

# Learning disabilities and autism:

A health needs assessment for children and adults in Cheshire and Merseyside

Jane Harris, Hannah Madden, Janet Ubido, Jane Oyston

January 2016

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## GLOSSARY

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ASCOF: Adult Social Care Outcomes Framework data

ASC-CAR: Adult Social Care Combined Activity Returns data

CCG: Clinical Commissioning Group

CSU: Commissioning Support Unit

CWP: Cheshire and Wirral Partnership Trust

EHC: Education, Health and Care Plans

IAPT: Improving Access to Psychological Therapies

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

LA: Local Authority

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

PMLD: Profound and Multiple Learning Difficulty

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.

SAE: 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

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## 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 Cheshire and Merseyside (Halton, Knowsley, Liverpool, Sefton, St Helens, Warrington, Wirral, Cheshire East, Cheshire West and Chester). It tries to determine the health and wellbeing needs of people with learning disabilities and autism living in Cheshire and Merseyside. The findings have been used to develop a set of recommendations for local commissioners.

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 Cheshire and Merseyside?**

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 known to GPs is broadly similar to the numbers local authorities have on their registers. However, there is a lot of variation in GP figures across practices and self-assessment framework (SAF) data does not always give an indication of the total population. 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 Cheshire and Merseyside, there are an estimated 35,896 people with a learning disability aged 18 and over, but there are only 7,775 who are known to services (2014/15). There is no data available on the numbers actually known to have profound and multiple learning disabilities (PMLD).

We estimate there are about 2,267 children and 14,582 adults in Cheshire and Merseyside with autism. We do not know how many of these have Asperger's syndrome, although data from two specialist NHS providers (Mersey Care and Cheshire and Wirral Partnership) reported just under 580 Cheshire and Merseyside residents with a diagnosis of Asperger's on their caseloads in 2015.

## 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 BMI information is limited which makes comparison to the local population difficult. However, high proportions of adults with learning disabilities do seem to be obese with the proportion in each local authority ranging from 34% in Cheshire East to 53.7% in Knowsley; this compared to an England average of 24%. Information on other co-morbidities is not routinely collected/reported with few areas able to provide details on additional diagnoses amongst people with learning disabilities. However rates of some conditions appear to be high including;

- Epilepsy – rates are high locally and nationally research shows epilepsy is at least 20 times higher amongst those with learning disabilities than for the general population.
- The other most common additional health conditions were asthma (four out of seven LAs which provided data) and dysphagia (difficulty swallowing; three out of seven which provided data). Coronary heart disease was the most common co-morbidity in one local authority which report 7.7% of people with learning disabilities in the area having CHD.

Local data on mortality of people with learning disabilities was very limited with the only data available coming from the LDSAF. However, this only included number of deaths in the previous 12 months and any values under 5 were suppressed. Therefore total number of deaths in each LA is not available. No causes of death or age at death were available.

Detailed hospital admissions data was not available from HES within the timeframe of this report and is no longer available on IHAL; however previous research has shown that 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).

As well as lifestyles, another major reason for poorer health could be worse 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. Cheshire and Merseyside as a region is performing substantially better than the England average on uptake and practice participation of health checks.

Screening data were available from most areas and shows a similar pattern to national research including:

- High rates of people with learning disability refuse or do not attend cervical cancer screening, compared to the population of all eligible women.
- Screening uptake for breast cancer was lower in women with learning disabilities compared to all eligible women; though higher than cervical cancer screening uptake.
- Bowel cancer screening varied between local authorities and in some areas was higher amongst people with learning disabilities compared to the general eligible population.

Information on uptake of contraception and sex and relationships education (SRE) for people with learning disabilities was limited. National research has shown that SRE needs to be improved for people with learning disabilities.

### **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% of people with a learning disability are in either part-time or full-time employment. Locally, all areas apart from Cheshire East and St Helens, have below the national average levels of employment for people with learning disabilities. The wide variation in employment locally 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 Cheshire and Merseyside are generally 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 disabilities referred to social services safeguarding teams is higher than the regional and national average in seven out of nine local authorities.

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. Data available on parental status is limited but the available data suggests that numbers of parents are small in each local authority, roughly 10-30 in each area. However, they are likely to have complex and on-going support needs.

### **Service Use and Provision**

There are three NHS providers; Mersey Care, Cheshire and Wirral Partnership (CWP) and 5 Boroughs Partnership, providing both community based and inpatient specialist care for people with learning disabilities.

Two of three providers (Mersey Care and Cheshire and Wirral Partnership) supplied data for this needs assessment. Each provider had between 1,500 and 2,000 individuals with learning disabilities on their caseload in 2015. The client profile reflected the demographics of those known to Local Authorities and CCGs with the majority being male, white and aged between 21 and 60 years old. The largest proportion of referrals were made by GPs.



The number of mean learning disability inpatient days per patient per year at Mersey Care and CWP were 12.5 and 18 days respectively with Mersey Care seeing a rise in the number of mean patient days and CWP seeing a decline. There were approximately 30,000 contacts per provider in 2014/15 of which two thirds were face to face and just under one in ten were unsuccessful; unsuccessful contacts include DNAs, appointments that were cancelled by the patient or provider and instances where the patient declined.

## 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 out in order to ensure equal access to services, as required by the Disability and Equality Act 2010:

### **Empowering individuals**

1.1 Ensure that people with learning disabilities in each local authority and CCG in Cheshire and Merseyside have the opportunity to contribute to needs assessments and the development of services. This is the second needs assessment produced across the two counties but it is vital that the data and evidence presented here is triangulated with insights from those living with a learning disability and/or autism.

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

1.4 Review the quality of housing for people living with learning disabilities including those who are living with family. The proportion of adults with learning disabilities in Cheshire and Merseyside living in their own home is above the national average but there is little indication of housing quality.

1.5 Ensure young people with learning disabilities have access to high quality sex and relationship education including raising awareness of sexual exploitation and healthy relationships.

1.6 Ensure that all services are actively working to reduce social isolation among people with learning disabilities by signposting and referring to community and third sector organisations and leisure activities.

1.7 Where a parent has a 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.

## **Right Care in the Right Place**

2.1 Ensure strong partnership and collaborations are in place between Local Authorities and Clinical Commissioning Groups to ensure that people with a learning disability have access to information, advocacy, support and care as and when they need it.

2.2 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.

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). Ensuring that all AT&T plans include measures to alleviate social isolation.

2.4 Introduce routine screening for learning disability in prison and make reasonable adjustments and develop easy read information to ensure prisoners with learning disabilities understand prison routines.

2.5 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).

2.6 Continue to promote annual health checks for people with learning disabilities at GPs and people with learning disabilities, with a 90% uptake rate target (IHAL, 2012).

2.7 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.

2.8 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.

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

2.10 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).

## **Workforce Development**

3.1 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:

3.1.1 Making all self-help and service information 'easy to read'.

3.1.2 Ensuring support is available where required, for example in housing application processes.

3.1.3 Providing 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.

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

3.3 Improve awareness among individuals, learning disability and criminal justice professionals the process for reporting disability related hate crime.

3.4 Provide training for those who work in the criminal justice system including police, court and custody suite staff on recognising, approaching, communicating and interviewing/questioning those with learning disabilities and autism.

3.5 Strengthen collaboration between adult and children's services to ensure that the needs of parents with learning disabilities and their children are being met.

3.6 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.

3.7 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).

3.8 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).

3.9 Provide better transport solutions for people with learning disabilities and autism, organised by councils, charities and communities in partnership, including increasing public and driver awareness of learning disabilities and autism and improving acceptance of disabled people on public transport.

3.10 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).

3.11 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.

3.12 Ensure provider organisations, families and carers have easy access to specialist support, assessment and intervention services from multi-disciplinary team to support any issues with challenging behaviour.

## **Data**

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

### *Definitions*

4.1 *Challenging behaviour*: 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.

4.2 *Learning disability among children*: introduce standard definition and collection of data on children with learning disabilities rather than relying on numbers with learning difficulty (as reported in the School Census). Liverpool City Council's work on producing a single dataset for children and young people will assist in this.

4.3 *Asperger's*: Ensure that data on Asperger's from Local Authority, GP practice and provider captures those with a primary and secondary diagnosis of Asperger's and allows for the identification of those with a diagnosis of learning disability and Asperger's who are not eligible for Specialist Autism Services.

#### *Monitoring and Quality*

4.4 Ensure that local authority and GP information systems across Cheshire and Merseyside allow for the collection of comparable data which can be shared across organisations to allow the needs of the population with learning disabilities and/or autism to be truly quantified.

4.5 Ensure GP information systems record data separately on numbers with learning disabilities, autism and Asperger's syndrome and profound and multiple learning disabilities (PMLD), for age groups under 18, 18-64 and 65 plus, and by ethnic group and gender.

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

4.7 In consultation with providers, develop a routine dataset specification for use in JSNAs, needs assessments and to inform planning and policy across Cheshire and Merseyside. This should include standard terms and definitions across the three providers (as detailed above) to allow for easy and timely extraction of data to inform decision making.

4.8 Parental status: improve the recording of parental status among adults with learning disabilities across GP practice, local authority and providers so that the needs of parents can be catered for including through joint working between health and social care and maternity services.

4.9 Improve reporting of accommodation status at both LA level and across NHS organisations to ensure individuals' needs are recognised and all adults with learning disabilities have access to the level and quality of support they need.

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

4.11 Within hospital IT systems 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.

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

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

4.14 Further investigate the needs of people with autism as data collection improves and consider a separate needs assessment for autism and Asperger's which uses engagement with service users and the wider population with autism and Asperger's to address some of the gaps in data.

# FULL REPORT

## 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).

The life expectancy of those with learning disabilities is shorter than the general population, though this has increased in recent years (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 (Tyrrer and McGrother, 2009).

Patterns of health need 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).

The Centre for Public Health, Liverpool John Moores University (LJMU) was commissioned by NHS England to deliver this rapid health needs assessment for learning disabilities and autism amongst adults and children for the nine local authority areas across Cheshire and Merseyside.

### 1.1 PROJECT VISION

The needs assessment should inform NHS England's Transforming Care (NHS England et al, 2015) work programme in Cheshire and Merseyside. In addition, this report can be used to 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.

### AIMS

- To determine the health and wellbeing needs of people with learning disabilities and autism living in Cheshire and Merseyside
- To provide accurate data to help inform the Transforming Care work programme for Cheshire and Merseyside
- 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 Cheshire and Merseyside.

- Describe key characteristics of the population with learning disabilities and autism in Cheshire and Merseyside relevant to commissioning health and social care services.
- Detail available data on service provision and use from local NHS providers of learning disabilities services.
- Identify priority health, care and wellbeing issues, barriers to accessing services and barriers to delivering services for people with learning disabilities and autism in Cheshire and Merseyside.
- Make recommendations for better addressing the health, care and wellbeing needs of people with learning disabilities and autism across Cheshire and Merseyside, 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 disabilities 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, Clinical Commissioning Group and NHS England. Data on service use and provision has been accessed directly from the three providers across Cheshire and Merseyside (Cheshire and Wirral Partnership, Mersey Care and 5 Boroughs partnership).

## 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 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 for 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**

	<b>IQ Levels</b>	<b>ICD Code</b>
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).

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### 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).

#### **Care Act (2014):**

*"The Care Act (2014)"* built upon recent reviews and reforms (outlined below) and replaced numerous existing laws with a single approach to adult social care in England. The key focus of the act is the statutory principle of individual wellbeing and aims to achieve: clearer and fairer care and support; physical, mental and emotional wellbeing of both the individual needing care and their carer; preventing, reducing and delaying the need for care and support and, putting people in control of their own care.

The Act places a requirement and duty on all Local Authorities to: collaborate and integrate with other public authorities (e.g. housing, health); to ensure that information, advice and independent advocacy is available to all when they need it; to provide people with a choice of diverse and high quality care providers and ensure no vulnerable person is left without the care they need; and, outlines a new statutory safeguarding framework.

The key processes of the act are firstly, that anyone who appears in need of support is entitled to an outcomes focused assessment and the local authority must apply a national eligibility threshold to

determine individual needs. Secondly the local authority must undertake a financial assessment where the type of care being considered is chargeable with deferred payments offered by April 2015 and a care account to set out the accumulated costs towards an individual's cap on care set out by April 2016. Lastly, a care and support plan must help an individual decide how the resources needed to meet their individual needs and this plan must be reviewed regularly.

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#### 1.4 NATIONAL REPORTS AND GUIDANCE

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).

##### **Transforming Care: Next Steps**

"*Transforming Care for people with learning disabilities –next steps*" (NHS England et al, 2015) is the latest report from NHS England and the Local Government association which builds upon the agenda set out in the original "Transforming Care" programme to drive system wide change and enable more people with learning disabilities to live in the community with the right support (DH 2012b). The programme focuses on five key areas, namely: empowering individuals; the right care in the right place; workforce development; regulation and inspection and, data.

The report was accompanied by "Building the Right Support" which outlined the national plan to develop community services and close inpatient facilities for people with a learning disability (NHS England et al, 2015a) and a service model (NHS England, 2015b) for the 49 Transforming Care Partnerships across England with the aim of reshaping local services and meeting individual needs.

##### **Winterbourne View- Time for change and Time is Running Out**

The Transforming Care next steps report was informed by the *Winterbourne View- Time for Change* (Acevo, 2014) in which NHS England asked Sir Stephen Bubb to make recommendations of a national commissioning framework for community based support for people with learning disabilities following the low levels of change actioned following the Winterbourne View scandal.

The independent review outlines two broad areas for change: firstly, putting in place community based support to safely discharge individuals currently in inpatient settings and secondly, supporting adults, young people and children in the community to prevent admissions. The recommendations covered strengthening rights, forcing the pace of commissioning, closure of inpatient institutions, building capacity in the community and holding people to account.

A second review, published six months after *Transforming care: next steps*, acknowledged that NHS England had made improving outcomes for people with learning disability a key strategic priority, but suggested that the pace of change had been too slow. The review identified two key areas where progress had been insufficient. Firstly, the issue of leadership with little being communicated to key stakeholders on how transformation will actually be achieved and a need to focus on equal partnership between providers, individuals and stakeholders. Secondly, despite promised closure programmes for inpatient services, little has been done to build capacity for community provision.

### **No voice unheard, no right ignored**

In March 2015, the government launched a consultation paper (DH, 2015) which sought views on strengthening the rights of people with learning disabilities, autism and mental health issues to enable them to live independently. The resulting government response (DH, 2015b) highlighted that while some progress towards the transforming care agenda had been made, this approach and the resulting health outcomes varied considerably across the country. It considered three phases which looked at early action to sustain current momentum, longer term changes including legislation and more radical solutions to longer term issues.

### **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.

An Enhanced Service (ES) is currently in place to support the provision of health checks. The Direct ES 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).

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## 1.5 HEALTH INEQUALITIES AMONGST PEOPLE WITH LEARNING DISABILITIES

Health inequalities are differences in health status between different groups of the population. A report by IHAL<sup>1</sup> 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.
- 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.

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<sup>1</sup> IHAL: Improving Health and Lives; Learning Disabilities Observatory

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 CHESHIRE AND MERSEYSIDE

### 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 an increased number of adults with learning disabilities and autism.
- *Gender:* Of those known to services, learning disability appears to be more prevalent amongst men.
- *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 disabilities (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.

### 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%
<b>Total</b>	<b>2.41%</b>	<b>1.62%</b>	<b>2.00%</b>

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)<sup>2</sup>.

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

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<sup>2</sup> 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)

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:

- Just under 16 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 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 Cheshire and Merseyside, 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
Wirral	33,016	104	38	1352	329
Liverpool city region	151,127	527	238	6,791	1,423
Cheshire East	33405	100.8	33.8	836.7	322.2
Cheshire West and Chester	31,453	98	34	977	309
Warrington	21,145	62	22	604	212
Cheshire and Warrington	86,003	260	89	2,417	844
Total Cheshire and Merseyside	237,130	787	327	9,208	2,267

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

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

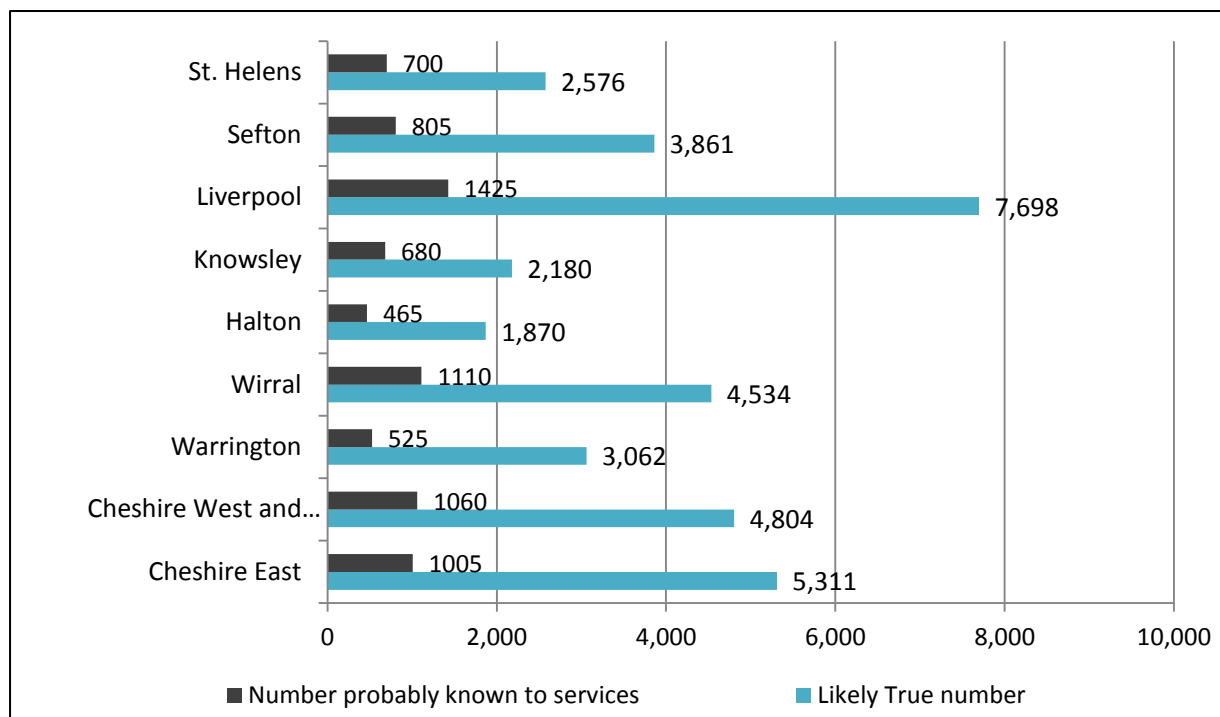
The severe learning difficulty category will not capture all those with learning disabilities. The moderate learning difficulty category is broad and will include many children with no learning disability. There is a need for data on the numbers of children with a learning disability.

### Adults

PANSI (Projecting Adult Needs and Service Information) have used Emerson and Hatton's (2004) paper to calculate estimate true prevalence of learning disability amongst adults for each local authority. Figure 1 compares these estimates for Cheshire and Merseyside with the number of adults known to each local authority taken from IHAL. Estimates relate to total learning disabilities (including mild, moderate and severe). The total numbers for Cheshire and Merseyside are 35,896 (estimated true prevalence) and 7,775 (number probably known to services) aged 18-64 years.

The estimates do not take into account local variations, so 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 Cheshire and Merseyside, there are relatively low proportions of people of South Asian origin.

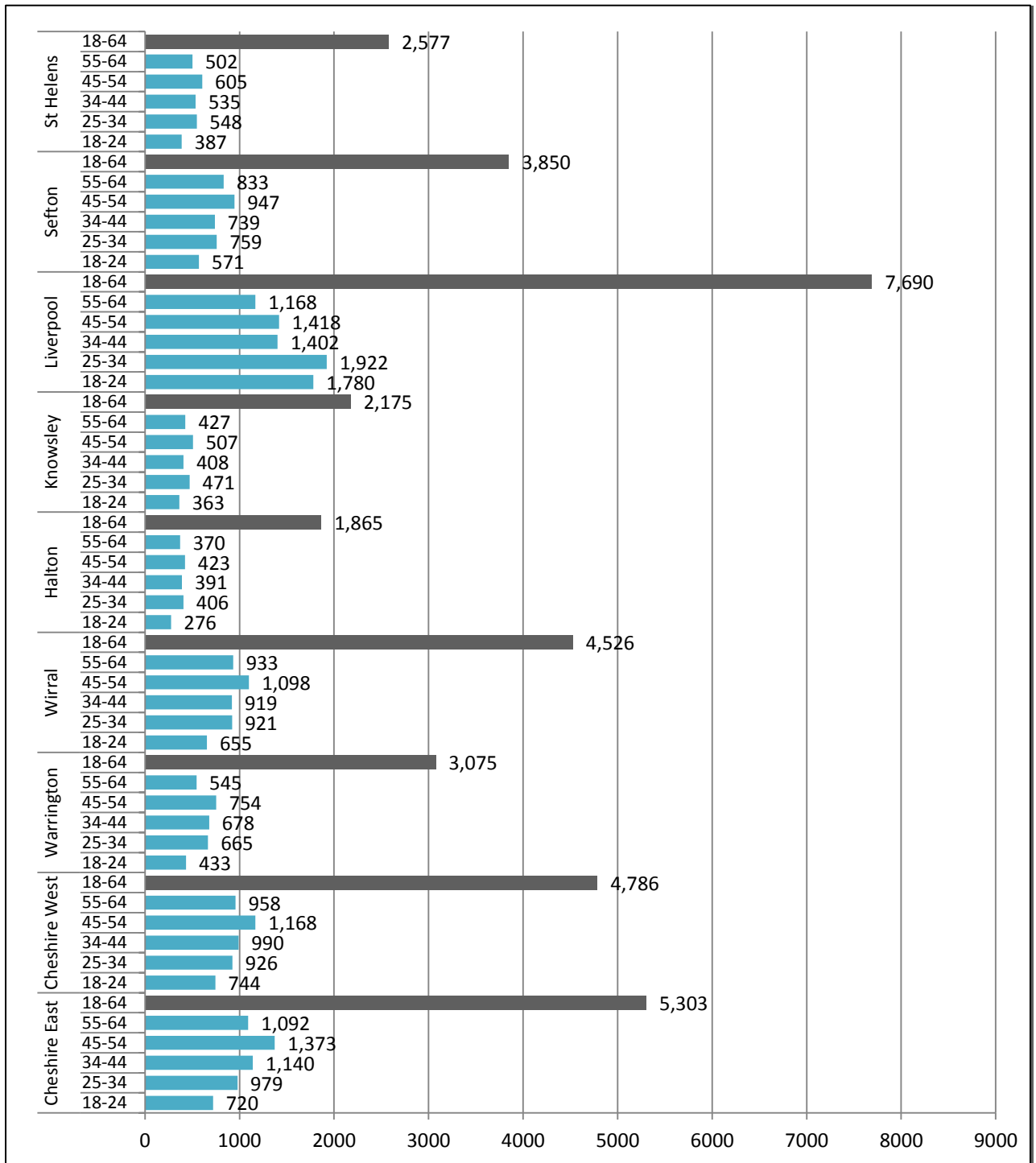
**Figure 1: Known prevalence and true prevalence estimates (numbers with learning disability age 18-64)**



Source: PANSI, 2015

Figure 2 shows the prevalence across Cheshire and Merseyside by 10 year age bands. In Liverpool, the proportion of people aged 25 and under estimated to have learning disabilities is relatively high (1,780). This reflects the high proportion in this age group amongst the general population in Liverpool (67, 297, 14%).

**Figure 2: Numbers of adults predicted to have a learning disability in Cheshire and Merseyside, by age group, 2015**

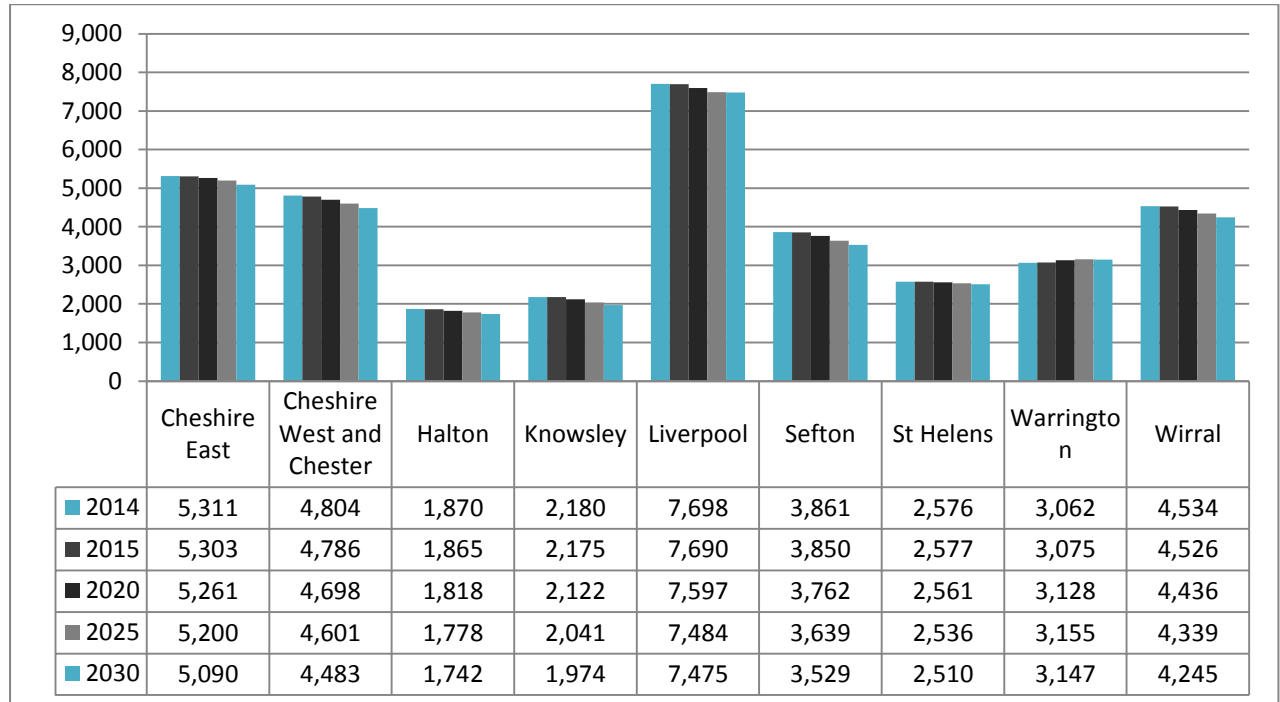


Source: PANSI-8

## PROJECTIONS

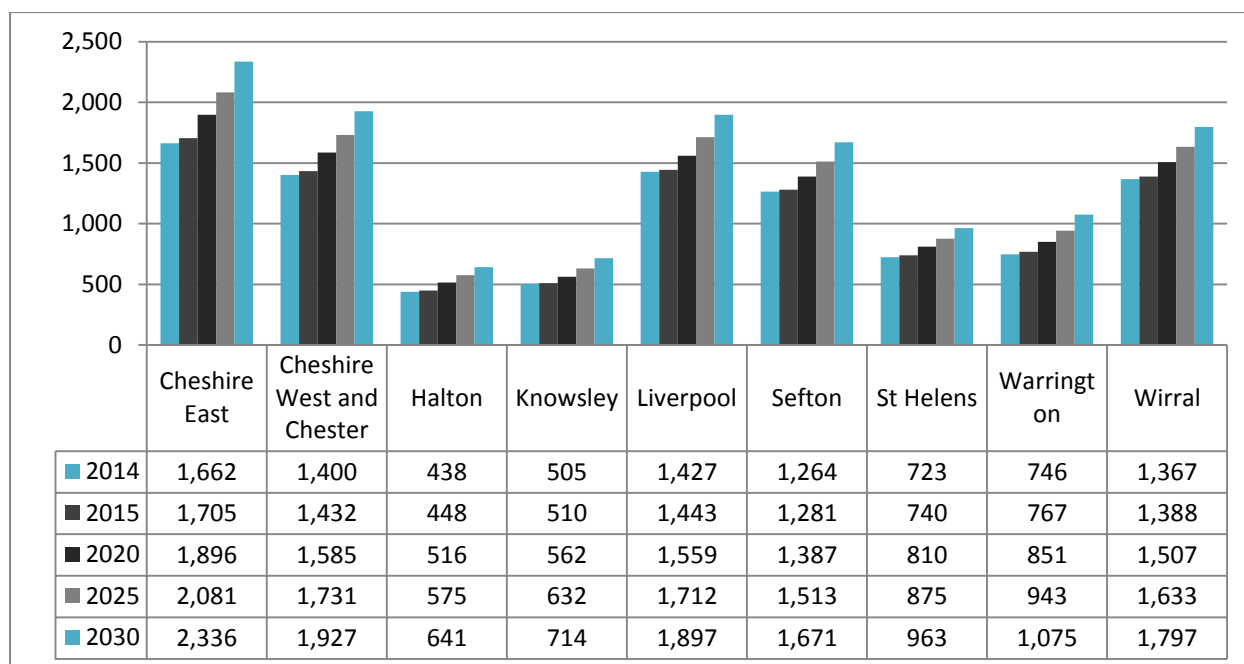
Projections of future numbers of people with learning disabilities are presented in the PANSI database. They are based on the prevalence rates in the report by Emerson and Hatton (2004) (see Table 2 above). Amongst those aged 18-64, the numbers with a learning disability are predicted to decrease slightly across all local authorities with the exception of Warrington where a small increase is predicted. Although the numbers in those aged 65 are considerably smaller (Figure 4) they are predicted to increase steadily for each local authority between 2014 and 2030.

**Figure 3: Projections to 2030 of numbers of people aged 18-64 predicted to have a learning disability**



Source: PANSI-8

**Figure 4: Projections to 2030 of people aged 65 years and over predicted to have a learning disability**



Source: POPPI-8

## 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.

### Cheshire and Merseyside

Table 4 shows numbers with moderate or severe learning disability for each local authority in Cheshire and Merseyside. 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 5,159 people with moderate and severe learning disability in Cheshire and Merseyside in 2013. The majority of this number (7775, 93%) were known to the local authority. In Warrington there were far fewer people known to services than would be expected from the estimated numbers (75%). Known numbers are also less than expected in an additional four local authorities (Liverpool, Sefton, Cheshire East and Cheshire West) whilst the remaining five local authorities had more people known to services than were estimated (see last column, Table 5).

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

<b>Local Authorities</b>	<b>2014</b>	<b>2015</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>
Halton	425	424	414	406	400
Knowsley	495	494	481	465	453
Liverpool	1,747	1,746	1,729	1,712	1,720
Sefton	876	873	853	827	809
St. Helens	586	586	582	578	576
Wirral	1,030	1,028	1,008	988	973
<b>Liverpool city region</b>	<b>5,159</b>	<b>5,151</b>	<b>5,067</b>	<b>4,976</b>	<b>4,931</b>
Cheshire East	1,210	1,208	1,197	1,184	1,165
Cheshire West and Chester	1,094	1,090	1,068	1,047	1,026
Warrington	698	701	713	721	723
<b>Cheshire</b>	<b>3,002</b>	<b>2,999</b>	<b>2,978</b>	<b>2,952</b>	<b>2,914</b>
<b>Cheshire and Merseyside total</b>	<b>8,161</b>	<b>8,150</b>	<b>8,045</b>	<b>7,928</b>	<b>7,845</b>

Source: PANSI-8

**Table 5: Numbers with learning disability known to Local Authorities age 18-64 years, 2013/14**

<b>Local Authority</b>	<b>2013/14</b>	<b>% predicted number</b>
Halton (321)	465	109.4
Knowsley (315)	680	137.4
Liverpool (316)	1425	81.6
Sefton (317)	805	91.9
St Helens (318)	700	119.5
Wirral (319)	1110	107.8
<b>Liverpool city region</b>	<b>5185</b>	<b>100.5</b>
Cheshire East	1005	83.1
Cheshire West And Chester (327)	1060	96.9
Warrington (322)	525	75.2
<b>Cheshire</b>	<b>2590</b>	<b>86.3</b>
<b>Cheshire and Merseyside</b>	<b>7775</b>	<b>95.3</b>

Source: NHS IC ASCCAR L2 (1<sup>st</sup> data column)

Table 6 shows future predicted numbers of those with severe learning disabilities. Between 2014 and 2030, numbers are expected to fall or remain constant in each local authority, with the exception of Warrington, where numbers are likely to rise from 184 in 2014 to 191 in 2030.



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

Local Authority	2014	2015	2020	2025	2030
Halton	112	112	109	107	106
Knowsley	131	130	127	123	121
Liverpool	477	476	469	465	469
Sefton	229	229	223	217	214
St. Helens	155	154	152	152	152
Wirral	270	270	263	259	257
Liverpool city region	1374	1371	1343	1323	1319
Cheshire East	316	315	310	308	306
Cheshire West and Chester	288	286	280	275	272
Warrington	184	184	186	189	191
Cheshire	788	785	776	772	769
Cheshire and Merseyside	2162	2156	2119	2095	2088

Source: PANSI-8

Numbers of those with profound multiple learning disabilities are smaller than those with severe learning disabilities. However, this group of people has particular needs and numbers, where available are presented below.

## 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

### 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*

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 so that decision makers understand what their needs are and plan appropriate services.

(Mencap 2013)

### Cheshire and Merseyside

There is no local data available on known numbers of adults and children with PMLD (only on children with profound and multiple learning *difficulties*). 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 shows the numbers of children aged between 7 to 15 expected to have profound and multiple learning difficulties in Cheshire and Merseyside. This is modelled data, calculated by IHAL, based partly on Spring term school census data. 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. Liverpool was the local authority with the highest rate of children with PMLD per 1,000 population (1.54) and the largest number of children (107).

**Table 7: Number of children aged 7-15 years expected to have profound and multiple learning difficulties, 2013/14**

Local Authority	Number of pupils	Number with profound and multiple learning difficulties	Rate per 1,000
Halton		*	*
Knowsley		*	*
Liverpool	69316	107	1.54
St. Helens	26385	30	1.14
Sefton		*	*
Wirral	50641	63	1.24
Warrington	31540	26	.82
Cheshire East	53708	63	1.17
Cheshire West and Chester	51070	55	1.08

Source: IHAL

Where rows are blank values have been suppressed by PHE for disclosure control due to a small count

Data from the annual school census, made available by Wirral for 2015, shows that there are less 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). The number reported by Warrington was slightly lower than the number predicted in table 7.

**Table 8 School Census data Pupils with PMLD with Statements and School Action Plus, 2015**

Local Authority	Number of children	
Wirral	Primary	53
	Secondary	5
	Total	58
Warrington	Total	24

Source: Local Authorities

### Adults

Despite the Department of Health call for local data (see Box 1 on previous page), local authority registers of learning disabilities 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 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. age 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.

### **Guidelines for people with Profound and Multiple Learning Disabilities**

Guidelines on the Care and Management of people with PMLD are summarised in the appendix

## 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 9 below shows data provided by Local Authorities on the numbers of children 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. Data for Liverpool was not available for 2015 so data from the previous needs assessment (2012 school census) has been included to give an indication of the numbers; however caution must be taken when comparing this data with other local authorities.

**Table 9: 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 2015	542	88	363	642

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

**Table 10: Pupils with Statements**

SEN Need Type	Moderate Learning Difficulty	Profound & Multiple Learning Difficulty	Severe Learning Difficulty	Specific Learning Difficulty
Warrington Jan 2015		24		
Wirral Jan 2015	329	50	359	231

Source: Warrington Borough Council, Wirral Borough Council; School Census

There is data available on learning disability amongst children from the Joint Health and Social Care Self-Assessment Framework (SAF); data from local authority level returns is summarised in table 11 below. Across Cheshire and Merseyside, 11% of people reported to the SAF were aged between 0 and 17 years. There was some variation in the proportion of 0-17 year olds across Local Authorities with the highest number seen in Sefton where just under one in five (19%) reported in the SAF were aged 17 years and under. The numbers reported by local authorities are considerably lower than the numbers of children predicted by IHAL to have learning difficulties (table 3).

**Table 11: Number of children (0-17 years) with learning disabilities, 2013**

	0-13 years	14-17 years	Total aged 0-17 years	Total population with LD reported	% of total population aged 0-17 years
Halton	26	29	55	732	8%
Knowsley	50	47	97	989	10%
Liverpool	144	131	275	2198	13%
Sefton	108	110	218	1152	19%
St Helens	65	49	114	929	12%
Wirral	91	93	184	1731	11%
Cheshire East	42	51	93	1100	8%
Cheshire West and Chester	48	46	94	1224	8%
Warrington	47	35	82	745	11%

Source: Joint Health and Social Care Needs Assessment, IHAL, 2013.

### **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 provide 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 2015/16 subject to data governance issues being met.

### **2014 Children and Families Act**

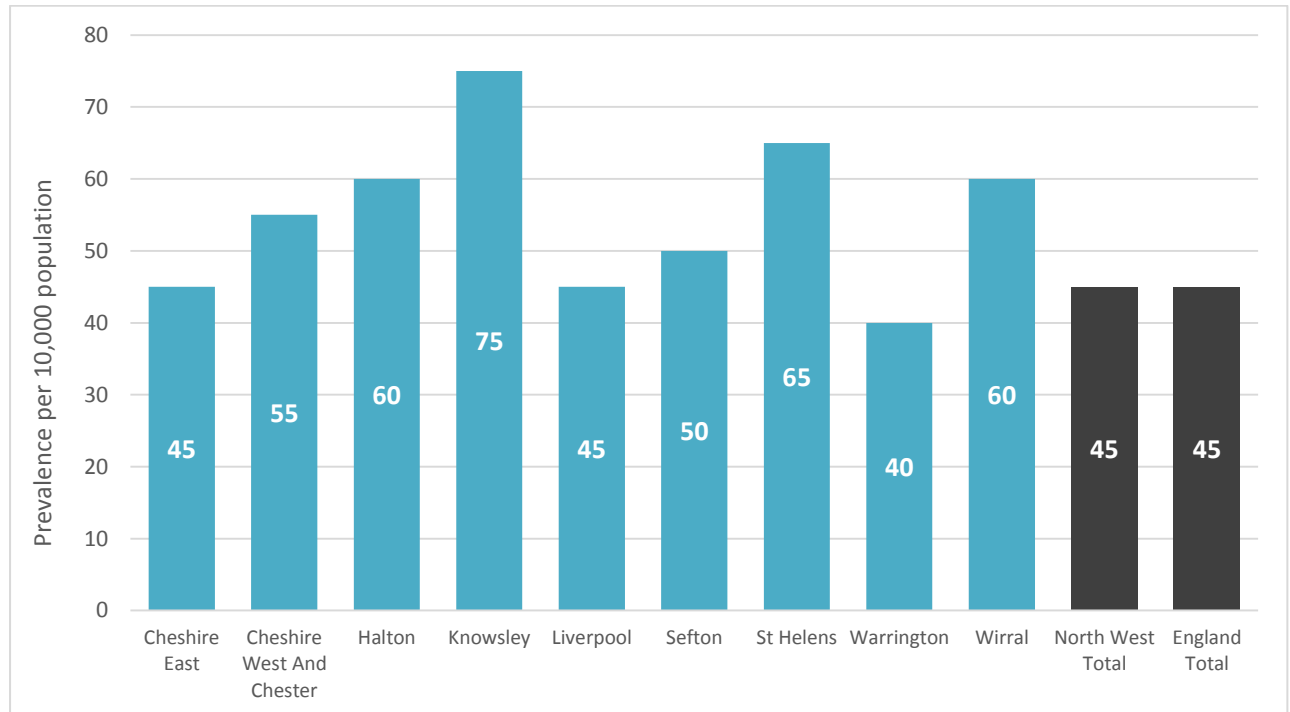
Following the passing of the Children and Families Act in 2014, SEN Statements and Learning Difficulty Assessments have been replaced by the 0 – 25 integrated Education, Health and Care Plan (EHC Plan) for individual children and young people with special educational needs and disabilities. EHC Plans cover young people with learning disabilities aged 0-25 years and have the same protection in law as SEN statements. The new arrangement should assist in ensuring that health service agreements (involving school nurses and health visitors) identifying those with learning disability and autism are built into tendering arrangements with schools and colleges. Data provided by local authorities for this needs assessment was mainly recorded by SEN and School Action plus but Wirral report on a small number of children with an EHC.

### **Adults 18-64**

Known prevalence data for ages 18-64 was obtained from the Adult Social Care Combined Activity Returns (ASCCAR, NHS Information Centre). Figure 5 shows the prevalence in each local authority per 10,000 general population (aged 18-64 years). Rates of learning disability are highest in Knowsley, at 70 per 10,000 population and lowest in Warrington, at 40 per 10,000 population. The numbers of people with learning disabilities known to local authorities in Cheshire and Merseyside is shown in Figure 6

below, with a total of 7,775 adults across the whole area (4,530 males and 3,240 females). The data relates to people of working age (18-64) and is broken down by sex.

**Figure 5: Prevalence of learning disabilities: People known to the local authorities as having a learning disability per 10,000 population aged 18-64, 2013/14**

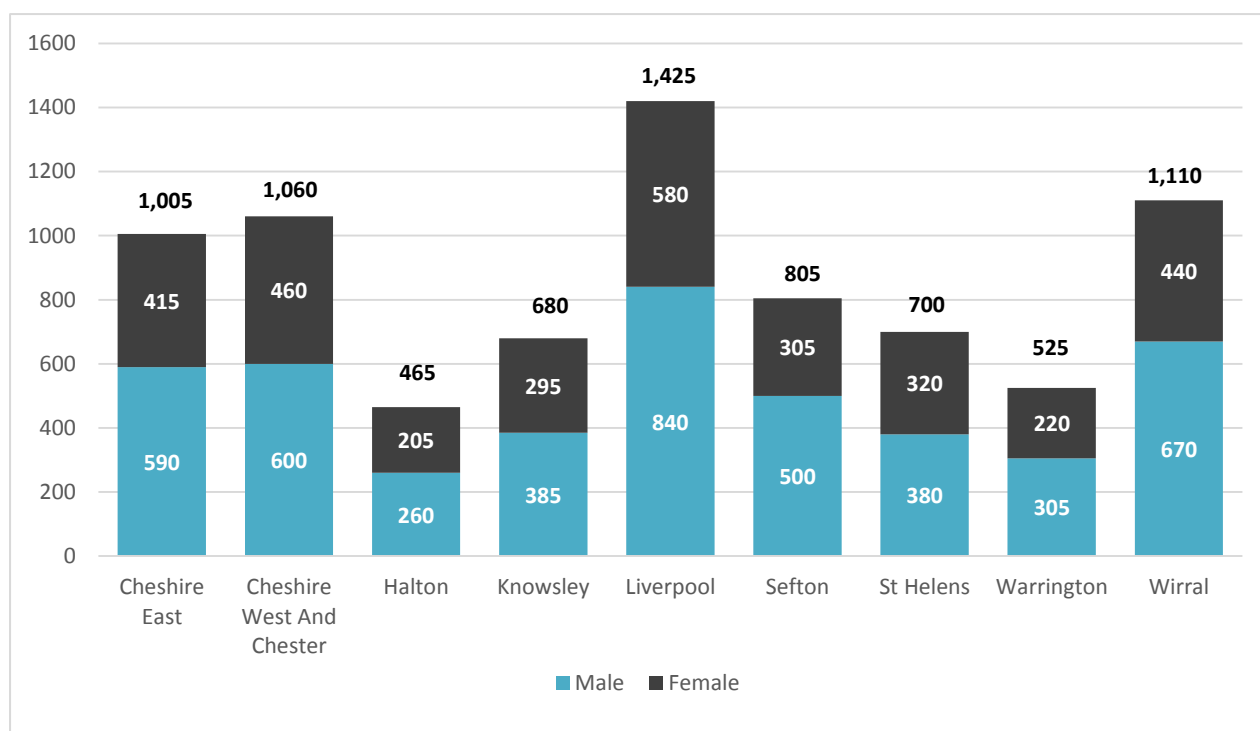


Source: NHS IC NASCIS, ASCCAR L2

### Gender

Of those known to services, learning disability appears to be more prevalent amongst men. Across Cheshire and Merseyside, the proportion of those with learning disabilities who are male ranges from 54% in St. Helens to 62% in Sefton (Figure 6). In 2013/14, 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: Number of people with learning disabilities known to Local Authorities, 2013/14**



	Male	Female
Cheshire East	59%	41%
Cheshire West And Chester	57%	43%
Halton	56%	44%
Knowsley	57%	43%
Liverpool	59%	41%
Sefton	62%	38%
St Helens	54%	46%
Warrington	58%	42%
Wirral	60%	40%
Cheshire and Merseyside	58%	42%
North West	58%	42%
England	58%	42%

Source: NHS IC NASCIS, ASCCAR L2

Data provided directly from Wirral Borough Council and taken from their Self-Assessment Framework (SAF) return in 2013/14, indicated that there were 1,470 people aged 18-64 with learning disabilities. This is higher than the 1,110 known to social services reported to the NHS Information Centre (ASCCAR) in 2013/14 (see Figure 6 above).

Similarly the number of people provided directly by Liverpool City Council reported 1,559 individuals with learning disabilities known to the local authority in 2015 which again is higher than the number reported in figure 6 (1,425 individuals).

Data provided by Sefton states there are 1,606 adults aged 18-64 which again is substantially higher than the 805 individuals reported to the HSCIC in figure 6.

In Warrington the numbers provided directly from the local authority were also slightly higher than the number reported in figure 6 at 573 compared with 525.

Conversely, data provided by Cheshire West and Chester council and supplied directly from their information system reports that there were 852 adults with learning disabilities known to the local authority which is less than the 1,060 individuals reported to the HSCIC in 2013/14 (figure 6). The data provided by the local authority is based on the ASCOF rules which count only those receiving a service for a learning disability and this may account for some of this difference.

The number provided by St Helens for 2014/15 states that 682 adults aged 16-84 years with learning disabilities are known to the local authority which is slightly lower than number reported to the HSCIC in figure 6.

### Ages 65+

Data for those aged 65 and over with learning disabilities is not available from the Adult Social Care Combined Activity Returns (ASCCAR, NHS Information Centre); however data on the number known to each partnership board is reported to the Joint Health and Social Care Self-Assessment Framework (SAF) and data from the 2013 SAF is included in table 11 below. The prevalence of learning disabilities in adults aged 65 years and over was highest in Knowsley (36.9 per 10,000) and lowest in Cheshire East (13.6 per 10,000 population). The overall prevalence of learning disabilities in Cheshire and Merseyside among older adults was 19.7 per 10,000.

**Table 11: Prevalence of learning disabilities in older adults (aged 65 years and over)**

	Adults with LD aged 65 plus	Total population aged 65 plus	Prevalence per 10,000 population
Halton	52	21013	24.7
Knowsley	90	24365	36.9
Liverpool	205	69305	29.6
Sefton	104	61153	17.0
St Helens	59	34845	16.9
Wirral	128	65998	19.4
Cheshire East	112	80564	13.9
Cheshire West and Chester	112	67564	16.6
Warrington	48	36066	13.3
Cheshire and Merseyside Total	910	460873	19.7

Source: Joint Health and Social Care SAF, IHAL, 2013 and ONS mid-2014 population estimates.

Data provided directly from Liverpool local authority reports 205 individuals with learning disabilities aged over 65 years of which 72% are aged between 65 and 74 years, 23% are aged between 75 and 84 years and 5% are aged 85 years and over.

Data provided directly from Sefton reports 249 adults aged 65 years and older known to the local authority which is considerably higher than the number reported to the SAF in table 11 above.

Data provided directly by St Helens reports 35 individuals aged 65-84 which is lower than the 59 reported to the SAF in table 14.



Warrington data reports 37 individuals known to the local authority aged 65 years and over of which 95% were aged between 65 and 74 years. This is again lower than the number reported in the SAF in table 14.

Data provided by Wirral on adults with learning disabilities aged 65 years and over for 2013/14 is slightly higher (148 individuals) than the number reported in the 2013 SAF (128 individuals, table 14) and this number has increased to 163 in 2014/15.

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### 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 Enhanced Service (ES) has been extended for 2015/16 to allow practices to offer medicals to patients (aged 14 years and older) and requires practices to produce a health action plan. Establishing and maintaining the GP Learning Disability Register is part of the 2015-16 Quality and Outcomes Framework (QOF) dataset.

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).

#### *Cheshire and Merseyside*

Table 15 shows that across Cheshire and Merseyside in 2014-15, levels of learning disability recorded in general practice were equal or higher than the national average of 0.44% in eight out of 12 CCGs. The four CCGs with a prevalence below 0.44% were all in Cheshire namely: East Cheshire, South Cheshire, West Cheshire and Warrington. Levels were highest in Knowsley and Halton, at 0.63% of the total practice population aged 18 plus in both CCGs.

As would be expected, levels and patterns are similar to local authority learning disability register data, where percentages were highest in Knowsley (0.75 %) and lowest in Warrington (0.40%) (see Section 2.2, Figure 5).

Table 12 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 2.11% in one practice. In the other 18 practices, the proportion on the register varies from 0.15% to 1.05%. In Liverpool, the prevalence in one practice was 1.52%, with the rest ranging from 0.06% to 1.40%.

**Table 12: Number and percentage on the GP Learning Disability Register, and range of learning disability (LD) prevalence across practices, 2014-15, ages 18+**

CCG Name	Estimated List Size 18+	Learning Disability Register	Prevalence Rate (per cent)	Lowest practice prevalence	Highest practice prevalence
NHS EASTERN CHESHIRE CCG	165,944	635	0.31	0.06	0.66
NHS SOUTH CHESHIRE CCG	143,009	614	0.34	0.11	0.83
NHS VALE ROYAL CCG	81,631	448	0.44	0.25	0.68
NHS WARRINGTON CCG	168,431	838	0.39	0.11	0.71
NHS WEST CHESHIRE CCG	209,906	939	0.36	0.09	0.88
NHS WIRRAL CCG	265,696	1,909	0.57	0.15	1.37
NHS HALTON CCG	100,147	802	0.63	0.2	0.87
NHS KNOWSLEY CCG	127,066	1,019	0.63	0.29	1.21
NHS SOUTH SEFTON CCG	119,067	654	0.44	0.11	1.01
NHS SOUTHPORT AND FORMBY CCG	101,119	749	0.61	0.15	2.11
NHS ST HELENS CCG	152,668	937	0.49	0.16	0.9
NHS LIVERPOOL CCG	409,607	2,468	0.49	0.06	1.52

Source: NHS IC QOF

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 Liverpool there are 2,468 people on the GP learning disability registered compared with 1,425 on the local authority register. Similarly Wirral GP register data reports 1,909 adults with learning disabilities compared with 1,110 on the Local Authority register.

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.

GP data was obtained for Wirral for 2014/15 which includes ethnic group. There were 23 people on the GP learning disability register from a minority ethnic group. This dataset also included numbers with learning disability by age groups 0-13; 14-18; 19-25; 26-64 and 65+ which is provided in table 13 below. This data is available because Wirral has 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 13: Wirral: Numbers on the GP learning disability register by age group**

Age group	Number of people with a Learning Disability	
	2013/14	2014/15
0-13 inclusive	144	180
14-17 inclusive	90	113
18-34 inclusive	563	706
35-64 inclusive	907	999
65+	148	163

**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).

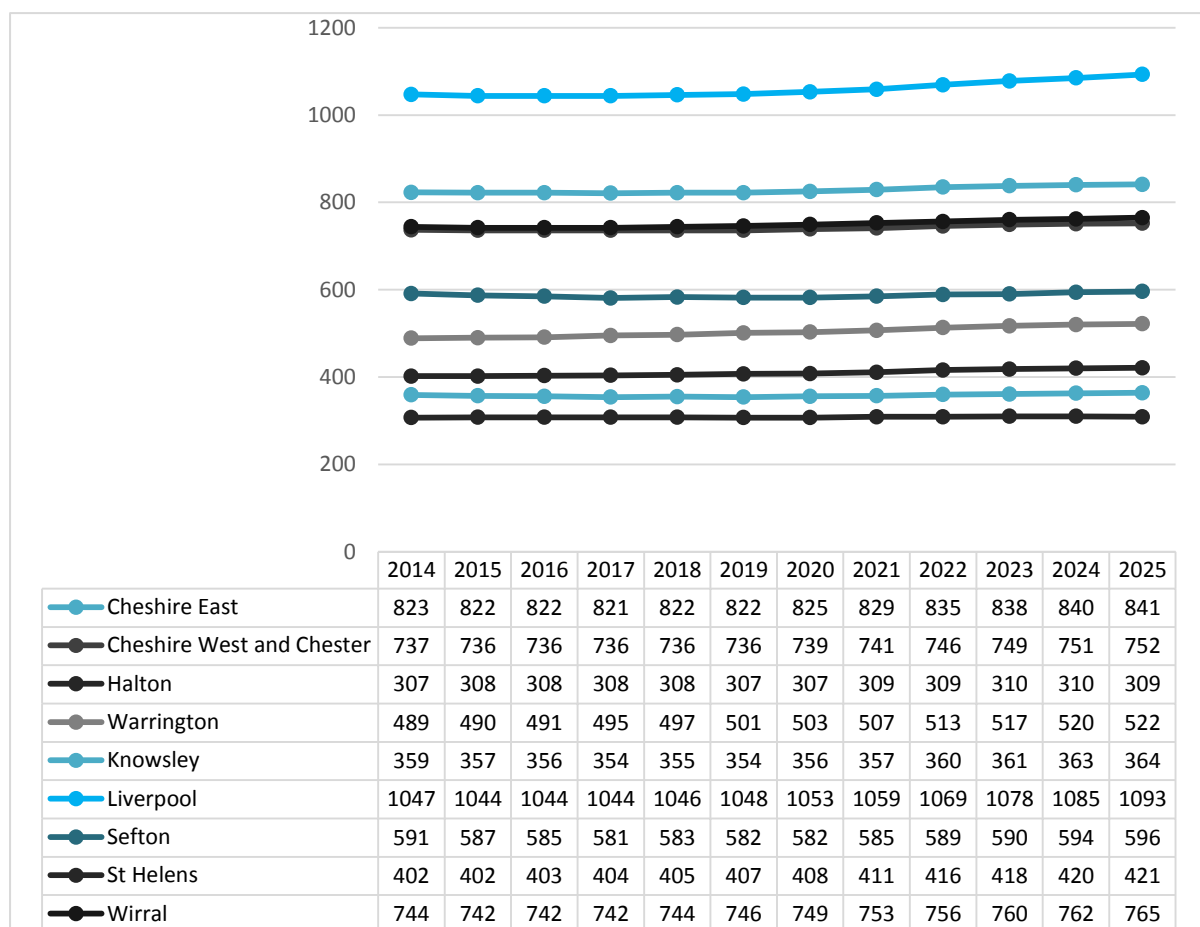
The European Commission (2005) highlights the problems associated with establishing prevalence rates for ASDs. These include inconsistencies of definition over time and between locations. Unlike learning disabilities, there is no register held by general practice. However, using data from prevalence 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 Cheshire and Merseyside, projected to 2025. In 2015, there were 5,488 children predicted to have autism. Numbers are set to rise slightly in each local authority across the region. By 2025, projections indicate that there will be 5,663 children with ASD across Cheshire and Merseyside.

**Figure 7: Projected estimates of numbers of children with ASD, 2014 to 2025**



Based on 1% prevalence estimate applied to 2012 population projections (ONS, 2014)

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 above, even those with autism who are intellectually able may still require support to help them to overcome communication difficulties.

**Known prevalence:** Data on the number of school pupils with statements or school action plus for ASD is recorded in the school census which is published in the special educational needs dataset by the department of education (table 14).

**Table 14: Pupils with ASD as primary special educational need (SEN), 2015**

	Autistic Spectrum Disorder	
	Number	% of all children with a statement of need
Cheshire East	17	6.0
Cheshire West and Chester	241	29.1
Halton	129	44.6
Knowsley	127	31.1
Liverpool	322	25.3
Sefton	233	41.4
St. Helens	156	39.4
Warrington	89	30.2
Wirral	210	20.9

*School census published in Special Educational Needs in England, 2015, DoFE*

Data on pupils with ASD was provided directly by just two local authorities. The Warrington 2015 census found that there were 315 pupils with ASD with statements. In Wirral there were 850 school children known to have ASD of which 132 had School Action Plus, 494 had a statement, 10 had an Education, Health and Care Plan. Overall 1.4% of school pupils were known to have ASD and 16% of children with statements or school action plus were known to have ASD. The data from both local authorities was considerably higher than the number published by the Department of Education but this may in part be because this data only publishes information based on primary SEN.

#### **ASD in adults:**

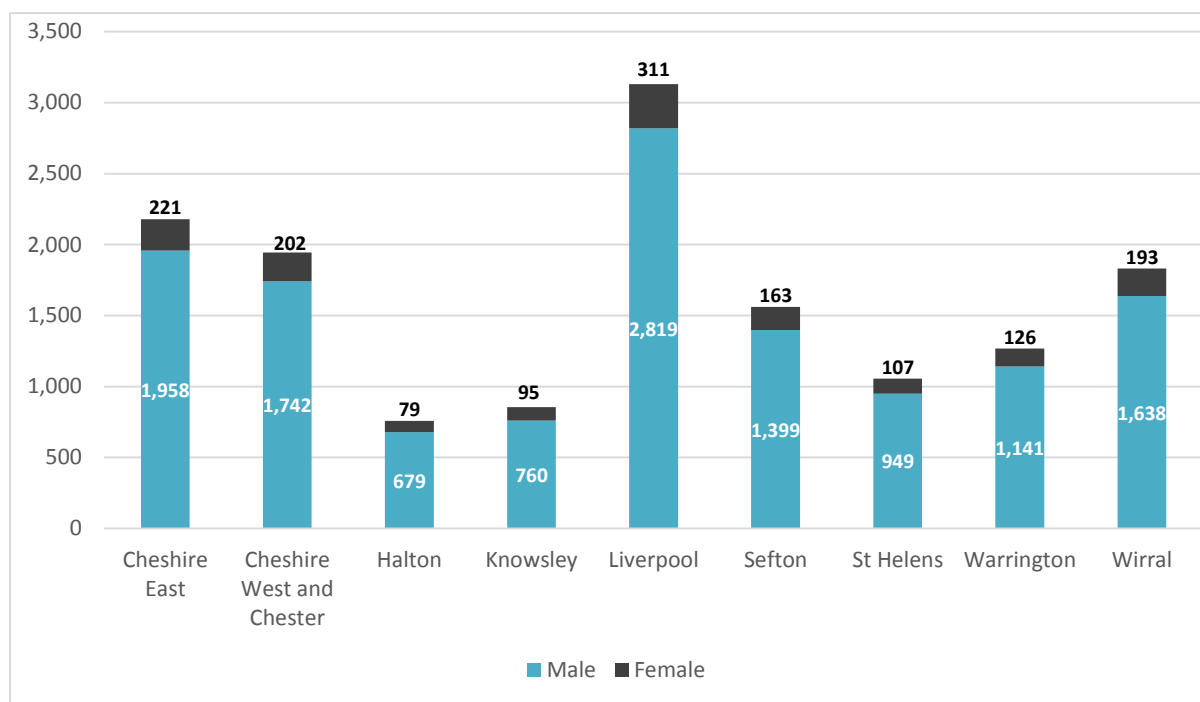
An assessment of the issues arising from completion of the local authority autism self-assessment framework in 2011 was undertaken (Roberts et al, 2012a). Issues included the identification of a major gap in local information about people with autism, such as the number of people with autism, and what 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 Cheshire and Merseyside, with 1,497 females and 13,085 males (14,582 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).

**Figure 8: Males and Females predicted to have an Autism Spectrum Disorder (ASD)**



Source PANSI, 2015

*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 **858** adults known to services with autism including **222** aged **65+**. This is substantially higher than the numbers provided in the previous needs assessment suggesting that these numbers may be based on projections rather than the numbers known to the LA.

Data obtained from **Cheshire West and Chester** reported that there were 65 people with autism. This is considerably lower than the number projected in figure 8 but the Local Authority acknowledged that this number is likely to be an underestimation due to data categorisation from health services.

Self-Assessment Framework data from South Sefton for 2014 indicated that there were 205 adults aged 18+ with learning disabilities who also had autism and were known to general practice.

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. 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

The Joint Adult and Social Care Self-Assessment Framework (SAF) shows the numbers of individuals having both learning disability and autism (Table 15). Amongst adults with learning disabilities, between 5% and 16% also had a diagnosis of autism.

**Table 15: Number of adults with Learning Disability and ASD, 2013**

	Number of people with Learning Disability and ASD	Total people with learning disability	%
Halton UA	54	732	7%
Knowsley	114	989	12%
Liverpool	101	2198	5%
St Helens	56	1152	5%
Sefton	135	929	15%
Wirral*		1731	
Warrington UA	121	745	16%
Cheshire East UA	81	1100	7%
Cheshire West And Chester UA*		1224	

Source: Joint Adult and Social Care Self-Assessment Framework, IHAL, 2013 \*Data field not completed

## 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](http://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. GP data is coded for Asperger's but this data was not readily available. Data from two providers reported around 580 people with Asperger's on their caseload for 2015.

In Cheshire and Merseyside there are two specialist Asperger's teams based in Liverpool and Sefton. Many other local authorities in the country do not have such support available. However, these teams do not deal with people who have Asperger's with a learning disability; these individuals would be the responsibility of the learning disability team so these numbers are likely to underreport both the number of individuals with Asperger's known to services and the number in the overall population.



In 2015, there were a total of 302 people on the Liverpool and Sefton Asperger's Team caseload of which 62% were resident in Liverpool CCG, 21% were resident in Southport and Formby CCG and 16% in South Sefton CCG. There were 123 referrals to the two specialist Asperger's Teams in 2015.

Cheshire and Wirral Partnership also provided data on the number of individuals with a primary or secondary diagnosis of Asperger's. There were 288 people with Asperger's who had contact with the service in 2015 of which 19 also had a diagnosis of learning disability. The majority of adults with learning disability were resident in Wirral CCG (43%).

Table 16 below shows the number of people with Asperger's accessing Mersey Care and Cheshire and Wirral Partnership (CWP) in 2015. The total number for each service is lower than the totals given above as both services have a small proportion of individuals accessing from outside of Cheshire and Merseyside. It is also possible that the totals given could represent some double counting if any individuals have moved across the two services during the year. Data from 5 Borough Partnership was not available at the time of publication and so the numbers for Knowsley, Halton, St Helens and Warrington are likely to be much lower than the numbers actually known to services.

**Table 16: Individuals with Asperger's known to services, 2015**

	Mersey Care	CWP	Total
NHS EASTERN CHESHIRE CCG		40	40
NHS SOUTH CHESHIRE CCG		33	33
NHS VALE ROYAL CCG		12	12
NHS WARRINGTON CCG		<5	<5
NHS WEST CHESHIRE CCG		40	40
NHS WIRRAL CCG		125	125
NHS HALTON CCG		<5	<5
NHS KNOWSLEY CCG	<5		<5
NHS SOUTH SEFTON CCG	47	<5	<50
NHS SOUTHPORT AND FORMBY CCG	63		63
NHS ST HELENS CCG		<5	<5
NHS LIVERPOOL CCG	188	13	201

*Source: Mersey Care and Cheshire and Wirral Partnership*

### **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. 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 disabilities, 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 disabilities (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 disabilities had higher rates of seizures (NHS IC, 2010). It was noted that patients with learning disabilities 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.

## MERSEYSIDE AND NORTH CHESHIRE DATA ON BURDEN OF DISEASE 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 data provided by local authorities and LDSAF information does demonstrate some consistency with the findings of national research described above. BMI and obesity is the only measure provided by all the LAs that includes a rate as well as an absolute number. For comparison the England average of percent of adults with a BMI over 30 and therefore classed as obese is 24% (PHE 2015).

### Cheshire East

Cheshire East provided some information on other health conditions on their LDSAF returns. No total figure or number of people with learning disability was provided on the LDSAF so it is not possible to display prevalence data. The data shows that in Cheshire East over a third of people with a learning disability are obese and the most common health condition is epilepsy.

**Table 17: Other health conditions for people with a learning disability in Cheshire East**

Health condition	Number of people (% where appropriate)
BMI recorded	705
BMI over 30	242 (34%)
BMI less than 18.5	6 (1%)
Coronary Heart Disease	8
Diabetes (type 1 & 11)	47
Asthma	78
Dysphagia	195
Epilepsy	247

Source: LDSAF return 2014.

### Cheshire West and Chester

Cheshire West and Chester were unable to provide data on the total number of people with learning disabilities so it is not possible to display prevalence. Over a third (39.2%) of people with learning disabilities are obese and the most common health condition is epilepsy.

**Table 18: Other health condition for people with a learning disability in Cheshire West and Chester**

Health condition	Number of people (% where appropriate)
BMI recorded	278
BMI over 30	109 (39.2%)
BMI less than 18.5	0
Coronary Heart Disease	-
Diabetes (type 1 & 11)	21
Asthma	54
Dysphagia	71
Epilepsy	96

Source: LDSAF return 2014.

Cheshire West and Chester provided some additional data on health conditions of people with learning disabilities living in the LA displayed in table 21.

**Table 19: Other health conditions for people with a learning disability in Cheshire West and Chester**

No of Health conditions	No of People	Learning, Development or Intellectual Disability	Long-Term Health Condition - Neurological	Long-Term Health Condition - Physical	Mental Health Condition	Sensory Impairment	No Relevant Long-Term Health Conditions
1	586	530	17	16	17	5	4
2	128	127	31	59	29	10	0
3	30	30	19	24	6	10	1
4	6	6	5	6	2	5	0

Source: provided by CWaC local authority

## Halton

Halton also provided some information on other health conditions on their LDSAF returns. A total of 774 people with learning disability was provided in the LDSAF so it has been possible to display prevalence data. The data shows that in Halton over half of people with a learning disability are obese and the most common health condition is epilepsy (19.6%).

**Table 20. Other health conditions for people with a learning disability in Halton**

Health condition	Number of people	% of patients with LD
BMI recorded	541	
BMI over 30	272	50.3
BMI less than 18.5	26	4.8
Coronary Heart Disease	13	1.7
Diabetes (type 1 & 11)	60	7.8
Asthma	70	9.0
Dysphagia	49	6.3
Epilepsy	152	19.6

## Knowsley

The only information available from Knowsley on other health conditions was included in their Joint Health and Social Care Learning Disabilities Self-Assessment Framework return (2014). Knowsley were unable to provide data on the total number of people with learning disabilities so it is not possible to display prevalence. Over half of the people with learning disabilities within Knowsley (for whom a BMI was recorded) were obese.

**Table 21: Other health conditions for people with a learning disability in Knowsley**

Health condition	No. people (% where appropriate)
BMI Recorded	795
BMI over 30	427 (53.7%)
BMI less than 18.5	24 (3%)
Coronary Heart Disease	12
Diabetes (type 1 & 11)	93
Asthma	81
Dysphagia	110
Epilepsy	226

Source Knowsley LDSAF

## Liverpool

The information available from Liverpool on other health conditions was included in their Joint Health and Social Care Learning Disabilities Self-Assessment Framework return (2014). Liverpool reported there were a total of 2326 people with learning disabilities in the area. Forty-two percent of people (for whom a BMI was recorded) were over obese and 17% of people with a learning disability also have epilepsy.

**Table 22: Other health conditions for people with a learning disability in Liverpool**

Health condition	No. people known	% of patients with LD
BMI recorded	1403	
BMI over 30	590	42%
BMI less than 18.5	66	4.7%
Coronary Heart Disease	178	7.7%
Diabetes (type 1 & 11)	167	7.2%
Asthma	155	6.7%
Dysphagia	98	4.2%
Epilepsy	406	17.5%

Source: Liverpool LDSAF

## Sefton

The information available from Sefton on other health conditions was included in their Joint Health and Social Care Learning Disabilities Self-Assessment Framework return (2014). Total number of patients with learning disabilities was unclear from the return so prevalence is not provided. Almost half (45%) of patients are obese and a high number have epilepsy.

**Table 23: Other health conditions for people with a learning disability in Sefton**

Health condition	No. people (% where appropriate)
<b>BMI recorded</b>	<b>1255</b>
<b>BMI over 30</b>	568 (45.2%)
<b>BMI less than 18.5</b>	86 (6.9%)
<b>Coronary Heart Disease</b>	35
<b>Diabetes (type 1 &amp; 11)</b>	121
<b>Asthma</b>	329
<b>Dysphagia</b>	28
<b>Epilepsy</b>	378

Sefton LDSAF return (2014)

### St Helens

The information available from St Helens on other health conditions was included in their Joint Health and Social Care Learning Disabilities Self-Assessment Framework return (2014). They reported a total of 944 patients in with a learning disability so prevalence is provided in table 24 below. Over half of the patients with a BMI recorded were obese and a fifth have epilepsy.

**Table 24: Other health conditions for people with a learning disability in St Helens**

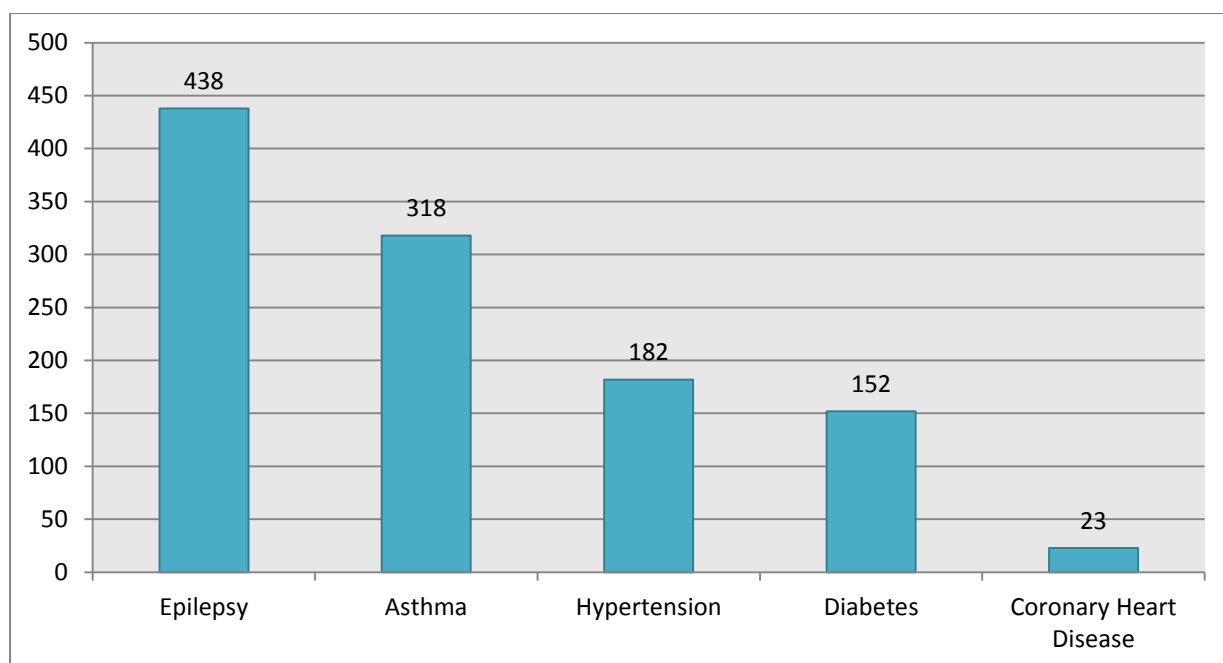
Health condition	No of people	% of patients with LD
Patients with BMI recorded	551	
BMI Over 30	284	51.5%
BMI Under 18.5	31	5.6%
CHD	8	0.8%
Diabetes	54	5.7%
Asthma	112	11.9%
Dysphagia	30	3.2%
Epilepsy	194	20.6%

St Helens LDSAF return (2014)

### Wirral

Wirral provided some additional information on the health profile of patients with learning disabilities registered at Wirral GP practice. The most common long term conditions for people with learning disabilities was epilepsy (20% of the learning disability register). High numbers of patients were overweight or obese and a fifth of the patients with a learning disability also had epilepsy.

**Figure 9: Learning disability patients with long term conditions in Wirral**



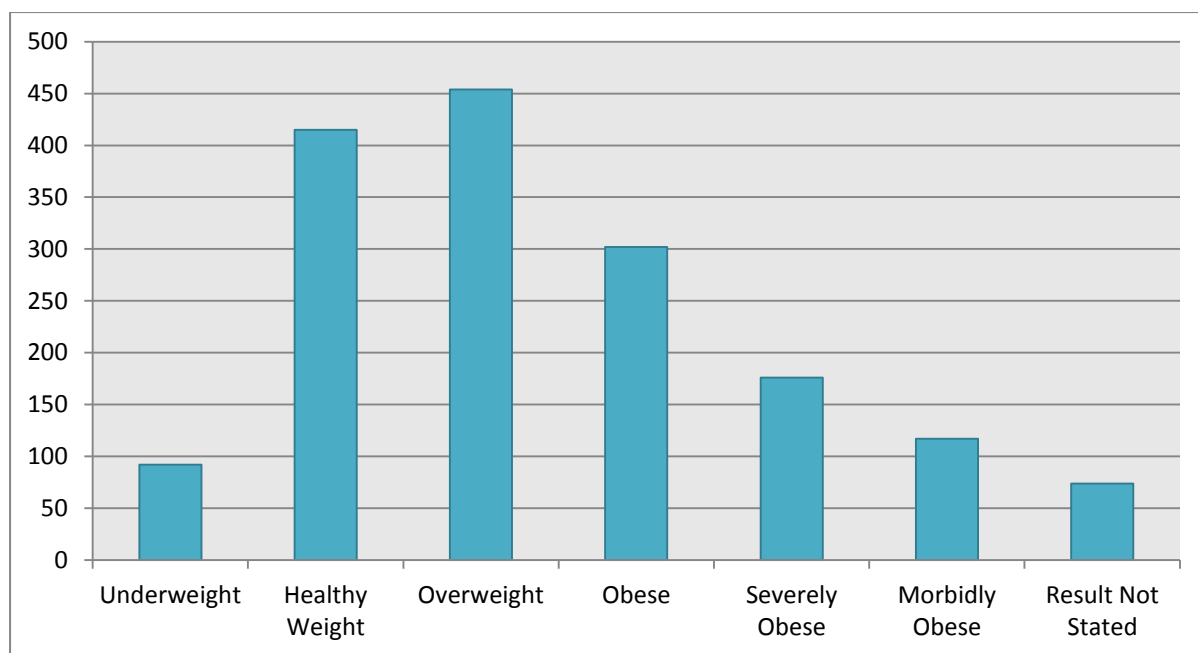
Source: Wirral Local Authority and CCG

**Table 25: Other health conditions for people with a learning disability in Wirral**

Condition	Number of LD Patients	% of patients with LD
Epilepsy	438	20
Asthma	318	15
Hypertension	182	8
Diabetes	152	7
Coronary Heart Disease	23	1

Source: Wirral Local Authority and CCG

**Figure 10: BMI Monitoring of patients with LD (aged 18+) Wirral**



Source: data provided by Wirral LA

#### **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](http://www.easyhealth.org) and [www.apictureofhealth.southwest.nhs.uk](http://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](http://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 disabilities 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).

In 2006, the Disability Rights Commission recommended the introduction of annual health checks for those with learning disabilities, 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 introduced in 2008-2009 it has been subsequently extended each year, most recently up until March 2015 (PHE (2014) The Uptake of Learning Disability Health Checks 2013 to 2014).

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).

It is not compulsory for GP practices to conduct the learning disability health checks and they can choose to opt-in or opt-out of the scheme. Checks should be undertaken by an appropriately trained provider and based on a protocol that included:

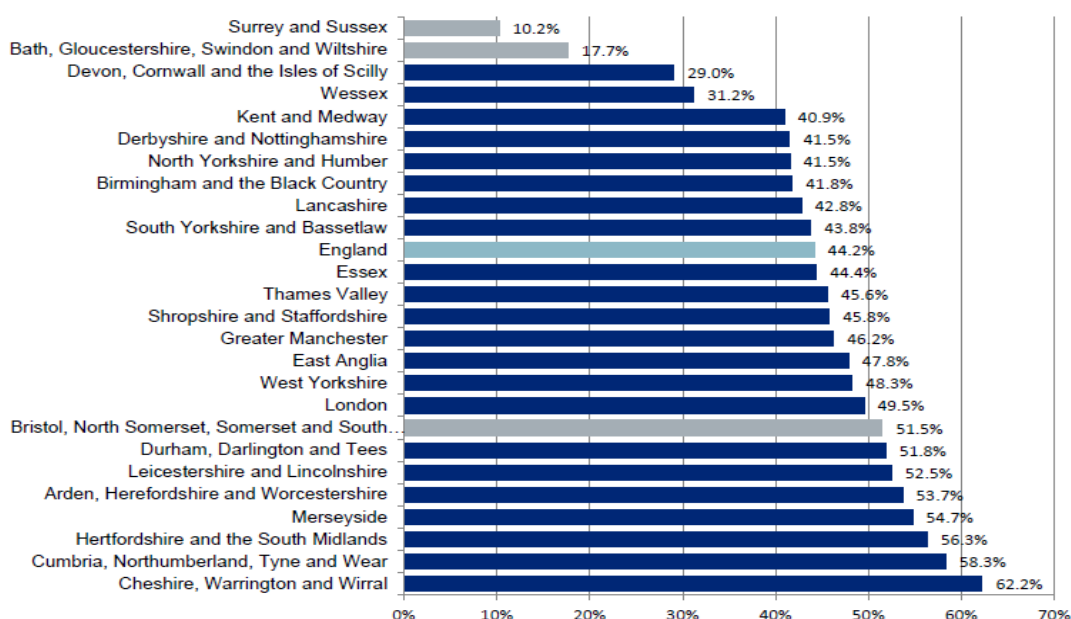
- a review of physical and mental health with referral through the usual practice routes if health problems are identified including:
- health promotion
- long-term illness and systems enquiry
- physical examination
- epilepsy
- dysphagia
- behaviour and mental health
- a specific syndrome check
- a check on the accuracy of prescribed medications
- a review of coordination arrangements with secondary care
- a review of transition arrangements where appropriate (PHE, 2014)

NICE (2015) recommends using a standardised template, such as the Cardiff health check questionnaire (RCGP 2010) to structure health checks.

### Local data

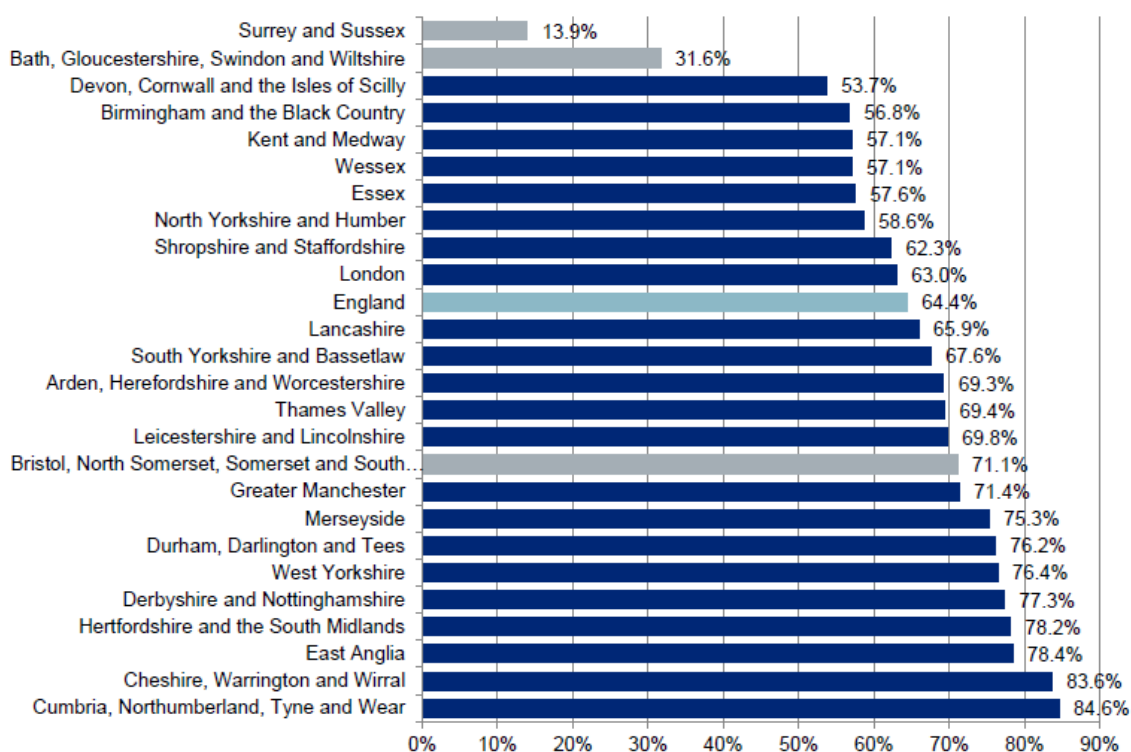
Nationally in England, of those known to either the GP or social services as having a learning disability, less than half (44.2%) had a health check during 2013-2014 (PHE 2014, figure 11) Merseyside (54.7%), Cheshire, Warrington and Wirral (62.2%) had coverage of health checks higher than the England average. In England 2013-2014 on average 64.4% of GP practices participated in the health checks scheme; this proportion was higher in Merseyside (75.3%) and Cheshire, Warrington and Wirral (83.6%) (PHE 2014, figure 11)

**Figure 11: Coverage by QOF of learning disability health checks for NHS England area teams, 2013 to 2014.**



Source: PHE, 2014

**Figure 12. Practice participation in learning disability health check scheme, NHS England Areas Teams, 2013 to 2014**



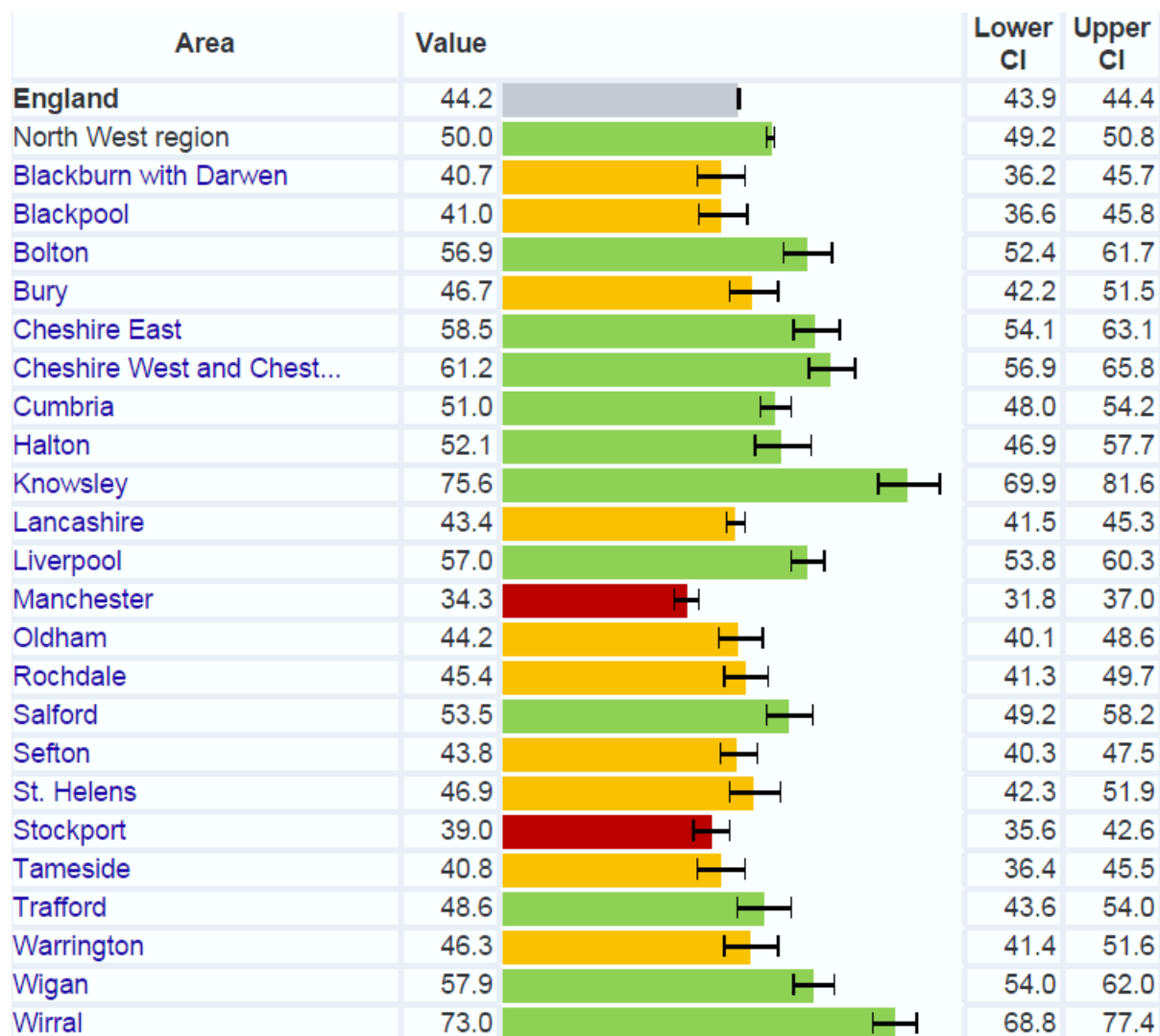
Source: PHE, 2014

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.). 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 CCGs through GPs, to ensure that people with learning disabilities receive a reasonable acceptable standard of primary medical care (Glover et al, 2012).

Data on health checks by local authority showed seven of the Cheshire and Merseyside areas were performing better than the England average with Knowsley having the highest coverage on health checks in 2014 (75.6%). Warrington had the lowest; however, this was still similar coverage to the England average at 46.3% (see figure 13a). Since the publication of this data, work has been undertaken locally to improve the uptake of health checks through a designated learning disability nurse. Data on health check uptake at the CCG level is also provided in figure 13b. Health Check uptake is lowest in South Cheshire CCG (34.4%); this low coverage is not evident at local authority level because of the high uptake in Eastern Cheshire (81.1%).

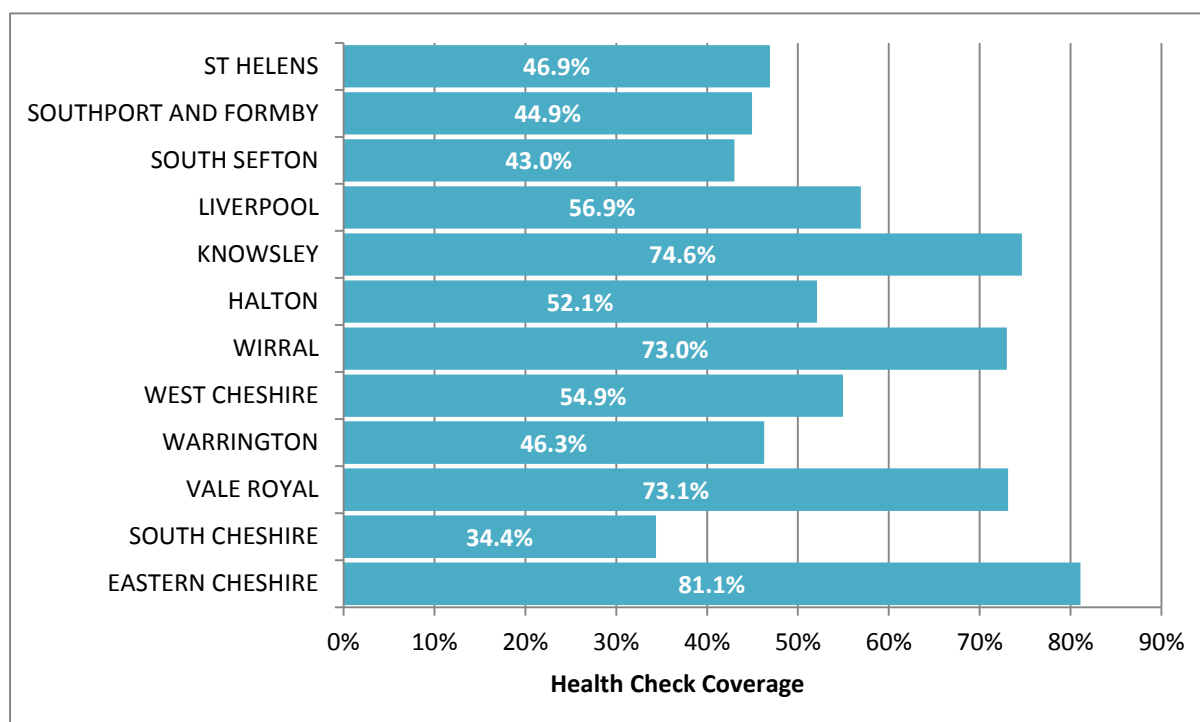
**Figure 13a: Proportion (%) of eligible adults with a learning disability having a GP health check by Local Authority 2013/14**



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

Source: PHE Learning Disability Profiles, 2014

**Figure 13b: Proportion (%) of eligible adults with a learning disability having a GP health check by CCG 2013/14**



Source: IHAL, 2014

### 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).

The data from Joint Health and Social Care Self-Assessment Framework in 2014 shows significant variation in participation rates across the three cancer screening programmes. The bowel screening programme had the highest national uptake, with 41.6% of people with learning disabilities having been screened (up from 28.1% in 2012/13). This is compared with 50.4% coverage for the general population. Breast cancer screening had the second highest coverage for people with learning disabilities, with 39.0% of women with learning disabilities being screened compared to 55.9% of the general population. Cervical screening uptake was the lowest with only 29% of women with learning disabilities having cervical smears compared to 69.1% for the population as a whole (PHE 2015), making reasonable adjustments to cancer screening.

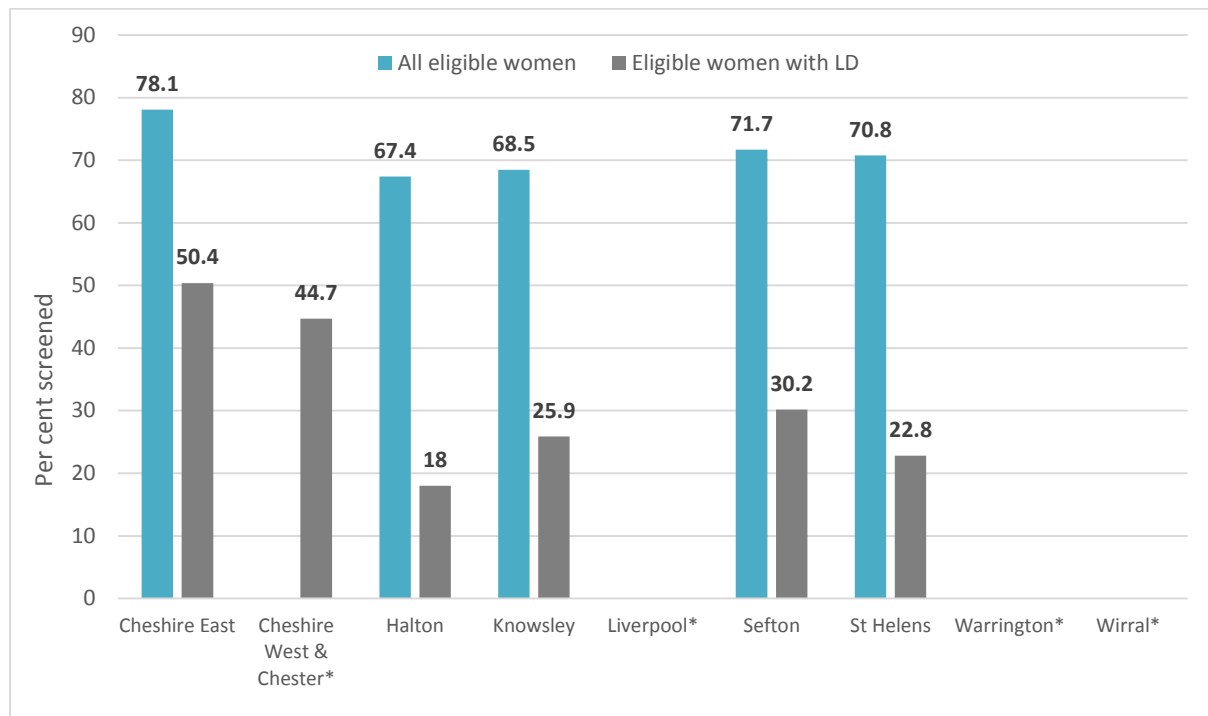
#### CERVICAL CANCER SCREENING

Cervical screening should be done every three to five years (depending on age) for women aged 25-64 who have not had a hysterectomy. Screening data for 2014 is provided in the LDSF returns. Figure 14 below includes data for the Cheshire and Merseyside LAs. Not all LA areas were able to provide data. The

LDSAF was not available for Warrington and Wirral provided their data in other age categories which are provided below.

Screening of all women eligible was relatively comparable across all areas and varied from 67.4% in Halton to 78.1% in Cheshire East. However screening rates were considerably lower and more varied in women with learning disabilities. In most areas uptake in women with LD was less than half uptake in all women. Halton had the lowest cervical cancer screening rates in women with LD (18%) and Cheshire East the highest (50.4%).

**Figure 14: Proportion of women screened for cervical cancer in prescribed period**



Source: Individual LDSAF 2014 returns. \* denotes areas unable to provide any of complete data, these do not represent 0% screening rates.

In Wirral, LDSAF 2014-15 data show lower uptake of all screening in people with learning disabilities. In 2014-15 cervical cancer screening uptake was lower in both age groups and particularly in the older ages (50-64 year of age 29.3% compared to 72.2% of all women). Screening rates have increased in all groups in the last year.

**Table 26: Cervical Cancer Screening uptake for women with Learning Disability, Wirral, 2013-2015**

Cervical Cancer Screening	2013/14		2014/15	
	Eligible population	Screening	Eligible population	Screening
Women aged 25-49 - all women	48662	60.1%	64588	64.3%
Women aged 25-49 – with LD	388	30.7%	391	35.8%
Women aged 50-64 - all women	26704	70.6%	35219	72.2%
Women aged 50-64 – with LD	137	21.2%	184	29.3%

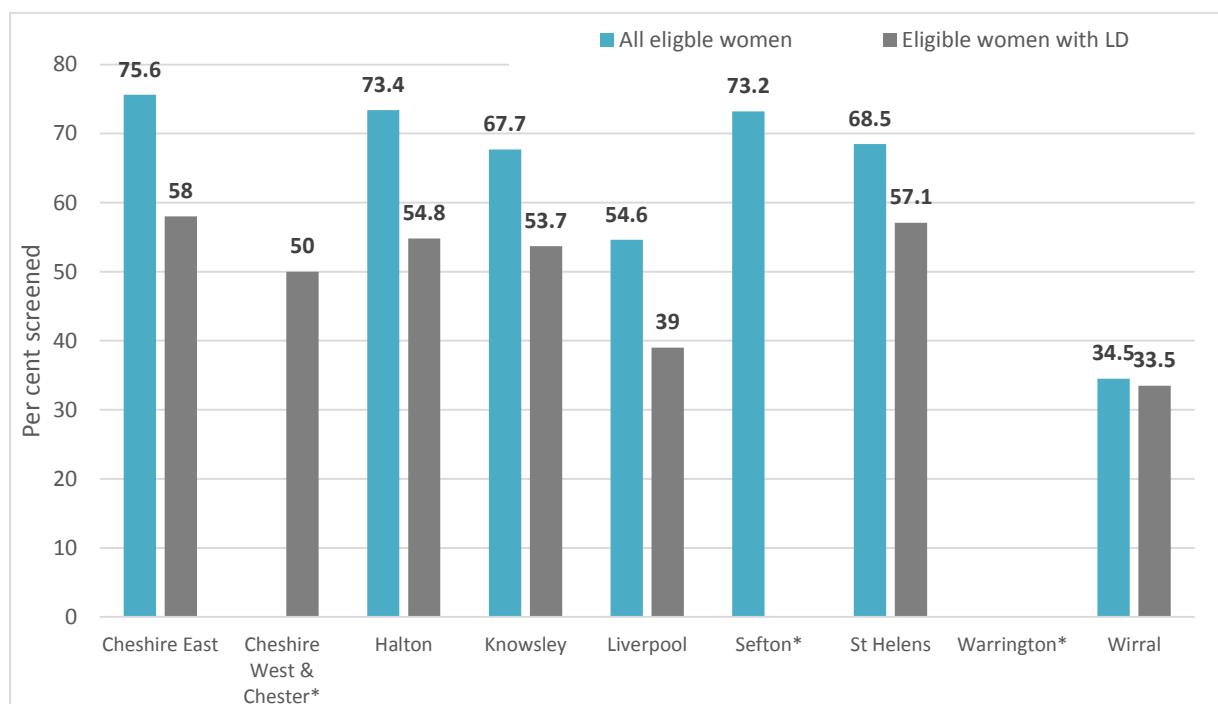
Data provided by Wirral LA, 2015

## BREAST CANCER SCREENING

Breast cancer screening is offered to all women ages 50-69 every three years. Screening data for 2014 is provided in the LDSF returns. Figure 14 below includes data for the Cheshire and Merseyside LAs. Not all LA areas were able to provide data. The LDSAF was not available for Warrington and Wirral provided their data in other age categories which are provided below.

Uptake of screening in all women (including those with LD and those without) varied across areas with Cheshire East having the highest uptake (75.6%) and lowest in Wirral (34.5%). Uptake of breast cancer screening in women with LD was lower than in all women, but the difference between groups not as dramatic as that of cervical cancer screening. Cheshire East had the highest uptake of breast cancer screening in women with LD (58%) and Wirral the lowest (33.5%).

**Figure 15: Per cent of eligible women screened for breast cancer in last three years**



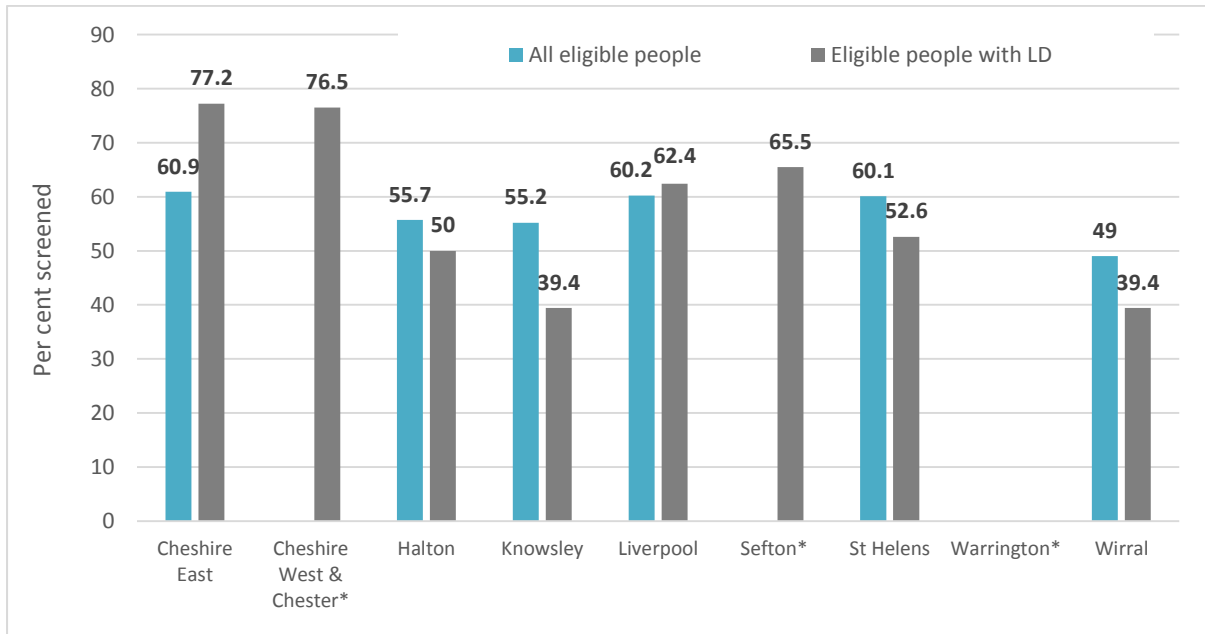
Source: Individual LDSAF 2014 returns



## BOWEL CANCER SCREENING

Bowel cancer screening is offered to men and women aged 60-69 every two years. Uptake in all people varied somewhat across all areas, varying from 60.9% in Cheshire East to 49% in Wirral. Screening uptake in people with learning disabilities was similar, and in some cases higher than in the general population, but varied considerably between areas. The highest uptake was in Cheshire East (77.2% and was higher than screening of all people); uptake was lowest in Wirral where just over a third of eligible people with learning disabilities were screened (39.4%).

**Figure 16: per cent of persons screened for bowel cancer in last two years**



Source: Individual LDSAF 2014 returns

### **Guidance: 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](http://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 disabilities can be compared and monitored across each CCG.

## **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 disabilities 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 depo 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 a Barnardo's and University of Coventry report in 2015 (Franklin, Raws and Smeaton 2015) which found that young people with learning disabilities are vulnerable to sexual exploitation due to factors that include overprotection, social isolation and society refusing to view them as sexual beings.

The report recommended the need for better education and information on sex and relationships and exploitation.

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'.

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### 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 disabilities (56%) never do sport/exercise, compared to a quarter (25%) of those with no learning disability.

Amongst adults with learning disabilities, 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 disabilities (80%) have lower levels of physical activity than recommended, compared to 53-64% amongst the general population.

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## 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 31<sup>st</sup> December 2008 (Oyinloye and Lee, 2010). It reported that:

- one in ten adults with learning disabilities use tobacco. This is less than the Knowsley average of one in four adults and is consistent with other research findings.
- those with learning disabilities 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%).

Data on BMI at a local authority level, where available, is included in the GP data above.

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## 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 disabilities included diabetes, constipation and influenza/pneumonia (Glover and Evison, 2013).

## Locally collected data

Detailed hospital admissions data was not available from HES within the timeframe of this report and is no longer available on IHAL. Data on hospital data comes from the LDSAF returns.

The LDSAF returns provide absolute numbers of the people who have attended hospitals in 2013-14. Data were unavailable for Warrington and Wirral and incomplete for Halton and Knowsley. In absolute numbers Liverpool saw the highest number of inpatient spells, outpatient attendances and A&E attendances. However St Helens has the highest number of patients with learning disabilities attending A&E more than three times.

**Table 27: numbers of learning disability patients attending as inpatients, outpatients and A&E. 2013-2014**

	Cheshire East	Cheshire West & Chester	Halton*	Knowsley*	Liverpool	Sefton	St Helens
<b>Hospital spells - inpatients. Persons with LD<sup>3</sup></b>	326	98	282	10633	760	11	481
<b>Hospital attendances - outpatients. Persons with LD<sup>4</sup></b>	831	323		361	3167	1030	909
<b>A &amp; E attendances. Persons with LD<sup>5</sup></b>	583	142			834	203	702
<b>No people attended A &amp; E more than 3 times. Persons with LD<sup>6</sup></b>	43	10			62	14	85

\* Incomplete data were provided on the LDSAF returns.

<sup>3</sup> How HOSPITAL PROVIDER SPELLS of inpatient Secondary Care were been received under any consultant specialty EXCEPT the psychiatric specialties (Specialty codes 700-715) between 1st April 2013 and 31st March 2014? Persons with LD

<sup>4</sup> How many Secondary Care Outpatient ATTENDANCES were been received by people under any consultant specialty EXCEPT the psychiatric specialties (Specialty codes 700-715) between 1st April 2013 and 31st March 2014? Persons with LD

<sup>5</sup> A & E attendances How many ATTENDANCES at Accident & Emergency between 01 April 2013 - 31 March 2014? Persons with LD

<sup>6</sup> A & E people with 3 or more attendances How many PEOPLE have attended Accident & Emergency 01 April 2013 - 31 March 2014 more than 3 times? (only required for persons with LD) Persons with LD

## 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](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).  
[http://www.rcn.org.uk/\\_data/assets/pdf\\_file/0004/78691/003024.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0004/78691/003024.pdf)

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### 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 (no date, 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 collate CAMHS commissioning arrangements across CCGs, to identify what tier one to three CAMHS services are providing for children with learning disabilities in each area and well as defining specialist commissioning tier 4 services.

*Local data:* no local data were available

### Adults

In 2013-14 there were 54 people with a learning disabilities in Cheshire West and Chester who also had a mental health condition (information provided by the LA).

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 28 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 Mersey Care NHS Trust is needed to give a more complete picture of access across Merseyside and to enable the calculation of rates.

**Table 28: 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 QINMAC (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->

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 new guidance on challenging behaviour and learning disability. NICE describe challenging behaviour as:

*"Some people with a learning disability display behaviour that challenges. 'Behaviour that challenges' is not a diagnosis and is used in this guideline to indicate that although such behaviour is a challenge to services, family members or carers, it may serve a purpose for the person with a learning disability (for example, by producing sensory stimulation, attracting attention, avoiding demands and communicating with other people). This behaviour often results from the interaction between personal and environmental factors and includes aggression, self-injury, stereotypic behaviour, withdrawal, and disruptive or destructive behaviour. It can also include violence, arson or sexual abuse, and may bring the person into contact with the criminal justice system" (NICE 2015)*

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.".'. "*

#### **Prevalence**

Between 10%-15% of people with learning disabilities have challenging behaviours (including aggression, destruction and self-injury (Emerson et al, 2012 literature review,) and rates are higher in teenagers and people in their early 20s, and in particular settings (for example, 30–40% in hospital settings; NICE 2015).

People with learning disabilities 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 guidance on challenging behaviour and learning disability

(NICE, 2015) noted adult and child health and social care teams should work jointly to provide assessment and services to young people and diagnosis and management need to be reviewed through transition between services. NICE (2015) suggest there should be clarity about who is the lead clinician to ensure continuity of care.

Challenging behaviour is more common in certain care environments including those with *“limited opportunities for social interaction and meaningful occupation, lack of choice and sensory input or excessive noise. It can also be more common in care environments that are crowded, unresponsive or unpredictable, those characterised by neglect and abuse, and those where physical health needs and pain go unrecognised or are not managed”* (NICE 2015).

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.

### **Guidelines: Challenging Behaviour**

NICE have recently released new guidance which offers evidence-based advice on prevention and interventions for children, young people and adults with a learning disability and behaviour that challenges (NICE 2015).

The NICE 2015 guidance set out some general principles of care:

- When providing support and interventions for people with a learning disability and behaviour that challenges, and their family members or carers:
  - take into account the severity of the person's learning disability, their developmental stage, and any communication difficulties or physical or mental health problems
  - aim to provide support and interventions:
    - in the least restrictive setting, such as the person's home, or as close to their home as possible, and
    - in other places where the person regularly spends time (for example, school or residential care)
  - aim to prevent, reduce or stop the development of future episodes of behaviour that challenges
  - aim to improve quality of life
  - offer support and interventions respectfully
  - ensure that the focus is on improving the person's support and increasing their skills rather than changing the person
  - ensure that they know who to contact if they are concerned about care or interventions, including the right to a second opinion
  - offer independent advocacy to the person and to their family members or carers.

The guidelines make it clear that carers and provider organisations should ensure that teams providing care have prompt and coordinated access to specialist assessment, support and intervention services which can provide advice, supervision and training from a range of staff to support the implementation of any care or intervention. Support should come from teams including psychologists, psychiatrists,

behavioural analysts, nurses, social care staff, speech and language therapists, educational staff, occupational therapists, physiotherapists, physicians, paediatricians and pharmacists.

The guidance also acknowledges the importance of early identification of behaviour that challenges and advises that carers and professionals should pay attention and record factors that may increase the risk of behaviour that challenges developing gradually. Effective assessment of behaviour that challenges should remain person-centred and be regularly reviewed.

The guidance made recommendations around personalised psychological and environmental interventions for children, young people and adults that are based on behavioural principles and a functional assessment of behaviour, tailored to the range of settings in which they spend time, and consist of:

- clear targeted behaviours with agreed outcomes
- assessment and modification of environmental factors that could trigger or maintain the behaviour (for example, altering task demands for avoidant behaviours)
- addressing staff and family member or carer responses to behaviour that challenges
- a clear schedule of reinforcement of desired behaviour and the capacity to offer reinforcement promptly
- a specified timescale to meet intervention goals (modifying intervention strategies that do not lead to change within a specified time).

Antipsychotic medication should be considered to manage behaviour that challenges only if:

- psychological or other interventions alone do not produce change within an agreed time or
- treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour or
- the risk to the person or others is very severe (for example, because of violence, aggression or self-injury)

The guidance made recommendations about the need for further research into:

- Preventing behaviour that challenges from developing in children aged under 5 years with a learning disability
- Interventions to reduce the frequency and extent of moderate to severe behaviour that challenges in community settings
- Locally accessible care

Source: NICE (2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (NG11).

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).

#### *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.

### 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, Heslop et al 2014)**

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, Heslop et al 2014). 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.

### Cheshire and Merseyside data

Recent data on individuals with learning disabilities who died in Cheshire and Merseyside was unavailable. The LDSAF returns include information on the number of people with learning disabilities who have died in the last year (2013-14). However as numbers under 5 are suppressed the information is very limited (see table 29). No data were available for Warrington or Wirral. Sefton and Liverpool saw the highest number of deaths however without full unsuppressed data it is not possible to compare mortality rates.

A mortality audit of learning disability related deaths is currently being undertaken across South Cheshire and Vale Royal CCGs following a number of recent cancer related deaths. The findings of the audit are expected in the second quarter of 2016.

**Table 29: number of people with learning disability who died in year to March 2014 by local authority.**

	Cheshire East	Cheshire West & Chester	Halton	Knowsley	Liverpool	Sefton	St Helens
Aged 0-13	0	0	0	0		0	0
Aged 14-17	0	0	0	<5		<5	0
Aged 18-34	<5	0	<5	<5		<5	<5
Aged 35-64	<5	5	<5	6	8	8	7
Aged 65 & over	5	<5	<5	<5	11	11	5

To stop identifying patients any numbers under 5 have been suppressed and numbers 1-4 have been replaced. Therefore columns cannot be totalled.

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 disabilities (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 30: 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.

Table 30. 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).

### **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'<sup>2</sup> 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](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

(Tyrer and McGrother, 2009)

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

<sup>2</sup> 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

In his 'Fair Society, Healthy Lives' review, Marmot recognises that health inequalities are the result of the interaction between 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, poor diet) and are related to other wellbeing factors such as stigma and bullying, all of which can have a negative impact on health and wellbeing.

### 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 31.

***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 31.

***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 disabilities 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 31: 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"> <li>• Owner Occupier/Shared ownership scheme</li> <li>• Tenant - Local Authority/Arm’s Length Management Organisation/Registered Social Landlord/Housing Association</li> <li>• Tenant - Private Landlord</li> <li>• Settled mainstream housing with family/friends (including flat-sharing)</li> <li>• Supported accommodation/Supported lodgings/Supported group</li> <li>• Adult placement scheme</li> <li>• Approved premises for offenders released from prison or under probation supervision</li> <li>• Sheltered Housing/Extra care sheltered housing/Other sheltered housing</li> <li>• Mobile accommodation for Gypsy/Roma and Traveller community</li> </ul>	<ul style="list-style-type: none"> <li>• *Rough sleeper/Squatting</li> <li>• *Night shelter/emergency hostel/direct access hostel</li> <li>• *Refuge</li> <li>• *Placed in temporary accommodation by Local Authority e.g., Bed and Breakfast</li> <li>• Staying with family/friends as a short term guest</li> <li>• Acute/long stay healthcare residential facility or hospital</li> <li>• Registered Care Home</li> <li>• Registered Nursing Home</li> <li>• Prison/Young Offenders Institution/Detention Centre</li> <li>• Other temporary accommodation</li> </ul> <p><i>*= severely unsatisfactory accommodation</i></p>

Source: IHAL (2013)

## CHESHIRE AND MERSEYSIDE

Table 32 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. According to the National Adult Social Care Intelligence Service (NASIS), in 2013/14, there were 4,530 male and 3,240 female adults with learning disability of working age in Cheshire and Merseyside who were known to social services. Of these, 86% 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 76%, and slightly lower than the North West average of 88% (NASIS, 2015).

Table 32 shows the differences in the proportion of service users in settled and non-settled accommodation across Cheshire and Merseyside. Proportions in settled accommodation are especially high in Knowsley (93%). Warrington has the lowest proportion in settled accommodation (79%) although Warrington did have a fairly high proportion of individuals whose accommodation status was unknown this proportion is still above the national average.

**Table 32: Accommodation status of people with learning disabilities (LD) aged 18-64, 2013/14**

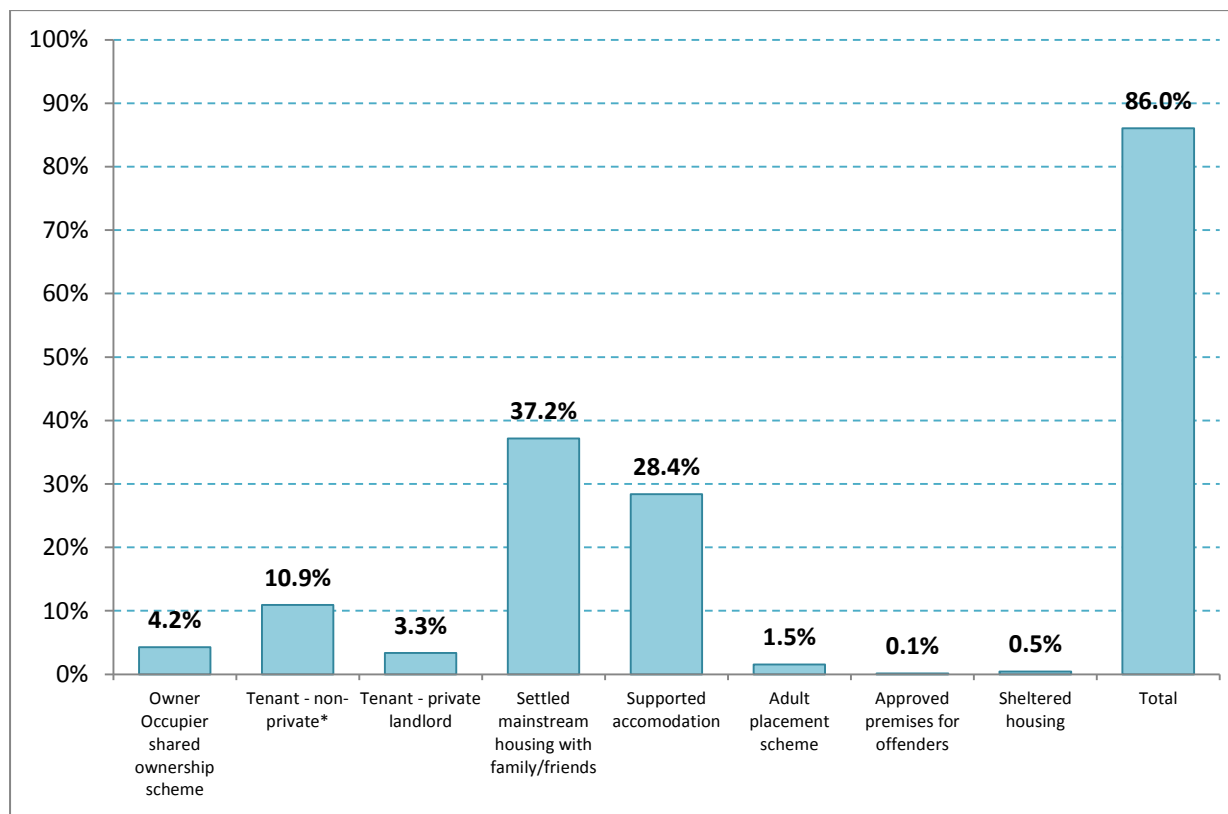
	Non-settled accommodation		Settled accommodation		Accommodation unknown**		Total
	number of service users	% of all with LD	number of service users	% of all with LD	number of service users	% of all with LD	
Halton	45	9.7	375	80.6	45	9.7	465
Knowsley	50	7.4	630	92.6	0	0.0	680
Liverpool	155	10.9	1265	88.8	5	0.4	1425
Sefton	135	16.8	670	83.2	0	0.0	805
St Helens	35	5.0	615	87.9	50	7.1	700
Wirral	160	14.4	950	85.6	0	0.0	1110
Liverpool City Region	580	11.2	4505	86.9	100	1.9	5185
Cheshire East	115	11.4	860	85.6	30	3.0	1005
Cheshire West And Chester	110	10.4	910	85.8	40	3.8	1060
Warrington	65	12.4	415	79.0	45	8.6	525
Cheshire	290	11.2	2185	84.4	115	4.4	2590
Cheshire and Merseyside	870	11.2	6690	86.0	215	2.8	7775
North West	2070	10.3	17685	87.9	375	1.9	20130
England	30845	21.7	106335	74.9	4800	3.4	141980

Source: NHS IC, ASCCAR L2

\*\*'Accommodation unknown' 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)

Figure 17 provides a breakdown of adults with learning disabilities (of working age) living in settled accommodation by accommodation type with percentages representing the proportion of working age adults with learning disabilities known to services. The largest proportion were living in settled mainstream housing with family or friends (including flat shares; 37%) followed by those living in supported accommodation (28%).

**Figure 17: Adults with LD living in settled accommodation by accommodation type, Cheshire and Merseyside, 2013/14**

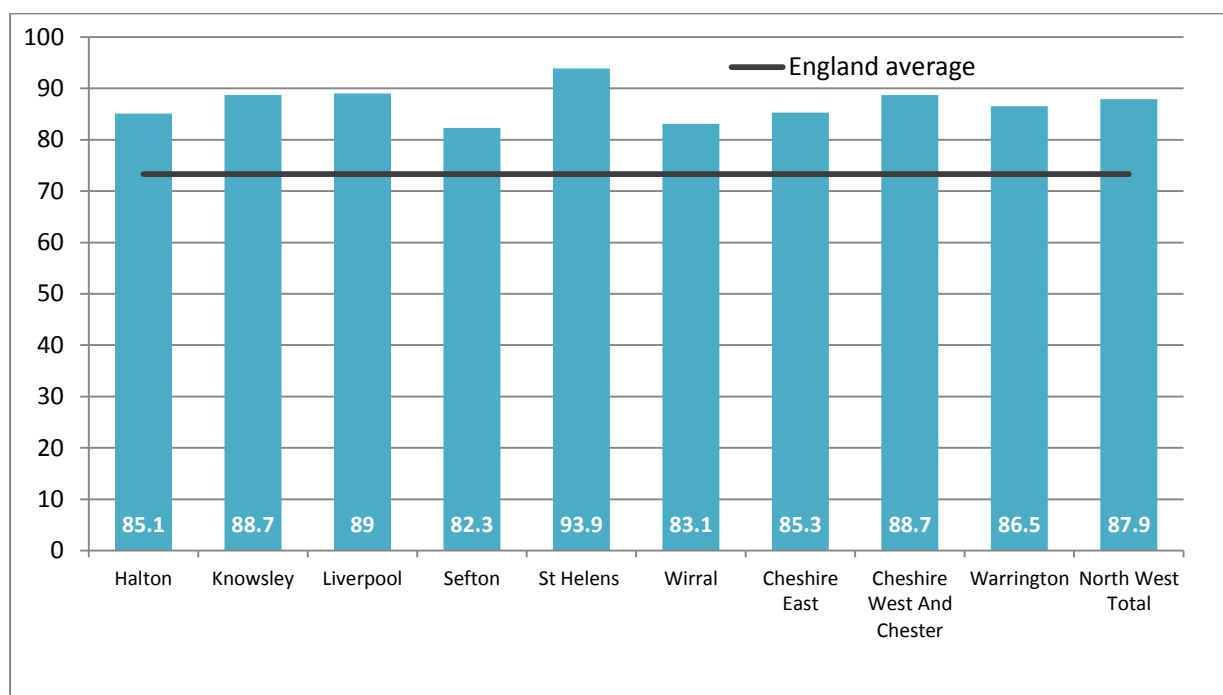


Source: NHS IC, ASCCAR L2

\* Tenant non-private includes tenants of Local Authority, Arms-length management organisations, registered social landlords and housing associations

Data from the Adult Social Care Outcomes Framework suggests that the number of adults with learning disabilities who live in their own home or with their family has increased slightly over the past five years rising from 70% in 2011/12 to 73% in 2014/15. In the North West the proportion is substantially higher at 88% in 2014/15. Figure 15 below shows the proportion of adults living in their own home or with family by local authority. All local authorities in Cheshire and Merseyside are above the national average.

**Figure 15: Proportion of adults with learning disabilities who live in their own home or with their family, Cheshire and Merseyside, 2014/15**



Source: HSCIC, ASCOF data

## NON-SETTLED

Nationally, just over one in five (21.7%) adults with learning disabilities age 18-64 live in non-settled accommodation. In Cheshire and Merseyside, the situation is much more favourable, but there are still six local authorities where the level is above the North West average of around 1 in 10 (10.3%). Levels are highest in Sefton (16.8%), Wirral (14.4%) and Warrington (12.4%) (see Table 22).

The largest proportion of individuals classified as living in “unsettled accommodation” in Cheshire in Merseyside were residing in a registered care home (76%) followed by a registered nursing home (14%), an Acute/long stay healthcare residential facility or hospital (3.4%) and staying with family and friends as a short term guest (2.3%).

### ***Living in permanent residential and nursing care homes***

The NHS IC term ‘unsettled accommodation’ includes those living in residential care homes. The largest proportion of individuals living in ‘unsettled accommodation’ in 2013/14 were residing in a registered care home (76%) with a further 14% residing in a registered nursing home. In Knowsley 100% of those in unsettled accommodation were living in nursing or care homes<sup>7</sup> whilst in St Helens the proportion was much lower (43%) with higher numbers of St Helens residents living in either a “acute/long stay healthcare residential facility or hospital’ (29%) or staying with friends and family as a short term guest (14%).

<sup>7</sup> In Liverpool the sum of those living in registered care homes and registered nursing homes (n=160) was greater than the total number reported to be in unsettled accommodation (n=155).

Adult Social Care Outcomes Framework data for 2014/15 includes permanent admissions to residential and nursing care of younger adults with learning disability. Table 33 gives the rate of admission per 100,000 of the general population for each local authority in Cheshire and Merseyside. Rates are lower than the national and regional average in each local authority except Wirral.

Actual numbers of permanent admissions are very small with Cheshire West and Chester and Wirral seeing the highest number of admissions (10 per local authority).

**Table 33: Permanent admissions of younger adults (aged 18 to 64) with learning disabilities (LD) to residential and nursing care homes, per 100,000 population (adjusted), 20013/14**

	Permanent admissions of young adults with LD to residential nursing homes	Total population aged 16-84	Rate per 100,000 general population aged 16-84
Cheshire East	*	219740	*
Cheshire West and Chester	10	199025	5
Halton	*	77510	*
Knowsley	*	89665	*
Liverpool	5	313100	1.9
Sefton	*	159455	*
St Helens	*	105980	*
Warrington	*	125745	*
Wirral	10	188205	6.4
North West	155	4341150	3.6
England	1665	33054185	5

Source: NHS Information Centre, Adult Social Care Outcomes Framework for 2013/14. \*= numbers too small to include

## SEVERELY UNSATISFACTORY

IHAL (2013) report that numbers for this indicator are 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 Cheshire and Merseyside, there were no adults recorded to be in severely unsatisfactory accommodation in 2013/14 (see table 21 above for a full definition).

## UNKNOWN

Table 32 shows that some of the variation in levels of settled and unsettled accommodation can be explained by the fact that in some areas the accommodation status of a sizeable minority of adults with learning disability is unknown to the local authority (as mentioned in the text preceding Table 32 above).

In Halton, the accommodation status of just under one in ten (9.7%) of adults with learning disability was unknown in 2013/14. Levels were also higher than the national average of 3.4% in Warrington, St Helens, Cheshire West and Chester.



## Gender

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

- In Sefton, women (24%) were twice as likely as men (12%) to be in unsettled accommodation
- Conversely, in St Helens men (7%) were over twice as likely as women (3%) to be in unsettled accommodation

### 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 client's 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](http://www.evidence.nhs.uk/qipp)*

### **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/>

## **'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](mailto:carolann1945@live.co.uk)*

*[Colin.Croxton@yourhousinggroup.co.uk](mailto:Colin.Croxton@yourhousinggroup.co.uk) Agency Services Manager  
[www.yourhousinggroup.co.uk](http://www.yourhousinggroup.co.uk)*

## 4.2 COMMUNITY CARE

Table 34 below shows the extent to which local authorities are providing community services for people with learning disabilities known to them. Community based services are services commissioned and provided by social services or and NHS Health Partner as part of a care plan following a Community Care Assessment and include home care, day care, meals, direct payments, short term residential care (excluding respite), professional support and equipment and adaptations. Nationally, just over eight in ten (82%) of those aged 18-64 years with learning disability were receiving community services in 2013/14. Across Cheshire and Merseyside, rates were higher than the national average with the exception of Sefton and St Helens where around three quarters (73% and 76% respectively) received community services.

**Table 34: Community Based Services received by those with learning disabilities, aged 18 to 64, 2013/14**

	Numbers receiving learning disability community services	Total population with a learning disability known to the local authority aged 18-64	% of all learning disability clients receiving community services
Halton	395	465	85%
Knowsley	640	680	94%
Liverpool	1405	1425	99%
Sefton	590	805	73%
St Helens	530	700	76%
Wirral	955	1110	86%
<b>Liverpool City Region</b>	<b>4515</b>	<b>5185</b>	<b>87%</b>
Cheshire East	945	1005	94%
Cheshire West And Chester	850	1060	80%
Warrington	430	525	82%
<b>Cheshire</b>	<b>2225</b>	<b>2590</b>	<b>86%</b>
<b>Cheshire and Merseyside</b>	<b>6740</b>	<b>7775</b>	<b>87%</b>
<b>North West Total</b>	<b>18080</b>	<b>20130</b>	<b>90%</b>
<b>National Total</b>	<b>117025</b>	<b>141980</b>	<b>82%</b>

Source: NHS IC NASCIS, RAP P1

## 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).

## **Hate Crime**

In 2010/11 the Equality and Human Rights Commission launched an inquiry ("Hidden in Plain Sight") into disability related harassment to investigate both the causes of disability related harassment and the actions of public authorities and transport operators in preventing it. Following on from the enquiry the Commission published "Out in the Open – A Manifesto for change" (EHRC, 2012) in which it made a commitment to encourage, guide and monitor the progress of local authorities and publish reviews into the impact of the enquiry at years one, three and five.

Baseline analysis from the Commission suggests that in England and Wales there are around 72,000 incidents of disability hate crime per year and 39,000 adults annually are the victims of disability hate crime. The incidence of personal disability hate crime was 8 per 10,000 adults and the household incidence was 15 per 10,000 households (EHRC, 2013). In addition, disabled people of all ages were more likely than non-disabled people to have experienced any type of crime in the past 12 months e.g. 42% of disabled people aged 16-24 had been victims in the past 12 months compared with 33% of non-disabled people. This difference was particularly marked in women whilst the differences between disabled and non-disabled men were not significant and disabled women were as likely as men to be the victim of crime whilst in the general population men are more likely to be the victim of crime than women.

Not all hate crimes will come to the attention of the police as not all victims will report them. Police were more likely to be informed of disability hate crime incidents (56% for personal crimes, 55% for household crimes) compared with crimes not motivated by identity (38%); however, there was no significant difference in the reporting of disability related hate crime when compared to other types of hate crime. The most common reasons for not reporting disability hate crime were the belief that the police could not have done anything (36%); that the police would not have been interested (31%) or that they were too trivial to report (17%). Victims of disability related hate crime were less likely when compared to victims of other hate crimes to say the incident was too trivial to report (17% vs 29%) but were more likely to say they were fearful of reprisal from the offender (11% vs 2%) (EHRC, 2013).

## **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).

Further analysis of the Millennium cohort study shows that a child aged 5 to 17 years with SEN (12%) and a child with a statement (11%) are twice as likely to be bullied “all the time” than a child with no SEN (6%) even when all other characteristics and circumstances are controlled for (Chatzitheochari et al, 2014; Chatzitheochari et al, 2015).

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 disabilities had infrequent contact with their families (compared to 9% of those with no learning disability)
- 31% of adults with learning disabilities 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.

### **Cheshire and Merseyside**

Table 35a shows local statistics relating to the abuse of vulnerable adults with learning disabilities across Cheshire and Merseyside in 2012/13. Abuse refers to “a violation of an individual’s human and civil rights by any other person or persons” and can include physical, sexual, emotional and psychological, financial, institutional, abuse as well as neglect and discrimination. It lists numbers and rates per 10,000 of referrals of adults with learning disabilities to the social service safeguarding teams. Across Cheshire and Merseyside there were 1,320 completed referrals of abuse of adults with learning disabilities during 2012/13. Further detail on the nature of the alleged abuse is provided in table 25b.

**Table 35a: Abuse of Vulnerable Adults: Number of completed referrals to Social Care Adult Safeguarding Teams by age of alleged victim with learning disabilities, 2012/13**

	Aged 18 to 64		Age 65 to 74		Age 75-84		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	Rate per 10,000 population	Number of completed referrals	Rate per 10,000 population	Number of completed referrals
Halton	45	5	0	0	0	0	0	0	45
Knowsley	75	10	5	0	0	0	0	0	80
Liverpool	250	10	25	5	5	0	0	0	280
Sefton	140	10	15	5	5	0	0	0	160
St Helens	110	10	0	0	0	0	0	0	110
Wirral	170	10	10	5	0	0	0	0	180
<b>Liverpool city region</b>	<b>790</b>		<b>55</b>		<b>10</b>		<b>0</b>		<b>855</b>
Cheshire East	275	10	15	5	10	5	0	0	300
Cheshire West And Chester	60	5	0	0	0	0	0	0	60
Warrington	100	10	5	5	0	0	0	0	105
<b>Cheshire</b>	<b>435</b>		<b>20</b>		<b>10</b>		<b>0</b>		<b>465</b>
Cheshire and Merseyside	1225		75		20		0		1320
<b>North West Total</b>	<b>2355</b>	<b>5</b>	<b>170</b>	<b>5</b>	<b>60</b>	<b>0</b>	<b>5</b>	<b>0</b>	<b>2590</b>
<b>Total</b>	<b>15305</b>	<b>5</b>	<b>1020</b>	<b>0</b>	<b>260</b>	<b>0</b>	<b>80</b>	<b>0</b>	<b>16665</b>

Source: AVA, NASCIS 2013/14

Amongst those aged 18-64, referral rates were higher than the North West and national average of 5 per 10,000 in seven of the nine local authorities in Cheshire and Merseyside. Cheshire East (275) and Liverpool (250) recorded the highest number of completed referrals. Rates in Halton and Cheshire West and Chester were the same as the North West and national average (5 per 10,000 population).

For those aged 65-74, none of the local authorities in Cheshire and Merseyside had a higher rate of referrals than the North West average of 5 per 10,000. Across Cheshire and Merseyside there were no referrals for those aged 85 years and over. For those aged 75 plus, numbers were too small to calculate meaningful rates; only three local authorities had referrals in adults aged 75 years and over; Liverpool (5), Sefton (5) and Cheshire East (10). Overall numbers of referrals amongst those aged 65+ were very small;

with 95 referrals in total across Cheshire and Merseyside; representing 7% of the total completed referrals.

There rate of completed referrals did not vary greatly between the sexes in numbers of vulnerable adults with learning disability who were referred to social services in 2012/13.

**Table 35b: Abuse of Vulnerable Adults: Number of completed referrals to Social Care Adult Safeguarding Teams by nature of alleged abuse for adults with learning disabilities (aged 18-64 years), 2012/13**

	Physical	Sexual	Emotional/ psychological	Financial	Neglect	Discriminatory	Institutional	Multiple	Total
<b>Cheshire East</b>	155	25	80	45	60	5	5	60	375
<b>Cheshire West And Chester</b>	25	5	10	15	15	0	0	10	75
<b>Halton</b>	10	5	15	15	15	0	5	5	65
<b>Knowsley</b>	45	10	25	15	10	0	0	0	105
<b>Liverpool</b>	120	25	35	45	75	0	0	0	295
<b>Sefton</b>	45	10	40	30	40	5	5	40	175
<b>St Helens</b>	55	10	25	15	10	0	0	10	115
<b>Warrington</b>	55	15	20	10	25	0	0	35	130
<b>Wirral</b>	65	15	40	30	30	0	5	0	180
<b>Cheshire and Merseyside</b>	575	120	290	220	280	10	20	160	1515
<b>North West Total</b>	1185	270	560	400	620	30	95	450	3155

Source: AVA 4b, NASCIS, 2012/13

Table 35b shows the nature of alleged abuse for referrals across Cheshire and Merseyside for adults (aged 18-64 years) with learning disabilities. The numbers presented in table 35b are higher than those in table 35a as they refer to all referrals made to Social Care Adult safeguarding Teams whilst table 35a uses data on completed referrals only. The largest proportion of referrals were for physical abuse (38%) with the highest absolute number of referrals for physical abuse made in Cheshire East (155 referrals) followed by Liverpool (120 referrals). The next highest proportion of referrals were made for emotional and psychological abuse (19%) followed by neglect (18%) and financial abuse (15%). Just over one in ten (11%) of unique referrals made were for multiple types of abuse.

Across Cheshire and Merseyside in 2012/13, a third of referrals among adults with learning disabilities (aged 18-64; 33%, 785) were substantiated and 12.5% partially substantiated (295 referrals). A further 29% were not substantiated and 25% were not determined or non-conclusive. Of completed referrals, 48% (610 referrals) among adults (aged 18-64) with learning disability were offered a Protection Plan. No further action was taken on 440 (35%) of referrals. None of the referrals led to a serious case review.

*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 for the previous needs assessment (Ubido et al, 2013). 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 notes 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.

#### 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).

Young people with learning disabilities also appear 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; Gayenteng et al, 2013) 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.

However, the true numbers of adults and young people entering the criminal justice system remains unknown. 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 and a recent inspection by the Criminal Justice Joint Inspection Group (2015) found that there is often an over reliance on offenders and their families to disclose a learning disability diagnosis. Recent

recommendations made by NHS England (2015), the Criminal Justice Joint Inspection Group (2015) and the Royal College of Psychiatrists (2014) highlight the importance of screening individuals for learning disabilities upon entering the CJS. The most recent Criminal Justice Joint Inspection report found that screening tools were not routinely used at the pre-sentence or induction stage and only one of the prisons visited during the inspection were routinely screening for learning disabilities during the reception process. A recent study used the LDSQ to screen 3,000 prisoners entering three English prisons and found that just under 7% of those screened were positive on the LDSQ (Murphy et al, 2015) with all the prisons making some reasonable adjustments to their procedures as a result. This study confirms the feasibility of introducing routine screening in the prison setting.

This failure to appropriately identify individuals with learning disabilities entering the CJS means that often these individuals are not receiving specialist provision or accessing the healthcare they need once in prison (NHS England, 2015; Prison Reform Trust, 2015). The most recent inspection by the Criminal Justice Joint Inspection Group (2015) stated *“little thought was given to the need to adapt regimes to meet the needs of prisoners with learning disabilities who may find understanding and following prison routines very difficult”*. Adults with learning disabilities in the CJS have a number of vulnerabilities including not understanding the processes or their rights, being acquiescent during interview and making unwise decisions and crucial points (Murphy, 2014). 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.

**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*

In addition, prisoners with learning disabilities are known to be disadvantaged in prisons and more susceptible to bullying, segregation, depression and anxiety (Murphy et al, 2015). 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). 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).

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).

### **Adults with Autism Spectrum Disorder (ASD).**

Many of the guidance documents considered below, including the most recent guidance produced by NHS England (2015) acknowledge that a disproportionately high number of prisoners have ASD however there is currently no national data to give the exact figures. In a recent systematic review King and Murphy (2014) acknowledge that it is not uncommon for people with ASD to show challenging behaviours which can become chronic thus requiring specialist interventions and putting the individual at risk of entering the criminal justice system. Four factors are suggested which may make people with ASD more likely to carry out criminal acts, namely: an increased social naivety which puts them at risk of manipulation by others; disruption of routine or over rigid adherence to rules may lead to aggression; poor negotiating skills and lack of understanding in social situations may lead to aggression and, obsessional interest and failure to recognise the implications of their behaviour may lead to committing and offence through pursuit of that interest.

Studies suggest that the prevalence of ASD in CJS is higher than the prevalence of ASD in the general population however this conclusion is modified by the poor methodologies and biased samples used in the studies which formed part of Murphy and King's review (2014). Similarly the prevalence of offending in ASD populations are also difficult to interpret but suggest that adults with ASD commit the same or fewer offences than those in non-ASD populations. This suggests that people with ASD are less likely to commit a criminal offence than other people of the same age and gender or that if they do show offending type behaviour this is dealt with outside the CJS. It is also difficult to draw conclusions from the available evidence about the types of offences committed by those with ASD however one study interestingly found that those with ASD are less likely to commit probation violations whilst another study found that people with ASD are more likely to commit crimes involving school disturbances perhaps reflecting the difficulties experience by some adults living with ASD when coping in the school environment (Murphy and King, 2014)

## **Guidelines: ASD and the Criminal Justice System**

*Austim: a guide for Criminal Justice Professionals (2011):* the National Autistic Society provides guidance for those working in the criminal justice system. The key focus of the document is to provide guidance for professionals on: recognising and approaching people with autism in the CJS and communicating with people with autism; this includes specific guidance on questioning and interviewing people with autism in the CJS.

*Autism Accreditation Programme:* The National Autistic Society has developed a set of standards for prisons which allow the prison to claim internationally recognised “autism accreditation”. The accreditation involves a self-audit process followed by a formal review against set criteria which evidence that the organisation has:

- Specialised knowledge and understanding of autism
- Knowledge and understanding that autism consistently informs the organisation, resources and management of the organisation
- Knowledge and understanding of autism consistently informs the assessment and support plan for people who use the service
- Knowledge and understanding of autism consistently informs all aspects of practice

## **Cheshire and Merseyside**

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, and HMP Kennet. In Cheshire there are two male prisons HMP Thorn Cross and HMP Risley. Female offenders from the Cheshire and Merseyside area are sent to HMP Styal in Cheshire.

The Alderley Unit in Cheshire is a low secure service unit for males with 15 beds for those with mild to moderate learning disabilities who have or are assessed likely to commit an offence.

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)

Across both Cheshire and Merseyside and the North West as a whole there were no individuals known to have learning disability recorded as being in custody. There were ten individuals known to have a learning

disability residing in approved premises in the community in 2013/14 all of whom resided in Wirral. 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 (Lewis and Scott-Samuel, 2013) 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).

**Equal Access, Equal Care. Guidance for Prison Healthcare staff treating patients with learning disabilities** (NHS England, 2015): this guidance for prison healthcare staff focuses on several key areas for adults with learning disabilities in prison including: tackling the social determinants of ill health in a prison setting, screening for possible learning disabilities in prison and the benefits of having learning disability nurses and practitioners in prison. It applies community healthcare policy and best practice regarding patients with learning disabilities to the prison healthcare setting.

## EXAMPLES OF LOCAL DELIVERY: CRIMINAL JUSTICE SYSTEM

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### 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'.

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## 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.

### **Cheshire and Merseyside**

There is a lack of readily available data on numbers of people with learning disabilities who are parents. Data was requested directly from local authorities via local intelligence leads and provided by Adult Social Care. The majority of LAs providing data said that parental status was not available. However, the data provided showed that

- In **Cheshire West and Chester** in 2014/15 there were 32 people with learning disability who were known to be parents who had a total of 55 children. None of the children were currently living in the same household as the parent with learning disabilities.
- **Sefton** data provided for the previous needs assessment from 2009/10, reported there were 16 people with learning disabilities identified as parents within the local authority (Sefton LD Partnership Board Self-Assessment report).
- In **St Helens**, as of July 2013, there were 16 adults with a learning disability recorded to have a child.
- In **Halton**, as at July 2013, there were 11 adults with a learning disability recorded to have a child.



## **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 (if 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.
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).

4. *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.

5. *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 2012/13, only 7% of working age adults with learning disabilities were in any form of paid or self-employment, part time or full time (9,845 individuals). The number in paid employment has increased nationally by 21.9% since 2008/9, although caution must be taken when interpreting this figure as the majority of this increase took place in a single year (2008/9 -2009/10) and may be due to local authorities improving their data collection. Recent reports in fact suggest that the numbers of adults with learning disabilities has in fact fallen slightly in the past few years. The majority (70.3%) of those in paid or self-employment worked for less than 16 hours per week. Men were more likely to be employment than women; 64% of adults with learning disabilities in employment are men, and more likely to be working 30 or more hours per week (79.5% of 1,075 individuals). In addition, 9,245

working age adults with learning disability were reported to be engaged in unpaid voluntary work (only) in 2012/13; this represents a 19.2% increase based on the number recorded in 2008/9 (HSCIC, 2014).

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)***

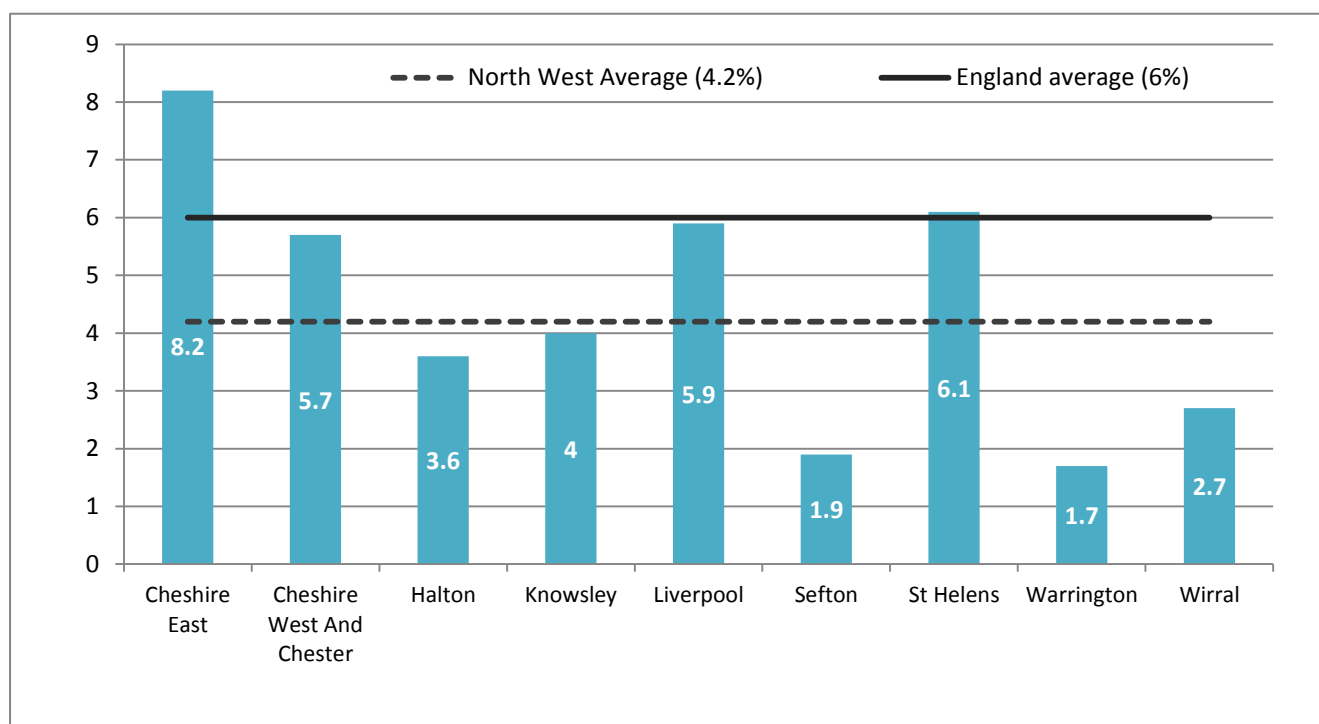
Figure 14 shows levels of paid employment amongst those of working age (18-64) who have a learning disability and who are known to social services. A paid employee will be earning at or above the minimum wage. For this dataset, being in paid employment is measured using the following two categories:

- 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 Cheshire and Merseyside local authorities shows that employment levels are highest in Cheshire East (8.2%) and St Helens (6.1%) as shown in Figure 14. These levels are above the national average of 6% and well above the average for the North West of 4.2% (2014/15).

Employment levels are very low in Warrington, Sefton and Wirral, at under 3% (2014/15).

**Figure 18: Proportion of working age adults with learning disabilities in any paid employment, 2014/15**



Source: NHS Information Centre, Adult Social Care Outcomes Framework for 2014/15 (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 34.

With the exception of Halton and Wirral, employment rates are higher amongst males compared to females in each local authority in Cheshire and Merseyside. Rates are highest amongst males in Cheshire East (9%) where the rate for females is also the highest (7%). Conversely, in Halton the rate of employment among females (5%) is twice that among males (2.5%)

**Table 34: 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, 2014-15.**

Any paid employment	Male		Female	
	number in employment	% in employment	number in employment	% in employment
Cheshire East	50	9%	25	7%
Cheshire West And Chester	30	5.7%	20	5.6%
Halton	5	2.5%	10	5%
Knowsley	15	4.1%	10	4%
Liverpool	50	6.2%	30	5.5%
Sefton	10	2.2%	5	1.4%
St Helens	20	7.6%	10	4.5%
Warrington	5	1.8%	5	1.6%
Wirral	15	2.7%	10	2.7%
North West	480	4.6%	270	3.7%
England	4660	6.4%	2765	5.3%

Source: NHS Information Centre, Adult Social Care Outcomes Framework for 2013/14 (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.

#### ***Paid employment of 16 hours or more per week***

In 2013/14, as few as 0.9% men and 0.4% women with learning disability worked for 30 or more hours per week. In Halton, Knowsley, Sefton, St. Helens and Warrington, 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 2013/14. In Liverpool there were 80 people, in Cheshire East there were 20, in Wirral there were ten and in Cheshire East there were five.

Table 35 shows the numbers of adults with learning disabilities working 16 hours or more in 2013-14 in paid employment (at or above the minimum wage). There were none recorded in Halton. In St Helens, whilst no males or females were recorded the total for the local authority was 5 as values under 5 have been suppressed. The local authority with the largest number of individuals working 16 hours or more was Liverpool (90 individuals) and the proportion of people with learning disability in paid work of 16 hours or more per week is three times the national average, at 6% of all those with a learning disability (2% nationally).

#### ***Gender***

Amongst males in Liverpool and Cheshire East, 8% and 7% respectively are working 16 hours or more (considerably higher than the national average of 3%). For females. Cheshire East had the highest proportion working 16 hours or more (6%) with Liverpool (3%), Sefton (2%) and Warrington (2%) also above the national average (1%) (Table 35).

**Table 35: 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, 2013-14.**

Paid work 16 hours or more per week	Male		Female	
	number in employment	% in employment	number in employment	% in employment
Cheshire East	40	7%	25	6%
Cheshire West And Chester	15	3%	5	1%
Halton	0	0%	0	0%
Knowsley	5	1%	0	0%
Liverpool	70	8%	20	3%
Sefton	5	1%	5	2%
St Helens	0	0%	0	0%
Warrington	5	2%	5	2%
Wirral	15	2%	0	0%
<b>North West</b>	305	3%	120	1%
England	2105	3%	835	1%

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

*Source: NHS Information Centre, Adult Social Care Combined Activity Returns data (ASC-CAR) for 2013/14. 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'.

Three local authorities; Cheshire West and Chester, Wirral and Sefton provided additional information on employment among adults with learning disabilities. The data provided by Cheshire West and Chester in 2014/15 suggests that the number of adults working 16 hours or more has remained stable compared with the Adult Social Care Combined Activity Returns for 2013/14 (20 individuals). The number reported by Wirral is considerably lower (4 individuals) when compared to the numbers in table 35 which may be due to differences or delays in reporting. Wirral also provided the number of individuals known to be seeking work; there were 63 individuals representing 6.8% of adults with learning disability known to the local authority.

Sefton provided further information on the type of work undertaken by 103 adults with learning disabilities known to the local authority who were in voluntary or paid employment. Fifty four individuals were employed in unpaid voluntary work. Of the 49 who were in paid employment, a third (33%) worked in the retail or catering industry (with roles including shop assistants and kitchen, bar and waitress roles) and just under a quarter (24%) worked in manual roles (including labouring, cleaning, gardening and handyman positions).

## **GUIDELINES: EMPLOYMENT**

The Care Act 2014: creates a duty for Local Authorities to promote individuals wellbeing including “participation in work, education, training or recreation” (Chapter 23, Part 1, Para 1)

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**

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

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## 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).

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## 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.

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)

## 5. LEARNING DISABILITY SERVICE PROVISION AND USE

### 5.1 TRANSFORMING CARE AGENDA

The number of adults with learning disabilities accessing long stay inpatient services has declined significantly over the past three decades from over 30,000 in 1987 to well below 5,000 in 2014/15. However, for a minority of people there remains an over reliance on inpatient services for those who could receive support at home and be closer to their families. Whilst hundreds of people have been discharged from hospital, others continue to be admitted to assessment and treatment units. This minority who display challenging behaviour are a diverse group; some may display self-harming or aggressive behaviour unrelated to a mental health condition, some are at risk of contact with the criminal justice system and some have been in inpatient care for many years. For those that do need specialist support in hospital, NHS England recommend that their stay be as short as possible.

Forty nine Transforming Care Partnerships have been established (between NHS England Specialist commissioners, CCGs and Local Authorities) who will engage with those experiencing these services, their carers and families to agree implantation plans, in line with those set out in Building the Right Support (NHS England, 2015a), by April 2016. These partnerships will work with providers to mobilise innovative care, support and housing which will focus on service redesign, scaling up community based services and securing the capital to deliver housing need. This will be achieved by reducing use of inpatient provision by approximately 50% over the next three years.

Changes to services are intended to ensure that people with learning disability and autism, like any person, can expect to live in their own homes, develop and maintain positive relationships and get the support they need to be healthy, safe and an active part of society. Key changes to services that the partnership boards will achieve include:

- Ensure that the right community support and housing package for those for whom hospital has in effect been a permanent home and ensuring dowries are in place so that those who have been an inpatient for five years or more are in place when they are ready to be discharged.
- Nationally, just under 40% of those who have been inpatients for five years of more have had referral and discharge dates agreed under care and treatment reviews. For those in inpatient settings due to clinical issues or Ministry of Justice restrictions the challenge is to build the right set of services in the community for the remainder of these individuals.
- Preventing new admissions and reducing the time spent as inpatients by providing alternative care and support is as important as discharging those currently in hospital. This will require advocacy, early intervention, prevention and ensuring the right set of services are available in the community.
- Transformation will meant redesigning services to meet a better range of needs particularly by better serving children, young people and adults with learning disability and/or autism who: have a mental health condition, display aggressive or self-injurious behaviour, display risky behaviour which could lead to criminal justice system contact and lower level support to those who may not be known to health and social care services from disadvantaged backgrounds who display behaviour and may lead to criminal justice contact.

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## CHESHIRE AND MERSEYSIDE

NHS England have commissioned a report to directly assess these issues including bed and admission levels and explore provider capacity (Vose, 2016). The aim of this section of the needs assessment is to complement the wider social and health issues previously discussed in this report by providing baseline data on service use among adults with learning disability and assisting informed decision making.

### 5.2 SERVICE PROVISION

There are three NHS providers of learning disability services in Cheshire and Merseyside: 5 Boroughs Partnership which provides services for residents of Halton, Knowsley, St Helens, Warrington and also Wigan; Cheshire and Wirral Partnership (CWP) which provides services for residents of Cheshire West and Chester, Cheshire East, Wirral and Trafford, and Mersey Care which provides services for residents of Liverpool, Sefton and Kirkby. All three organisations provide both community and inpatient based services for people with learning disabilities.

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### 5 BOROUGH PARTNERSHIP

5 Borough Partnership has four Specialist Community Learning Disability Nursing Teams based in Warrington, St Helens, Knowsley and Halton. The team provide community based support for people with learning disabilities including health promotion, co-ordination of care, medication monitoring and behavioural intervention. Advice and practice is also provided in areas such as: behavioural difficulties, mental health assessments, interventions, sexual health and knowledge assessments and guidance, dementia assessments and support and, epilepsy management. In addition, they provide individual therapies such as bereavement counselling, specialist physiotherapy and Solution Focused Intervention.

5 Borough Partnership also provide inpatient care for residents of Halton, Warrington and Wigan at the Byron Assessment and Treatment Unit at Hollins Park Hospital, Warrington which provides care for adults with learning disability and mental health problems who have been admitted formally under the Mental Health Act or informally.

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### CHESHIRE AND WIRRAL PARTNERSHIP

Cheshire and Wirral Partnership (CWP) has four Specialist Community Learning Disability Teams for Wirral, West Cheshire; with bases in Cheshire and Winsford, Cheshire East with bases in Macclesfield and Crewe, and Trafford. The team plan and provide a range of services for people with learning disabilities who experience additional health needs as well as advice and training for family, carers and support staff. The teams consist of community learning disability nurses, psychiatrists and clinical psychologists, speech and language and occupational therapists, physiotherapists and health facilitation nurses.

CWP has two assessment and treatment units providing specific inpatient assessment and treatment for people with learning disability; the Eastway Assessment and Treatment Unit in Chester and the Greenways Assessment and Treatment Unit in Macclesfield. In addition they provide adult respite care at Crook Lane Respite Unit in Winsford and Thorn Heys Unit in Oxton, Wirral. The respite units provide short breaks for adults with learning disabilities who have additional complex needs such as profound and multiple disabilities or challenging behaviour. CWP also provides a low secure service at the Alderley Unit; a 15 bed all-male unit for adults with mild to moderate learning disabilities who have or are assessed likely to commit and offence.

## MERSEY CARE

Mersey Care has two Learning Disabilities Community Teams in Sefton and Liverpool which support people with learning disabilities and substantial and complex health needs. The team also provides a bespoke care pathway for people with Down's syndrome and dementia. In addition, Mersey Care has a Learning Disabilities Community Focus Team based in Southport which provides daily activity for people with learning disability through physical engagement, social assessment of needs and assessing the local community. Mersey Care has two specialist Asperger's Services which diagnoses and provides specialist support for people living with Asperger's based in Liverpool and Sefton. Sefton also has an adult Attention Deficit Hyperactivity Disorder (ADHD) service which provides assessment and diagnosis for adults transferred by their GP as well as supporting patients transitioning from CAMHS and community paediatrics.

Mersey Care provides inpatient services for people with learning disabilities and additional needs through the STAR Assessment and Treatment Unit based at Mossley Hill Hospital. The Unit also provides inpatient services for young people aged 16 to 18 years who are transitioning from children's services and are already in the care of a learning disabilities consultant. Learning disabilities assessment and respite is also provided a Wavertree Bungalow for those with learning disabilities and additional complex health needs. The Bungalow has five beds for respite breaks and one assessment bed. Finally, Mersey Care also provides a Forensic Personality Disorder and Autism Spectrum Disorder Assessment and Liaison Service (FPAALS) which is a specialist assessment and liaison service for people from Merseyside and Cheshire who experience significant personality disorder or autism spectrum disorder problems who are also thought to pose a potential serious harm to others.

### 5.3 SERVICE USE

Two of the three providers supplied information on patient referrals, initial assessments, referrals, contacts with community teams; inpatient stays, and discharge from services. Data was provided for a minimum of one year with data from Mersey Care and 5BP covering a three period and CWP covering a five year period. The data for each provider is summarised below but the key findings for all three services suggest that:

- Mersey Care and CWP had 1,415 and 1,927 individuals respectively with learning disabilities on their case load in 2015.
- The majority of clients attended the services in their LA of residence although there was some crossover within and across both provider organisations
- Three fifths of clients at Mersey Care and CWP services were male; the majority were between 21 and 60 years and of white ethnicity.
- There were roughly 3,500 patients referred to each provider across the three year period with the exception of 5 boroughs where the number of referrals was lower at just under 2,000. Across the three services, the majority of referrals where source was known were made by GPs. The number of patients with a repeat referral in a 12 month period differed between services with 13% of Mersey Care patients re-referred compared with 47% of CPW patients.
- Mersey Care have seen an increase in the mean number of inpatient days (from 10.3 in 2012/3 to 12.5 in 2014/15) whilst CWP has seen a decline (from 26.9 in 2012 to 18.9 in 2014).
- Both Mersey Care and CWP had roughly 30,000 contacts each in the last year of which approximately two thirds were seen face to face. Just under one in ten contacts were

unsuccessful with the majority being due to the client not attending or cancelling the contact. At 5BP the number of community team contacts was slightly lower at just over 17,000.

- The majority of discharges for all three providers were made on medical/ professional advice.

## MERSEY CARE

### PATIENT CHARACTERISTICS

There were 1,415 individuals with LD on the Mersey Care caseload in 2015 (as of 24/11/2015). The vast majority (99%) of clients were resident in Cheshire and Merseyside with the largest proportion residents of Liverpool CCG (54%) followed by Southport and Formby (24%) and South Sefton (21%). Three fifths (60%) of clients were males and there was little variation across the teams and the majority of clients (88%) were of white British ethnicity. The accommodation status and employment status of the majority of clients (81.6%) was unknown.

The majority of patients were aged 21-64 years (82.3%) with 9.8% under 21 years and 7.6% aged 65 years and over. Individuals on the Asperger's team caseloads were younger (18.5% under 21 years) than on the learning disability teams caseloads (7.4% under 21 years) while a higher proportion learning disability team clients were aged 65 years and older (9.3% compared with 1% of those accessing Asperger's Teams)

Liverpool Learning Disability Team had the largest number of clients (564 individuals, 39.9%) followed by Southport Learning Disability Team (25.8%) and Liverpool Asperger's Team (194 individuals, 13.7%).

### REFERRALS

Across 2012/13 – 2014/15 there were 3,865 referrals made to the community learning disability and Asperger's Teams; the largest proportion of these were made to the Liverpool Learning Disability Team (40%) followed by the Liverpool Asperger's Team (25%). There is a significant drop in the number of referrals in 2015 (from 1,438 in 2014 to 329 in 2015) although it is important to note that data for 2015 was extracted in mid-November (19/11/2015) so does not reflect a full year's worth of data. Data was provided on the referral reason but the majority were recorded as unknown or unspecified (99.8%). In total, 3,863 of the 3,865 referrals made were accepted (99.9%).

**Table 36: Mersey Care Learning Disability Referrals by year and team.**

Team	2012	2013	2014	2015	Grand Total
Asperger Team Sefton	<5		139	47	188
Aspergers Team Lpool	210	304	377	76	967
Community Focus Team	<5				<5
Liverpool	384	533	531	117	1565
Sefton	127	166	170	32	495
Southport	154	217	220	57	648
West Lancs			<5		<5
<b>Grand Total</b>	<b>878</b>	<b>1220</b>	<b>1438</b>	<b>329</b>	<b>3865</b>

Detailed information was provided on referral source; a full breakdown is provided in Appendix M1. The largest proportion of referrals over the four year period (2012-2015) were made by a general practitioner

(32%, 1,233 referrals). A further 12% were referred by either a social worker or social services. Ten percent were referred by a carer and 3% self-referred.

### REPEAT REFERRALS

Of 3865 Learning Disabilities referrals (2719 individual patients) between 01/04/2012 and 31/03/2015 a total of 501 patients were re referred to LD Services. In 2014, 1208 Patients were referred with a total of 1438 referrals, of the 1208 Patients, 200 patients were re referred to LD Services.

### INITIAL ASSESSMENTS

Data was provided on 1660 initial assessments undertaken between 2012 and 2015. The breakdown of assessments by year is shown in figure 19 below

**Figure 19: Number of initial assessments, 2012-2015, Mersey Care**

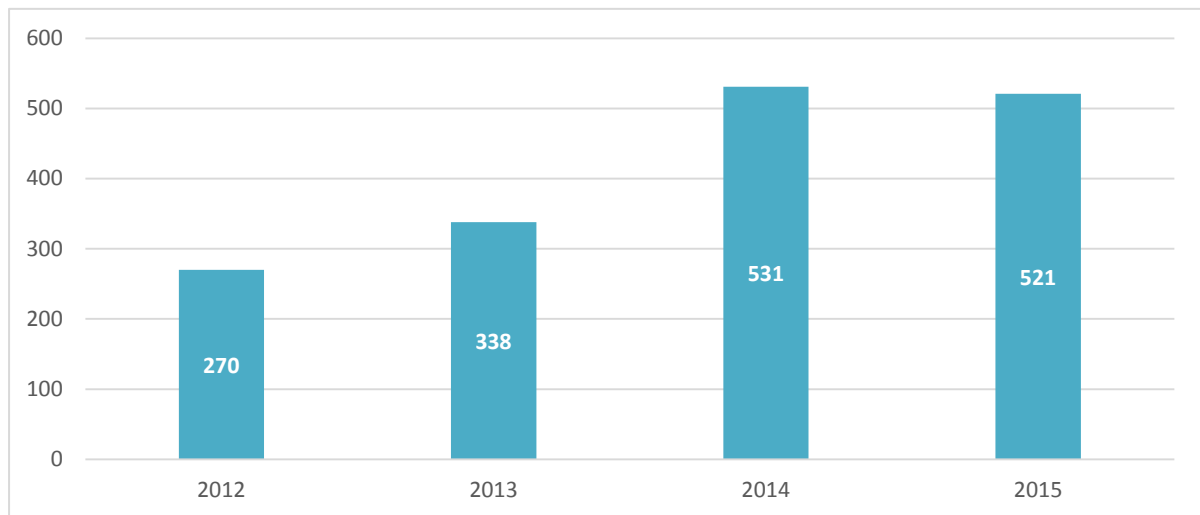


Table 37 below shows the outcome of initial assessments undertaken between 2012 and 2015. The majority either had another contact to be arranged (36.6%) or had another appointment given (19.8%). 8.3% had no further contact after the initial assessment.



**Table 37: Outcome of initial assessments 2012-15, Mersey Care**

Outcome of assessment	Total	%
Another Appointment Given	328	20%
Appointment /Contact Later	94	6%
Appointment /Contact TBA	425	26%
Discharge From Care	32	2%
Discharge to Other Agency	<5	
No further Contact	137	8%
Ref CI Nurse Spec	<5	
Ref Other Services	<5	
Ref to Alternatives	6	0.4%
Ref to CMHT	<5	
Ref to Consultant	<5	
Ref to GP	<5	
Review Again	<5	
Admitted to Ward	<5	
Null	625	38%
<b>Total</b>	<b>1660</b>	

### LD CONTACTS

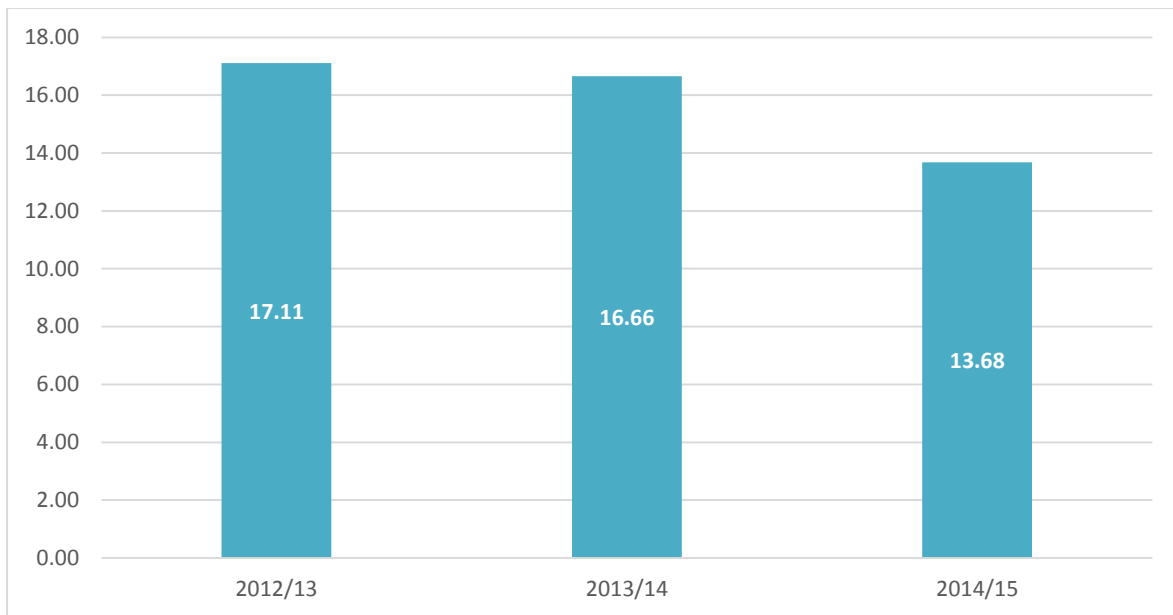
In total, patients with Learning Disabilities known to Mersey Care had 113,666 contacts for learning disability over the three year period (2012/13 – 2014/15). This figure is based on contacts for learning disability made with any team including non-Mersey Care services in West Lancashire. In 2014/15 there were 35,165 contacts of which 67% (23,593 contacts) were seen and a further 24% (8,440 contacts) were non-face-face contact. Of the remaining 9%, where the contact was not successful, the majority were because the service user did not attend (4%, 1,342) or were cancelled by the service user (3%, 975 contacts).

### LD COMMUNITY TEAMS

Across the three year period 3,693 patients who had a total of 112,545 contacts with the Learning disability community teams, specialist Asperger's team, Community Focus Team and Mental Health and Learning Disability Physio Team. In this case contact includes those not only seen but also contacts that were DNAs, cancelled or declined.

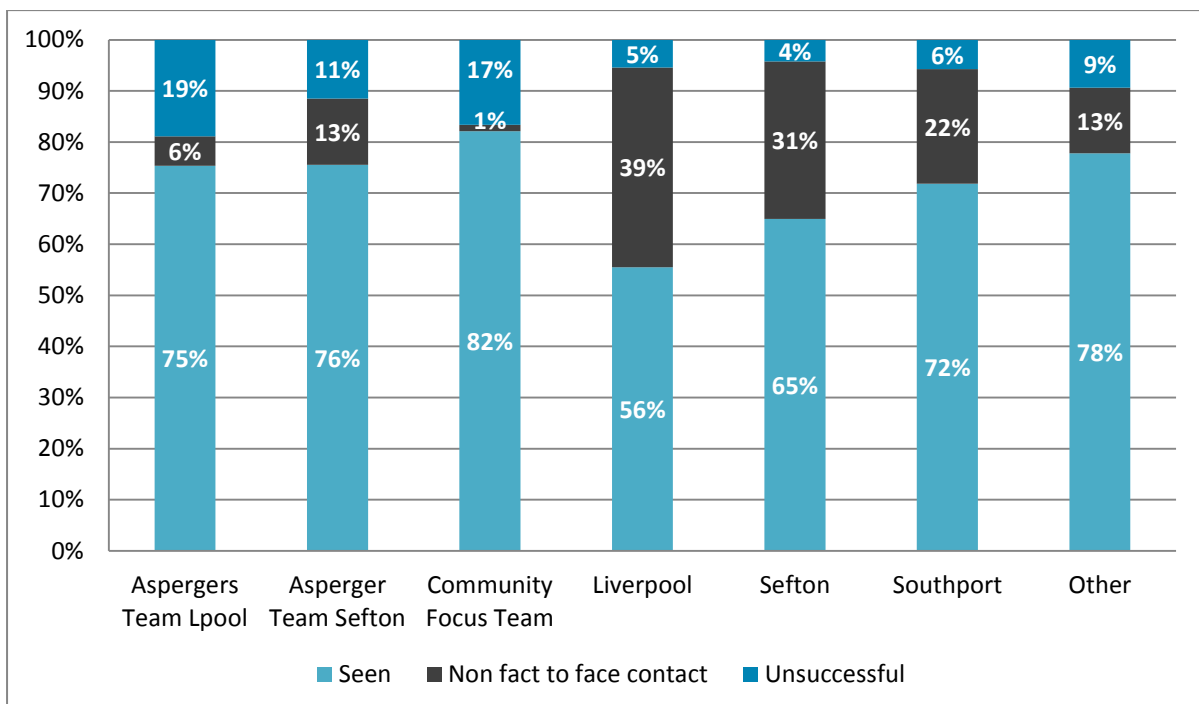
The mean number of contacts per year per person has declined over the three year period from 17.1 in 2012/13 to 13.7 in 2014/15.

**Figure 20: Mean number of annual contacts with Community Learning Disability teams, Mersey Care**



As previously highlighted, 67% of contacts in 2014/15 were seen face to face and a further 24% were non-face-to-face contact. Of all contacts, 9% were unsuccessful. Figure 21 below provides the proportion of contacts which were seen, non-face-to-face contact and unsuccessful; the proportion across the teams was fairly similar however the Liverpool and Sefton Asperger’s teams and the Community Focus Team had a slightly higher proportion of unsuccessful contacts and the Liverpool and Sefton Community Learning Disability Teams had a slightly higher proportion of non-face-to-face contacts.

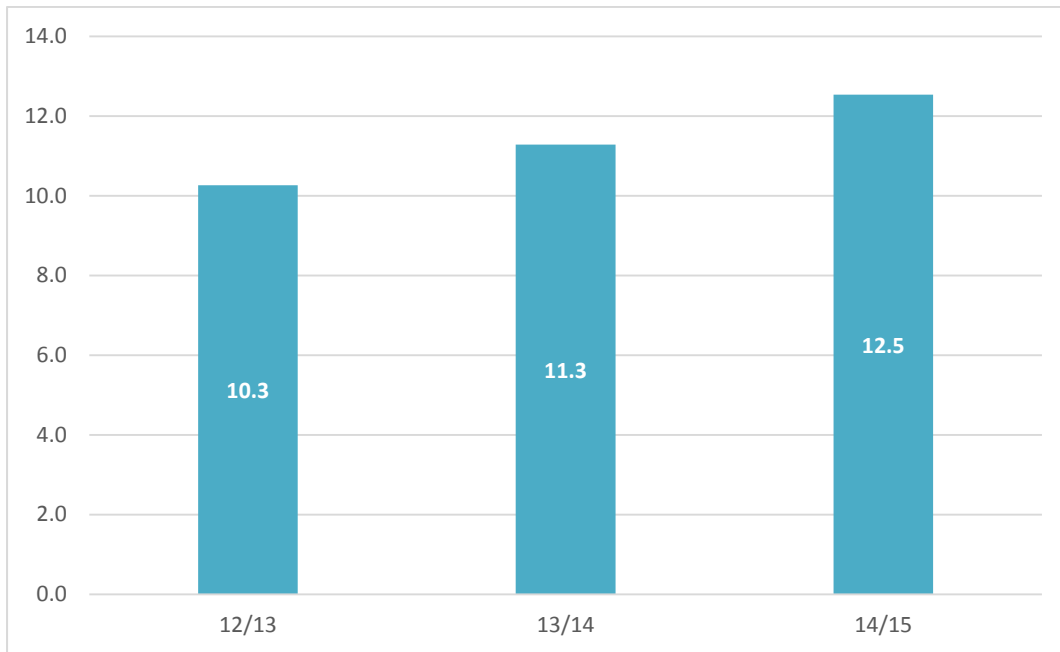
**Figure 21: Contact outcome by Learning Disability Service, Mersey Care 2014/15**



## LENGTH OF INPATIENT STAY

The total number of inpatient days remained steady between 2012/13 and 2014/15 at just over 4,500 per year. The mean length of inpatient stay as increased by one day per year over the three year period from 10.3 in 2012/13 to 12.5 in 2014/15.

**Figure 22: Mean length of inpatient stay, Mersey Care**



## NUMBER OF DISCHARGES BY REASON

There were 1,229 discharges recorded across the three year period (2012/13 – 2014/15) of which the vast majority (99%) were on medical advice.

**Table 38: Discharge of individuals with Learning Disabilities by reason, Mersey Care**

Year	On Medical Advice	Medical Advice - Expected Return	Self Or Relative	Died	Total
12/13	451	<5		<5	453
13/14	399	<5			401
14/15	370	<5	<5		375

PATIENT CHARACTERISTICS

There were 1,927 individuals with learning disability on the CWP caseload in 2015 (as of November 2015). The vast majority of clients were resident in Cheshire and Merseyside (91%) with the vast majority of all clients resident in Wirral (42%) followed by Cheshire West and Chester (25%) and Cheshire East (21%). Three fifths of clients (60%) were male. The employment status of just over half of clients was unknown (55%). A further 25% were known to be in employment, 9% were in unpaid voluntary work and 8% were unemployed and seeking work. The accommodation status of just over half of clients was unknown (54%). A further 22% were in settled mainstream housing, however the next largest proportion (7%) were reported to be squatting.

The majority (65%) of clients were aged between 21 and 60 years. A quarter of clients were aged 20 years and under 2% were aged 10 years and under. Older adults (aged 61 years and over) accounted for 10% of clients with those aged 71 years and over accounting for 3%. Clients with learning disability were slightly younger than those with Asperger’s; data was compared across the four year period as the number of clients with Asperger’s in a single year was quite small. Overall, 41% of clients with LD were aged between 11 and 20 years compared with 5% of those with Asperger’s. A considerably higher proportion of those with Asperger’s were aged between 31 and 50 years (54%) compared with those with LD (21%).

REFERRALS

There were 7,836 referrals made for 2,132 individuals with Learning Disability at CWP over the five year period. The average number of referrals made per patient over the 5 years period was 3.7 (range 1 to 97). The majority of referrals were community teams (60%) followed by inpatient services (29%).

Table 39 shows the source of referral for people with learning disability. Please note that the total number is greater than the number of patients as individuals may have been referred by more than one referral source over the period. The largest proportion were referred from sources categorised as other (48%). This was followed by GP referrals (22%) and referrals from staff (17%) within the provider or in community teams including learning disabilities, mental health and alcohol. A further 6% were referred by an outside agency, 5% by a contact which included carers, relatives and ‘concerned other’, 1% were referred by a school and 1% self-referred.

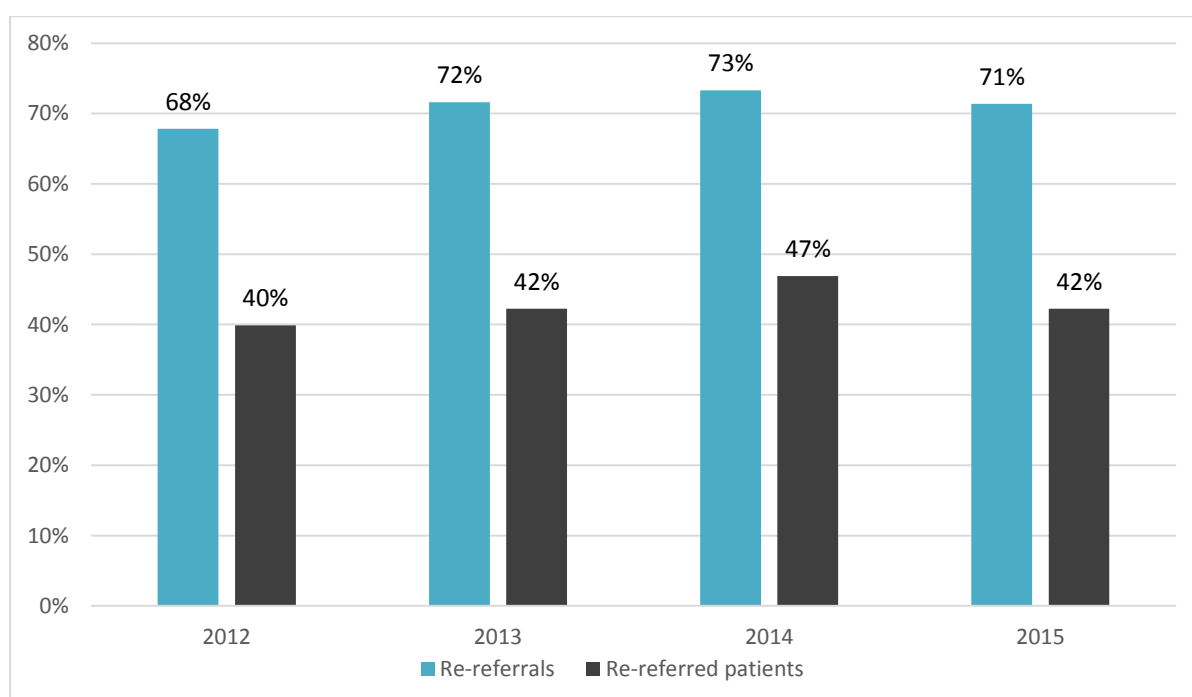
**Table 39: Referrals by source, 2010-2015, Cheshire and Wirral Partnership**

Referral source	Number of referrals	%
Agency	209	6%
Contact	162	5%
GP	765	22%
Other	1629	48%
School	48	1%
Self	39	1%
Staff	572	17%
<b>Total</b>	<b>3424</b>	

## REPEAT REFERRALS

Between 2012 and 2015, there were 11,762 referrals made for 3187 patients; of these 10,910 were re-referrals (93%) over the four year period for 2,335 patients (73%). Figure 23 below shows the proportion of re-referrals in a 12 month period; the blue bar indicates the number of re-referrals which occurred in each 12 month period whilst the red bar indicates the proportion of patients referred during the 12 month period who were referred more than once. Data for 2015 is partial data, but the preceding years suggest that the number of re-referrals has increased year on year from 68% on 2012 to 73% in 2014. The number of patients re-referred has also increase from 40% in 2012 to 47% in 2014.

**Figure 23: Repeat referrals, 2012-2015, Cheshire and Wirral Partnership**



## INITIAL ASSESSMENTS

There were 2,183 initial assessments undertaken over the five year period of which 920 were outpatient assessments.

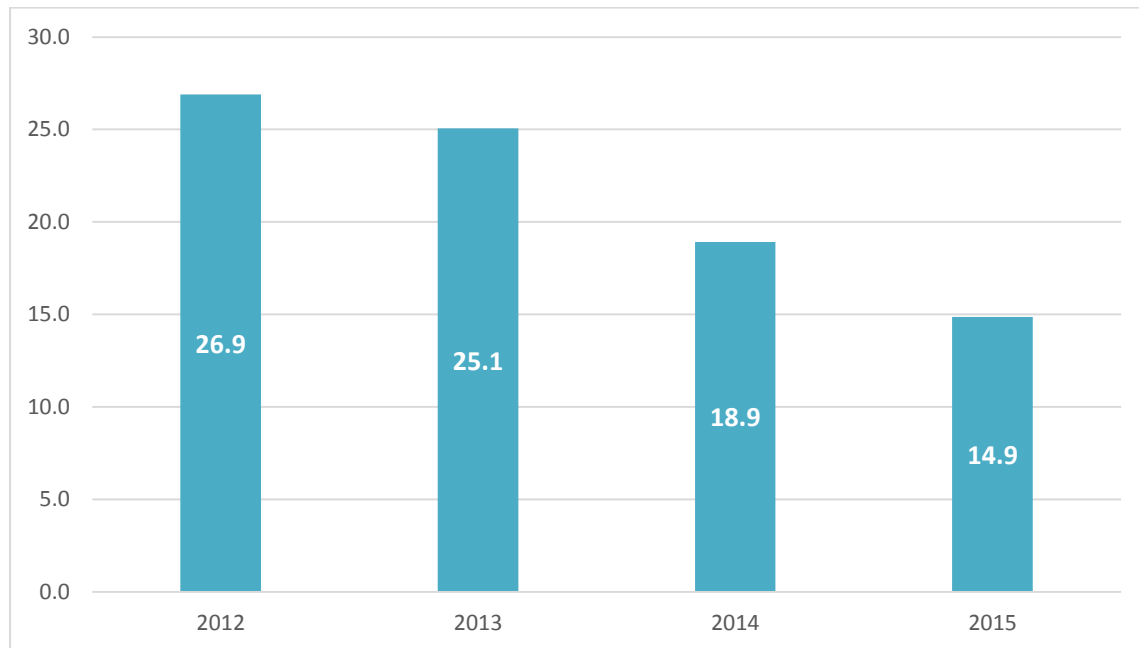
## LEARNING DISABILITY CONTACTS

In total 3,964 Cheshire and Wirral Partnership clients with Learning Disability had 112,599 contacts (including outpatient appointments) between 2012 and 2015. In 2014 there were 27,873 contacts of which 67% (17,208 contacts) were seen and a further 30% (8,448 contacts) were non-face-to-face contacts including telephone and Telecare, email and text message. Overall 8% of contacts were unsuccessful and in the majority were because the patient did not attend (4% of total contacts) or were cancelled by the patient (2% of total contacts).

## LENGTH OF INPATIENT STAY

Between 2012 and 2015, there were 42,042 inpatient days. The total number of inpatient days has declined from 13,235 in 2012 to 10,067 in 2014. At the point of data extraction, there had been 5,633 inpatient days in 2015; suggesting a further decline. Figure 24 shows the mean number of inpatient days per inpatient episode per year. The mean number of inpatient days has declined from 26.9 in 2012 to 18.9 in 2014.

**Figure 24: Mean length of inpatient stay, 2012-2015. Cheshire and Wirral Partnership**



As expected there was considerable variation in the mean length of inpatient days by location. Pine Lodge Children and Young People's Therapeutic Ward had the highest number of mean inpatient days (438.5 days) whilst Respite Wards at Primrose Avenue, Crook Lane and Thorn Heys had the lowest mean inpatient days (4.5, 8.6 and 8.8 days respectively).

## DISCHARGES

There were 5,972 discharges between 2012 and 2015. Just over four in ten (41%) were discharged by a medical professional with an additional 16% recorded as treatment completed and 10% referred on.

## 5 BOROUGH PARTNERSHIP

### REFERRALS

Across 2013/14 to 2015/16, there were 1,732 referrals made to the 5bp community Learning Disability Teams with the largest proportion made to the Knowsley Team (n=488; 28%). There was a decline in the number of referrals made from 2013/14 (n=786) and 2014/15 (n=697).

**Table 40: 5bp Learning Disability Referrals by year and team.**

Team	2013/14	2014/15	2015/16	Grand Total
Halton Community LD Team	178	181	55	<b>414</b>
Knowsley Community LD Team	213	204	71	<b>488</b>
St Helens Community LD Team	155	147	61	<b>363</b>
Warrington Community LD Team	240	165	62	<b>467</b>
Annual Total	<b>786</b>	<b>697</b>	<b>249</b>	<b>1732</b>

Detailed information was provided on the source of referral which is presented in table 41 below. The majority of referrals across the 2013-2016 period were made by social services (31%) followed by 'other health service/speciality' (22%) and General Practice (20%).

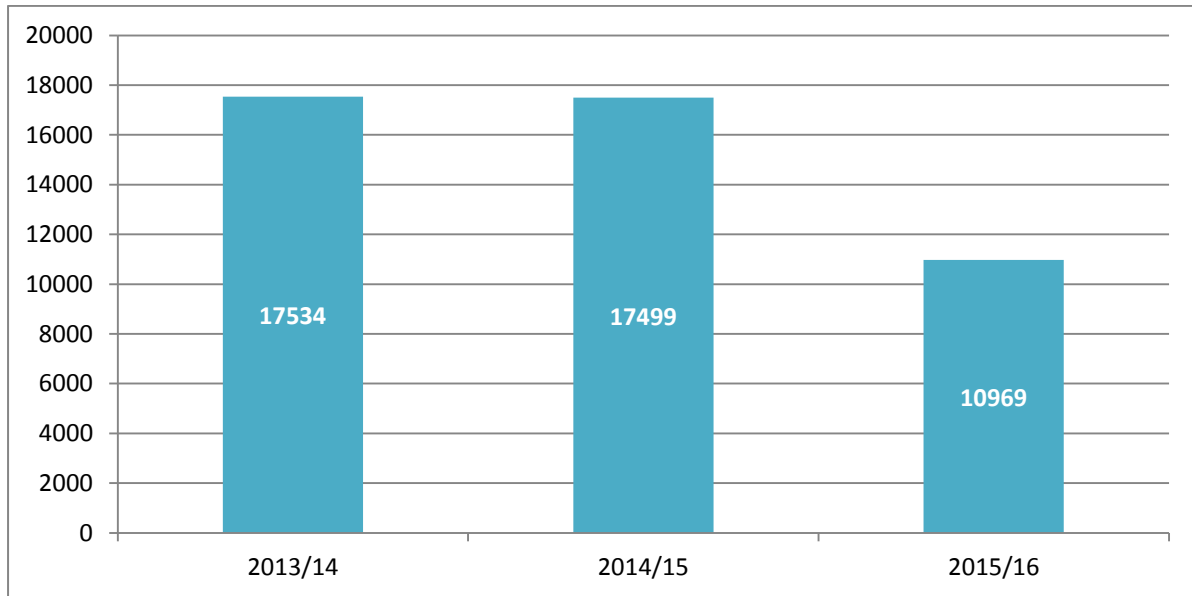
**Table 41: 5bp Learning Disability Referrals by referral source 2013/14-2015/16.**

Source	Total
Internal	<b>246</b>
Carer	<b>38</b>
Education Service	<b>17</b>
General Practice	<b>341</b>
Legal system	<b>&lt;5</b>
Other department if LA	<b>&lt;5</b>
Other health service/specialty	<b>385</b>
Other source	<b>121</b>
Police	<b>&lt;5</b>
Prison Service	<b>&lt;5</b>
Relative/friend	<b>26</b>
Self	<b>9</b>
Social Services	<b>535</b>
Transfer by graduation from local Child & Adolescent MH Services	<b>5</b>
Unknown	<b>&lt;5</b>
Youth Offending Team	<b>&lt;5</b>
Annual Total	<b>1732</b>

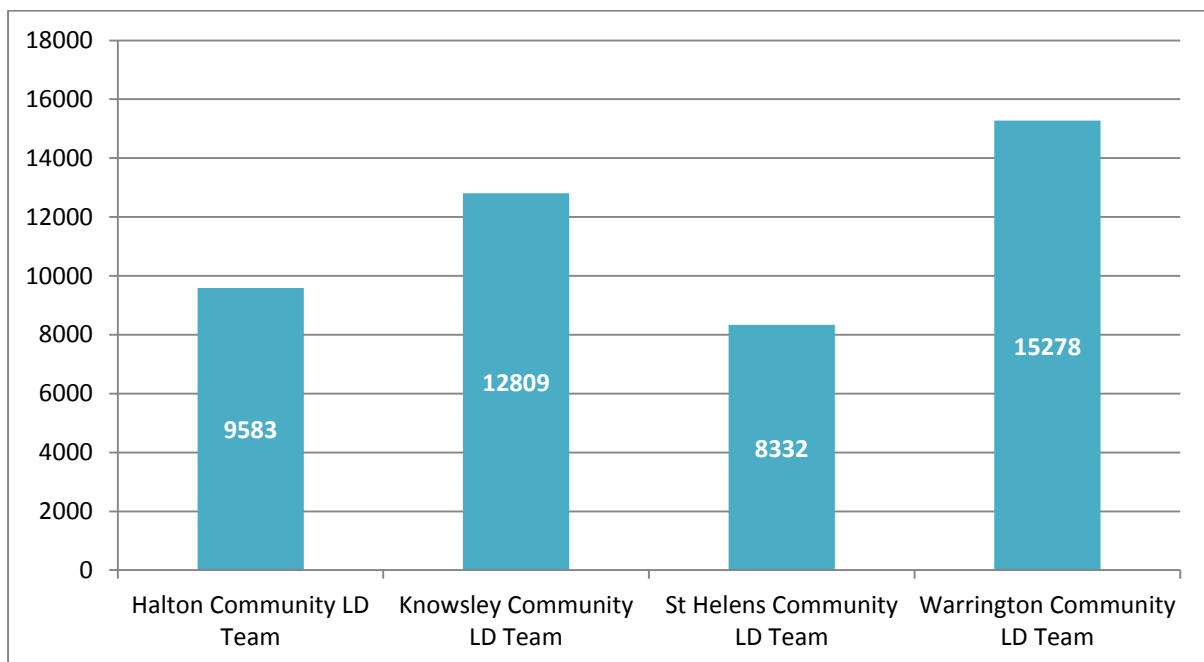
## LEARNING DISABILITY COMMUNITY TEAM CONTACTS

Across the three year period there were a total of 46,002 contacts with the four community learning disability teams. There was a decline in the number of contacts between 2014/15 and 2015/16 has declined from 17,499 to 10,969 but this is at least partly due to the fact that 2015/16 data is only available until November 2015 and so does not represent a full year of data. The number of contacts between 2014/14 and 2014/15 remained relatively stable with just a small decline from 17,534 in 2013/14 to 17,499 in 2014/15.

**Figure 25: 5bp Learning Disability Community Team Contacts by year**



**Figure 26: 5bp Learning Disability Community Team Contacts by team 2013/14 -2015/16**

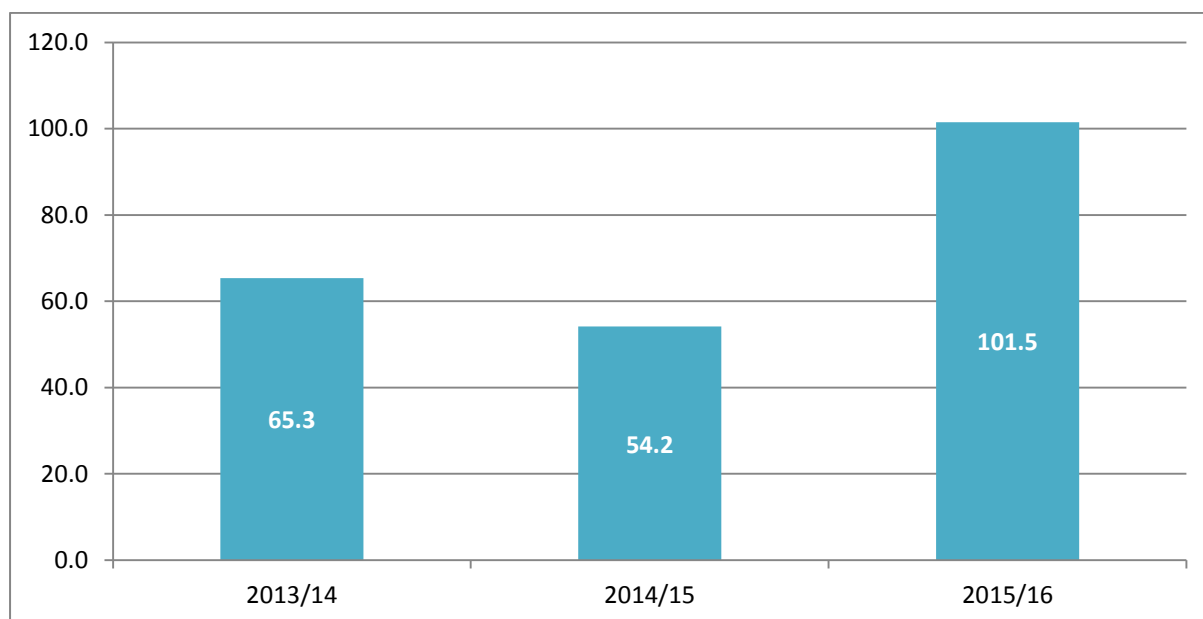




## LENGTH OF INPATIENT STAY

In total there were 7,302 occupied bed days between April 2013 and November 2015. Figure 27 presents that mean length of inpatient stay per year (please note 2015/16 represents data until November 2015 and is not a full years data). The mean length of inpatient stays have increased over the three year period from 65.3 in 2013/14 to 101.5 in 2015/16. Please note that in the case of 5BP, the average length of stay is calculated cumulatively for each financial year and is reset in the April of each new financial year and so the numbers presented here are not directly comparable with other providers

**Figure 27: Mean length of inpatient stay, 5 borough partnership, 2013/14 – 2015/16**



## NUMBER OF DISCHARGES BY REASON

There were 1,694 discharges across the three year period. The largest number were made by Knowsley Community Learning Disability Team (the team which also had the largest number of contacts across the period).

**Table 42: Discharged from care, 5bp by team and year**

Team	2013/14	2014/15	2015/16	Grand Total
Halton Community LD Team	165	187	122	<b>474</b>
Knowsley Community LD Team	176	190	122	<b>488</b>
St Helens Community LD Team	154	149	109	<b>412</b>
Warrington Community LD Team	181	81	58	<b>320</b>
Annual Total	<b>676</b>	<b>607</b>	<b>411</b>	<b>1694</b>

The majority of discharges were made on professional advice (72%). A further 16% were referrals which were not accepted.

## 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 out in order to ensure equal access to services, as required by the Disability and Equality Act 2010:

### **Empowering individuals**

1.1 Ensure that people with learning disabilities in each local authority and CCG in Cheshire and Merseyside have the opportunity to contribute to needs assessments and the development of services. This is the second needs assessment produced across the two counties but it is vital that the data and evidence presented here is triangulated with insights from those living with a learning disability.

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, Transforming Care, 2015).

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

1.4 Review the quality of housing for people living with learning disability including those who are living with family. The proportion of adults with learning disability in Cheshire and Merseyside living in their own home is above the national average but there is little indication of housing quality.

1.5 Ensure young people with learning disabilities have access to high quality sex and relationship education including raising awareness of sexual exploitation and healthy relationships.

1.6 Ensure that all services are actively working to reduce social isolation among people with learning disabilities by signposting and referring to community and third sector organisations and leisure activities.

1.7 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.

### **Right Care in the Right Place**

2.1 Ensure strong partnership and collaborations are in place between Local Authorities and Clinical Commissioning Groups to ensure that people with a learning disability have access to information, advocacy, support and care as and when they need it.

2.2 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.

2.3 Reduce reliance on inpatient beds in line with the Transforming Care (2015) Programme by reducing the length of inpatients stays and ensuring that care and treatment needed by those with learning disabilities is available in the right place at the right time.

2.4 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). Ensuring that all AT&T plans include measures to alleviate social isolation.

2.5 Introduce routine screening for learning disability in prison and make reasonable adjustments and develop easy read information to ensure prisoners with learning disabilities understand prison routines.

2.6 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).

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

2.8 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 and health checks. This should tackle issues around reasons for high refusal and non-attendance (DNA) rates and would include the provision of 'easy read' materials.

2.9 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.

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

2.11 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).

### **Workforce Development**

3.1 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:

3.1.1 Making all self-help and service information 'easy to read'.

3.1.2 Ensuring support is available where required, for example in housing application processes.

3.1.3 Providing 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.

3.2 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.

3.3 Work collaboratively with partners to ensure that safeguarding referrals are being made appropriately.

3.4 Improve awareness among individuals, learning disability and criminal justice professionals the process for reporting disability related hate crime.

3.5 Provide training for those who work in the criminal justice system including police, court and custody suite staff on recognising, approaching, communicating and interviewing/questioning those with learning disabilities and autism and strengthen collaboration between health and social care providers and partners

3.6 Strengthen collaboration between adult and children's services to ensure that the needs of parents with learning disabilities and their children are being met.

3.7 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.

3.8 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).

3.9 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).

3.10 Provide better transport solutions for people with learning disabilities and autism, organised by councils, charities and communities in partnership, including increasing public and driver awareness of learning disabilities and autism and improving acceptance of disabled people on public transport.

3.11 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).

3.12 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.

3.13 Ensure provider organisations, families and carers have easy access to specialist support, assessment and intervention services from multi-disciplinary team to support any issues with challenging behaviour.

## **Data**

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

### *Definitions*

4.1 *Challenging behaviour*: 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.

4.2 *Learning disability among children*: introduce standard definition and collection of data on children with learning disability rather than relying on numbers with learning difficulty (as reported in the School Census). Liverpool City Council's work on producing a single dataset for children and young people will assist in this

4.3 *Asperger's*: Ensure that data on *Asperger's* from Local Authority, GP practice and provider captures those with a primary and secondary diagnosis of *Asperger's* and allows for the identification of those with a diagnosis of learning disability and *Asperger's* who are not eligible for Specialist Autism Services.

#### *Monitoring and Quality*

4.4 Ensure that local authority and GP information systems across Cheshire and Merseyside allow for the collection of comparable data which can be shared across organisations to allow the needs of the population with learning disabilities can be truly quantified.

4.5 Ensure GP information systems record 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.

4.6 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.

4.7 In consultation with service users, providers and commissioners, develop a routine dataset specification for use in JSNAs, needs assessments and to inform planning and policy across Cheshire and Merseyside. This should include standard terms and definitions across the three providers (as detailed above) to allow for easy and timely extraction of data to inform decision making.

4.8 Parental status: improve the recording of parental status among adults with learning disabilities across GP practice, local authority and providers so that the needs of parents can be catered for including through joint working between health and social care and maternity services.

4.9 Improve reporting of accommodation status at both LA level and across NHS organisations to ensure individuals' needs are recognised and all adults with learning disabilities have access to the level and quality of support they need.

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

4.11 Within hospital IT systems 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.

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

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

4.14 Further investigate the needs of people with autism as data collection improves and consider a separate needs assessment for autism and *Asperger's* which uses engagement with service users, the wider population with autism and *Asperger's* to address some of the gaps in data.

4.15 Further investigate the needs of children with learning disabilities and/ or autism spectrum disorders particularly those who are transitioning to adult services. Collaborative work with partners in health,

social care and education is needed to assist in the collection of a dataset on children with learning disabilities and autism spectrum disorders to allow the health needs of this group to be fully assessed.

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## 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) ([http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4132145](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-cg142/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.

### **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](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 data and provided guidance and assistance for this report, including:**

Jackie Rooney, NHS England

Chris Williamson, Liverpool City Council

Colin Vose, Consultant

Paul Horwood, Sefton Council

Paul Langton and Gavin Roberts, Knowsley Council

Tracey Flute, Warrington Council

Sara Deakin and Joyce Baxter, Cheshire West and Chester Council

John Highton, Alan Ging and Sarah Kinsella, Wirral Council

Steve Knuckey and Mark Switonski, St Helens Council

Aysha Gunal, NHS England

Ruth Waldron and Irene Byrne Watts, Mersey Care

Jennifer Prest, Neil Griffiths and Vikram Palanisamy, Cheshire West and Wirral Partnership

Mike Roscoe and Alastair Barrowcliffe, 5 Borough Partnership NHS Trust

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