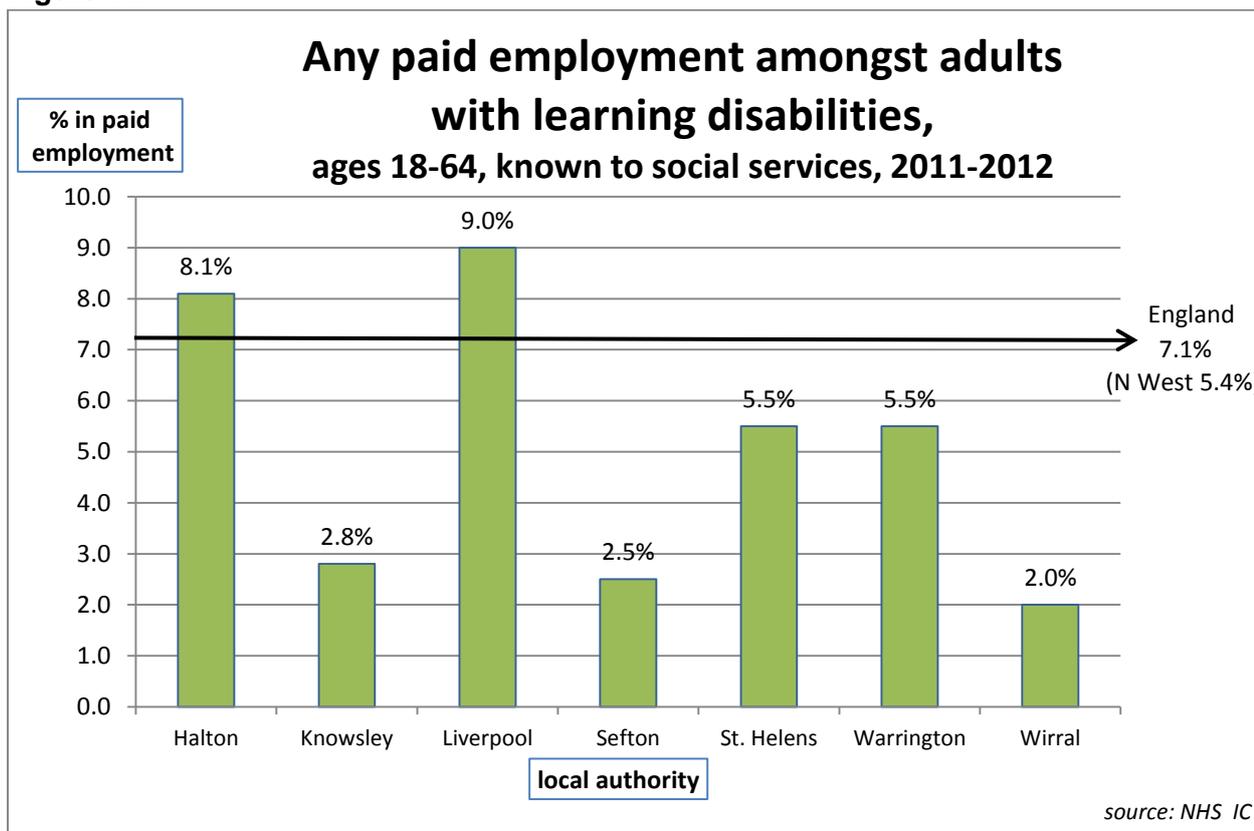
- Working as a paid employee or self-employed (16 or more hours per week); and,
- Working as a paid employee or self-employed (up to 16 hours per week).

Data for Merseyside and North Cheshire local authorities shows that employment levels are highest in Liverpool (9%) and Halton (8.1%) as shown in Figure 14. These levels are above the national average of 7.1% and well above the average for the North West of 5.4% (2011/12).

Employment levels are very low in Wirral, Sefton and Knowsley, at under 3% (2011/12).

Data for 2012/13 was starting to become available as the deadline for this report approached, and suggests that the current economic climate is having a major impact on the ability to find suitable employment – for example data from Breakthrough, Connexions and NWCS Access in Liverpool shows that employment levels amongst those with learning disability have fallen from 9% in 2011/12 to 7.8% in 2012/13. In Knowsley, although levels are still low, at 3.2% in 2012/13, they are an improvement on the 2.8% in 2011/12.

Figure 14



Source: NHS Information Centre, Adult Social Care Outcomes Framework for 2011/12 (ASCOF measure 1E). Adults with learning disabilities known to Councils with Adult Social Services Responsibilities (CASSRs) in paid employment at the time of their latest review.

Gender

Nationally and in the North West, males with learning disability have higher levels of employment than females, as shown in Table 26.

Within Merseyside and North Cheshire, there are large differences in rates by sex between local authorities, probably partly due to the small numbers involved, as shown in Table 26.

With the exception of Halton and Wirral, employment rates are higher amongst males compared to females in each local authority in Merseyside and North Cheshire. Rates are highest amongst males in Liverpool, at 11.3%, which is around twice as high as the 5.7% rate for females in Liverpool. Levels of employment are much lower in Sefton, but similarly around twice as high amongst males (3.0%) compared to females (1.8%).

Halton has the highest rate of employment amongst females with learning disability, at 10.4%, compared to 6.3% amongst males.

Table 26**Any paid employment amongst male and female adults with learning disabilities**

Numbers in paid employment as % of all those with learning disability of working age (18-64) and known to adult social services, 2011-12.

Any paid employment	Male		Female	
	number in employment	% in employment	number in employment	% in employment
Halton	15	6.3%	20	10.4%
Knowsley	15	3.5%	5	2.0%
Liverpool	95	11.4%	35	5.7%
Sefton	15	3.0%	5	1.8%
St. Helens	20	6.3%	10	4.6%
Warrington	15	5.7%	10	5.1%
Wirral	10	1.5%	10	2.7%
North West		5.9%		4.6%
England		7.9%		6.1%

Source: NHS Information Centre, Adult Social Care Outcomes Framework for 2011/12 (ASCOF measure 1E). Adults with learning disabilities known to Councils with Adult Social Services Responsibilities (CASSRs) in paid employment at the time of their latest review, receiving at least the minimum wage. Final report, Feb 15th 2013.

Paid employment of 16 hours or more per week

As mentioned at the start of this section, in 2010/11, as few as 1.6% men and 0.4% women with learning disability worked for 30 or more hours per week. In Halton, Knowsley, Sefton, St. Helens and Wirral, there was no-one with a learning disability known to social services recorded as being in paid employment for 30 hours or more per week in Merseyside and North Cheshire, 2011-12. In Liverpool there were 110, and in Warrington there were 5.

There might be a problem with recording here, as in Liverpool, there was no-one recorded as working between 16-30 hours. It is possible that some of the 110 people recorded as working 30 hours or more were in fact working 16 hours or more.

Table 27 shows the numbers of adults with learning disabilities working 16 hours or more in 2011-12 in paid employment (at or above the minimum wage). There are none recorded in Halton, St. Helens or Wirral. There are 10 recorded in Knowsley, Sefton and Warrington. In Liverpool, the proportion of people with learning disability in paid work of 16 hours or more per week is more than three times the national average, at 7.6% of all those with a learning disability (2.2% nationally).

Gender

Amongst males in Liverpool, around 1 in 10 of those with a learning disability are working 16 hours or more (9.5%). For females in Knowsley, the proportion is 1.7%, and Liverpool is 5%, both of which are above the national average of 1.5% (Table 27).

Table 27**Paid employment of 16 hours or more per week amongst male and female adults with learning disabilities**

Numbers in paid employment 16 hours+ as % of all those with learning disability of working age (18-64) and known to adult social services, 2011-12.

Paid work 16 hours or more per week	Male		Female		Total	
	number in employment	% in employment	number in employment	% in employment	number in employment	% males & females in employment
Halton	0	0%	0	0.0%	0	0.0%
Knowsley	5	1.4%	5	1.7%	10	1.5%
Liverpool	80	9.5%	30	5.0%	110	7.6%
Sefton	5	1.1%	5	1.5%	10	1.3%
St. Helens	0	0.0%	0	0.0%	0	0.0%
Warrington	0	0.0%	0	0.0%	10*	2.2%
Wirral	0	0.0%	0	0.0%	0	0.0%
North West		2.8%		1.5%		2.3%
England		2.7%		1.5%		2.2%

*Note: totals of less than 5 would have been recorded as 0, because of the suppression of small numbers.

In Warrington, there were 5 people working 16 to less than 30 hours per week, and a further 5 working 30 or more hours per week. Broken down by sex, there would have been fewer than 5 in each category, so male and female totals would have been recorded as 0.

Source: NHS Information Centre, Adult Social Care Combined Activity Returns data (ASC-CAR) for 2011/12. Adults with learning disabilities known to Councils with Adult Social Services Responsibilities (CASSRs) in paid employment at the time of their latest review, receiving at least the minimum wage.

It should be noted that interpretation of this data needs to take into account the possibility that low levels of employment could be an indication of success. A person with learning disability who becomes employed may be taken off the social services register. Also, as noted in the introduction to this section, different local authorities may have different ways of interpreting who to include as 'employed'.

Guidelines: employment

Social determinants of health: The CCG Commissioning Guide noted that CCGs will need to work with Local Authorities and public health to tackle the social determinants of poorer health, such as housing, discrimination, unemployment and social exclusion (IHAL, 2012). Commissioning responsibility for these issues sits with Local Authorities.

If more employers had specialist recruitment schemes that made it easier for people with learning disabilities to apply for jobs, then a lot more would be in work. The National Autistic Society are working with the Government to improve employer awareness of how to support people with autism in the workplace. As part of their campaign '*The undiscovered workforce*', they are encouraging MPs to take a lead on these issues in their own constituencies (Bancroft et al, 2013).

The Joseph Rowntree Foundation have produced a guide for employers on employing people with learning disabilities (JRF, 2004)

Examples of local delivery: Employment

The Department of Health have produced a guide that sets out learning and best practice from the government's Valuing People Now Employment Demonstration sites. It is aimed at those who want to develop good employment support for people with learning disabilities in their locality (DH, 2011b).

Norton Priory museum, gardens and visitor centre, Halton

Halton Community Services have opened new work based opportunities across the borough which will enable people with disabilities to learn pre-employment skills in order to access the workplace. Resources were diverted from traditional 'bricks and mortar' based day care services to create opportunities structured for business and linked to the commercial world. This was made possible through strong links with Norton Priory Museum, a key service partner, which provides work experiences for those with learning disability and autism in various settings, including the Refectory Cafe, Tea Room, Ice-cream making Parlour, Norton Brewing (a real ale brewery), the Bottling Plant and the Craft Shop.

The 22 community venues across the borough provide meaningful daytime activity and multiple work experience opportunities for 145 adults with a learning disability or autism.

Contact: shirley.dempsey@halton.gov.uk

Sefton coast and countryside biodiversity and access project

The Biodiversity and Access Project values and involves people with learning disabilities and other hard to reach groups. The groups are involved in practical environmental projects along the coast and in the countryside. Individuals are offered the chance to improve their skills by being involved in the project. They can also learn new skills and improve their health and wellbeing, gaining qualifications and work experience along the way.

For more information, go to <http://sefton.ldpb.info/data/file/file/BAP%20Transitions.pdf>

Achieving People: Sefton

'Achieving People' supports people aged 18 – 64 in Sefton who have a learning disability into unpaid work placements and paid employment.

Clients are supported on a one to one basis by a mentor in their chosen opportunity.

Further details:

http://www.volunteeringsefton.org.uk/index.php?option=com_content&view=article&id=105&Itemid=89

Benefits

Mencap (2012) noted that changes to the benefits system under the Welfare Reform Act 2012 place a greater focus on those with high-level needs, reducing the availability of benefits for those with low and moderate needs.

The Act changes the way many housing options are funded, which will affect the ability of local authorities to support independent living for people with a learning disability.

Many judgements relating to workplace capability assessments have been overturned on appeal. There are likely to be even more individuals who have been wrongly assessed but have not appealed. Often, people will not feel strong enough or have enough support to go through with an appeal. Mencap pointed out that learning disability is a lifelong condition that is not going to get better (Mencap Liverpool on Radio Merseyside, Feb 2013).

4.7 Transport

People with learning disability rely greatly on public transport, as most do not drive. Public transport is important for independence, but many face problems such as bullying or stigma. Transport was one of the main issues identified in a consultation exercise in Sefton (see Section 5).

Supported by the Brandon Trust, the '100 People, 100 Voices' learning disabilities conference in 2012 gave a voice to over 150 people with learning disabilities. They spoke about the problems they face in gaining employment and using public transport. A report was produced following on from the conference, entitled '100 Voices On Transport' (Brandon Trust, 2012). The report was written for and by people with learning disabilities and autism, and outlines public transport-related issues, offering possible solutions along with case studies.

In the report, people with learning disabilities and autism said that using public transport is very difficult for them, because:

- It is too expensive

- Lack of availability, in terms of both routes and times
- Lack of accessibility. This refers to every aspect of transport: from the vehicles themselves, to train and bus stations, to timetables and signage
- Fear of being abused or of being mistreated and disrespected by bus drivers, train and station staff and other passengers. Some people reported frightening experiences, especially on buses (bullying and teasing)
- Lack of understanding, on behalf of the general public, of the barriers a person with a learning disability faces when travelling alone on public transport. Some people can be impatient and rude
- Inability to use concessionary bus passes before 9.30am and therefore having to pay for a taxi to go to college or work
- Lack of appropriate training and support on how to use public transport for people with a moderate learning disability

(Brandon Trust, 2012)

Guidelines: Transport

People with learning disability and autism at the 100 Voices conference said that they would like to see:

- Better transport solutions for people with learning disabilities, organized by councils, charities and communities in partnership
- Wider time coverage of concessionary travel passes so that they are not restricted to certain hours
- Training for bus and taxi drivers, and other transport staff, on the needs of people with learning disabilities
- More public awareness of learning disabilities and increased acceptance of disabled people on public transport. This can be achieved through media coverage and campaigns
- Better accessibility on buses and trains, fewer environmental barriers
- Easy read complaints procedures
- Easy read timetables
- A telephone number displayed at bus stops or in train stations that people can call if the bus/train is late or if they require assistance
- Cameras on buses to capture abusive behaviour
- More travel and transport training for people with learning disabilities, like the 'Travel Buddy' scheme
- More engagement with local MPs and people who can influence social policy so that the views of people with learning disabilities are heard.

(Brandon Trust, 2012)

Local authorities on Merseyside could consider working with Merseytravel to extend the Transport Community Card scheme in St. Helens to the whole of Merseyside

Examples of local delivery: Transport

Transport Community Card, St. Helens

Community Card: Merseytravel, working with St. Helens Council, has been developing a pioneering initiative called the Community Card which is a multi-functional 'smart card' which accesses a budget that enables eligible users to access a more personalised transport so that users can spend more time at their day opportunity, less time travelling and give more independence. The pilot has enabled people with learning disabilities previously using the council in-house bus to access a more personalised service using a scheduled taxi service. This has seen journey times reduced from up to an hour down to an average of 11 minutes and is significantly cheaper for the authority, allowing additional resources to be re-invested into services.

When users were asked what they most liked about using the card, the following comments were made;

"More independence"

"Card was easy to use"

"Felt very independent"

"Convenient"

"Being on my own and getting there quicker"

"Found it interesting and exciting"

"Felt responsible"

The pilot is currently being extended to elderly service users with aspirations of a Merseyside wide infrastructure, enabling the card to be used in other areas and services and ultimately a personal transport budget to enable access to transport whenever the user needs it.

Paul Weston, Merseytravel, 3/4/13

Contact: paul.weston@merseytravel.gov.uk

Travel Buddy service, Hounslow

The travel buddy service trains and supports people with a learning disability to feel confident about travelling on their own on public transport. It employs six fully trained travel buddies who have learning disabilities themselves to shadow and support others with the same disability. The Travel Buddy service has therefore been able to create meaningful paid employment and social activities for these individuals and as such, increase independence and feel part of the wider community.

http://www.hounslow.gov.uk/index/health_and_social_care/adult_social_care/disabilities/learning_disabilities/travel_buddy_service.htm

Travel training in Knowsley

Knowsley Borough Council commission travel training for people with learning disabilities from CIC as identified by review and assessment procedures. This is commonly associated with people accessing supported employment. (CIC is Community Integrated Care, a large care provider also offering vocational support).

For details, contact: Stuart.Sheridan@knowsley.gov.uk

5. User perspectives

Ideally, user input should be an important part of the health needs assessment. Some users groups had expressed an interest in providing feedback for the project. Once the summary and recommendations were complete, they were translated into 'easy read' format. They will be submitted to user and carer's groups for feedback in each local area within Merseyside and North Cheshire.

Some users' views were obtained from members of the health needs assessment project group who gathered feedback from their Learning Disability Partnership Boards, local advocacy groups and any other sources that would capture the views of users. The following is a summary of this feedback.

Warrington

'Warrington Speak Up' is a self-advocacy project, supporting adults with learning difficulties to speak up for themselves. General themes from their consultation and engagement work include the following:

Bad practice

- Difficulty getting appointments, phone systems tricky or just can't get through.
- Still doctors/health professionals talking to the support worker or carer rather than the individual.
- Letters that are sent out re appointments to specialist services are generic – not at all easy read in fact the opposite, often support staff struggling to understand them.
- Not enough time in with the doctor, feel rushed.
- Hard to remember what they say when you came out.
- Hospital experiences continue to vary but very little evidence of a coordinated and consistent approach re sharing information, using health passports.
- Hospital have been keen to develop easy read information – not seen it in use as yet.

Good practice

- Texts to remind of appointments.
- Some really smart new facilities in Warrington that people like and are easy to access, good bus routes etc.
- General awareness of annual health checks good, experience varies from practice to practice though.

Knowsley

Knowsley Disability Concern reported the following issues that keep coming up from the self advocacy 'Big group' around health and attending GP surgeries:

- Members of the group feel GP's attitudes need to change. They feel not listened to or understood
- To book an appointment to see the GP is hard as they again feel rushed in the conversation
- Same story of parents/carers being spoke to rather than the person themselves
- Information is still not in accessible form. This is something that came up when we looked at the confidential inquiry - if people cannot understand the information, how do they know what health issue they have.

Halton

Self advocacy group feedback relating to young people in Halton:

'the overriding theme that keeps coming from the young people relate to the availability of employment opportunities as opposed to young people going on to attend a variety of different college courses which show little link into the young people's own aspirations'

From Halton Short Breaks Statement:

'In Halton, we have worked closely with disabled young people; parents and carers, service providers and partner agencies to develop a range of Short Breaks services that provide carers with a break from their caring responsibilities. They also provide disabled children with positive and enjoyable experiences.

.... we have organised 3 Powerful Voices conferences since 2008 that have been attended by carers, young people and professionals. These have been used to gain everyone's views about Short Breaks and which services they have found to be most beneficial. Smaller consultation events, questionnaires and feedback from individual families and groups have also contributed to the development of the range of services that are available in Halton'.

<http://www3.halton.gov.uk/healthandsocialcare/childrenandfamilycare/disabledchildrenandyoungpeopleshortbreaks/>

St. Helens

Details of the 'What Lies Ahead' Project: family led housing scheme in St. Helens are presented in a box at the end of Section 4.1 above.

Sefton

People First Merseyside is a Self Advocacy Organisation for adults with learning difficulties and disabilities made up of People First Liverpool and People First Sefton.

People First aims to assist and enable people with learning disabilities and learning difficulties to:

- speak up for themselves
- enjoy the same rights as everyone else
- attain greater independence
- attain greater freedom of choice and participation in the community

People First Merseyside's GIG (getting involved group) has between 6 to 8 meetings per year. The GIG is also part of the Learning Disability Partnership Board in Sefton. People First Sefton has an office base in Bootle, where individuals can meet throughout the week.

In a recent consultation involving GIG, the main themes were as illustrated in Figure 15 on the next page. Participants were asked to cast three votes each.

People First Merseyside (Sefton Group) is featured as a case study in a publication by the IHAL Learning Disability Observatory entitled 'Advocacy by and for adults with learning disabilities in England' (Roberts et al, 2012b).

Further details about '*People First Sefton*', can also be found via the following link:

http://www.mysignpost.org/People_First_Sefton-Ist936.html

Guidelines: users and carers

The learning disability commissioning guide for Clinical Commissioning Groups (CCGs) noted that commissioners should demonstrate that people with learning disabilities, families and carers are involved in the process of planning and decision making, so that their needs, choices and preferences are understood, and services are available to reflect individual choice (SAF indicator, quoted in IHAL, 2012).

6. Recommendations

Recommendations resulting from the findings of this report and relevant identified guidelines are presented here. All the recommendations are aimed at ensuring that reasonable adjustments for people with learning disabilities and autism are carried in order to ensure equal access to services, as required by the Disability and Equality Act 2010:

1. Actions for both health and social care services

Joint working

1.1 Ensure partnership working arrangements are in place, with Clinical Commissioning Groups (CCGs) taking lead responsibility for the commissioning of specialist and general health services for people with learning disabilities and autism. Local authorities will be responsible for services relating to personal care and the wider determinants of health and wellbeing, such as housing, discrimination, unemployment and social exclusion.

1.2 Demonstrate that people with learning disabilities and autism, families and carers are involved in the process of planning and decision making, so that their needs, choices and preferences are understood, and services are available to reflect individual choice (IHAL, 2012).

1.3 Ensure that each local authority and CCG circulates the report (including the 'easy read' version) widely amongst user and carer groups and that feedback is obtained.

1.4 Challenging behaviour:

1.4.1 Agree on a standard definition across the region and maintain a register of those with challenging behaviour (DH, 2012). Use the register to enable the development of appropriate jointly commissioned local services for people who challenge.

1.4.2 Enable the pooling of resources to support and assist people held in secure accommodation to return back to community placements (where appropriate) in their home borough.

Access/support

1.5 Introduce accessible information and offer support to ensure equal access to all health and social services. Remove physical barriers to access and make whatever alterations are necessary to policies, procedures, staff training and service delivery to ensure that they work equally well for people with learning disabilities, including:

1.5.1 Make all self-help and service information 'easy to read'.

1.5.2 Ensure support is available where required, for example in housing application processes.

1.5.3 Provide appropriate staff awareness training across all services. This will help to tackle the issues around reasons for high refusal and non-attendance (DNA) rates for example in screening.

1.5.4 Include an exemption clause in DNA (did not attend) policies for people with learning disabilities and autism.

Data

1.6 Ensure that collection of all health and social care data relating to learning disability and autism becomes more co-ordinated and systematic.

- 1.6.1 Ensure that local authority and GP information systems allow for the collection of data separately on numbers with learning disability, autism and Asperger's syndrome and profound and multiple learning disability (PMLD), for age groups under 18, 18-64 and 65 plus, and by ethnic group and gender.
- 1.6.2 Develop the use of GP clinical systems so that data on lifestyle, screening and disease management for those with learning disability and autism can be monitored and compared across each area and with the general population.
- 1.6.3 The needs of people with learning disabilities and autism should be reflected in JSNAs (Joint Strategic Needs Assessments).

1.7 Collect information on numbers of children with a learning disability, with added details on issues such as numbers in foster care, or on short breaks. Liverpool City Council's work on producing a single dataset for children and young people will assist in this and should be in place by 2014/15.

1.8 Ensure that health service agreements (school nurses and health visitors) on identifying those with learning disability and autism are built into tendering arrangements with schools and colleges.

1.9 Collect and use data on numbers of parents and prospective parents with learning disabilities and autism, so that their needs can be catered for, involving joint working between maternity units and health and social care services.

1.10 Further investigate the needs of people with autism as data collection improves (due to the availability of data, the health and social profile sections of this report have focussed more on learning disability than autism).

2. Local authorities (recommendations in addition to those for joint action in section 1 above)

Housing

2.1 Include specific plans for improving the housing situation of people with learning disability and autism in local housing strategies. An action plan designed around promoting independent living should accompany any such plans (Mencap, 2012), with housing and social care working together.

2.2 Ensure the accommodation status of all those with learning disabilities and autism is recorded by all local authorities.

Assistive technology

2.3 Ensure care managers and commissioners of packages of support consider what assistive technology and telecare (AT&T) can do as part of a package of support (Beyer et al, 2008).

Parents

2.4 Where a parent has learning disability or autism, enable children to live with their parents (if this is consistent with their welfare) by providing the support that they and their families need (DH and DfES, 2007). This would include ensuring equal access to services, such as parenting support and information services and support through any court processes.

Sex and relationships education

2.5 Consider developing sex and relationships policies in schools and services for children and adults with learning disabilities and autism, to include staff training. This needs to be collaborative with CCGs so healthcare staff can raise the issue and support people with appropriate contraceptive and sexual health advice.

Violence and stigma

2.6 Explore the possibility of using newly available disability hate crime statistics to help to identify problems relating to this issue (from the Merseyside Police SIGMA unit).

Employment

2.7 Improve employer awareness to support people with learning disability and autism in the workplace. Use simple adjustments like making job interviews more accessible and providing assistance to understand the 'unwritten rules' of the workplace (Broad, 2007).

2.8 Across all local authorities, ensure consistency of definitions and recording of numbers of people with learning disability and autism in employment.

Transport

2.9 Provide better transport solutions for people with learning disabilities and autism, organized by councils, charities and communities in partnership. To include:

- increasing public and driver awareness of learning disabilities and autism and improving acceptance of disabled people on public transport.
- working with Merseytravel to consider extending the Transport Community Card taxi scheme in St. Helens to the whole of Merseyside.

3. Clinical Commissioning Groups (CCGs)

(recommendations in addition to those for joint action in section 1 above)

Psychological Therapies

3.1 Ensure that the needs of people with learning disabilities and autism are reflected in contracting for Improving Access to Psychological Therapies (IAPT). 'Reasonable adjustments' would include the provision of longer sessions than usual, to take account of the person's varying levels of understanding and need (DH, 2009a).

3.2 Make data available on numbers of people with learning disability and autism accessing psychological therapies, so that access can be monitored.

Health checks

3.3 Continue to promote annual health checks for people with learning disability, with a 90% uptake rate target (IHAL, 2012).

Screening

3.4 CCGs should work with Public Health England to ensure appropriate support is offered to individuals with a learning disability and/or autism to improve access to screening programmes. This

should tackle issues around reasons for high refusal and non-attendance (DNA) rates and would include the provision of 'easy read' materials

Sexual health

3.5 Ensure healthcare staff are trained to raise sexual health issues with people who have learning disabilities and autism and to support them with appropriate contraceptive and sexual health advice (see 2.5 above).

Hospital admissions

3.6 Ensure that the performance of each acute provider Trust is monitored against quality indicators which relate to the needs and experiences of patients with learning disabilities and autism.

3.7 Monitor action taken by provider Trusts to ensure that reasonable adjustments are carried out, as identified in recommendations 4.1 to 4.3 below.

3.8 Carry out local monitoring to identify potentially avoidable hospital admissions amongst those with learning disabilities and autism.

Avoidable deaths

3.9 Focus prevention strategies on areas where deaths are more avoidable, such as aspirational pneumonia, seizures, heart disease and accidental deaths (Tyler and McGrother, 2009).

4. Hospital Trusts

4.1 Ensure the identification and coding of people with learning disabilities and autism and the ability to track episodes of care and an individual's movement within a hospital trust, including which specialities/departments have been required.

4.2 Ensure there is a senior person identified in each acute hospital Trust with responsibility for patients with learning disabilities and autism (possibly an acute liaison nurse) and that this individual puts in place reasonable adjustments to meet the specific needs of such patients.

4.3 Notify the GP and the community learning disabilities team when a patient with learning disabilities or autism is discharged after having being admitted with an Ambulatory Care Sensitive Condition (i.e. a condition which shouldn't need hospital care).

5. Criminal Justice System

5.1. Address the under-reporting of learning disability and autism for people in the Criminal Justice System and the need for improved identification at the point of first contact. This will include those in custody, also offenders serving community sentences and those on probation.

References

NOTE: Publically available URLs have been given here. These links may therefore not always lead to the full article.

About Learning Disabilities (online A) How to Define and Categorise Learning *Disabilities*. Website accessed 19/6/13
<http://www.aboutlearningdisabilities.co.uk/how-define-categorise-learning-disabilities.html>

About Learning Disabilities (online B) *Vulnerable Adults and Protection from Crime*. Website accessed 16/4/13
<http://www.aboutlearningdisabilities.co.uk/vulnerable-adults-protection-from-crime.html>

AET (2012) *Transition Toolkit: helping you support a child through change*. Autism Education Trust
<http://www.autismeducationtrust.org.uk/resources/transition%20toolkit.aspx>

Bancroft K, Batten A, Lambert S, Madders T (2013) *The way we are: autism in 2012*. The National Autistic Society. London.
<http://www.autism.org.uk/get-involved/50th-birthday/survey-report.aspx>

Bean C. (2012) Personal correspondence, 18/12/12. Mostly taken from a literature search carried out by Chris Bean, former Integrated Commissioning Manager, NHS Merseyside

Beyer S, Perry J, Meek A (2008) *A Guide to Implementing Assistive Technology for People with Learning Disabilities: A product of the TATE project*. Welsh Centre for Learning Disabilities. School of Medicine, Cardiff University.
http://www.learningdisabilitywales.org.uk/pdfs/implementing_atandt.pdf

BILD (2013) *Housing and Support*. BILD (British Institute for Learning Disabilities) website accessed 17/6/13
<http://www.bild.org.uk/information/ageingwell/housing/>

Brandon Trust (2012) *100 Voices On Transport. A report on transport - related issues, by people with learning disabilities and autism*. The Brandon Trust
http://www.brandontrust.org/Data/Sites/1/downloads/100voices_transport_report.pdf

Broad M (2007) Employment barriers for people with learning disabilities. *Community Care*. 31/5/07.
<http://www.communitycare.co.uk/articles/31/05/2007/104643/employment-barriers-for-people-with-learning-disabilities.htm>

Brodrick D, Lewis D, Worth A, Marlan A (2011) One-page patient passport for people with learning disabilities. *Nursing Standard*. 25, 47, 35-40.
<http://nursingstandard.rcnpublishing.co.uk/archive/article-one-page-patient-passport-for-people-with-learning-disabilities>

Care Quality Commission (2009) *The Strategic plan 2010-2015 – position statement and action plan for learning disabilities*, CCQ
(http://www.cqc.org.uk/sites/default/files/media/documents/cqc_learning_disability_position_statement_and_action_plan_0.pdf)

Care Quality Commission (2009a) *National study – Specialist inpatient learning disability services – Follow-up audit of services 2008/09*. CQC.
http://archive.cqc.org.uk/db/documents/CQC_Specialist_Learning.pdf

Caroline Walker Trust (2007) *Eating well: children and adults with learning disabilities*
<http://www.chimat.org.uk/resource/item.aspx?RID=92957>

Challenging Behaviour Foundation (2010) *Developing better commissioning for individuals with behaviour that challenges – a scoping exercise*. Challenging Behaviour Foundation.
<http://www.challengingbehaviour.org.uk/cbf-resources/commissioners-resources.html>

CHIMAT (2008) *Guidance on bullying involving children with SEN*. Child and Maternal Health Intelligence Network
<http://www.chimat.org.uk/resource/item.aspx?RID=92960>

CIPOLD (2013) *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)*. University of Bristol and Department of Health.
<http://www.bris.ac.uk/cipold/fullfinalreport.pdf>

Cleaver H and Nicholson D (2008) *Parental Learning Disability and Children's Needs: Family Experiences and Effective Practice. Executive Summary*. University of London and Department for Children Schools and Families.
<http://webarchive.nationalarchives.gov.uk/20130401151715/https://www.education.gov.uk/publications/eOrderingDownload/DCSF-00273-2008.pdf>

Learning disabilities and autism: A health needs assessment for children and adults in Merseyside and North Cheshire.
Liverpool Public Health Observatory

DfE (2013) Children and Families Bill 2013. Department for Education.
<http://www.education.gov.uk/a00221161/>

Directgov. *Disability and the Equality Act 2010*: Directgov - Disabled. [Online]. Available from:
http://www.direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG_4001068 (Accessed 28/1/13)

DH (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. Department of Health.
<http://www.archive.official-documents.co.uk/document/cm50/5086/5086.htm>

DH (2002) *Fair Access to Care Services: Practice Guidance*, London: Department of Health.
www.dh.gov.uk/assetRoot/04/01/97/34/04019734.pdf

DH (2007) *Commissioning Specialist Adult Learning Disability Health Services*. London. Department of Health.
<http://www.debramooreassociates.com/Resources/DH%20Commissioning%20Specialist%20LD%20Adult%20health%20services.pdf>

DH (2007a) *Services for people with learning disabilities and challenging behaviour or mental health needs*. Mansell Report. London. Department of Health.
http://www.kent.ac.uk/tizard/research/research_projects/dh2007mansellreport.pdf

DH and DfES, (2007) *Good practice guidance of working with parents with a learning disability*. Department of Health and Department for Education and Skills, London
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_075118.pdf

DH (2008) *Healthcare for all. Report of the independent inquiry into access to healthcare for people with learning disabilities*. Michael J, Sir. London: Department of Health
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255

DH (2008a) *Health Action Planning and Health Facilitation for people with learning disabilities: good practice guidance*. Department of Health.
<http://learningdisabilitynurse.com/wp-content/uploads/2012/02/good-practice-guidance.pdf>

DH (2009) *Valuing People Now: a new three-year strategy for learning disabilities*. London. Department of Health.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377

DH (2009a) *IAPT. Learning Disabilities: Positive Practice Guide*. London. Department of Health.
<http://www.iapt.nhs.uk/silo/files/learning-disabilities-positive-practice-guide.pdf>

DH Bradley Report (2009) *Lord Bradley's Review of people with mental health problems and learning disabilities in the criminal justice system*. April 2009. Department of Health.
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_098694

DH (2010) *Fulfilling and rewarding lives. Fulfilling and rewarding lives: the strategy for adults with autism in England*. Department of Health.
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

DH (2010a) *Raising our Sights: services for adults with profound intellectual and multiple disabilities*. London. Department of Health.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

DH (2011) *The Government Response to Raising our Sights: services for adults with profound intellectual and multiple disabilities*. Department of Health.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_124252

DH (2011a) *Positive Practice, Positive Outcomes: A Handbook for Professionals in the Criminal Justice System working with Offenders with Learning Disabilities*. Department of Health.
<http://www.justice.gov.uk/downloads/youth-justice/effective-practice-library/positive-practice-positive-outcomes.pdf>

DH (2011b) *How to guide: learning from the Valuing People Now employment demonstration sites*. London. Department of Health.
http://www.preparingforadulthood.org.uk/media/159112/how_to_guide_-_learning_from_the_vpn_employment_demonstration_sites.pdf

- DH (July 2012) *Department of Health Review: Winterbourne View Hospital. Interim Report*
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/141591/Department-of-Health-Review-Winterbourne-View-Hospital-Interim-Report1.pdf
- DH (2012) *Transforming care: A national response to Winterbourne View Hospital. Final Report*. London: Department of Health, 2012. <http://www.dh.gov.uk/health/2012/12/final-winterbourne/>
- DRC (2006) *Equal Treatment Closing the Gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems*. Disability Rights Commission.
<http://disability-studies.leeds.ac.uk/files/library/DRC-Health-FI-main.pdf>
- Emerson, C (1995) *Challenging Behaviour. Analysis and Intervention in People with Learning Difficulties*. Cambridge University Press. Cambridge
- Emerson E, Hatton C (2004) *Estimating the current need/demand for supports for people with learning disabilities in England*. Institute for Health Research, Lancaster University.
http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7008_Estimating_Current_Need_Emerson_and_Hatton_2004.pdf
- Emerson E, Malam S, Davies I, Spencer K (2005) *Adults with learning difficulties in England 2003/04*. Department of Health.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_4120033
- Emerson E and Robertson J (2008) *Commissioning person-centred, cost-effective, local support for people with learning difficulties*. Social Care Institute for Excellence.
www.scie.org.uk/publications/knowledgereviews/kr20.asp
- Emerson E (2009) *Estimating future numbers of adults with profound multiple learning disabilities in England*. Centre for Disability Research, Lancaster.
http://www.lincs2life.org.uk/Libraries/Local/825/Docs/News/Estimating_PMLD.pdf
- Emerson E, Baines S (2010) *The Estimated Prevalence of Autism among Adults with Learning Disabilities in England: Improving Health and Lives*, Learning Disabilities Observatory. <http://www.improvinghealthandlives.org.uk/publications/2010>
- Emerson E (2011) Health status and health risks of the 'hidden majority' of adults with intellectual disability. *Intellectual & Developmental Disabilities* ;49:155-65
<http://www.aaidjournals.org/doi/abs/10.1352/1934-9556-49.3.155>
- Emerson E, Baines S, Allerton L and Welch V (2012) *Health Inequalities & People with Learning Disabilities in the UK: 2012*. IHAL, Improving Health and Lives: Learning Disabilities Observatory.
http://www.improvinghealthandlives.org.uk/publications/1165/Health_Inequalities_&_People_with_Learning_Disabilities_in_the_UK:_2012
- European Commission (2005) *Some elements about the prevalence of Autism Spectrum Disorders (ASD) in the European Union*. European Commission, Health & Consumer Protection Directorate-General
http://ec.europa.eu/health/ph_information/dissemination/diseases/autism_1.pdf
- Foundation for People with Learning Disabilities (2004) *Green light for mental health. How good are your mental health services for people with learning disabilities? A service improvement toolkit*. Published by the Mental Health Foundation.
<http://www.learningdisabilities.org.uk/content/assets/pdf/publications/green-light.pdf>
- Foundation for People with Learning Disabilities (online) *Learning Disability Statistics: Mental Health Issues*. Website accessed 17/6/13
<http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187699/>
- GAIN (2010) *Caring For People with a learning disability in general hospital settings*. GAIN (Guidelines and audit implementation network).
http://www.workingwithdiversity.org/xd_files/Caring_for_people_with_a_learning_disability_in_general_hosp_setting.pdf
- Giles D (2013) 'DSM-V is taking away our identity': The reaction of the online community to the proposed changes in the diagnosis of Asperger's disorder. *Health (London)*. Sage publications. Published online 5 June 2013.
<http://hea.sagepub.com/content/early/2013/06/05/1363459313488006.full.pdf+html>
- Glover G, Emerson E, Evison F (2012) *The Uptake of Health Checks for Adults with Learning Disabilities: 2008/9 to 2011/12*. IHAL, Improving Health and Lives: Learning Disabilities Observatory.

http://www.improvinghealthandlives.org.uk/uploads/doc/vid_16402_IHAL2012-07%20Health%20Checks%20for%20People%20with%20Learning%20Disabilities%202008-9%20to%202011-12v3.pdf

Glover G and Emerson E (2012) *Have you got a learning disability? Asking the question and recording the answer for NHS healthcare providers*. IHAL, Improving Health and Lives: Learning Disabilities Observatory.
http://www.improvinghealthandlives.org.uk/securefiles/130716_1351/IHAL2012-08%20AskingTheQuestion.pdf

Glover G and Evison F (2013) Hospital Admissions That Should Not Happen. Admissions for Ambulatory Care Sensitive Conditions for People with Learning Disabilities in England. IHAL, Improving Health and Lives: Learning Disabilities Observatory.
<http://www.improvinghealthandlives.org.uk/news.php?nid=2228>

Grinnell S (2012) *A Concurrent Rapid Health Impact Assessment for the Redesigning of In-patient and Community Health Services for Adults with Learning Disabilities for Halton & St Helens, Knowsley, and Warrington Primary Care Trusts*. IMPACT, University of Liverpool.
<http://www.apho.org.uk/resource/item.aspx?RID=116992>

Harrington R, Bailey S (2005) *Mental Health Needs and Effectiveness of Provision for Young Offenders in Custody and in the Community*
<http://www.yjb.gov.uk/Publications/Resources/Downloads/MentalHealthNeedsfull.pdf>

Health Service Ombudsman and Local Government Ombudsman (2009) *Six Lives: the provision of public services to people with learning disabilities*.
<http://www.ombudsman.org.uk/improving-public-service/reports-and-consultations/reports/health/six-lives-the-provision-of-public-services-to-people-with-learning-disabilities>

Hermon, C., et al., Mortality and cancer incidence in persons with Down's syndrome, their parents and siblings. *Annals of Human Genetics*, 2001. 65: p. 167-176. <http://www.ncbi.nlm.nih.gov/pubmed/11427176>

HM Government (2009) *Healthy Children, Safer Communities. A strategy to promote the health and wellbeing of children and young people in contact with the youth justice system*. DH, DCSF, MOJ, HO. London.
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalasset/documents/digitalasset/dh_109772.pdf

HSCIC (2009) *Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007*. Health and Social Care Information Centre in September 2009.
<http://www.hscic.gov.uk/pubs/asdpsychiatricmorbidity07>

Hughes K, Bellis M, Jones L, Wood S, Bates G, Eckley L, McCoy E, Mikton C, Shakespeare T, Officer A (2012). Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies. *The Lancet*, 379, 9826, 1621–1629.
http://www.who.int/disabilities/publications/violence_children_lancet.pdf

IDeA (2008) *Person-centred commissioning - now: a pathway approach to commissioning learning disability support*. Improvement and Development Agency (IDeA).
<http://northlancsleads.net/Libraries/Local/914/Docs/Person-centred%20commissioning%20now.pdf>

IHAL (online) *Our working definition of Learning disabilities*. Improving Health and Lives. Learning Disability Observatory
<http://www.improvinghealthandlives.org.uk/about/definition/detail>

IHAL (2012) *Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups*. IHAL, Improving Health and Lives: Learning Disabilities Observatory.
<http://www.improvinghealthandlives.org.uk/publications/1134/>

IHAL (2013) *About the indicators: Learning Disabilities Profile 2012*. IHAL, Improving Health and Lives: Learning Disabilities Observatory
<http://www.improvinghealthandlives.org.uk/profiles/index.php?view=E06000006/>

Jacobs-van der Bruggen MA, Bos G, Bemelmans WJ, Hoogenveen RT, Vijgen SM, Baan CA (2007) Lifestyle interventions are cost-effective in people with different levels of diabetes risk: results from a modeling study. *Diabetes Care*, 30(1): 128-134.
<http://care.diabetesjournals.org/content/30/1/128.full>

Jones J, Bellis M, Wood S, Hughes K, McCoy E, Eckley L, Bates G, Mikton C, Shakespeare T, Office A (2012). Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies. *The Lancet*, 380, 9845, 899–907
<http://press.thelancet.com/childrendisabilities.pdf>

Learning disabilities and autism: A health needs assessment for children and adults in Merseyside and North Cheshire.
Liverpool Public Health Observatory

JRF (2004) *Employing people with learning disabilities: A handbook for employers*. Joseph Rowntree Foundation.
<http://www.jrf.org.uk/sites/files/jrf/1859352413.pdf>

Lambeth Mencap (2010) *Lambeth PMLD project: Understanding the lives and needs of people with profound and multiple learning disabilities in Lambeth*. Lambeth Mencap.
http://www.mencap.org.uk/sites/default/files/documents/2010-10/Lambeth%20PMLD%20report%20-%20FINAL_v4.pdf

Lewis C and Scott-Samuel A (2013) *Health needs assessment of young offenders in the youth justice system on Merseyside*. Liverpool Public Health Observatory, report series, no.95.
http://www.liv.ac.uk/PublicHealth/obs/publications/report/obs_report.htm

Loucks N (2007) *No One Knows, briefing, Offenders with learning difficulties and learning disabilities: the prevalence and associated needs of offenders*. London: The Prison Reform Trust.
<http://www.prisonreformtrust.org.uk/uploads/documents/NOKNL.pdf>

Marmot (2010) *Fair Society, Healthy Lives*. The Marmot Review. <http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review>

McAteer S, Du Plessis R (2012) *Public Health Evidence & Intelligence Guide to Health Needs Assessments*. NHS Merseyside, c/o Public Health Evidence & Intelligence Team NHS Halton & St Helens.

Mencap (2007) *Death by Indifference*. Mencap, the voice of learning disability
<http://www.nmc-uk.org/Documents/Safeguarding/England/1/Death%20by%20Indifference.pdf>

Mencap (2010) 'Raising our sights' for people with profound disabilities. 'MENCAP the voice of learning disability' website news. Mencap, the voice of learning disability
<http://www.mencap.org.uk/news/article/raising-our-sights-people-profound-disabilities>

Mencap (2012) *Housing for people with a learning disability*. Mencap, the voice of learning disability.
http://www.mencap.org.uk/sites/default/files/documents/2012.108%20Housing%20report_V7.pdf

Mencap (2013) *About PMLD: Latest news*. Mencap, the voice of learning disability. Website accessed 21/5/13
<http://www.mencap.org.uk/all-about-learning-disability/information-professionals/pmld/about-pmld>

Monitor (2013) *Compliance Framework 2013/14*. London.
<http://www.monitor-nhsft.gov.uk/sites/default/files/publications/ToPublishComplianceFramework201314March13.pdf>

National Autistic Society (2011) *NICE publishes draft guidelines for children and young people with autism*. Website accessed 30/5/13
<http://www.autism.org.uk/news-and-events/news-from-the-nas/nice-publishes-draft-guidelines.aspx>

National Autistic Society (2013) *Statistics: how many people have autism spectrum disorders?* Website accessed 26/3/13
<http://www.autism.org.uk/about-autism/myths-facts-and-statistics/statistics-how-many-people-have-autism-spectrum-disorders.aspx>

National Development Team for Inclusion (2010) *Guide for commissioners of services for people with learning disabilities who challenge services*. National Development Team for Inclusion.
http://www.ndti.org.uk/uploads/files/Challenging_behaviour_report_VERY_final_v7.pdf
and
http://www.ndti.org.uk/uploads/files/Challenging_Behaviour_Audit_final.pdf

NHS IC (2010) *Access to Healthcare for People with Learning Disabilities. Analysis of Primary Care Data to Support the Work of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*. The NHS Information Centre, Prescribing Support and Primary Care Services. <https://catalogue.ic.nhs.uk/publications/social-care/vulnerable-adults/anly-prim-care-data-supp-work-ind-eng-acc-ld/acc-heal-care-peop-lear-disa-rep.pdf>

NHS England (2013) *2013/14 General Medical Services (GMS) Contract. Guidance and audit requirements for new and amended services. Version 1 April 2013*. NHS Employers and NHS England.
<http://www.nhsemployers.org/Aboutus/Publications/Pages/2013-14-GMS-contract-Guidance-and-audit-requirements.aspx>

NHS Leeds (2009) *Puberty and Sexuality for Children and Young People with a Learning Disability*. Leeds: NHS Leeds.
<http://www.nursingtimes.net/puberty-and-sexuality-for-children-with-learning-disabilities/5002600.article>

NICE (2011) *Autism: recognition, referral and diagnosis of children and young people on the autism spectrum*. National Institute for Health and Clinical Excellence, Clinical guidelines, CG128
<http://www.nice.org.uk/CG128>

NICE (2012) *Autism: recognition, referral, diagnosis and management of adults on the autism spectrum*. National Institute for Health and Clinical Excellence, Clinical guidelines, CG142
<http://www.nice.org.uk/CG142>

NICE (2013) *Challenging behaviour: prevention and interventions for people with learning disability and challenging behaviour. Scoping document*. National Institute for Health and Care Excellence.
http://apps.bps.org.uk/publicationfiles/consultation-responses/NICE_Challenging_behaviour.pdf

NLDDN (online) National Liaison and Diversion Development Network, website accessed 25/6/13
<http://www.nliddn.org.uk/>

NSPCC (2006) *"It doesn't happen to disabled children"*. *Child Protection and Disabled Children*. London: NSPCC.
http://www.nspcc.org.uk/Inform/publications/downloads/itdoesnthappentodisabledchildren_wdf48044.pdf

Oyinloye A and Lee J (2010) *A Health Needs Assessment Report For Adults with Learning Disabilities in Knowsley*. Draft, May 2010. NHS Knowsley and Knowsley Council.

PMLD Network. *About profound and multiple learning disabilities: PMLD Factsheet. Profound and multiple learning disabilities*
<http://www.pmldnetwork.org/pmld%20definition%20factsheet%20-%20standard.pdf>

Prison Reform Trust (2012a) *Fair access to justice*. Prison Reform Trust.
<http://www.prisonreformtrust.org.uk/Portals/0/Documents/FairAccesstoJustice.pdf>

Prison Reform Trust (2012b) *Bromley Briefings Prison Factfile*.
<http://www.prisonreformtrust.org.uk/Portals/0/Documents/FactfileNov2012small.pdf>

Reed T (2013) *personal correspondence*, 26/3/13.

RCN (2010) *Mental health nursing of adults with learning disabilities. RCN Guidance*. Royal College of Nursing.
http://www.rcn.org.uk/_data/assets/pdf_file/0006/78765/003184.pdf

RCN (2011) *Learning from the past – setting out the future: Developing learning disability nursing in the United Kingdom*. Royal College of Nursing.
http://www.rcn.org.uk/_data/assets/pdf_file/0007/359359/003871.pdf

RCPsych et al (2007) *Challenging behaviour: a unified approach*. Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists. College Report CR144
<http://www.rcpsych.ac.uk/files/pdfversion/cr144.pdf>

RCPsych (2009) *Developing Mental Health Services for Children and Adolescents with Learning Disabilities. A Toolkit for Clinicians*. Royal College of Psychiatrists and National CAMHS Support Service
www.rcpsych.ac.uk/PDF/DevMHservCALDbk.pdf

RCPsych (2010) *Service Standards, 3rd Edition*. Quality Network for Community CAMHS. Royal College of Psychiatrists.
<http://www.rcpsych.ac.uk/pdf/QNCC%20Service%20Standards%203rd%20Edition.pdf>

RCPsych (2010a) *Information for people with learning disability and their carers*. Royal College of Psychiatrists and Leicestershire Partnership NHS Trust
<http://www.rcpsych.ac.uk/expertadvice/problemsdisorders/learningdisabilities.aspx>

Roberts H, Baines S, Glover G, Hatton C (2012a) *Autism Self Assessment 2011: Issues from local authorities*. Improving Health and Lives. Learning Disability Observatory (IHAL)
http://www.improvinghealthandlives.org.uk/uploads/doc/vid_17474_Ihal%202012-%2010%20Autism%20self%20assessment%202010-11.pdf

Roberts H, Turner S, Baines S, Hatton C (2012b) *Advocacy by and for adults with learning disabilities in England*. Improving Health and Lives. Learning Disability Observatory (IHAL)
http://www.ndti.org.uk/uploads/files/IHAL_2012-03_Advocacy.pdf

Safer St.Helens (online) website accessed 29/7/13:
<http://safer.sthelens.gov.uk/crime-types/hate-crime/>

Simpson S; Andrews C, Isaac N (2010) *Sex education for children with learning disabilities: rolling out a national resource*. *Nursing Times*; 106: 6, early online publication (google title for full text article)
<http://www.nursingtimes.net/nursing-practice/clinical-zones/sexual-health/sex-education-for-children-with-learning-disabilities-rolling-out-a-national-resource/5011481.article>

St. Helens JSNA (2012) *St. Helens Joint Strategic Needs Assessment 2012*.

Talbot, J (2008) *Prisoners' Voices: Experiences of the criminal justice system by prisoners with learning disabilities and difficulties*, London: Prison Reform Trust.

<http://www.mandbf.org/policy-and-evidence/building-the-evidence/research-and-project-evaluation-directory/no-one-knows-prisoners-voices-experiences-of-the-criminal-justice-system-by-prisoners-with-learning-disabilities-and-difficulties>

Tyrer F & McGrother C (2009) Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disabilities. *Journal of Intellectual Disability Research*, 53: p. 898-904.

<http://www.ncbi.nlm.nih.gov/pubmed/19694898>

University of Birmingham (2006) *Guidelines for Services for Young People (14–25 Years) with Learning Difficulties/Disabilities and Mental Health Problems/ Challenging Behaviours*.

<http://www.chimat.org.uk/resource/item.aspx?RID=92238>

University of Leeds (2009) *Talking about sex and relationships: the views of young people with learning disabilities*. The final report of the sexuality project by CHANGE 2007-2010.

<http://disability-studies.leeds.ac.uk/files/library/change-final-report-read-copy.pdf>

University of Ulster, Family Planning Association (2006) *Out of the Shadows*. Ulster: University of Ulster.

<http://www.fpa.org.uk/media/uploads/professionals/publications/out-of-the-shadows-look-inside.pdf>

Weston C, Beck C, Marshall E, Holley K (2012) *A health needs assessment for adults with a learning disability in Lincolnshire. Full Report*. NHS Lincolnshire.

<http://www.research-lincs.org.uk/UI/Documents/LD%20HNA%20report%20v1.pdf>

WHO (online) *Violence against adults and children with disabilities*. World Health Organisation. Website accessed 17/4/13

<http://www.who.int/disabilities/violence/en/>

Appendices

Appendix Map 1



**Map showing Merseyside and North Cheshire
Local Authorities and Clinical Commissioning Groups (CCGs)**

Local authorities share boundaries with CCGs, with the exception of Sefton, where there are two CCGs.

Liverpool City Council | Millennium House | Victoria Street |
Liverpool L1 6JD | T: 0151 233 4644 | E: sophie.kelly@liverpool.gov.uk



© Crown copyright and database rights 2012 Ordnance Survey 100018351

Date: 24/4/2013

Scale:

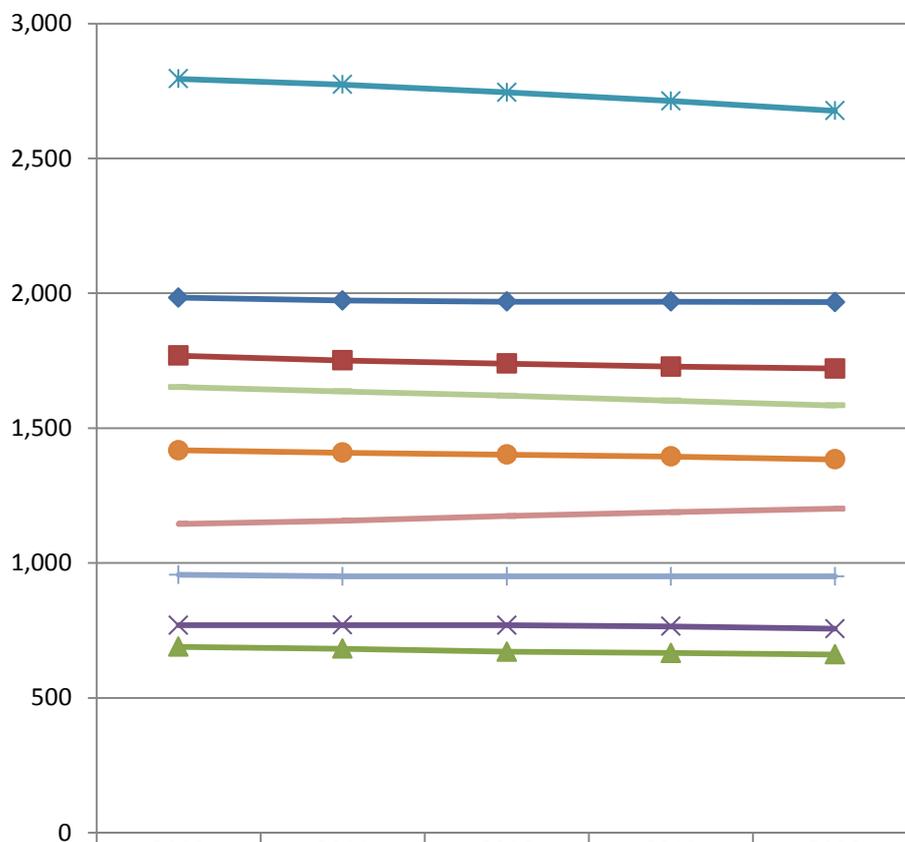
Status:

FINAL



Appendix Figure A1

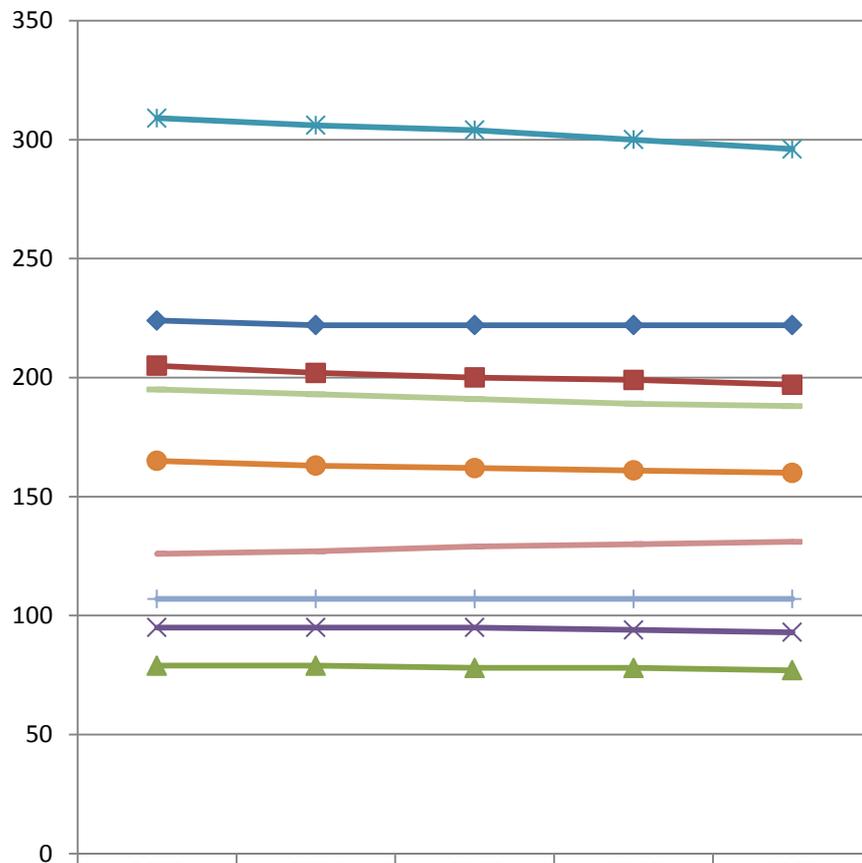
Number of males aged 18-64 predicted to have autistic spectrum disorders, projected to 2020



	2012	2014	2016	2018	2020
◆ Cheshire East	1,984	1,973	1,969	1,969	1,967
■ Cheshire West and Chester	1,769	1,751	1,739	1,728	1,721
▲ Halton	689	682	671	666	661
✕ Knowsley	769	770	769	765	756
✱ Liverpool	2,795	2,774	2,745	2,713	2,677
● Sefton	1,418	1,409	1,402	1,395	1,384
+ St.Helens	956	950	950	950	950
— Warrington	1,145	1,157	1,174	1,188	1,201
— Wirral	1,652	1,636	1,620	1,602	1,584

Appendix Figure A2

Number of females aged 18-64 predicted to have autistic spectrum disorders, projected to 2020



	2012	2014	2016	2018	2020
◆ Cheshire East	224	222	222	222	222
■ Cheshire West and Chester	205	202	200	199	197
▲ Halton	79	79	78	78	77
× Knowsley	95	95	95	94	93
* Liverpool	309	306	304	300	296
● Sefton	165	163	162	161	160
+ St. Helens	107	107	107	107	107
— Warrington	126	127	129	130	131
▲ Wirral	195	193	191	189	188

Appendix guidelines: care and management

Profound and multiple learning disabilities

'*Raising our sights*' (DH, 2010a) was a report commissioned as part of the 'Valuing People Now' delivery plan. It called for the wider development of personalised services for people with profound and multiple learning disabilities. Although recognising existing good practice, the report highlighted prejudice, discrimination and low expectations as obstacles to its wider implementation. There is a concern that because of the funding crisis and the enormous pressure on social services the Government is going to avoid committing to expensive packages of support, which people with PMLD will often need, and only provide care in a crisis (Mencap, 2013). However, 'Raising our Sights' noted that a lack of resources may restrict the speed of change, but that this shouldn't affect its direction.

Raising Our Sights (DH, 2010a) makes 33 recommendations across areas such as health, wheelchairs, assistive technology and day activities. As well as emphasising personalisation, it says that good services should treat the family members of the disabled person as experts, focus on the quality of staff relationships with the person and sustain the package of care. A film accompanies the report, using the experiences of five people with PMLD and their families to show how good services can work in practice (Mencap 2010).

This report: There is a need for accurate locally available data on numbers with PLMD.

Autism

Fulfilling and rewarding lives (DH, 2010) is statutory guidance that focuses on the seven areas required by the Autism Act 2009, in each case identifying what health and social services bodies are already expected to do, and then setting out any additional requirements introduced by the strategy. The additional requirements are focused on achieving two key outcomes:

- improving the way health and social care services identify the needs of adults with autism, and
- ensuring identified needs are met more effectively to improve the health and wellbeing of adults with autism.

NICE reports on autism:

Children

The National Institute for Health and Clinical Excellence (NICE) guideline for the management and support of children and young people with autism was published in September 2011 (NICE, 2011). The guideline makes recommendations on the most effective ways that health and social care professionals can provide support, interventions and help for children and young people with autism and their families and carers, from the early years through to their transition into young adult life (up to 19).

The National Autistic Society commented that they particularly welcome NICE's recommendations on adapting mental health interventions for children with autism and the central role for local autism teams in the delivery and management of care. They note that 71% of children with autism have at least one co-occurring mental health problem, while 40% have two or more (National Autistic Society 2011).

Recommendations vary in strength, from interventions that must (or must not) be pursued, which professionals are under a legal obligation to follow, to those which professionals should follow as best practice. NICE have said the following interventions for children and young people with autism must not be used in any context: secretin, chelation, hyperbaric oxygen therapy. They also rule out using psychiatric medication (anti-depressants, anti-convulsants, anti-psychotics) and exclusion diets for treating the core features of autism.

The guidelines relating to service organisation were as follows:

Local pathway for recognition, referral and diagnostic assessment of possible autism: Strategy group

- A local autism multi-agency strategy group should be set up, with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and carer service users, and the voluntary sector.
- The local autism strategy group should appoint a lead professional to be responsible for the local autism pathway for recognition, referral and diagnosis of children and young people. The aims of the group should include:
 - improving early recognition of autism by raising awareness of the signs and symptoms of autism through multi-agency training
 - making sure the relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access diagnostic services
 - supporting the smooth transition to adult services for young people going through the diagnostic pathway
 - ensuring data collection and audit of the pathway takes place.
- In each area a multidisciplinary group (the autism team) should be set up. The core membership should include a:
 - paediatrician and/or child and adolescent psychiatrist
 - speech and language therapist
 - clinical and/or educational psychologist.
- The autism team should either include or have regular access to the following professionals if they are not already in the team:
 - paediatrician or paediatric neurologist
 - child and adolescent psychiatrist
 - educational psychologist
 - clinical psychologist
 - occupational therapist.
- Consider including in the autism team (or arranging access for the team to) other relevant professionals who may be able to contribute to the autism diagnostic assessment. For example, a specialist health visitor or nurse, specialist teacher or social worker.
- Provide a single point of referral for access to the autism team.

Adults:

The NICE guidelines for adults with autism emphasise that support and care should take into account peoples' needs and preferences (NICE, 2012). People with autism should have the opportunity to make informed decisions about their care, in partnership with their healthcare professionals. NICE note that if adults with autism do not have the capacity to make decisions, healthcare professionals should follow the Department of Health's advice on consent and the code of practice that accompanies the Mental Capacity Act. Good communication between healthcare professionals and people with autism and their families, partners and carers is essential. It should be supported by evidence-based written information tailored to the person's needs. If the person with autism agrees, families, partners and carers should have the opportunity to be involved in decisions about support and care. Families, partners and carers should also be given the information and support they need.

Transition: Care of young people in transition between paediatric services/child and adolescent mental health services (CAMHS) and adult services should be planned and managed according to the best practice guidance described in the Department of Health's Transition: getting it right for young people

(http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4132145)

Adult and paediatric healthcare/CAMHS teams should work jointly to provide assessment and services to young people with autism. Diagnosis and management should be reviewed throughout the transition process, and there should be clarity about who is the lead clinician to ensure continuity of care. All staff working with adults with autism should take time to build a trusting, supportive, empathetic and non-judgemental relationship as an essential part of care

In order to effectively provide care and support for adults with autism, the local autism multi-agency strategy group (see under 'children' on preceding pages) should include representation from managers, commissioners and clinicians from adult services, including mental health, learning disability, primary healthcare, social care, housing, educational and employment services, the criminal justice system and the third sector. There should be meaningful representation from people with autism and their families, partners and carers.

Autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should appoint a lead professional responsible for the local autism care pathway. The aims of the strategy group should include

- developing clear policy and protocols for the operation of the pathway
- ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway
- making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services
- supporting the integrated delivery of services across all care settings
- supporting the smooth transition to adult services for young people going through the pathway
- auditing and reviewing the performance of the pathway

(<http://www.nice.org.uk/guidance/CG123>).

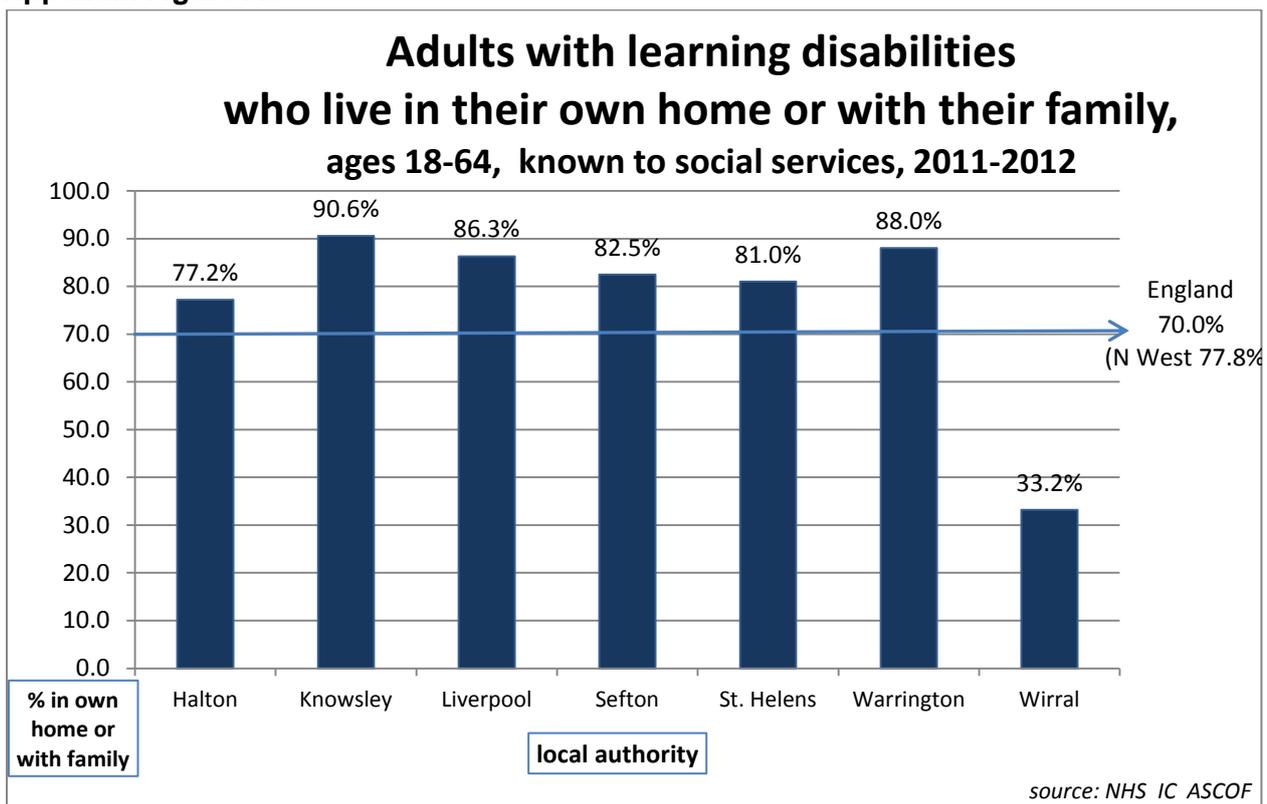
In addition, this NICE report (NICE, 2012) also provides guidance on interventions for autism, interventions for challenging behaviour, interventions for coexisting mental disorders, and assessment and interventions for families, partners and carers

(<http://publications.nice.org.uk/autism-recognition-referral-diagnosis-and-management-of-adults-on-the-autism-spectrum-cq142/guidance#interventions-for-autism>).

The Autism Education Trust has produced a '*Transition Toolkit: helping you support a child through change*' (AET, 2012). The toolkit is a summary of common issues surrounding transition for young people on the autism spectrum, as well as a guide to the considerations that should be taken by those supporting them.

Recommendation from this report: There is a need for further exploration of how autism affects males and females differently.

Appendix Figure A3



NOTE: St. Helens estimates were taken from the NHS IC provisional report – see footnote to Table A1 in Appendix

Appendix Table A1

Living in own home or with family:

% of all male and female adults with learning disabilities aged 18-64 and known to adult social services, 2011-12 who are living in their own home or with family

local authority	Male			Female			Total
	number of male clients living in their own home or with their family (aged 18-64)	total male LD population (aged 18 to 64)	% males living in their own home or with their family (aged 18 to 64)	number of female clients living in their own home or with their family aged 18-64	total female LD population (aged 18 to 64)	% females living in their own home or with their family (aged 18 to 64)	%total males & females in own home or with family (aged 18-64)
Halton	170	220	76.9	135	175	77.5	77.2
Knowsley	335	370	90.3	275	300	91.1	90.6
Liverpool	735	845	87.4	510	600	84.7	86.3
Sefton	405	470	85.7	255	325	77.8	82.5
St. Helens	230	285	79.4	215	260	82.6	81.0
Warrington	235	260	88.9	170	195	86.7	88.0
Wirral	195	620	31.5	145	405	35.7	33.2
Merseyside & North Cheshire	2305	3070	75.1	1705	2260	75.4	75.0
North West			78.0			77.4	77.8
England			69.6			70.6	70.0

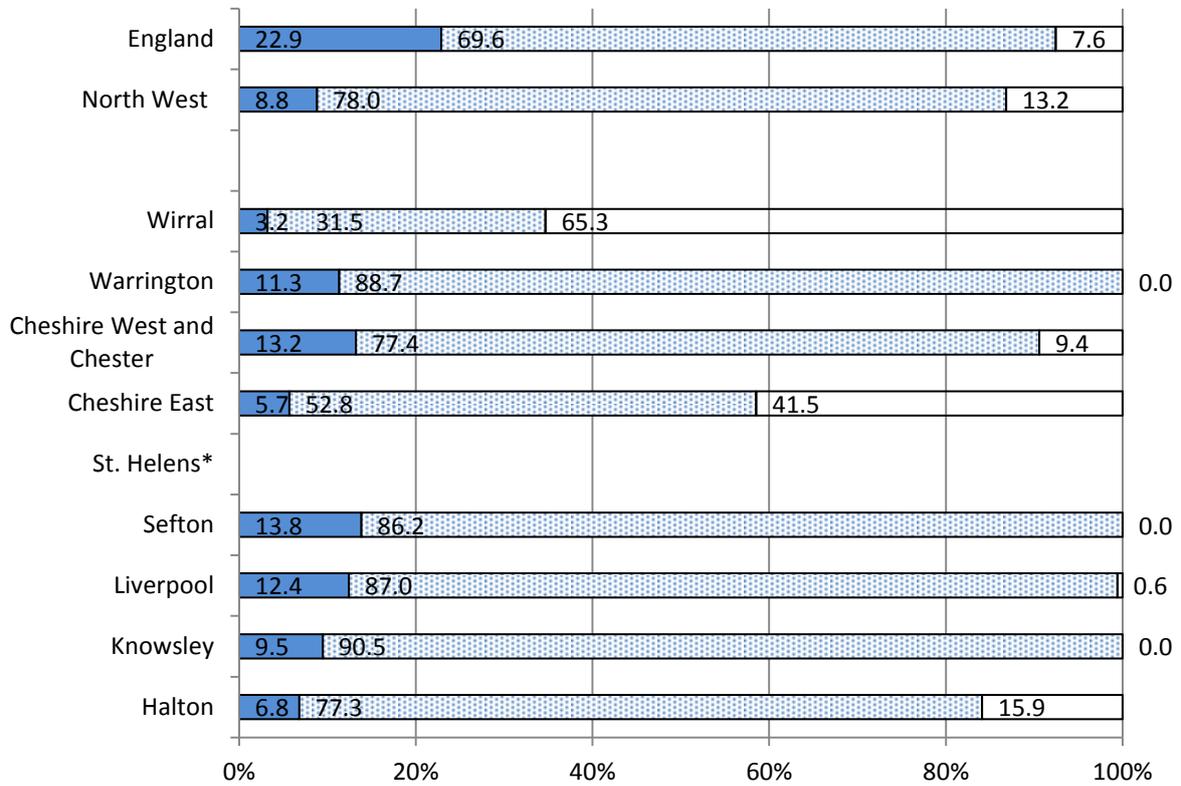
Source: NHS Information Centre, Adult Social Care Outcomes Framework for 2011/12. Adults with learning disabilities known to Councils with Adult Social Services Responsibilities (CASSRs). Final report, Feb. 15th 2013.

Note: The NHS IC produced its provisional report in 2012. In the Final report (Feb 2013), the LD working age population estimates for St. Helens (& therefore the outcome measures) were taken out, with a note that this data was 'not available'. But the same estimates were included in the NHS IC employment report (1E) - so they have been left in here for now. Corrections to the North West and England data have been included.

Appendix Figure A4

Males and Accommodation Status

% of males with learning disabilities in accommodation either non-settled, settled or unknown, ages 18-64, 2011/12



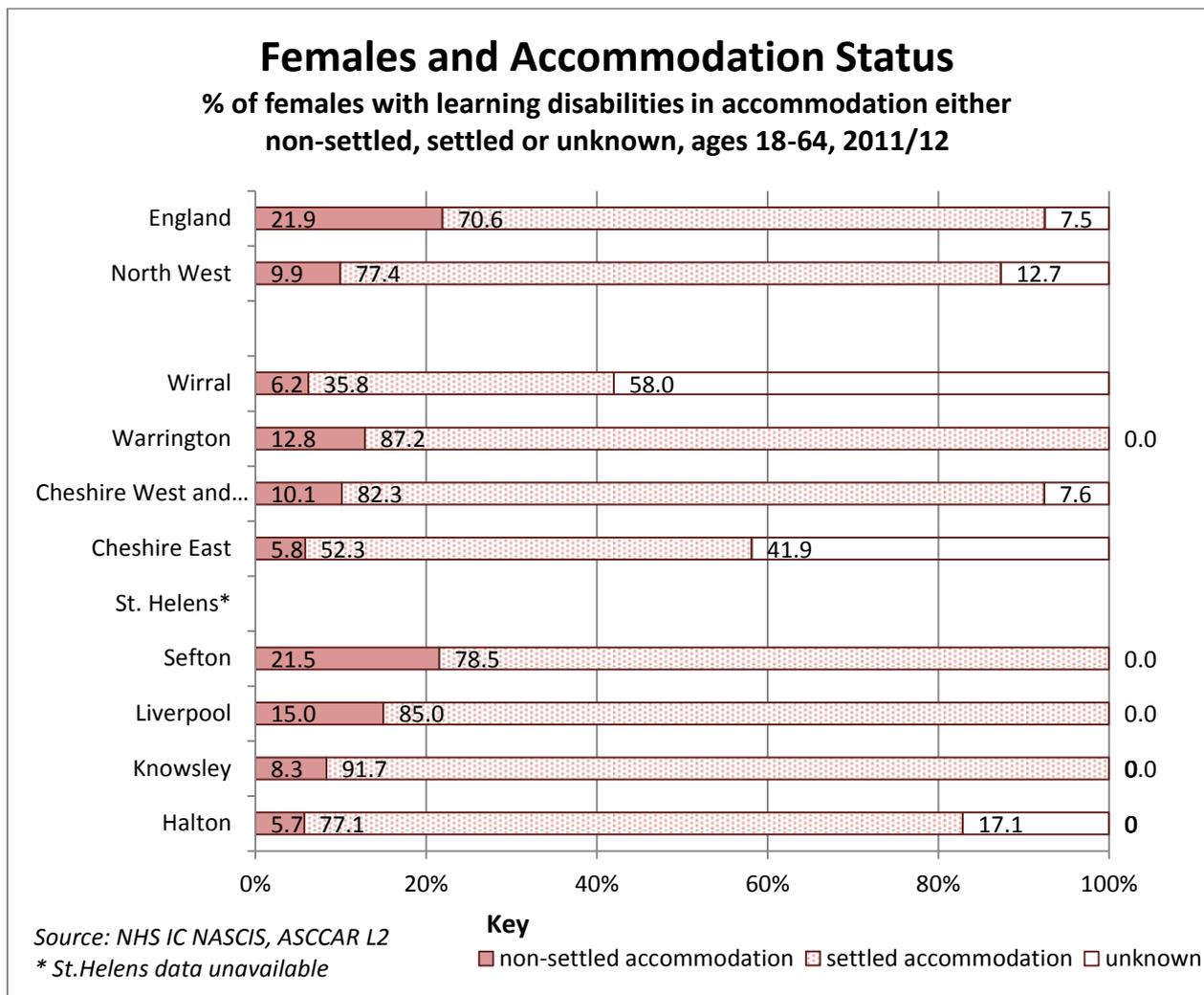
Source: NHS IC NASCIS, ASCCAR L2

* St. Helens data unavailable

Key

■ non-settled accommodation ■ settled accommodation □ unknown

Appendix Figure A5



Appendix 6

Winterbourne View

Winterbourne View hospital was a private hospital that was registered to provide assessment and treatment and rehabilitation for people with learning disabilities. The hospital had 24 beds for patients with learning disabilities. Most patients had been placed at the hospital under the Mental Health Act. One of the main reasons they were placed in Winterbourne View was to manage a crisis, suggesting a lack of local services to support people with challenging behaviour. However, many were in the hospital for long periods - some patients were there for more than 3 years. The number of times patients were restrained by staff at Winterbourne View hospital was very high and unacceptable. For example - a family provided evidence that their son was restrained 45 times in 5 months. The Serious Case Review provides evidence of poor quality care in Winterbourne View hospital. For example: some people had poor dental health care. Families were not allowed to visit patients on the ward or in their bedrooms, which made the abuse of patients even harder to spot.

The patients at Winterbourne View had very little access to advocacy, and patients' complaints were not handled properly. South Gloucestershire Council were told about safeguarding issues in Winterbourne View but failed to identify a trend in the number of times they were contacted. A whistleblower told the Care Quality Commission that he was worried about the way patients at Winterbourne View were being treated, but the Care Quality Commission failed to respond to the concerns raised by the whistleblower. The Mental Health Act Commission were told about incidents at Winterbourne View and said there was a need to improve but did not follow up to make sure improvements had happened. 29 incidents were reported to the police. 8 of the reported incidents concerned staff using physical restraint on patients. The police didn't follow up the incidents because they believed the reasons given by staff at Winterbourne View. These concerns were not responded to until a BBC Panorama programme, documenting the incidents at Winterbourne, was shown in May 2011.

In December 2012, the government published a response to what had happened at Winterbourne:

*Transforming care: Transforming care: A national response to Winterbourne View Hospital
Department of Health Review: Final Report, December 2012.*

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127310/final-report.pdf.pdf

Acknowledgements and author details

Many thanks to all those who contributed to the report, including the following:

Project working group

Project Lead: Sharon McAteer, Public Health Development Manager, Halton BC
Koon Lan Chan, Public Health Developmental Manager, Sefton MBC
Lynne Edmondson, Commissioning Manager, Halton Clinical Commissioning Group
John Edwards, Service Manager Commissioning, St. Helens MBC
John Engwall, Assistant Programme Delivery Manager, (Mental Health, Learning Disability & Dementia), Liverpool CCG
Tracy Flute; Head of Public Health Analysis, Warrington BC Public Health Knowledge and Intelligence Team
Ruth Hunter; Partnership Commissioning Manager, St Helens CCG
Karen Kauffman Family Support and Parenting Commissioner, St. Helens MBC
Sophie Kelly; Public Health Epidemiologist, Liverpool City Council
Sarah Kinsella; Public Health Information Specialist, Wirral BC
Sam Murtagh Integrated Commissioning Manager, IYSS & Commissioning Team, Halton BC
Eileen Oakes; Team Leader: Assessment, Resource & Provision Planning, Vulnerable Pupils Support, Sefton MBC
Tracy Reed; Primary Healthcare Facilitator. Mersey Care NHS Trust
Suzanne Robinson, Primary Health Care Facilitator/LD Nurse, Mersey Care NHS Trust
Stuart Sheridan, Commissioning Manager - ASD, Employment and Partnerships, Integrated Commissioning Team, Knowsley MBC
Chris Williamson, Lead Public Health Epidemiologist, Liverpool City Council

Thanks also to:

Chris Austin, Team Manager -Liverpool Asperger Team
Fran Bailey, Administrator, Liverpool Public Health Observatory
Chris Bean, former Integrated commissioning Manager, NHS Merseyside
Charles Beck, Lecturer & Honorary Specialty Registrar in Public Health, Nottingham City Hospital
Paul Blackburn, Educational Technologist, University of Liverpool
Carolann Bowers, Carers Support Group, St. Helens
Eileen Clarke, Performance Manager, Halton Community Services
Colin Croxton, Agency Services Manager, Your Housing Group, St. Helens
Philip Dearden. Head of Clinical Flows, Whiston Hospital
Shirley Dempsey, Senior Day Service Co-ordinator Halton BC
Martin Dobson, Director, Easy-Read-Online Limited
Barry Fearnough, Manager - Governance & Intelligence, Strategy & Support, Liverpool City Council
Amanda Fitzsimmons, Community Learning Disability Nurse Merseycare
Gyles Glover, Co-Director, Learning Disabilities team, Public Health England
Andrew Holden, Business Intelligence Support, Merseyside Commissioning Support Service
Sharon Howard, Commissioning Support Manager, NHS England (Merseyside)
Paulette Lappin, Community Partnerships Manager, Merseytravel
Ian McAleavy, Project Officer, Sefton Biodiversity and Access Project, Sefton MBC
Jill Oakley, Public Health Analysis Manager, Cheshire
Chris Weston, Consultant in Public Health, Lincolnshire County Council
Paul Weston, Project Manager, Merseytravel

Author details

Janet Ubido and Cath Lewis, Senior Researchers, Liverpool Public Health Observatory, Department of Public Health and Policy, University of Liverpool
Sharon McAteer, Public Health Development Manager, Halton BC
Sophie Kelly; Public Health Epidemiologist, Liverpool City Council
Alex Scott-Samuel, Director, Liverpool Public Health Observatory, Department of Public Health and Policy, University of Liverpool

Contact: j.ubido@liv.ac.uk

Liverpool Public Health Observatory

Department of Public Health and Policy
Whelan Building
Quadrangle
University of Liverpool
Liverpool L69 3GB

Tel: 0151 794 5570/81

Fax: 0151 794 5588

E-mail: obs@liv.ac.uk

WWW: <http://www.liv.ac.uk/PublicHealth/obs>



UNIVERSITY OF
LIVERPOOL