

**Learning Disabilities and Autistic
Spectrum Disorder
Joint Strategic Needs Assessment
(JSNA)**

December 2017

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1 Introduction

This JSNA aims to assess both the needs of people living in Cumbria with learning disabilities or autism; behaviours viewed as challenging (and mental health conditions – see [Mental Health JSNA Chapter](#)); as well as assess the care, support and services which are available across the county. This JSNA will assess both children and adults.

The Department of Health Review “Transforming care: A national response to Winterbourne View Hospital; Final Report, December 2012” followed investigations and reviews including from service users and their families and those who represent them, where they identified that many people do not receive good quality care. The Review found widespread poor service design, failures in commissioning, failure to transform services in line with good practice, and failures in developing a person-centred and multidisciplinary approach to service provision.

The Department of Health stipulated that by June 2014, the way that services are commissioned and delivered should be transformed so that people are not placed in hospitals where there is not a need for them, provide the right model of care, and improve the quality of care and support for people with learning disabilities and/or autism, challenging behaviour, and mental health conditions.

Cumbria County Council and organisations across the health and care system are committed to transforming care for people with learning disabilities and/or autism and mental health problems or behaviour that challenges.

2 Key facts

2.1 Learning disabilities

- The number of estimated adults with a learning disability and pupils with a learning difficulty in Cumbria is much greater than those registered on Learning Disability GP Practice Registers.

- There are an estimated 9,409 adults (18+) with a learning disability in Cumbria; while there are just 2,614 people (all ages) on GP Registers with a recorded learning disability (0.5% of all patients)
- There are 1,359 Adult Social Care (ASC) service users (18+) with a recorded learning disability (1 in 5 ASC service users) of those 1,063 are being cared for.
- There are 4,176 children (pupils aged 3-18 years known to CCC) with a learning difficulty (SEND)
- A total of 1,675 people are in contact with Learning Disability and Autism (LDA) services in Cumbria. (845 people through CPFT; while 830 people through NHS Cumbria CCG)
- There are around 22 inpatients with a learning disability and/or autism in Cumbria in NHS hospital beds
- People with learning disabilities tend to have poorer health than the rest of the general population, of which can often be avoidable
- 1 in 3 deaths (37%) of people with learning disabilities are avoidable
- Men with learning disabilities die on average 13 years earlier than those without
- Women with learning disabilities die on average 20 years earlier than those without
- The most common underlying causes of death are heart and circulatory disorders; and cancer
- Cumbria County Council recognise that learning disability needs of Adult Social Care service users may not always be picked up and met through Assessments

2.2 Autism

- There are an estimated 5,353 people (all ages) in Cumbria with autism
- There are an estimated 1,060 children (0-18yrs) in Cumbria with autism
- Nationally, estimates of autism are greater in men (1.5%) than women (0.2%)
- There are 815 children (pupils aged 3-18 years) with Autistic Spectrum Disorder
- There are 97 Adult Social Care service users with recorded autism or Aspergers
- There is currently no requirement for GPs to record autism separately on an Autism Register
- Research shows that substance misuse services do not have the required skills and training to support autistic people
- It is recognised that there is a need to understand premature mortality amongst autistic people
- Leading causes of death in autistic people are neurological disorders (i.e. epilepsy) and suicide

- Accessing support can be difficult – there are few services which specify that they provide support to people with autism

3 Policy background

3.1 Learning Disabilities

A learning disability affects the way a person learns new things; how they understand and interpret information; and how they communicate. A learning disability can be mild, moderate or severe, all with varying levels of personal ability and need. Some individuals may have a profound and multiple learning disabilities (PMLD), while others may be able to cope and look after themselves.

In some cases there are no known causes for a learning disability, however, often they occur when the development of the brain is affected either before birth, during birth or in early childhood. There are many factors which may cause a learning disability including: illness of the mother during pregnancy; lack of oxygen to the brain during birth; genetic development; inherited genetics; illness (i.e. meningitis) or injury in early childhood.

Learning disabilities are often associated with other conditions, for example cerebral palsy, Down's syndrome; and epilepsy (around 30%). Furthermore, some people with learning disabilities also have autism (approximately 33%).

There are an estimated 9,409 adults (18+) with a learning disability in Cumbria. Whilst the overall number of people with Learning Disabilities is fairly stable, with a small reduction predicted. There are two significant trends:

- The first is a growth in people with Learning Disabilities who are over 65 and who will have a high chance of frailty and of early onset dementia.
- The second is the increase in complexity of the young people transitioning from children's services, in particular people with multiple disabilities and others whose behaviour presents challenges. There is significant demand arising from the predicted needs of young people in transition to adulthood. To manage the demand a re-distribution of resources is expected to handle this pressure.

People with learning disabilities tend to have poorer health than the rest of the general population, of which can often be avoidable. These health inequalities are often the result of barriers to accessing timely and appropriate health care which can have a significant impact.

As well as having a poorer quality of life, people with learning disabilities die at a younger age than people without a learning disability. The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) in 2013 found that men with learning disabilities died on average 13 years younger than men without learning disabilities; while women with learning disabilities died 20 years younger than women without. The Inquiry also found that people with learning disabilities are three times more likely to die from an avoidable condition, something which could be avoided through provision and access to good quality healthcare. If improvements were made then health outcomes of people with learning disabilities would also be improved.

3.2 Autism

“Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them.” (Source: The National Autistic Society <http://www.autism.org.uk/about/what-is.aspx>)

Autism is a spectrum condition and while individuals may share certain difficulties it will affect them in different ways. The term Autism is used to describe all diagnostic autism profiles including Asperger syndrome and Pathological Demand Avoidance (PDA). Asperger syndrome is associated with individuals who are on the autism spectrum but do not have learning disabilities, have good language skills but have social communication difficulties. PDA describes a person who may significantly avoid demands and expectations caused by high levels of anxiety relating to conforming to social demands; and of not being in control of a situation.

Autism is often diagnosed alongside other conditions such as Attention Deficit Hyperactivity Disorder (ADHD); hearing impairment; visual impairment; Down’s syndrome; dyslexia; dyspraxia; epilepsy; Foetal Anti-Convulsant syndrome (FACS); Fragile X syndrome; Hyperlexia; learning disabilities (approximately 50%); social communication disorder; and mental health issues (approximately 70%) (Source: National Autistic Society).

The exact cause of autism is currently unknown. It is a complex condition that may occur as a result of genetic predisposition, environmental or unknown factors.

There are around 700,000 people in the UK living with autism, equating to more than 1 in 100 people (1.08 per 100 people). If we were to apply this rate to Cumbria’s total population (497,906 as at mid-2016) this would equate to an estimated 5,353 people.

The estimated cost of supporting an individual diagnosed with autism in the UK is £0.92 million, with residential care, supportive living accommodation and individual productivity loss contributing the highest costs (Buescher et al. 2014). However, it is not possible to provide a total cost as the total number of adults with autism is unknown (source: Adult Psychiatric Morbidity Survey 2014).

The Royal College of General Practitioners (RCGP) recognise the health inequalities experienced by autistic people and the statistical invisibility of autism in the health system. Whilst most autistic people should live long and healthy lives a recent survey reported that these individuals receive 'worse' or 'much worse' health care than non-autistic people. They face significant risks to their health and die unacceptably early (source: Westminster Commission on Autism "A Spectrum of Obstacle", 2016).

3.3 Care Act: Protecting adults from abuse or neglect

The Care Act 2014, sets out a clear legal framework for how local authorities and other parts of the health and care system should protect adults at risk of abuse or neglect.

The framework includes Adult Safeguarding which is aimed at adults with care and support needs who may be vulnerable and at risk of abuse or neglect - a key responsibility for local authorities. Public services, Local Authorities and individuals with safeguarding responsibilities must work together to identify and protect those most at risk and help to keep them safe. Source: Care Act 2014; Factsheet 7: Protecting adults from abuse or neglect.

3.4 Autism Act 2009

The Autism Act 2009 was the first disability-specific law in England. It committed the Government to do two things: publish an Adult Autism Strategy which would help to transform services for adults with autism; and provide statutory guidance on its implementation to local councils and health agencies/organisations. In March 2010, the first Strategy was published; and in December 2010 the guidance was published. The 2013/14 review of this strategy Think Autism identified 15 priority challenges for action under three main headings:

- An equal part of my local community
- The right support at the right time during my lifetime
- Developing my skills and independence and working to the best of my ability

3.5 Equality Act 2010 - Learning Disabilities and/or Autism

A person is disabled under the Equality Act 2010 if they have a “physical or mental impairment which has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities.” Both learning disabilities and autism may be treated as a disability under the Equality Act depending on the effect it has on an individual’s daily life.

3.6 Mental Health Act 2007

The Mental Health Act 2007 is there to support people with a mental health disorder which includes: a mental illness; a learning disability (and autism); personality disorder. A person may be detained (sectioned) under the Mental Health Act, for assessment or treatment. The Act provides rights for people with learning disabilities and autism, and introduces safeguards for Deprivation of Liberty – individuals lacking capacity in hospital and care homes. Autism is viewed as a mental disorder under the Act, however, it is recognised that autism (and learning disabilities) are not like mental illnesses which can be treated as such, and that support should be provided in a local community setting as opposed to detention (source: Mental Health Act Code of Practice, 2015).

3.7 North East and Cumbria Learning Disability Network

The North East & Cumbria Learning Disability Network works collaboratively with all Clinical Commissioning Group (CCGs), healthcare providers and local authorities in the region in order to identify and implement initiatives for people with learning disabilities; ensure initiatives consider the needs of people with learning disabilities; identify and share best practice; and to regularly engage with people with learning disabilities and with their carers.

The Network has a Transformation Plan and Programme which sets out the aims of the Network and the ways in which it will go about achieving transforming care for people with learning disabilities, and/or autism, mental health needs or behaviour that challenges.

4 Recommendations for consideration for commissioners

The Transforming Care programme is based on the assumption that children, young people and adults with a learning disability and/or autism with behaviours described as challenging have the right to live satisfying and valued lives and to be treated with dignity and respect.

The way that services are commissioned and delivered should be transformed so that people are not placed in hospitals where there is not a need for them, provide the right model of care, and improve the quality of care and support for people with learning disabilities and/or autism, challenging behaviour, and mental health conditions. Consideration should be made to the introduction of two Clinical Commissioning Groups in Cumbria: North Cumbria; and Morecambe Bay, as from April 2017.

It is recommended that Commissioners of Learning Disability and/or Autism services consider the following:

- The aims of the North East and Cumbria and North West & Lancashire Transformation Programmes
- The key recommendations for improving health and social care services for people on the autism spectrum, as set out in the Autism Act
- The population needs included in this document

5 What is the population overview?

There are around 1.5m people in the UK who have a learning disability; and an estimated 350,000 people living with a severe learning disability. In Cumbria, there are an estimated 9,409 adults who have a learning disability, equating to around 2.3% of Cumbria's adult population. In addition, there are 4,176 pupils (aged 3-18yrs in mainstream nurseries/schools) with a learning difficulty (special educational need and disability).

There are around 700,000 people in the UK living with autism, equating to more than 1 in 100 people (1.08 per 100 people). If we were to apply this rate to Cumbria's total population (497,996 as at mid-2015) this would equate to an estimated 5,353 people.

5.1 GP Practice Register Patients

In Cumbria, in 2015-16, there were 2,614 people (all ages) on Cumbria GP Practice Registers registered with a learning disability, equating to 0.50% of all patients in Cumbria Clinical Commissioning Group (525 people per 100,000); this compares to 0.46% in England (Source: Quality Outcomes Framework, 2015-16). Furthermore, there were 3,976 people on GP Practice Registers with epilepsy, equating to 0.93% of all patients (aged 18+); this compares to 0.80% in England. Currently there is no requirement for GPs to keep a register of autistic people, however, NICE has recommended that one should be developed and that autistic people would receive better care if GPs developed a national register. (Source: NICE: <https://www.nice.org.uk/news/article/autistic-people-will-receive-better-care-if-gps-develop-a-national-register-says-nice>).

6 Who is at risk & why?

6.1 Health and Care of People with Learning Disabilities: 2015-16

Primary Care within NHS Digital, have collected information on people with and without learning disabilities from more than half of all GP Practices across England, in order to identify possible differences in the treatment, health status and outcomes of people with learning disabilities compared to the rest of population. 0.45% of the GP population were recorded as having a learning disability. Key findings:

- 52.3% of females aged 65-69 years had received a breast cancer screening
- 3 in 4 eligible patients received colorectal cancer screening
- Fewer than 1 in 3 eligible females received cervical cancer screening, this compares to 3 in 4 females without a learning disability
- 46.0% of patients received a health check
- 41.3% of patients received a flu immunisation
- Obesity is twice as common in people aged 18-35 with learning disabilities, being underweight is twice as common in people aged over 64 with learning disabilities, compared with patients with no learning disabilities
- Mortality rates of people with a learning disability are almost 3 times higher than those without a learning disability
- Mortality rates in females with a learning disability were significantly higher

- Females with a learning disability have an 18 year lower life expectancy than females in the general population (combined data (2014-15 and 2015-16))
- Males with a learning disability have a 14 year lower life expectancy than males in the general population

6.2 Substance Misuse

Some people with LD misuse alcohol or drugs and some misuse prescribed medications, however, evidence indicates that people with LD are less likely to misuse substances than the general population. Various studies have considered the extent of substance misuse in people with LD, however, it is difficult to measure and the problem is likely to be underestimated as studies are often based on people known to LD services and not those who do not come into contact with services; it is this hidden/unknown group of people with more mild learning disabilities who are most likely to misuse alcohol or drugs.

People with LD who are most at risk of substance misuse are:

- People with a borderline/mild LD
- Young and male
- Have mental health problems
- Living independently
- Boredom/lack of a meaningful occupation
- Desire to be socially included/loneliness
- Limited social skills/low self-esteem
- Lack of family contact
- Impulsivity
- Negative life events (i.e. neglect, abuse, bereavement)
- Unemployment
- Poverty

Although only a small proportion of people with LD are known to have substance misuse problems they are a vulnerable group and therefore there is a need for appropriate services, treatment and support. Research shows that often neither LD services nor substance misuse services have the skills and training resources to support people with LD who have substance misuse problems. (Source: Public Health England: Substance misuse and people with learning disabilities: making reasonable adjustments to services; February 2017).

Equally, there is limited and ambiguous data on substance-use related problems amongst the autistic population. Whilst there has been an assumption that substance misuse is rare a recent study has suggested that there is a doubled risk of substance-use related problems in this population (Butwicka et al., 2016). For more information on Cumbria's Drug & Alcohol services see the Stay Safe chapter of the JSNA [here](#).

6.3 Adult Psychiatric Morbidity Survey (APMS) 2007 and 2014

The Adult Psychiatric Morbidity Survey (APMS) provide data on the prevalence of both treated and untreated psychiatric disorders in the adult population (aged 16 and over) in England. Data from 2007 and 2014 have been combined. Key finding from the survey are set out below:

- The estimated prevalence of autism in adults in private households in England was estimated to be around 0.8% (95% CI: 0.5% to 1.3%)
- Autistic Spectrum Disorders (ASD) were higher in men at 1.5% (95% CI: 0.8% to 2.6%) than women at 0.2% (95% CI: 0.1% to 0.6%)
- No person from an ethnic minority group was identified with autism (this is likely to be due to the small sample size)
- Employment status was not significantly related to whether or not a person had autism (employment and autism is a complex topic which needs further study and research)
- Autism was associated with educational qualification - rates of autism are greater in individuals with no qualifications; fewer adults with autism were qualified to degree level
- Individuals with autism are no more likely than the general adult population to make use of mental/emotional health services

6.4 The National Autistic Society – facts and figures

The National Autistic Society report a series of facts of figures relating to people with autism, and highlight multiple risks and concerns as set out below:

- Autistic people and their families are at risk of being isolated and developing mental health problem

- Autism affects both children and adults
- Autism is a hidden disability
- 34% of children report being bullied at school
- 63% of children are not in suitable schools
- 17% of children have been suspended from school; almost half (48%) had been suspended 3+ times; 4% had been expelled from one or more schools
- 70% of adults say that they are not getting the help they need from social services
- 70% of adults reported that with more support they would feel less isolated
- At least 1 in 3 adults are experiencing severe mental health difficulties due to a lack of support
- 16% of adults in the UK are in full-time paid employment; 32% are in some kind of paid work
- 10% of adults receive employment support while 53% say they would like to receive it

6.5 Life Expectancy of people with Learning Disabilities and/or autism

Evidence tells us that people with learning disabilities (LD) in England die much sooner than the rest of the population, often from deaths which are preventable. People with LD are three times more likely to die from an avoidable condition, which could be avoided through access to good quality healthcare. If improvements were made then health outcomes of people with learning disabilities would improve. *(Source: PHOF).*

The median age of death for people with LD is 16 years younger than the rest of the population. Men with LD die on average 13 years younger; while women with LD die 20 years younger. In Cumbria, this would equate to around 66.2 years for men (average life expectancy is 79.2 years (2013-15)); and 62.9 years for women (average life expectancy is 82.9 years (2013-15)). The CIPOLD also reported that fewer deaths of people with LD are reported to the Coroner, 38% compared to 46% of the general population.

There has not been an Autism Mortality Review in the UK but NHS Choice has acknowledged that a recent Swedish study has highlighted a real need to understand premature mortality amongst the autistic population in England. The Swedish study showed that autistic people die 16 years prematurely, the highest risk being amongst those autistic people who also have a learning disability, particularly women. Leading causes of death included neurological disorders such as epilepsy, and suicide. Autistic people described as

'high functioning' had a nine-fold increased suicide risk. (Source: Premature Mortality in Autism Spectrum Disorder; British Journal of Psychiatry; March 2016).

6.6 Mortality and premature deaths

In 2013 a Confidential Inquiry (The Confidential Inquiry into Premature Deaths of People with Learning Disabilities CIPOLD, 2013) was set up looking into the avoidable or premature deaths of 247 people each with LD, aimed at identifying why people with LD die sooner than the rest of the population. Some of the key findings from the CIPOLD were:

- the most common underlying causes of death were heart and circulatory disorders (22%) and cancer (20%), similar to deaths of the general population
- the most common reason of eventual death was a chest/respiratory infection
- 43% of the deaths were unexpected
- 42% of the deaths were premature
- the main reasons for premature deaths related to: delays, problems with diagnosis, treatment, identifying needs; and providing appropriate care
- significant proportion of individuals were underweight and those who were died at a much younger age
- high prevalence of impairments and other multiple health conditions i.e. epilepsy, cardiovascular disease and hypertension
- The number of prescribed medication was relatively high (an average of 7 per person)
- Most individuals had received an annual Health Check
- More than one third had difficulties in identifying or communicating their pain (lack of documented pain assessment tool)
- issues with accessing the bowel screening service were apparent
- Most individuals had high level needs and required support in many aspects of their lives including accessing healthcare; mobility; eating and drinking; continence; decision making and literacy
- More than a quarter had not had their support plans reviewed for over 1 year
- Levels of smoking and alcohol use was much lower than the general population; few had current or previous issues with drugs misuse
- 11% of individuals had had a previous safeguarding concern investigated

The CIPOLD highlights that the quality and effectiveness of health and social care given to people with LD is deficient in a number of ways. There is clear evidence that people with LD can face a greater risk of having their health and social care needs overlooked. The CIPOLD found that people with LD and Autism continue to have poor experience and outcomes of health and social care compared to the general population.

6.7 Safeguarding

6.7.1 Adults Safeguarding

There are procedures in place through the Cumbria Safeguarding Adults Board if a person becomes concerned about an individual's welfare and possible risks of abuse or neglect. Through Adult Social Care/Adult Safeguarding, a Safeguarding Concern may be raised in connection with or on behalf of a service user; following careful consideration some may then proceed to a Section 42 Safeguarding Enquiry, under the 2014 Care Act.

Throughout 2016-17, a total of 1,107 individuals were involved in a safeguarding concern; of those, 136 were relating to individuals with Learning Disability support as their primary support; 71 then proceeded into a Section 42 Safeguarding Enquiry.

6.7.2 Children's Safeguarding

There are procedures in place through the Cumbria Safeguarding Hub if a person is concerned about a child who may be at risk of neglect, emotional harm, physical abuse and sexual abuse. The Cumbria Local Safeguarding Children Board provide strategic and operational direction of safeguarding and monitoring of performance in Cumbria.

Throughout 2016/17, there were more than 18,000 safeguarding contacts made via the Cumbria Safeguarding Hub. Contacts made to the hub do not always identify whether the child has a learning disability or autism therefore it is not possible to report. Some of the contacts made to the Hub will develop into an Early Help Assessment and may then progress to Special Educational Needs and Disabilities support in school; and for those with complex needs they may have in place an Education, Health and Care Plan (see Appendix 1 for more details).

6.8 Carers

During 2016/17, a total of 10,771 carers were known to Adult Social Care providing care to 8,693 people (cared for). Of those being cared for, 1,063 (12%) had learning disability support as their primary support reason; 52 of those (4.9%) received direct support; 124 (11.7%) received information and advice only; while 887 (83.4%) did not receive any direct support.

Across Adult Social Care localities, the areas with the greatest number of carers (all carers) are Furness (2,367) and Copeland (2,321) (up to the end of June 2017).

Depending on the needs of an individual with a learning disability and/or autism, individuals may require a Carers Assessment (see Appendix 1). As reported in the Autism Self-Assessment Tool (see Appendix 1), carers of adults with autism (and all other social clients) are offered an assessment of their needs, as stipulated in the Care Act 2014, however carers can and do decline this offer.

In March 2017, there were 1,366 young carers (aged up to 24 years) in Cumbria (carers known to Cumbria County Council). Of those, 84 were caring for people with learning disabilities and/or autism, accounting for 6.1%. Across Cumbria, 66 of those young carers were in the Barrow locality, accounting for 78.6%; while 14 were located in the Carlisle locality, accounting for 16.7%.

For more information about carers in Cumbria please visit the [Carer's Chapter of the JSNA](#).

7 What is the level of need and gaps?

[See Appendix 1 for data]

There are significantly fewer people with learning disabilities known to health services compared to estimates numbers: there are an estimated 9,409 adults (18+) with a learning disability in Cumbria yet there are just 2,614 people (all ages) recorded on GP Registers with a learning disability, therefore the health needs of this population may not be being picked up.

There are an estimated 5,353 people with autism in Cumbria, yet fewer are known to services. Autistic people and their families are at risk of being isolated and developing

mental health problems; with some reporting that they do not receive the help that they need.

The majority of learning disability patients in Cumbria are aged between 11-29 years, while the greatest proportion are aged 20-24 years. Fewer patients in Cumbria with learning disabilities receive bowel cancer screening; breast cancer screening; and cervical screening, compared to all other patients without. Levels of obesity in LD patients in Cumbria are more than double the levels in all other patients.

As reported in the CIPOLD, there is a high prevalence of impairments and other multiple health conditions in people with learning disabilities such as epilepsy, cardiovascular disease and hypertension.

People with learning disabilities die much earlier than the rest of the population. Mortality rates of people with a learning disability are three times greater than those without. Life expectancy in people with learning disabilities is therefore significantly lower than the rest of the population; for females the gap is 20 years; for males the gap is 13 years. As reported in the CIPOLD, the most common underlying causes of death are heart and circulatory disorders and cancer, similar to the general population. There is a need to understand premature mortality amongst the autistic population in England and Cumbria.

8 Geographical differences in need

8.1 Allerdale

Demographics

- There are an estimated 1,805 adults (18+ years) with a learning disability
- There are an estimated 765 adults (18+ years) with Autistic Spectrum Disorder
- There are 477 patients on Learning Disability GP Registers, accounting for 0.48% of all patients (similar to Cumbria CCG and England average)
- There are 1,156 Adult Social Care service users of which 289 have a recorded learning disability; 27 service users have recorded autism/Aspergers
- 195 (1.3%) pupils are registered with autism
- 2,173 pupils are registered with Special Educational Needs & Disabilities

At risk groups

- There are 3,732 Disability Living Allowance (DLA) claimants, of which, 535 are claiming due to a learning difficulty condition
- There are 2,998 Personal Independence Payment claimants, of which 183 are claiming for a learning disability
- There are 1,951 carers known to Adult Social Care.

8.2 Barrow-in-Furness

Demographics

- There are an estimated 1,269 adults (18+ years) with a learning disability
- There are an estimated 536 adults (18+ years) with Autistic Spectrum Disorder
- There are 441 patients on Learning Disability GP Registers, accounting for 0.62% of all patients (greater than Cumbria CCG and national average)
- There are 1,390 Adult Social Care service users (in the Furness Locality) of which 262 have a recorded learning disability; 21 service users have recorded autism/Aspergers
- There are 98 (1.0%) pupils were registered with autism
- There are 1,538 pupils with Special Educational Needs & Disabilities

At risk groups

- There are 4,213 Disability Living Allowance (DLA) claimants, of which, 433 are claiming due to a learning difficulty condition
- There are 2,511 Personal Independence Payment claimants, of which 152 are claiming for a learning disability
- There are 2,367 carers known to Adult Social Care.

8.3 Carlisle

Demographics

- There are an estimated 2,032 adults (18+ years) with a learning disability
- There are an estimated 857 adults (18+ years) with Autistic Spectrum Disorder
- There are 498 patients on Learning Disability GP Registers, accounting for 0.46% of all patients (similar to Cumbria CCG and England average)
- There are 1,437 Adult Social Care service users of which 318 have a recorded learning disability; 14 service users have recorded autism/Aspergers

- There are 104 (0.7%) pupils were registered with autism
- There are 2,240 pupils registered with Special Educational Needs & Disabilities

At risk groups

- There are 3,876 Disability Living Allowance claimants, of which, 530 are claiming due to a learning difficulty condition
- There are 3,339 Personal Independence Payment claimants, of which 186 are claiming for a learning disability
- There are 1,210 carers known to Adult Social Care.

8.4 Copeland

Demographics

- There are an estimated 1,324 adults (18+ years) with a learning disability
- There are an estimated 566 adults (18+ years) with Autistic Spectrum Disorder
- There are 502 patients on Learning Disability GP Registers, accounting for 0.72% of all patients (greater than Cumbria CCG and national average)
- There are 724 Adult Social Care service users (in the Copeland Locality) of which 161 have a recorded learning disability; 14 service users have recorded autism/Aspergers
- There are 158 (1.7%) pupils registered with autism
- There are 1,290 pupils with Special Educational Needs & Disabilities

At risk groups

- There are 3,032 Disability Living Allowance (DLA) claimants, of which, 422 are claiming due to a learning difficulty condition
- There are 2,307 Personal Independence Payment claimants, of which 124 are claiming for a learning disability
- There are 2,321 carers known to Adult Social Care.

8.5 Eden

Demographics

- There are an estimated 1,006 adults (18+ years) with a learning disability
- There are an estimated 430 adults (18+ years) with Autistic Spectrum Disorder

- There are 212 patients on Learning Disability GP Registers, accounting for 0.41% of all patients (similar to Cumbria CCG and England average)
- There are 662 Adult Social Care service users of which 123 have a recorded learning disability; 15 service users have recorded autism/Aspergers
- There are 41 (0.6%) pupils registered with autism
- There are 1,037 pupils with Special Educational Needs & Disabilities

At risk groups

- There are 1,308 Disability Living Allowance (DLA) claimants, of which, 189 are claiming due to a learning difficulty condition
- There are 959 Personal Independence Payment claimants, of which 73 are claiming for a learning disability
- There are 1,438 carers known to Adult Social Care.

8.6 South Lakeland

Demographics

- There are an estimated 1,962 adults (18+ years) with a learning disability
- There are an estimated 835 adults (18+ years) with Autistic Spectrum Disorder
- There are 458 patients on Learning Disability GP Registers, accounting for 0.41% of all patients (similar to Cumbria CCG and England average)
- There are 948 Adult Social Care service users of which 163 have a recorded learning disability; 6 service users have recorded autism/Aspergers
- There are 219 (1.6%) pupils registered with autism
- There are 1,974 pupils with Special Educational Needs & Disabilities

At risk groups

- There are 2,530 Disability Living Allowance (DLA) claimants, of which, 460 are claiming due to a learning difficulty condition
- There are 1,792 Personal Independence Payment claimants, of which 114 are claiming for a learning disability
- There are 1,615 carers known to Adult Social Care.

9 Housing

More ASC service users with LD in Cumbria live in their own home or with their family compared to the rest of England at 82.7% compared to 75.4%; there were more males living in their own home or with family than females, at 83.8% compared to 81.1%.

As at 30th September 2017, there were a total of 445 Adult Social Care service users with a learning disability/and or autism in Supported Living in Cumbria. In addition, there were a total of 290 LD service users in residential care.

9.1 Extra Care Housing and Supported Living accommodation

Extra Care Housing (ECH), also known as 'assisted living' or 'very sheltered housing' is available to meet the needs of older people; while Supported Living, also known as 'accommodation with care' is provided to younger adults, often with learning disabilities and sometimes physical disabilities. ECH and Supported Living aim to support those who have social care needs at a level that would otherwise be met with intensive domiciliary care packages or in residential care. Compared to other local authority areas, Cumbria has a low level of supply of Extra Care housing (ECH).

There are a total of 111 Supported Living properties across Cumbria, with the availability of 337 units; by district this is split as follows: Allerdale: 24 properties, 68 units; Carlisle: 34 properties, 101 units; Copeland: 13 properties, 36 units; Eden: 11 properties, 31 units; Furness: 11 properties, 45 units; and South Lakes: 18 properties, 56 units. A potential additional 53 units are in development.

The Extra Care Housing and Supported Living Strategy, 2016-25, highlights the increasing level of need in younger adults; and that younger people with high-level profound and multiple disabilities are living into adulthood and therefore requirements/demands/needs are increasing. A programme of in-depth work including a review of people in existing supported living accommodation is planned/underway. Further information can be found in the Extra Care Housing and Supported Living Strategy, 2016-25 (<https://www.cumbria.gov.uk/elibrary/Content/Internet/327/6548/425289574.pdf>)

10 Current Services and Assets including projections

Public Health England have produced a series of guides for making “reasonable adjustments” to a range of health services for people with LD, including: blood tests; cancer screening; constipation; health checks; obesity and weight management; substance misuse; dysphagia (swallowing); pharmacies ; which can be found here: <https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities>

10.1 Advocacy Service - People First

Cumbria County Council commission People First Independent Advocacy and Carlisle and Eden Mind to provide statutory independent advocacy services, which includes Independent Mental Capacity Advocacy; Independent Care Act Advocacy, Independent NHS Complaints Advocacy and Independent Mental Health Advocacy. Adults with Autism who are eligible for these services have equal access to the service for support to participate meaningfully in needs assessments, care and support planning, appeals, reviews, or safeguarding processes.

People First also provide independent advocacy support and representation to eligible people through the Deprivation of Liberty safeguards (DoLS) process. Some people who have been diagnosed with Autism and have been assessed as lacking the capacity to consent to where they live, are not free to leave and are under continuous supervision and control may access this support.

10.2 Supporting People

Supporting People via Cumbria County Council provides support to vulnerable people who require housing related support.

10.3 Adult Social Care – Learning Disability, Autism & Transition Team

Within Adult Social Care in Cumbria we now have Learning Disability, Autism and Transition teams. This has made the routes into social care easier to navigate in that all adults with autism seeking Care Act assessments are referred into this team, unless they have mental

health needs. As a result it has been possible to identify the specific needs of this population, and understand the gaps in services locally, which primarily relate to those individuals with autism who do not have learning disabilities. An individual on the Autism spectrum requesting a Care Act Assessment will be seen by a social worker from the Learning Disability, Transition and Autism Team; with the exception of those who have a mental health issue (they will be supported by the Community Mental Health Team).

10.4 Accessing support

Information is hard to find but this seems to reflect the fact that there are very few services that specify that they provide support to people with autism, and there are only a very small number that are autism specific. Cumbria has an online support directory which is dependent on service providers to upload their details.

10.5 Promotion of employment for people with autism

The Department for Work and Pensions is working with employer organisations in Cumbria to raise awareness of the benefits of employing people with autism; and provide advice on the adjustments needed. It meets with employers twice a year to take this work forward. It has also produced, with the National Autistic Society, and a range of employers, guidance entitled 'Untapped Talent', which was launched in 2012.

10.6 Providers

Services for adults with learning disabilities and autism are delivered by a range of specialist professionals through Cumbria Partnership Foundation Trust (CPFT), details are listed below:

Table 1: Services for adults with learning disabilities and/or autism; Cumbria Partnership Foundation Trust

| | Location |
|--|------------|
| Physiotherapists | Countywide |
| Educational and Clinical Psychologists | Countywide |
| Psychiatrists | Countywide |
| Speech & Language Therapists | Countywide |
| Registered Learning Disability Nurses | Countywide |
| Support Staff | Countywide |

Services for children with learning disabilities and autism are delivered through the Community Learning Disability and Behaviour Support Service at CPFT, details are listed below:

Table 2: Services for children with learning disabilities and/or autism; Cumbria Partnership Foundation Trust

| | Location |
|--|------------|
| Early Intervention Behaviour Support Pathway – parent programmes and workshops | Countywide |
| Learning Disability Individual Support Pathway | Countywide |

There are a range of other services and support delivered by Cumbria County Council, independent providers, voluntary and third sector organisations, some of which are listed below:

Table 3: service providers for adults and children with learning disabilities and/or autism

| Organisation | Services/description | Location |
|------------------------|--|---------------|
| Cumbria County Council | Adult Social Care | Countywide |
| | Day Services | Countywide |
| | Independent Day Services | Countywide |
| Cumbria CCG | GPs | Countywide |
| Carlisle Mencap | Support people with a learning disability, and their families and carers. | North Cumbria |
| Prism Arts | Develop projects that enable disabled people, young people and older people to engage in the arts. | Countywide |

10.7 Estimates and projections

Estimates and projections provided by PANSI (Projecting Adult Needs and Service Information) are much greater than the numbers of patients on GP Registers; in 2017, there are an estimated 9,409 adults (18+ years) predicted to have a learning disability, equating to around 2.3% of Cumbria's adult population. This number is projected to remain relatively stable due projected reductions in Cumbria's working age population (see Table 4 below).

Table 4: Cumbria and districts: Total population (aged 18 and over) predicted to have a learning disability, 2017-2030.

| | 2017 | 2018 | 2020 | 2025 | 2030 |
|-------------------|-------|-------|-------|-------|-------|
| Cumbria | 9,409 | 9,408 | 9,400 | 9,381 | 9,407 |
| Allerdale | 1,805 | 1,805 | 1,809 | 1,797 | 1,801 |
| Barrow-in-Furness | 1,269 | 1,271 | 1,261 | 1,252 | 1,240 |
| Carlisle | 2,032 | 2,035 | 2,040 | 2,040 | 2,060 |
| Copeland | 1,324 | 1,316 | 1,319 | 1,307 | 1,299 |
| Eden | 1,006 | 1,008 | 1,011 | 1,016 | 1,020 |
| South Lakeland | 1,962 | 1,968 | 1,974 | 1,973 | 1,980 |

(Source: Projecting Adult Needs and Service Information (PANSI) 2017)

There are an estimated 3,996 adults (18+ years) predicted to have Autistic Spectrum Disorder, equating to around 1.0% of Cumbria's adult population. This number is projected to remain relatively stable due projected reductions in Cumbria's working age population (see Table 5 below).

The estimates set out below are produced by the Projecting Older People Population Information service and are based on prevalence rates in the Adult Psychiatric Morbidity Survey 2007; the prevalence of ASD was found to be 1.0% of the adult population in England, while the rate in men (1.8%) was higher than in women (0.2%). The prevalence rate of 1% have been applied to ONS population projections.

Table 5: Cumbria and districts: Adults (aged 18+) predicted to have autistic spectrum disorders, 2017-2030.

| | 2017 | 2018 | 2020 | 2025 | 2030 |
|-------------------|-------|-------|-------|-------|-------|
| Cumbria | 3,996 | 3,999 | 4,004 | 4,025 | 4,048 |
| Allerdale | 765 | 767 | 771 | 775 | 775 |
| Barrow-in-Furness | 536 | 538 | 536 | 534 | 529 |
| Carlisle | 857 | 859 | 861 | 873 | 887 |
| Copeland | 566 | 567 | 570 | 566 | 561 |
| Eden | 430 | 436 | 438 | 444 | 447 |
| South Lakeland | 835 | 834 | 838 | 845 | 851 |

(Source: PANSI & POPPI 2017)

Table 6: Cumbria and districts: People aged 18-64 predicted to have autistic spectrum disorders, 2017-2030.

| | 2017 | 2018 | 2020 | 2025 | 2030 |
|-------------------|-------|-------|-------|-------|-------|
| Cumbria | 2,859 | 2,842 | 2,806 | 2,712 | 2,605 |
| Allerdale | 544 | 542 | 536 | 518 | 496 |
| Barrow-in-Furness | 398 | 396 | 390 | 376 | 356 |
| Carlisle | 642 | 638 | 634 | 618 | 600 |
| Copeland | 417 | 415 | 411 | 389 | 368 |
| Eden | 297 | 301 | 297 | 289 | 275 |
| South Lakeland | 559 | 552 | 546 | 530 | 507 |

(Source: Projecting Adult Needs and Service Information (PANSI) 2017)

Table 7: Cumbria and districts: People aged 65+ predicted to have autistic spectrum disorders, 2017-2030.

| | 2017 | 2018 | 2020 | 2025 | 2030 |
|-------------------|-------|-------|------|------|------|
| Cumbria | 1,137 | 1,157 | 1198 | 1313 | 1443 |
| Allerdale | 221 | 225 | 235 | 257 | 279 |
| Barrow-in-Furness | 138 | 142 | 146 | 158 | 173 |
| Carlisle | 215 | 221 | 227 | 255 | 287 |
| Copeland | 149 | 152 | 159 | 177 | 193 |

| | | | | | |
|----------------|-----|-----|-----|-----|-----|
| Eden | 133 | 135 | 141 | 155 | 172 |
| South Lakeland | 276 | 282 | 292 | 315 | 344 |

(Source: Projecting Older People Population Information (POPPI) 2017)

11 Evidence of what works

11.1 Significant Incident Learning Process – Safeguarding Review

The 2014 Care Act sets out the requirement of Safeguarding Adult Boards (SAB) to conduct Safeguarding Adults Reviews when an adult in their area dies as a result of abuse or neglect (known or suspected) and where there is concern that agencies could have worked more effectively to protect the person. The Reviews are there to help to prevent future deaths or serious harm occurring again.

In Cumbria, each time there is a death of an individual with learning difficulties, a Safeguarding Review takes place. In May 2016, a Review into the death of an individual named Judy Benn was undertaken by People First on behalf of the Cumbria Safeguarding Adults Board - “Judy Benn – The Critical Last Days; A Significant Incident Learning Process (SILP), May 2016”. Judy had severe learning disabilities; she was receiving 24 hour professional care; and she died of a treatable complaint. The Coroner involved in Judy’s death concluded that if Judy had not had learning difficulties and was able to express herself she might have received more timely treatment and could have survived; the fact that Judy was a woman with learning difficulties and had difficulty in communicating had a significant impact on her death. The actions following this review were for those involved to ensure that lessons are learned so that the risks of death of individuals with learning difficulties are reduced.

The National Institute for Health & Care Excellence (NICE) provide a range of guidance for Learning Disabilities and Autism:

Table 8: NICE guidance for Learning Disabilities and Autism

| Guide | Link |
|-----------------------------------|---|
| People with Learning Disabilities | https://www.nice.org.uk/guidance/population-groups/people-with-learning-disabilities |
| Autism | https://www.nice.org.uk/guidance/qs51 |

12 Key Contacts

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13 Related Documents

Mental Health JSNA; and Carers JSNA: <https://www.cumbriaobservatory.org.uk/jsna/>

14 Links to data sources

Public Health Profiles: <http://fingertips.phe.org.uk/>

NHS Digital: <https://digital.nhs.uk/>

North East and Cumbria Learning Disabilities Transformation Programme:

<http://www.necchangingcare.org.uk/>

Mental Health Services Data Set: <http://content.digital.nhs.uk/mhsds>

Learning Disability Census: <http://content.digital.nhs.uk/ldcensus>

Adult Psychiatric Morbidity Survey 2014: <http://content.digital.nhs.uk/catalogue/PUB21748>

Adult Social Care Outcomes Framework: <http://content.digital.nhs.uk/article/3695/Adult-Social-Care-Outcomes-Framework-ASCOF>

15 References

The Department of Health Review "Transforming care: A national response to Winterbourne View Hospital; Final Report, December 2012":

<https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response>

The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD), 2013: <http://www.bris.ac.uk/cipold/>

Buescher et al. 2014; Autism Spectrum Disorder:
<http://content.digital.nhs.uk/catalogue/PUB21748/apms-2014-autism.pdf>

Westminster Commission on Autism “A Spectrum of Obstacle”, 2016:
<http://nationalautismproject.org.uk/westminster-commission-autism-spectrum-obstacles>

The Royal College of General Practitioners: <http://www.rcgp.org.uk/>

Autism Act 2009: <https://www.legislation.gov.uk/ukpga/2009/15/contents>

Equality Act 2010: <https://www.gov.uk/guidance/equality-act-2010-guidance>

Mental Health Act 2007: <https://www.legislation.gov.uk/ukpga/2007/12/contents>

Care Act 2014: <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

National Autistic Society:
http://www.autism.org.uk/?gclid=EAlalQobChMlpaKRsd_11qIVa77tCh20PQhIEAAYASAAEqKIWvD_BwE

Judy Benn: The Critical Last Days; A Significant Incident Learning Process; People First, May 2016

Premature Mortality in Autism Spectrum Disorder; British Journal of Psychiatry; March 2016. Hirvikoski T, Mittendorfer-Rutz E, Boman M, et al.

NHS Choices: People with Autism are dying younger:
<https://www.nhs.uk/news/neurology/people-with-autism-are-dying-younger-warns-study/>

NICE: Autistic people will receive better care if GPs develop a national register; August 2017: <https://www.nice.org.uk/news/article/autistic-people-will-receive-better-care-if-gps-develop-a-national-register-says-nice>

Appendix 1: Data

Learning Disability Patients in Cumbria

The North East & Cumbria Learning Disability Network produce regular reports in relation to the demographic profile, health needs, and services provided to LD patients in Cumbria CCG as set out in the tables below. *[Cumbria CCG level data is based on the CCG boundary prior to April 2017].*

Age Profile

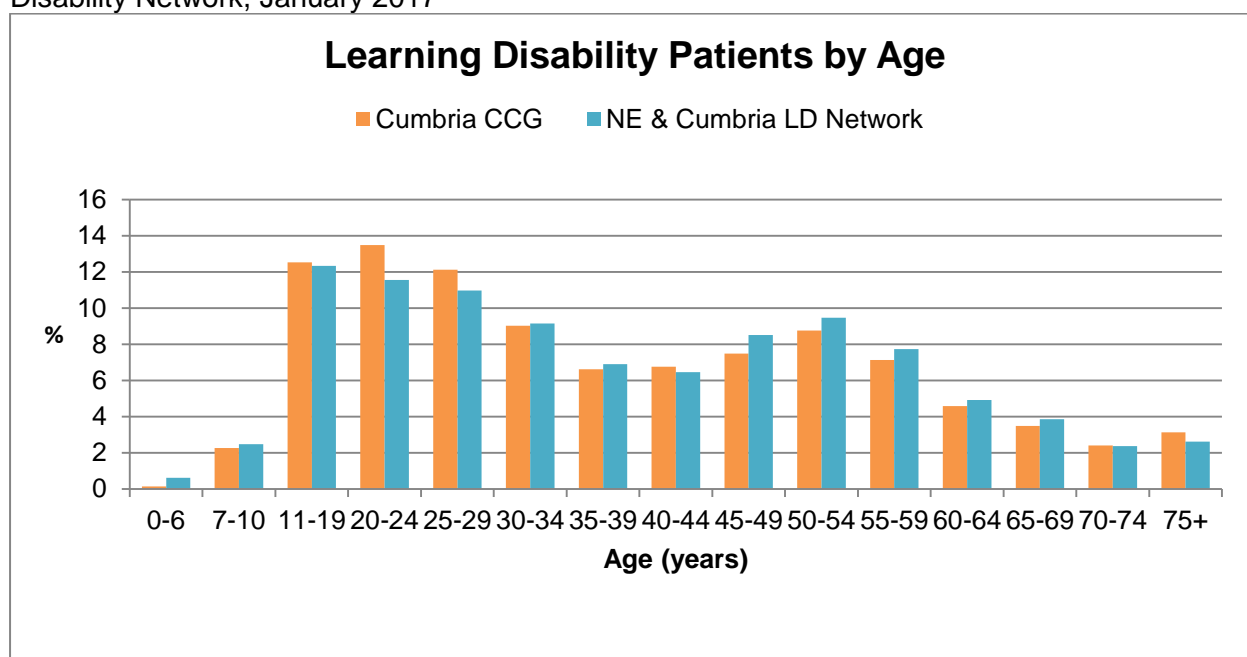
There are 2,202 learning disability patients in Cumbria (as at January 2017), accounting for 0.5% of all patients; of those 1,365 are male (62.0%) while 837 are female (38.0%), reflective of the regional and national picture. The majority of learning disability patients are aged between 11-29 years, while the greatest proportion are aged 20-24 years at 13.5%.

Table 9: Patients with Learning Disabilities in Cumbria; and NE & Cumbria, January 2017

| | Cumbria CCG | | NE & Cumbria LD Network | |
|----------|-------------|------|-------------------------|------|
| | Number | % | Number | % |
| 0-6yrs | - | 0.1 | 116 | 0.6 |
| 7-10yrs | 50 | 2.3 | 471 | 2.5 |
| 11-19yrs | 276 | 12.5 | 2342 | 12.3 |
| 20-24 | 297 | 13.5 | 2192 | 11.6 |
| 25-29 | 267 | 12.1 | 2084 | 11.0 |
| 30-34 | 199 | 9.0 | 1737 | 9.2 |
| 35-39 | 146 | 6.6 | 1311 | 6.9 |
| 40-44 | 149 | 6.8 | 1227 | 6.5 |
| 45-49 | 165 | 7.5 | 1615 | 8.5 |
| 50-54 | 193 | 8.8 | 1796 | 9.5 |
| 55-59 | 157 | 7.1 | 1468 | 7.7 |
| 60-64 | 101 | 4.6 | 933 | 4.9 |
| 65-69 | 77 | 3.5 | 733 | 3.9 |
| 70-74 | 53 | 2.4 | 450 | 2.4 |
| 75+ | 69 | 3.1 | 496 | 2.6 |
| Total | 2,202 | | 18,971 | |

Source: North East & Cumbria Learning Disability Network, January 2017

Figure 1: Learning Disability Patients by Age: Cumbria; and North East & Cumbria Learning Disability Network, January 2017



Source: North East & Cumbria Learning Disability Network, January 2017

Flu Vaccinations

During the 2016/17 flu period, 656 LD patients in Cumbria CCG received the flu vaccination, accounting for 62.7%; compared to 65.8% of all patients.

Table 10: Total Population Eligible for Flu Vaccination in the last Flu Period (01/09/2016 to 31/03/2017):

| | | Eligible Population | Number | | Proportion | |
|----------------------|-----|---------------------|---------|---------|------------|-------|
| | | | Yes | No | Yes | No |
| Cumbria CCG | All | 146,478 | 96,405 | 50,073 | 65.8% | 34.2% |
| | LD | 1,046 | 656 | 390 | 62.7% | 37.3% |
| North East & Cumbria | All | 968,070 | 550,301 | 417,769 | 56.8% | 43.2% |
| | LD | 7,995 | 4,754 | 3,241 | 59.5% | 40.5% |

Source: North East & Cumbria Learning Disability Network, January 2017

Bowel Screening

38 LD patients aged 60-74 years have received a bowel screening in the last 2 years, accounting for 16.5% of the LD eligible population, compared to 31.2% of all patients.

Table 11: Population aged between 60 and 74 years with Bowel Screening in the last 2 years

| | | Population 60-74 yrs | Number | | Proportion | |
|----------------------|-----|-------------------------|---------|---------|------------|-------|
| | | | Yes | No | Yes | No |
| Cumbria CCG | All | 84,320 | 26,333 | 57,987 | 31.2% | 68.8% |
| | LD | 231 | 38 | 193 | 16.5% | 83.5% |
| North East & Cumbria | All | 528,349 | 128,900 | 399,449 | 24.4% | 75.6% |
| | LD | 2,116 | 323 | 1,793 | 15.3% | 84.7% |

Source: North East & Cumbria Learning Disability Network, January 2017

Breast Screening

101 female LD patients aged 50-69 years have received a breast screening in the last 3 years, accounting for 44.5% of the LD eligible population, compared to 67.6% of all patients.

Table 12: Female Population aged between 50 and 69 years with Breast Screening in the last 3 years

| | | Population 50-69 yrs | Number | | Proportion | |
|----------------------|-----|-------------------------|---------|---------|------------|-------|
| | | | Yes | No | Yes | No |
| Cumbria CCG | All | 62,757 | 42,422 | 20,335 | 67.6% | 32.4% |
| | LD | 227 | 101 | 126 | 44.5% | 55.5% |
| North East & Cumbria | All | 416,035 | 210,788 | 205,247 | 50.7% | 49.3% |
| | LD | 2,196 | 756 | 1,440 | 34.4% | 65.6% |

Source: North East & Cumbria Learning Disability Network, January 2017

Cervical Screening

40 female LD patients aged 50-64 years have received a cervical screening in the last 5 years, accounting for 20.3% of the LD eligible population, compared to 56.3% of all patients.

Table 13: Female Population aged between 50 and 64 years with Cervical Screening in the last 5 years

| | | Population 50-64 yrs | Number | | Proportion | |
|----------------------|-----|-------------------------|---------|---------|------------|-------|
| | | | Yes | No | Yes | No |
| Cumbria CCG | All | 47,125 | 26,547 | 20,578 | 56.3% | 43.7% |
| | LD | 197 | 40 | 157 | 20.3% | 79.7% |
| North East & Cumbria | All | 319,890 | 185,168 | 134,722 | 57.9% | 42.1% |
| | LD | 1,854 | 458 | 1,396 | 24.7% | 75.3% |

Source: North East & Cumbria Learning Disability Network, January 2017

84 female LD patients aged 25-49 years have received a cervical screening in the last 3 years, accounting for 24.1% of the LD eligible population, compared to 57.5% of all patients.

Table 14: Female Population aged between 25 and 49 years with Cervical Screening in the last 3 years

| | | Population 25-49 yrs | Number | | Proportion | |
|----------------------|-----|-------------------------|---------|---------|------------|-------|
| | | | Yes | No | Yes | No |
| Cumbria CCG | All | 62,889 | 36,192 | 26,697 | 57.5% | 42.5% |
| | LD | 348 | 84 | 264 | 24.1% | 75.9% |
| North East & Cumbria | All | 499,083 | 288,714 | 210,369 | 57.8% | 42.2% |
| | LD | 3,123 | 868 | 2,255 | 27.8% | 72.2% |

Source: North East & Cumbria Learning Disability Network, January 2017

Obesity

381 LD patients are classed as obese (a BMI over 30), accounting for 17.3% of the total LD population, compared to 7.8% of all patients.

Table 15: Obesity: Adult Population with a BMI over 30

| | | Population | Number | | Proportion | |
|----------------------|-----|------------|---------|-----------|------------|-------|
| | | | Yes | No | Yes | No |
| Cumbria CCG | All | 431,145 | 33,414 | 397,731 | 7.8% | 92.2% |
| | LD | 2,202 | 381 | 1,821 | 17.3% | 82.7% |
| North East & Cumbria | All | 3,167,774 | 307,280 | 2,860,494 | 9.7% | 90.3% |
| | LD | 18,971 | 4,227 | 14,744 | 22.3% | 77.7% |

Source: North East & Cumbria Learning Disability Network, January 2017

Health Checks (GP)

1,368 LD patients have received a Health Check, accounting for 65.5% of the total LD population, compared to 17.1% of all patients.

Table 16: Learning Disability Health Check: Population aged 14+ years

| | | Population 14+ years | Number | | Proportion | |
|----------------------|-----|-------------------------|---------|-----------|------------|-------|
| | | | Yes | No | Yes | No |
| Cumbria CCG | All | 371,676 | 63,613 | 308,063 | 17.1% | 82.9% |
| | LD | 2,088 | 1,368 | 720 | 65.5% | 34.5% |
| North East & Cumbria | All | 2,690,010 | 385,760 | 2,304,250 | 14.3% | 85.7% |
| | LD | 17,777 | 13,035 | 4,742 | 73.3% | 26.7% |

Source: North East & Cumbria Learning Disability Network, January 2017

Adult Social Care – Learning Disability service users

1 in 5 Adult Social Care Social (ASC) service users in Cumbria have a learning disability. There are a total of around 6,500 ASC service users across Cumbria, of which, 1,359 have a recorded learning disability (LD) accounting for 1 in 5 (20.9%) of all ASC service users. 1,330 of those individuals have LD as their main reason (primary category) for receiving services; while the other 29 people have LD as their secondary reason.

There are 97 LD service users who have a record of autism or Asperger's, the greatest number are in the locality of Allerdale (27) followed by Furness (21). There are more male ASC service users with a LD than females, 806 (59%) compared to 553 (41%). As we would expect, the majority of ASC service users with a LD are aged 18-64 years, accounting for 9 in every 10 (89%); while almost 1 in 4 (23%) are aged between 25-34 years. Of those known, 98.4% are white British. The greatest number and proportion of LD service users are resident in the locality of Carlisle (318, 23.4%); followed by Allerdale (289, 21.3%). The districts of Eden and Copeland have the lowest number of service users with a learning disability.

As expected due to the age profile of LD service users, the majority (79.6%) are receiving community based support; 17.8% are receiving support in residential care; and just 2.6% are receiving nursing care. Around half (608, 44.7%) of LD service users are receiving day services; while 225 (16.6%) are receiving support at home. Many LD service users have additional health conditions. Of those recorded, more than 200 have a long-term health condition; some have a mental health condition; while some have a sensory (sight/hearing) impairment.

Up to March 2017, more than 4,500 full assessments of ASC service users were carried out, aimed at identify needs and support required. In addition to this, a further 1,800 carers assessments were carried out. In addition to full assessments, around 7,000 reviews of existing assessments/plans took place. It is acknowledged that LD needs may not always be picked up and met; and that Assessments should be more detailed and focussed around learning disabilities.

There are around 2,500 support plans for service users in place across the county, with a further 1,800 support plans for carers. Across the ASC localities, the greatest rate (per 10,000) of assessments were carried out in Furness (131.8) compared to Copeland (98.1) where they were the lowest. The greatest rate of reviews is in Carlisle (237.7) compared to Copeland (130.1) where they are the lowest.

Table 17: ASC service users, by Learning Disability, by Health & Social Care District, as at 31st March 2017

| Health & Social Care district | Total ASC Service Users | Learning Disability (Primary Category) | Learning Disability as (All – Primary & Secondary Category) | Learning Disability - Autism/ Asperger's |
|-------------------------------|-------------------------|--|---|--|
| Allerdale | 1,156 | 280 | 289 | 27 |
| Carlisle | 1,437 | 313 | 318 | 14 |
| Copeland | 724 | 160 | 161 | 14 |

| | | | | |
|-------------|-------|-------|-------|----|
| Eden | 662 | 118 | 123 | 15 |
| Furness | 1,390 | 255 | 262 | 21 |
| South Lakes | 948 | 161 | 163 | 6 |
| Unknown | 197 | 43 | 43 | 0 |
| Total | 6,514 | 1,330 | 1,359 | 97 |

Source: Adult Social Care, Cumbria County Council

Table 18: Learning Disability ASC Service users, by Health & Social Care District, as at 31st March 2017

| Age band | All ASC service users | | | | Learning Disability service users | | | |
|----------|-----------------------|--------|-------|------|-----------------------------------|--------|-------|------|
| | Male | Female | Total | % | Male | Female | Total | % |
| 18-24 | 208 | 123 | 331 | 5.1 | 152 | 100 | 252 | 18.5 |
| 25-34 | 272 | 153 | 425 | 6.5 | 207 | 106 | 313 | 23.0 |
| 35-44 | 184 | 165 | 349 | 5.4 | 115 | 75 | 190 | 14.0 |
| 45-54 | 265 | 283 | 548 | 8.4 | 140 | 114 | 254 | 18.7 |
| 55-64 | 304 | 296 | 600 | 9.2 | 110 | 84 | 194 | 14.3 |
| 65+ | 886 | 1278 | 2164 | 33.2 | 79 | 67 | 146 | 10.7 |
| 85+ | 501 | 1596 | 2097 | 32.2 | ~ | ~ | 10 | 0.7 |
| Total | 2,620 | 3,894 | 6,514 | | 806 | 553 | 1,359 | |

Source: Adult Social Care, Cumbria County Council, 31st March 2017

Mental Health Minimum Dataset (MHMDs) previously the Learning Disabilities Census

Following the Department of Health's "*Transforming Care: A national response to Winterbourne View Hospital*" the Learning Disability Census was established to provide an audit of current services for people with learning disabilities, autistic spectrum disorder, and/or challenging behaviour. The Census provided a snapshot of the profile and circumstances of individuals/inpatients receiving treatment or care, type of provision, numbers of out or area placements and lengths of stay. The Learning Disability Census took place in 2013, 2014 and 2015; in 2016 this was replaced with the Mental Health Services Data Set (MHSDS).

At the end of January 2017, a total of 16,580 people in Cumbria were in contact with Mental Health services; while a total of 1,675 people were in contact with Learning Disability and Autism (LDA) services. 845 people were in contact with LDA services through Cumbria Partnership NHS Foundation Trust (CPFT); while 830 people were in contact with LDA services through NHS Cumbria Clinical Commissioning Group (see Table 19).

Table 19: Number of People in contact with MH and LDA services in Cumbria

| Provider | Number of people in contact with Mental Health services | Number of people in contact with Learning Disability & Autism services |
|--|---|--|
| Cumbria Partnership NHS Foundation Trust | 7,685 | 845 |
| NHS Cumbria CCG | 8,895 | 830 |
| TOTAL | 16,580 | 1,675 |

Source: Monthly Mental Health Minimum Dataset, January 2017

Learning Disabilities Services Monthly Statistics (LDSM)

Record-level data is collected from Commissioners of learning disability services which in Cumbria includes Cumbria Partnership Foundation Trust and Cumbria Clinical Commissioning Group.

As at November 2017, there were 22 learning disability inpatients in Cumbria. A profile of these patients is not available, however, nationally, 3 in 4 are male (75%) and half (50%) are aged 18-34 years. Nationally, around half (56%) were diagnosed with a learning disability only; 18% were diagnosed with autism only; while 23% were diagnosed with both a learning disability and autism. (Length of stay; and care plan data is available at national level but not at local level).

Additional health conditions (co-morbidities)

Additional health conditions (co-morbidities) are common in people with learning disabilities or autism; some of which are presented in Table 20 below. Epilepsy is the most common co-morbidity with almost 1 in 5 people with epilepsy (19.47%).

Table 20: Co-morbidities of learning disability patients in Cumbria, and North East & Cumbria Learning Disability Network

| | % of learning disability patients with: | | | | |
|----------------------|---|----------|--------|-----------|----------|
| | Coronary Heart Disease | Diabetes | Asthma | Dysphagia | Epilepsy |
| Cumbria | 1.75% | 8.29% | 8.50% | 1.63% | 19.47% |
| North East & Cumbria | 1.81% | 7.22% | 8.20% | 3.48% | 20.46% |

Source: North East and Cumbria Learning Disabilities Baseline Data, August 2015

Adults with Learning Disabilities in Employment

There is clear evidence that good employment is a key factor in the health and wellbeing of a person. The review “Is work good for your health and wellbeing, 2006” concluded that work was good for both physical and mental health and wellbeing. Employment is therefore key to not just the general population but for people with learning disabilities.

In 2015-16, 4.2% of adults with learning disabilities in Cumbria (known to Adult Social Care) were in paid employment (at the time of their latest assessment or review); this is below the England average of 6.0%. There were more males than females with learning disabilities in paid employment at 4.9% compared to 3.1%, reflecting the national picture (source: Adult Social Care Outcomes Framework, 2015/16).

Employment rates of people with learning disabilities are generally lower than the rest of the population. In Cumbria, the gap in the employment rate between those with a learning disability and the overall employment rate is worse than the national average at 72.3 percentage points compared to 68.1, therefore suggesting that fewer people with learning disabilities are in paid employment in the county than the rest of England. Although the gap in males is greater than the gap in females, the gap in females in Cumbria is worse than the national average at 70.5 percentage points compared to 63.6 (Source: Annual Population Survey, 2015/16).

Nationally, around 1 in 3 people with learning disabilities of working age (16-64 years) are in employment. As reported in the 2015 Annual Population Survey, nationally the employment rate of people with learning disabilities was 31.8% compared to 73.7% of the overall working age population.

Benefit Claimants – Disability Living Allowance

There are 18,685 Disability Living Allowance (DLA) claimants in Cumbria (as at February 2017), of which, 2,571 are claiming due to a Learning Difficulty condition, accounting for 13.8%. Overall, the split between male and female claimants is relatively equal at 51.7% and 48.3% respectively; however for LD DLA claimants there are fewer females than males at 31.5% and 68.5%. The majority of claimants are aged under 16 years (45.5%); but given that DLA has been replaced by Personal Independence Payment (PIP) to individuals of working age this is expected. 1 in 4 claimants (25.6%) are aged between 25-49 years. The

districts of Carlisle and Allerdale have the greatest numbers of benefit claimants. (see Table 21 below)

Due to changes in Welfare Reform, it is important to note that from April 2013, DLA for people of working age (16-64 years) was replaced with PIP, therefore all new claimants will now be in receipt of PIP, these should therefore be considered in addition to DLA (existing claimants).

There are 13,910 PIP claimants in Cumbria, of which 837 are claiming for a learning disability, accounting for 6.0% of all claimants. The majority of PIP claimants are aged 25-49 years (38.2%). The majority of PIP claimants are female (53.0%), however, the majority of LD PIP claimants are male (57.6%). The districts of Allerdale and Carlisle have the greatest number of claimants (see Table 22).

Table 21: Disability Living Allowance: Learning Difficulties benefit claimants by Age, Cumbria and Districts

| | DLA | Condition - Learning Difficulties | | | | | |
|-------------------|--------|-----------------------------------|----------|-------|-------|-------|-----|
| | Total | Total | Under 16 | 16-24 | 25-49 | 50-64 | 65+ |
| Cumbria | 18,685 | 2,571 | 1,170 | 362 | 657 | 245 | 127 |
| Allerdale | 3,732 | 535 | 233 | 60 | 144 | 59 | 29 |
| Barrow-in-Furness | 4,213 | 433 | 183 | 76 | 109 | 34 | 22 |
| Carlisle | 3,876 | 530 | 196 | 72 | 162 | 62 | 29 |
| Copeland | 3,032 | 422 | 232 | 55 | 82 | 29 | 13 |
| Eden | 1,308 | 189 | 85 | 28 | 41 | 26 | 6 |
| South Lakeland | 2,530 | 460 | 233 | 66 | 105 | 37 | 9 |

Source: DWP, February 2017

Table 22: Personal Independence Payment: Learning Disability benefit claimants by Age, Cumbria and Districts

| | PIP | Condition - Learning Difficulties | | | | | |
|-------------------|--------|-----------------------------------|-------|-------|-------|-------|-----|
| | Total | Total | 16-19 | 20-24 | 25-49 | 50-59 | 60+ |
| Cumbria | 13,910 | 837 | 157 | 131 | 320 | 148 | 82 |
| Allerdale | 2998 | 183 | 33 | 32 | 63 | 40 | 19 |
| Barrow-in-Furness | 2511 | 152 | 28 | 18 | 67 | 26 | 10 |
| Carlisle | 3339 | 186 | 39 | 31 | 70 | 34 | 10 |
| Copeland | 2307 | 124 | 24 | 20 | 54 | 17 | 14 |
| Eden | 959 | 73 | 6 | 16 | 27 | 13 | 11 |
| South Lakeland | 1792 | 114 | 21 | 18 | 51 | 26 | 7 |

Source: DWP, July 2017

Children with Autism

Based on the National Autistic Society's prevalence rate of 1.08 people per 100, there are an estimated 1,060 children (aged 0-18 years) in Cumbria with autism.

In the January 2017 School Census, 815 pupils in Cumbria were registered to be on the autistic spectrum, accounting for 1.2% of all pupils. Across the districts, Copeland has the greatest proportion of pupils with autism at 1.7%. These numbers are low and are likely to be underrepresented. And these are children only known to Cumbria County Council, so there may be more for example those who are schooled at home.

Table 23: Cumbria and districts: total number of pupils and pupils with an Autistic Spectrum Disorder (ASD), January 2017

| | Total number of pupils | Number of pupils with ASD | % of all pupils |
|-------------------|------------------------|---------------------------|-----------------|
| Allerdale | 14,731 | 195 | 1.3% |
| Barrow-in-Furness | 9,615 | 98 | 1.0% |
| Carlisle | 15,054 | 104 | 0.7% |
| Copeland | 9,195 | 158 | 1.7% |
| Eden | 7,032 | 41 | 0.6% |
| South Lakeland | 14,104 | 219 | 1.6% |
| Cumbria | 69,731 | 815 | 1.2% |

(Source: Cumbria County Council, January 2017 School Census)

Children with Special Educational Needs and Disabilities (SEND)

Special educational needs and disabilities (SEND) can affect a child or young person's ability to learn; socialise; read and write (for example dyslexia); ability to understand; concentration levels (for example Attention Deficit Hyperactivity Disorder); and physical ability. A child may be eligible for SEND support in school and for those with complex needs they may have in place an Education, Health and Care Plan (EHCP), up to the age of 25years.

In the January 2017 Census, 10,252 pupils in Cumbria were registered to have a SEND, accounting for 14.7% of all pupils. Of those, 2,141 had an EHCP, accounting for 3.1% of all pupils. Across the districts, Barrow-in-Furness had the greatest proportion of pupils with a SEND at 16.0%; while Copeland had the greatest proportion of pupils with an EHCP at 3.9%. (See Table 24)

Table 24: Cumbria and districts: Number and proportion of SEND and EHCP/ Statemented pupils, January 2017

| | SEND | | EHCP/Statemented | |
|-------------------|--------|-----------------|------------------|-----------------|
| | Number | % of all pupils | Number | % of all pupils |
| Allerdale | 2,173 | 14.8% | 360 | 2.4% |
| Barrow-in-Furness | 1,538 | 16.0% | 347 | 3.6% |

| | | | | |
|----------------|--------|-------|-------|------|
| Carlisle | 2,240 | 14.9% | 460 | 3.1% |
| Copeland | 1,290 | 14.0% | 360 | 3.9% |
| Eden | 1,037 | 14.7% | 153 | 2.2% |
| South Lakeland | 1,974 | 14.0% | 461 | 3.3% |
| Cumbria | 10,252 | 14.7% | 2,141 | 3.1% |

(Source: Cumbria County Council, January 2017 Census)

There were 4,176 pupils with a learning difficulty related SEND, accounting for 40.7% of all SEND pupils. The majority of SEND pupils (2,104, 20.5%) have a “specific learning difficulty.”

Table 25: Cumbria: Special Educational Need - by Type/Need, January 2017

| | Need | Cumbria | |
|------|--|---------|---------------------|
| | | Number | % of all SEN pupils |
| ASD | Autistic Spectrum Disorder | 815 | 7.9% |
| HI | Hearing Impairment | 135 | 1.3% |
| MLD | Moderate Learning Difficulty | 1,473 | 14.4% |
| MSI | Multi-sensory impairment | 12 | 0.1% |
| NSA | SEN support but no specialist assessment of type of need | 943 | 9.2% |
| OTH | Other difficulty/disorder | 1,040 | 10.1% |
| PD | Physical disability | 284 | 2.8% |
| PMLD | Profound and multiple learning difficulty | 106 | 1.0% |
| SEMH | Social, Emotional and Mental Health | 1,238 | 12.1% |
| SLCN | Speech, Language & communication needs | 1,528 | 14.9% |
| SLD | Severe learning difficulty | 493 | 4.8% |
| SPLD | Specific learning difficulty | 2,104 | 20.5% |
| VI | Visual Impairment | 81 | 0.8% |
| | Total | 10,252 | |

(Source: Cumbria County Council, January 2017 Census)

For further information on children and young people in Cumbria, go to the [Children & Families JSNA Chapter](#).

Autism Self-Assessment Framework (AutSAF) Audit Tool 2015-16

The Autism Self-assessment Framework allows Local Authorities and partners to monitor their progress in implementing the Autism Strategy - Think Autism in 2014. The Self-Assessment was to enable local strategy groups to review progress and support future planning with partners including people with autism and their families. The Autism Self-Assessment Tool collects data on training; diagnosis; care and support; housing and accommodation; employment; and work with the Criminal Justice Service.

Some of the key findings from the Self-Assessment were:

- In the school year 2015-2016, there were 167 children across Year 10 to Year 13 identified as having autism; while 21 children completed transition
- In Adult Social Care, 71 adults were assessed as having autism who met social care eligibility criteria; 26 people with both Autism and LD met social care eligibility criteria; while 6 people assessed as having autism and met eligibility criteria were also in receipt of treatment for mental health problems
- 53 adults were assessed as being eligible for adult social care services who have a diagnosis of autism and in receipt of a personal budget; 83.0% of those have a diagnosis of Autism and LD, similar to the national median average of 83.2%.
- Lack of training plans and a lack of training available to all staff working in health and social care;
- Housing Strategy and/or Market Position Statements do not specifically identify autism;
- Lack of access to occupational therapy assessments;
- Longer average waiting times between referral to assessment (26 weeks compared to a median average of 16 weeks).

Learning Disability Self-Assessment Framework (LDSAF) Audit Tool 2014

The Learning Disability Self-Assessment Tool (produced by national PRIMIS and hosted by the University of Nottingham) supports the Joint Health & Social Care Learning Disabilities Self-Assessment Framework in Cumbria. In Cumbria, the last LDSAF was last completed in 2014. Some of the key findings were:

- 2,460 people known to services have a learning disability; of which 449 have LD with complex or profound disability
- 260 people have LD with Autistic Spectrum Disorder
- During 2013/14, 1,453 learning disabilities patients known to GP's had a Health Check. Of those, 933 (64.2%) also had a Health Action Plan
- There were 673 women aged 25-64 who had received a cervical cancer screening test
- There were 253 women aged 50-69 years eligible for breast cancer screening; of which 92 had been screened

- There were 251 people aged 60-69 years eligible for bowel cancer screening; 53 of those had been screened
- 690 people (out of 2,110) had a BMI of 30 and over (32.7%); 204 had diabetes; 209 had asthma; 40 had dysphagia; and 479 had epilepsy