

**Key national policies**

- 2009: Autism Act
- 2010: National Autism Strategy for Adults *Fulfilling and Rewarding Lives*
- 2014 *Think Autism. Update to the 2010 strategy for England*

**3 key themes**

1. An equal part of my local community
2. The right support at the right time during my life
3. Developing my skills and independence and working to the best of my ability

**Contents**

Prevalence in childhood and gender differences ..... Page 2

    Geographical and age variations in childhood prevalence ..... Page 3

Needs, strengths and interventions ..... Page 5

Current service delivery: education provision ..... Page 6

Adulthood..... Page 7

    Housing, employment and challenges for action ..... Page 8

Older age..... Page 9

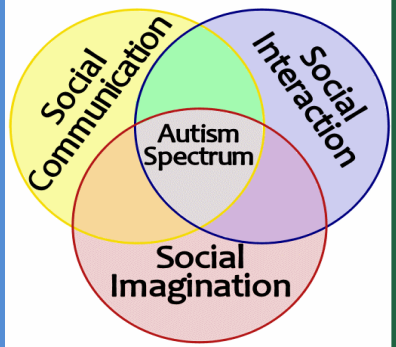
Current service delivery: health referral pathways .....Page 10

Assets ..... Page 11

Feedback from the public and planned changes .....Page 12

Opportunities for improvement .....Page 13

**Three Main Difficulties**



**Key messages**

- Autism spectrum disorder (including conditions such as Asperger’s Syndrome) occurs in about 1.5% of children, about half of whom have autism. This means 110 of the 7300 babies currently born in Cheshire\* each year will have autism spectrum disorder
- Autism spectrum disorder commonly co-exists with a learning disability, a range of physical health problems and an increased risk of mental health problems
- Opportunities exist to:
  - develop processes for identifying children early and referring them for assessment (usually by the age of 36 months), commissioning intensive behavioural programmes for children with autism from the age of 24 months
  - reduce diagnostic waiting times for children and young people
  - increase the proportion of pupils whose special educational needs can be effectively met in their local mainstream school, college or early years setting
  - improve identification and awareness of autism spectrum conditions in adulthood, particularly in older age, to ensure needs are fully understood and can be met
  - review how well needs are currently met and outcomes achieved at all ages

\*For the purposes of this needs assessment, Cheshire refers to Cheshire East and Cheshire West and Chester local authority areas.

Autism spectrum disorder describes a range of conditions including Autism, Asperger's syndrome, Rett syndrome, Pervasive Developmental Disorder and others.

### NICE Guidance:

- Assessment within 3 months of referral
- Individual case co-ordinator
- Discussion about information sharing
- Assessment to include physical health conditions and mental health problems
- Consideration of other assessments, developmental past history and observation to support diagnosis

## Prevalence

About half of parents of children with autism report having concerns about their child during the first year of life, and most are aware of problems between the ages of one and two. **Despite these clear concerns that there are indications of additional needs, children with autism are often not diagnosed until much older.**

Autism spectrum disorder is an umbrella term which includes a range of conditions (see left-hand box). It is generally accepted that there has been a steady rise in the numbers of recognised cases of autism, with the current prevalence thought to be about 1.5% of children. About half have autism. Most of the remaining children have Asperger's syndrome, which has similar characteristics of poor social interaction and repetitive behaviours but generally normal to high level of intelligence and communication. This means that **nearly 110 of the 7300 babies currently born in Cheshire each year will have autism spectrum disorder.** Data Sources: Fonagy P et al. Pervasive Developmental Disorders. (2015) In: What works for whom? Second edition. The Guilford Press.

**Autism spectrum conditions are present from birth and have a range of presentations, but are normally diagnosed when the child exhibits symptoms in 3 core areas of functioning; social interaction, verbal and nonverbal communication, and restriction of interest and resistance to change.**

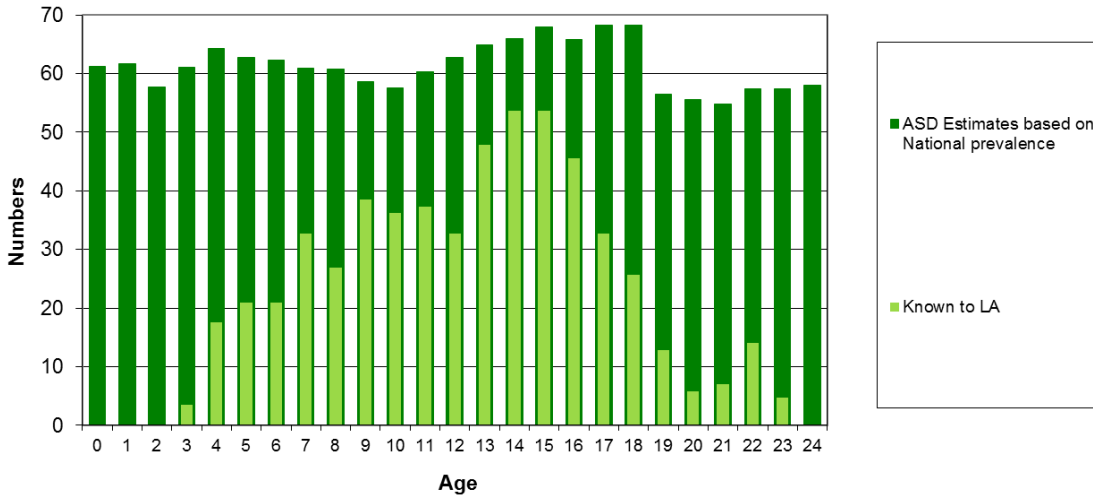
## Gender and autism spectrum disorder

**More males than females have a diagnosis of autism.** Various studies and anecdotal evidence reported by the National Autistic Society have identified men/women ratios ranging from 2:1 to 16:1. A study by Lorna Wing (1981) found that among people with 'high-functioning autism' or Asperger syndrome there were as many as 15 times as many males as females, while in people with learning difficulties as well as autism the ratio of males to females was closer to 2:1.

**This could suggest that, while females are less likely to develop autism, when they do they are more severely impaired. Or alternatively, 'high-functioning' women and girls with autism have been underdiagnosed, compared to men and boys.**

Females with Asperger's syndrome may be better at masking their difficulties in order to fit in with their peers and may generally have a more even profile of social skills. Girls with undiagnosed autism are painstakingly copying some behaviour, this tends not to be picked up and therefore any social and communication problems they may be having are also overlooked. Current ICD-10 diagnostic criteria do not give examples of types of difficulties shown in girls. Another theory to help explain the gender imbalance in diagnoses is the 'extreme male brain' theory of autism (Baron-Cohen, 2002). This relates to thinking about sex differences in general in terms of 'empathising' and 'systemising': autism seen as an extreme of the male 'systemising' dimension (National Autistic Society).

**Numbers of children and young adults (age 0-24 years) with Autistic Spectrum Disorder (ASD) within Cheshire East 2012**



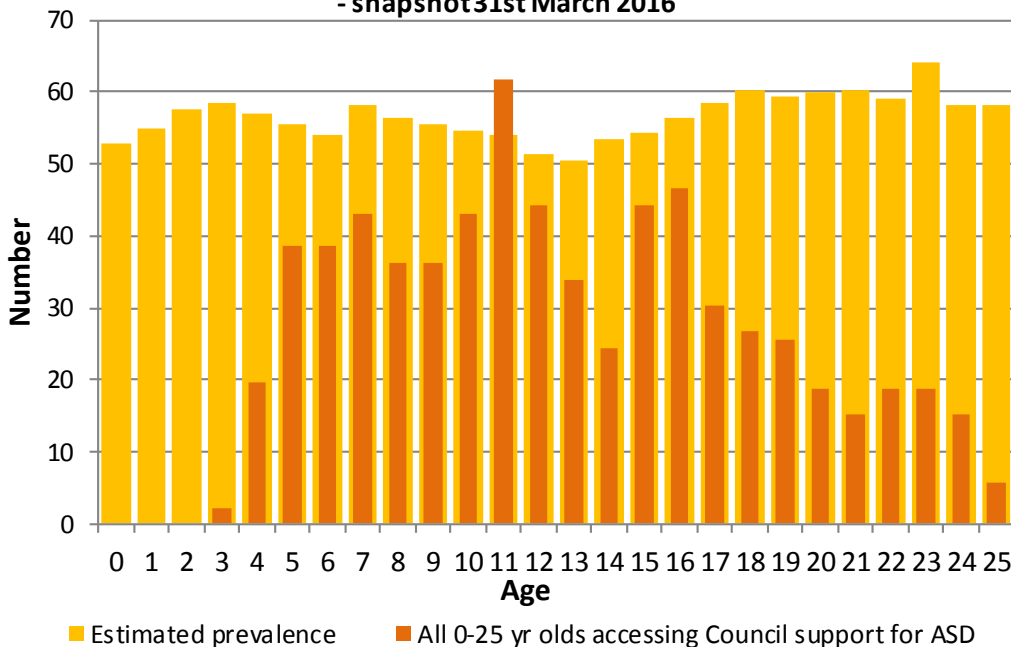
	Expected number of residents	Actual number of residents known	% known
Nantwich	52	15	29%
Crewe	375	95	25%
Sandbach	71	23	32%
Middlewich	60	10	17%
Alsager	47	13	28%
South Cheshire CCG Rural	169	46	27%
Congleton	105	29	28%
Knutsford	52	21	40%
Wilmslow	124	47	38%
Macclesfield	248	111	45%
Poynton	49	18	37%
Eastern Cheshire CCG Rural	182	63	35%
Eastern Cheshire CCG	760	289	38%
South Cheshire CCG	774	202	26%
<b>Cheshire East</b>	<b>1534</b>	<b>491</b>	<b>32%</b>

Data sources:  
 Estimated numbers: Fonagy P et al. Pervasive Developmental Disorders. (2015) In: What works for whom? Second edition. The Guilford Press. National prevalence of 1.5% applied to 2012 single year of age mid year population estimates  
 Actual number of residents known to the Local Authority in 2012 calculated from combined data from various Cheshire East Council Services

It should be noted that children and young people being identified as requiring support from services does not mean they have been medically diagnosed as having autism spectrum disorder. The age distribution of children and young people suggests that recording of autism spectrum disorder within Cheshire East is better at secondary school age than at primary school age. Very few children are identified in local authority services in their first 4 years of life and numbers known are lower than expected at all ages. Awareness and recording of autism spectrum appears to be better in the towns in the north of the borough, particularly Macclesfield, Knutsford, Wilmslow and Poynton.

Work is currently ongoing to improve the recording of 0-25 year old residents with an Education, Health and Care Plan through the creation of a robust single dataset of pupils. There are future plans to extend this dataset to include pupils receiving SEN Support.

**Numbers of children and young adults with Autism Spectrum Disorder (ASD) in Cheshire West and Chester**  
- snapshot 31st March 2016



Prevalence estimates for Cheshire West and Chester localities and CCG's	Expected autism numbers 0-25 (based on 2014 ONS Pop estimates)	Actual CWAC residents 0-25 years accessing support	% Known
Chester	389	160	41%
Ellesmere Port	276	129	47%
Northwich and Winsford	456	165	36%
Rural Communities	353	136	39%
NHS Vale Royal	456	165	36%
NHS West Cheshire	1,017	425	42%
<b>Grand Total</b>	<b>1,473</b>	<b>590</b>	<b>40%</b>

Data sources::

Estimated numbers: Fonagy P et al. Pervasive Developmental Disorders. (2015) In: What works for whom? Second edition. The Guilford Press. National prevalence of 1.5% applied to 2012 single year of age mid year population estimates

Actual numbers known in Cheshire West and Chester 2016, includes data where an indicator of autism/Asperger's is present from the Cheshire West and Chester children's social care services system (LCS), Integrated Early Support and partner services system (eTaf), Adult Social Care services (LAS), Carenotes system and CWAC schools education systems (CYPD). Carenotes is the only data set known to include a medical diagnosis.

As in Cheshire East, children and young people being identified as requiring support from services does not mean they have been medically diagnosed as having autism spectrum disorder. The age distribution shows lower than expected numbers of school age children identified as requiring support from ASD services than would be expected using latest national prevalence estimates. Levels of identified need peak at age 11 years, the age children move to secondary school, when the number of children in contact with services exceeds those that might be expected. Numbers known to services reduce as young people leave school.

Localities in the west of the borough (Chester and Ellesmere Port) appear better at identifying and recording autism spectrum disorder than the Rural and eastern areas.

## Recommendations for commissioners:

- Develop processes for identifying children early and referring them for assessment usually by the age of 36 months. The statutory two and a half year check should be the opportunity to identify the last few of these children
- Commission intensive behavioural programmes for children with autism from the age of 24 months. The aim should be to ensure that the majority of children with autism are receiving programmes of treatment by the age of 36 months.

### Needs:

As described earlier, autism is associated with difficulties in three core areas of functioning; social interaction, verbal and nonverbal communication, and restriction of interest and resistance to change.

Autism spectrum disorder commonly co-exists with a **learning disability**, and children may also have a **range of health problems** including gastrointestinal and sleep disorders. Seizures and epilepsy may develop, particularly during adolescence, and be associated with deterioration in behaviour including hyperactivity, aggressiveness and self-destructiveness.

Autistic people, particularly those who have no spoken language, sometimes resort to **challenging behaviours** to meet their needs and express their feelings. Children and young people with autism or Asperger's syndrome are also at particular **risk of being teased or bullied** and of developing depression and/or attention deficit hyperactivity disorder, and so they benefit from having clear referral processes to child and adolescent mental health services. The National Autistic Society state that **71% of children with autism have a mental health problem, such as anxiety disorders, depression, and obsessive compulsive disorder (OCD); it is estimated that 40% have two or more** (National Autism Society, 2014).

### Strengths

Having autism can cause a person problems in some areas of life, but the **characteristics associated with autism mean that there are some things that they may be able to do better than other people**. Many people with autism - particularly those with Asperger syndrome - are intelligent, with high IQ levels. Typical strengths include accuracy and attention to detail, while also being able to provide novel "big picture" insights due to different ways of looking at things, ideas, and concepts. They have strong visual skills, can focus intently and have an excellent memory. They are often reliable and honest, with a strong understanding of and working with rules.

### Interventions:

The key requirements for young children with autism spectrum disorder are to be identified at an early age, followed by rapid assessment, and then to be provided with a tailored treatment plan without any unnecessary red tape and delay. Families also require the practical support and help that they need to bring up their child.

Because of the wide range of presenting symptoms, children with autism spectrum disorder require careful and thorough assessment before interventions can be planned. **It is important that there is early referral for assessment, as although autism is a life-long condition, intensive structured programmes of analytical behavioural interventions in early childhood (from the age of 24 months) have been shown to be effective in increasing IQ, verbal skills and adaptive behaviours, and in leading to significant improvement in outcomes.** There have been very few trials of interventions for Asperger syndrome, but those that have been carried out, have shown social skills training programmes to be beneficial.

## Pupils on the autistic spectrum can .....

- be educated within mainstream schools with SEN Support from within the school's resources and/or with support and advice from the Autism Team within each local authority area
- have needs identified via a statement or, from September 2014, an education, health and care (EHC) plan and receive additional support. These pupils may attend a mainstream school, a school with additional resourced provision or a special school (on a daily or residential basis)

### Pupils with ASD attending Cheshire East Schools

	January 2014 Census		January 2015 Census		January 2016 Census	
	Autism Spectrum Disorder	Rate per 1,000 pupils	Autism Spectrum Disorder	Rate per 1,000 pupils	Autism Spectrum Disorder	Rate per 1,000 pupils
Primary schools	147	5.2	168	5.9	175	5.9
Secondary schools	166	7.5	184	8.4	170	7.8
Special schools	12	36.5	17	51.7	53	161.1
<b>Total</b>	<b>325</b>	<b>6.1</b>	<b>369</b>	<b>6.8</b>	<b>398</b>	<b>7.7</b>
England schools	<b>76,015</b>	<b>9.1</b>	<b>90,775</b>	<b>10.8</b>	<b>100,012</b>	<b>12.6</b>

Source: SFR 26/2014 and SFR 25/2015. Special educational needs schools census

### Pupils with ASD attending Cheshire West and Chester schools

	January 2014 Census		January 2015 Census		January 2016 Census	
	Autism Spectrum Disorder	Rate per 1,000 pupils	Autism Spectrum Disorder	Rate per 1,000 pupils	Autism Spectrum Disorder	Rate per 1,000 pupils
Primary schools	132	5.0	163	6.1	206	7.5
Secondary schools	122	6.1	184	8.9	166	8.5
Special schools	214	248.5	241	279.9	247	286.9
<b>Total</b>	<b>468</b>	<b>9.2</b>	<b>561</b>	<b>10.9</b>	<b>619</b>	<b>12.9</b>
England schools	<b>76,015</b>	<b>9.1</b>	<b>90,775</b>	<b>10.8</b>	<b>100,012</b>	<b>12.6</b>

Source: SFR 26/2014 and SFR 25/2015. Special educational needs schools census

Note: 2014 data relates to pupils with statements or at School Action Plus; 2015 data relates to pupils with either EHC plans /statements or at School Action Plus/SEND Support

The rate of autism spectrum disorder in pupils attending Cheshire East schools is lower than expected when compared to the England rate and the estimated birth prevalence. More children live in Cheshire East and attend special schools in other Local Authority areas than those who live in other areas and attend Cheshire East special schools. This is reflected in a lower rate of pupils in Cheshire East special schools (161.1 per 1,000) compared to Cheshire West and Chester (286.9 per 1,000). The Local Authority intends to increase the number of pupils with Special Educational Needs who are educated in their local school, supporting mainstream schools to meet needs where possible. The increase in the 2016 special school rate is in part due to the opening of Church Lawton, also reflected in the total rate increase (6.8 to 7.7 per 1,000).

#### Specialist provision: Cheshire East

- There are **resource bases** for pupils with autism spectrum disorder in 4 primary schools (2 in Macclesfield, 1 in Holmes Chapel and 1 in Wilmslow) and 2 secondary schools (in Wilmslow and Middlewich)
- **Church Lawton**: a specialist free school for more able pupils on the spectrum (aged 4-19 years) opened in Sept 2015 near **Alsager**

The rate of autism spectrum disorder identified was slightly higher in Cheshire West and Chester schools in 2016 compared to 2015. The overall rate is consistently higher than the England rate as 95% of school pupils who live in Cheshire West and Chester attend a school in Cheshire West and Chester and these schools are also attended by Cheshire East residents.

#### Specialist Provision: Cheshire West and Chester

- There are **resource bases** for pupils with autism spectrum disorder in 2 primary schools (1 in Chester and 1 in Frodsham) and 2 secondary schools (1 in Chester and 1 in Northwich)
- **Rosebank School**: a specialist primary with provision for children with Autism, Asperger's Syndrome and Social and Communication Difficulties near **Northwich, Cheshire**. Rosebank are commissioned to provide after school provision which is open to young people within and external to the school as part of Cheshire West and Chester's short breaks provision.
- Other special schools include **Hinderton School, Ellesmere Port** (Primary), **Greenbank School, Northwich** (secondary), **Dee Banks, Chester** (age 2-19 years)

The needs of adults with autism may have been significantly influenced by experiences within education and children’s service s. It is thought that early intervention, and interventions throughout childhood can have a significant bearing on the individual skills and abilities of adults with autism.

A study by the Health and Social Care Information Centre (2012) combined data with a new study of the prevalence of autism. This estimates the overall prevalence of autism spectrum disorder in adults at 1.1%, higher in men (2.0%) than women (0.3%). Based on this the expected numbers affected are shown in the table below.

### Estimated prevalence of autism spectrum disorder in 18-64 year olds

Age Group	2015 Estimates					
	Cheshire East			Cheshire West		
	Males	Females	Persons	Males	Females	Persons
18-24	276	38	313	270	42	312
25-34	390	59	449	370	56	426
35-44	456	71	526	390	63	453
45-54	574	90	664	488	77	564
55-64	476	72	548	416	65	480
<b>18-64</b>	<b>2171</b>	<b>329</b>	<b>2500</b>	<b>1933</b>	<b>302</b>	<b>2235</b>

Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey. HSCIC, 2012

### Needs

Issues tend to arise at times of major change but can present very acutely at that time in multiple ways. Reasonable adjustments are easier to make at such times if the diagnosis is clear and the person’s strengths, needs and aspirations are known. People with autism can struggle to explain themselves at times of stress or crisis even more than neurotypicals facing the same challenges. Times of major developmental change in adult life include but aren’t limited to:

- Getting their first job, moving on from/losing first job
- Getting into their first significant relationship and ending first significant relationship
- Getting to independent living/moving on from first independent living
- Having children
- Moving area
- Redundancy/retirement
- Changes in physical and mental health of the person or their key network

### Recorded prevalence of autism spectrum disorder in 18-64 year olds

There is a lack of accurate data available about the numbers of adults with autism. Although social care services hold some information, the figures are far lower than expected. Although autism became a clinical priority within the Royal College of GPs, there isn’t a requirement for GPs to hold a register other than the overall one for those with a learning disability.

### Numbers known to adult social care aged 15 and over with a diagnosis of autism spectrum disorder recorded

#### Cheshire East Council:

	15-24y	25-34y	35-44y	45-54y	55-64y
Males	57	44	20	15	14
Females	28	6	4	1	2
<b>Total</b>	<b>85</b>	<b>50</b>	<b>24</b>	<b>16</b>	<b>16</b>

Data source: Cases in Cheshire East adult social care system (Paris) with a Health Condition of Autism or Asperger’s recorded (January 2015)

#### Cheshire West and Chester Council:

	15-24y	25-34y	35-44y	45-54y	55-64y
Males	87	37	20	12	15
Females	31	12	12	8	7
<b>Total</b>	<b>118</b>	<b>49</b>	<b>32</b>	<b>20</b>	<b>22</b>

Data source: All open referral records aged 15+ with an indicator of ASD or Asperger’s within the Cheshire West and Chester adult social care system (March 2016)

## Housing

- Some people **live independently** without support; others live semi-independently and receive a level of outside support with certain tasks, known as **supported living**
- People with autism may also live with others, or in a shared house, while some people needing 24-hour support may live in a **residential or group home**
- Some people with an autism diagnosis have not succeeded in moving away from the **family home** and have little or no network or interactions outside the immediate family.
- **Support is needed for those moving between types of accommodation**

Nationally, 15 priority **Challenges for Action** have been identified by people with autism, carers, professionals and others who work with people with autism (Think Autism, 2014):

## Employment

- Employment support needs of adults with autism are considered by local authorities, representatives from Jobcentre Plus and employers
- Cheshire East Council Supported Employment and Cheshire West and Chester Council helps those with autism into paid work through the DWP funded **Work Choice Programme** delivered in partnership with the Shaw Trust
- The **Bren Project** and **Cheshire Autism Practical Support** also provide employment support while Autism Inclusive are seeking funding for this (see assets page)
- The care planning process for **adult social care** needs **should consider employment** as a key outcome and whether personal budgets can be used to support adults with autism to become work ready
- NICE advises that every adult with autism who does not have a learning disability or who has a mild one should be offered an **individualised support programme** if they are having difficulty obtaining or maintaining employment
- Feedback from adults indicates their **interests and skills are not always taken into account** when being offered work opportunities (see feedback page)

- **I want to be accepted for who I am within my local community**
- **I want my views and aspiration taken into account**
- **I want to know how to connect with other people, including through local autism peer groups, family groups and low level support**
- **I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am**
- **I want to be safe in my community and free from the risk of discrimination, hate crime and abuse**
- **I want my gender, race and sexual orientation noted**
- **I want a timely diagnosis from a trained professional. I want relevant information throughout the diagnostic process**
- **I want person centred local health, care and support services, based on good information about local needs, to be available for people with autism**
- **I want staff in health and social care services to understand that I have autism, how this affects me and to adapt their support, even if I sometimes communicate through behaviours which others may find challenging**
- **I want my family to get help and support when they need it**
- **I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies**
- **I want the same opportunities as others to enhance my skills and be as independent as possible**
- **I want support to get a job and support from my employer to help me keep it**



Older adults with autism have received little attention to date. Autism was only identified in the 1940s and the first generation of adults to be diagnosed in childhood are only now moving into older age. Most of the information in this section is based on the report: **Getting On? Growing older with autism (National Autistic Society, 2013)**

**Axia (who diagnose adults upto age 75 in Cheshire East and Vale Royal) are involved with research into Autism and Maturity.**

**Number of people with autism aged 65 and over**

2015 Estimates	Aged 65 plus	
	Cheshire East	Cheshire West
Males	754	632
Females	134	113
<b>Total</b>	<b>888</b>	<b>745</b>

There is a lack of accurate data available about the actual numbers of older adults with autism. Although Cheshire East social care services hold some information, the figures are too small to be published. In Cheshire West and Chester adult social care services there were 5 females and less than 5 males aged 65 and over recorded in March 2016. This highlights the need to improve the identification of autism in older adults to ensure needs are being met effectively.

**Diagnosis**

Lack of awareness contributes to under-diagnosis. Ideally, an autism diagnosis requires third-party information on early developmental history as well as face-to-face assessment. Older people often struggle to provide information on their developmental history. Parents may no longer be around, and documents such as school reports have often been lost. Even when such information is available, the required level of detail cannot be provided.

**Needs**

- Difficulties in recognising and communicating ill health, and in accessing treatments
- Dementia may be difficult to diagnose because of symptom crossover and communication difficulties, and few clinicians are familiar with both autism and dementia
- Individuals’ needs and support networks may change
- Social isolation is high

**Recommendations for commissioners:**

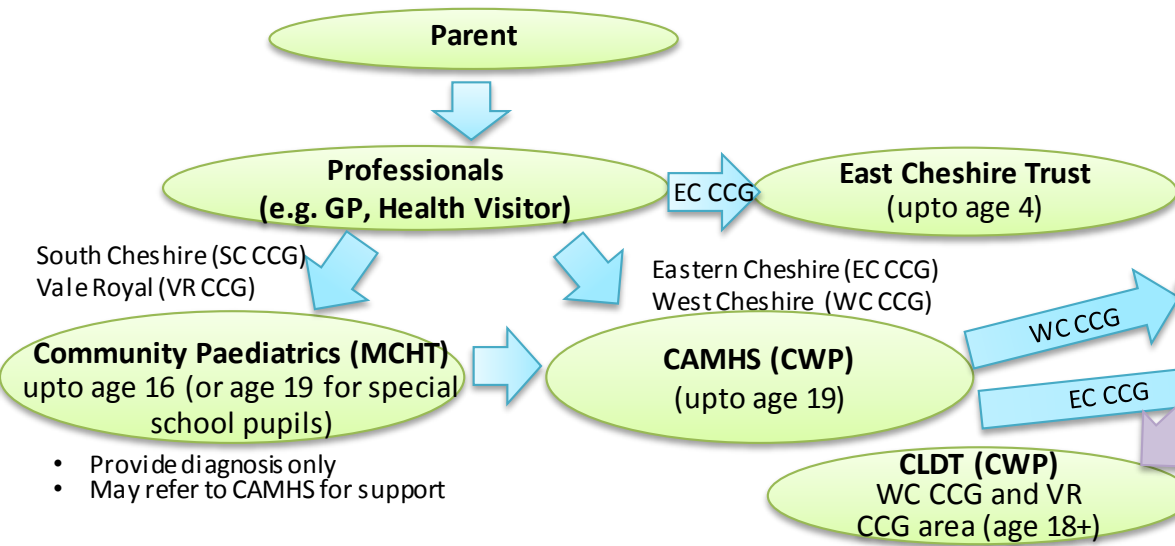
A strategy for autism in older people should include:

- plans for retirement, financial implications, safe housing or residential accommodation
- coping with loss or changes in life circumstances
- ensuring other medical issues are not missed as a result of autism

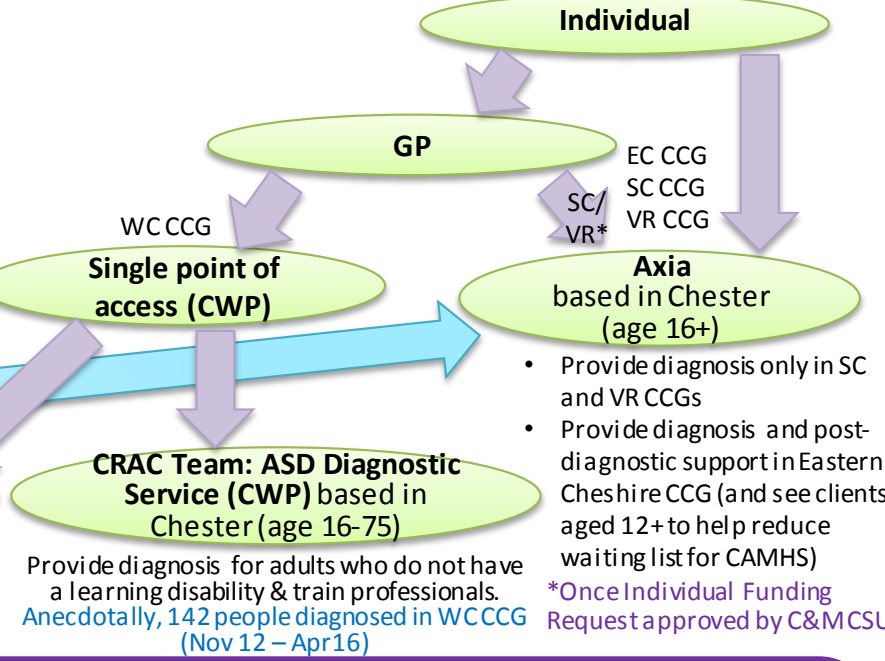
The Autism Act statutory guidance suggests that:

- Local authorities should consider volunteer-led models to support older people in developing local commissioning plans, and fund such services to meet need
- All local authorities and local NHS bodies should ensure staff working in all services for older people are trained in autism

## Referral pathways for children and young people



## Referral pathways for adults



### There is a **statutory requirement**:

- for all health care staff to have autism awareness training
- to provide specialist training for key staff which includes GPs
- for local commissioners to develop accessible autism diagnostic services and for these to be fully available to General Practitioners, recognizing that GPs have a gatekeeper role to services in the UK

### NICE guidance on diagnosing a new adult with autism is very similar to that for children

- The initial trigger can come from the individual realising behavioural difficulty throughout their life. The 10 item autism spectrum quotient (AQ-10) can be used as an initial screening tool
- Where an adult scores above 6 on the AQ-10, or based on clinical judgement autism is suspected, refer for a more comprehensive assessment
- Care and interventions for adults with autism should include psychosocial support, social learning and programmes for life skills, rather than the use of biomedical interventions (medication, dietary and physical)

A diagnosis can help explain what had previously been unknown or misunderstood and helps people access relevant services and benefits. Professionals working with people with autism need to know how to make a referral for a diagnosis. People need good, prompt information about autism and where to get support. Clear and appropriate information about local services for people with autism needs to be made available.

### Abbreviations:

CAMHS: Child and Adolescent Mental Health Services  
 CLDT: Community Learning Disability Team  
 CRAC: Complex Recovery, Assessment and Treatment  
 CWP: Cheshire and Wirral Partnership Trust  
 C&M CSU: Cheshire & Merseyside Commissioning Support Unit  
 MCHT: Mid Cheshire Hospital Trust

**Cheshire East and Cheshire West and Chester Councils each have autism teams:**  
**Cheshire East Autism Team (CEAT)** is a **small school-focused team** of teaching and support staff, experienced and qualified in the autism spectrum. They **provide specialist support for pupils** in years 1 to 13 **in mainstream schools**. There is a **resource library** in Sandbach for an annual membership fee.  
**The Autism Team for Cheshire West and Chester** supports **mainstream schools** to meet the needs of pupils with social and communication difficulties and autism spectrum conditions. It is a **multi-professional outreach service** of specialists, experienced and qualified in the autism spectrum, who provide **direct interventions with children and families**. A speech and language therapist focuses on early assessment and intervention, monitors pupil needs and provides **training to school staff**.



**Autism Inclusive** was set up in 2014 to **support people in Cheshire and beyond**. It is a not for profit organisation, **based in Crewe**, which aims to provide autism specific specialist support, training and consultancy services which recognise the unique challenges that people with autism experience.

Support provided includes:

- **Parent Support Group** – weekly drop-in sessions
- **Adults with Autism Support Group** meets weekly
- **1-2-1 support** for adults provided by resident autism consultant and/or speech and language therapist (including employment advice and support)
- **Film society**

They are also seeking funding for **employment support** to support interview and employment based social skills for the potential employee. A key focus would also be on greater employer awareness of the benefits and strengths of employing people with autism and on appropriate on-going support for those in or new to employment.

**Space for autism**, based in **Macclesfield**, provide **support groups and activities** to children, young people, adults & families



**Wishing Well** support young people with autism in **South CCG area** through direct payments



**Autism Networks** is a parent-led organisation formed in **Crewe** in 2002. A **Resource Centre** helps to identify needs of those with autism and their carers. They hold **leisure and social events** every week ([www.autismnetworks.org.uk](http://www.autismnetworks.org.uk))

**Cheshire West and Chester** will be re-tendering **short breaks services** following a disabled children's service review. These will include specialist support to meet the needs of autistic young people.

**Cheshire Autism Practical Support (ChAPS)** provide the following for children and adults:



- **Social skills and independence training**
- **Counselling**
- **Employment support**
- **Parenting courses**
- **Activities**
- **Online info and advice**

**National Autistic Society: Cheshire West and Chester branch** is a parent-led support group providing **information for parents and professionals** via a newsletter, library, information line, **carers groups** (Chester and Northwich) and **meetings with statutory agencies** for parents.

**Carers Trust 4all** run **social skills groups** for people with Asperger's Syndrome. Groups in **Ellesmere Port** support people aged 8+ and groups in **Chester and Northwich** support adults.

**Autism Together** run a facilitated **peer support** group with some **social skills training** in **Chester** for **16-25 year olds** with ASD to make new friends and socialise.

The **Bren Project based in Chester** offer **supportive work placements, including travel training**, for people with autism and/or learning disabilities **throughout Cheshire**.



There is a **support group in Middlewich** for people on the autistic spectrum or those with ADHD.

## Feedback from parents/carers

In September 2016, **Space4Autism** gathered views from families and professionals, identifying:

- Need to **improve the skills and knowledge of teachers** (including SENCOs), home to school **taxi drivers** and **professionals** in relation to autism and how it affects individual pupils
- Need **more support for parents** on how to meet their child's needs, including an information sharing facility and parenting courses tailored for parents of children with autism
- Parents have to **fight for support** in schools

Based on conversations with carers, **Healthwatch Cheshire East** highlighted the following experiences and concerns:

- significant disparity in the **timescales for diagnosis** in children
- a **disparity in schools' approach** to these children
- **lack of crisis care and support** for families
- a feeling of a **'blame culture'** from the professionals
- problems with appointments and everyday life
- **lack of knowledge of the support available** to families
- **lack of support for adults** living with autism spectrum disorder

Cheshire East parents reported a **lack of understanding in the workforce about autism and behaviour that challenges** (Review of children and young people with learning disabilities who challenge services, National Development Team for Inclusion, March 2016)

Adults accessing the Adult Diagnostic Service for ASD in CWP reported that difficulties in educational attainment and/or social skills leads to them being treated as intellectually less able than they are: they are only **offered access to unskilled jobs** by courses and career advisers, **who do not take account of their interests and skills.**

In Cheshire West and Chester, families consulted with have identified a **lack of crisis care and support.**

In a Cheshire West and Chester survey of pupils with an Education, Health and Care Plan and their parents/carers, the **lowest levels of satisfaction** related to **having enough information to make decisions** about support, **being able to change support**, having support to **do things in their local area** or **being part of the local community**. Less than half of disabled young people consulted in a separate exercise also said information was good and 48% rated life in their community as poor.

See the Cheshire West and Chester SEN JSNA for more information.

## Planned changes

**Eastern Cheshire CCG** has approved a plan to improve the autism diagnostic and support service for 4 to 18 year olds. Service users, families, carers and other stakeholders have been involved in designing a service model and the CCG plans to work with Cheshire East Council to provide a **fully integrated model of care with a single point of access and ongoing support** for children and young people. By combining funding streams, input from the voluntary sector and additional investment in child and adolescent mental health services they aim to **improve waiting times for assessment**, initially down to 8 months, then to 3 months of referral in 2018.

**Cheshire West and Chester** are addressing the lack of crisis care and support as part of the **Disabled Children's Service review.**

They are also part of a Personal Care and Support tender (including 7 Local Authorities and all 8 associated CCGs) which will begin delivery on 1st November 2016 - this will **offer more tailored individual choice** in terms of individual support packages.

## Further information:

- [National Autism Strategies](#) (2010 and 2014)
- Department of Health [statutory guidance](#) (2015) to ensure implementation of the adult autism strategy by local authorities and the NHS
- [Autism Education Trust](#); a national partnership of individuals and voluntary, public and private sector organisations focused on improving the education of children and young people with autism
- [Getting on? Growing older with autism. A policy report](#) (2013)
- JSNA sections on Special Educational Needs:
  - [Cheshire West and Chester](#)
  - Cheshire East is currently being drafted
- [Gender and autism](#) (National Autistic Society)
- [Cheshire and Merseyside Transforming Care for people with Learning Disabilities \(and autism\) Plan 2016-19](#)

## Opportunities for improvement / future developments

- Develop understanding across the workforce on autism and behaviour that challenges

### Service delivery processes:

- Reduce waiting times for an autism diagnosis and increase the percentage going through the diagnostic process
- Enable early identification of autism and commission interventions starting from 24 months of age
- Ensure smooth transitions through childhood to adulthood and older age for all individuals and their families

### Support/interventions:

- Develop holistic, person centred outcome plans for people of all ages with ASD, including identifying future support mechanisms and networks (e.g. when parents will no longer be able to provide support)
- Review capacity and efficacy of parenting support for families of children and young people with autism
- Review existing peer support available and identify the scope for developing/enhancing peer support networks
- Develop appropriate special educational needs support for pupils with autistic spectrum disorder, enabling pupil's needs to be met in mainstream settings where appropriate
- Transforming care so needs causing challenging behaviour are met in the community, rather than in inpatient beds

### Improving outcomes:

- Increase the percentage of people with autism who are employed by supporting individuals and raising employer awareness of the benefits of employing people with autism, their strengths and how best to engage them
- Ensure local housing strategies fit the needs of our autistic population

## What we don't know but would like to know...

- More robust understanding of numbers of people known to services including:
  - numbers in all areas known to GPs and/or numbers diagnosed by adult diagnostic services for Eastern Cheshire, South Cheshire and Vale Royal CCG areas and Community Learning Disability Team for West Cheshire (& Vale Royal?)
- How well the needs of people of all ages on the autism spectrum are being met and outcomes are being achieved

## Version control

Publication date	Changes made	Sign-off
November 2016	New JSNA section created	Guy Hayhurst & Helen Bromley (Public Health)

**JSNA section contributors:** Sumeet Khosla, Helen John, Sara Deakin, Anna Whitehead, Jill Oakley, Rory Strand, Gillian Cowan, Helen Pickin-Jones (Public Health), Debbie Foss (CE adult social care), Sam Murtargh, Julie Karmy (CWaC Commissioning), Ian Davidson (CWP)