

Wirral JSNA: Autism

Chapter Summary

- Autism in children, young people and adults will vary enormously, but will all share the two 'core' features of autism; these are persistent difficulties with social communication and social interaction: and restricted, repetitive patterns of behaviour, interests, or activities.
- Some people with autism also have significant strengths which can include reliability, a good eye for detail, ability to produce highly accurate work, an excellent memory for facts and figures and the ability to thrive in a structured, well-organised work environment
- There are a number of key inequalities for those people with autism and they include:
 - Prone to social and economic exclusion
 - Services that are not available consistently; different adults with autism in the same area can have very different experiences
 - Risk of severe health and mental health problems, homelessness, descending into crime or addiction for those without support.
 - Although many adults with autism make successful and important contributions to their communities, the economy and their families, too many could be dependent on benefits
 - There is more vulnerability to anxiety, depression and mental health issues in people with autism and with or without a co-occurring issue
 - There is an incomplete picture locally around information, needs, experiences and outcomes for adults with autism who may also have mental health problems.
- PANSI (2013) estimates suggest that approximately 1,847 adults aged 18 – 64 years old with autism are currently living in Wirral. This will reduce to around 1,829 by 2014. Though local service experience suggests a rising number.
- Brugha (2012) estimation method suggests a population prevalence for Wirral in the region of 2,103 adults with autism with 1,853 males and 294 females* (*rounded).
- PANSI (2013) estimates point to a small overall reduction in the number of adults with autism by 4.07% by 2020.
- Using Wirral's 2013 School Census data, around 1.30% of Wirral school children have a primary or secondary diagnosis of autism and this is higher than the suggested national prevalence rate of 1.0%
- Using Emerson & Baines (2010) prevalence estimates of autism in children and young people suggest between 676 (1.0%) and 1,014 (1.5%) of children and young people with autism in Wirral (birth to 18 years of age).
- There are a number of issues that require further local development which could contribute to local improvements, these include:
 - Beyond estimates, the numbers of people with autism are not known accurately – in population and in service
 - This in part could be due to the need for more systematic recording of people known to services who have an autism diagnosis
 - The evidence base evaluating services for people with autism needs further development
 - Although there has been a range of autism linked training by local providers for specific groups or teams, there remains some uncertainty as to the numbers and extent of knowledge and skills held by the range of health or social care staff that work with people with autism. This is likely to have a significant impact on their service experience and meeting of support needs.
 - Further understanding is required of the needs of people with autism from a range of backgrounds, in particular minority ethnic and cultural groups, women and older people.
 - A greater depth of content and views from service users, from those diagnosed with autism and their carers to influence local approaches
 - Greater understanding of the experience of Wirral residents with autism in terms of local employment, housing and the criminal justice system

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What do we know?

Overview

Autism is a lifelong neurodevelopmental condition. Often termed [heterogeneity of autism](#), it is characterised by persistent difficulties in social interaction and communication and the presence of stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests. The way that autism is expressed in individual people differs at different stages of life, in response to interventions, and with the presence of coexisting conditions such as [learning disabilities](#) (also called 'intellectual disabilities').

There are a number of terms that individuals, groups and professionals prefer to use including autistic spectrum disorder, autistic spectrum condition and autistic spectrum difference. This needs assessment will use the term 'autism' as an umbrella term for all such conditions, including asperger syndrome. This is in line with the approach to terminology adopted by key autism representative organisations, including National Autistic Society (NAS).

People with autism also commonly experience difficulty with cognitive and behavioural flexibility, altered sensory sensitivity, sensory processing difficulties and emotional regulation difficulties. Some of the features of autism may range from mild to severe, and in response to external changes in circumstances, can fluctuate over time.

A significant proportion of adults with autism (across the whole autistic spectrum) experience social and economic exclusion. Their condition can be overlooked by healthcare, education

and social care professionals create the barriers to accessing the support and services they need to live independently. In addition, people with autism are more likely to have coexisting mental and physical disorders, and other developmental disorders. Some may have contact with the criminal justice system, as either victims of crime or offenders, and it is important that their needs are recognised.

The causes of autism are multi-factorial, with the most likely explanation being an interaction between genetic and environmental factors. Current evidence appears to confirm a strong genetic link, whereas studies on environmental factors are not yet able to confirm specific environmental causes. [Forms of autism](#)

Autism: Understanding the issues

Autism is classified as a developmental disability in the World Health Organisation's International Classification of Diseases (ICD) diagnostic manual in the same class as Intellectual Disabilities or Attention Deficit Hyperactivity Disorder, complex lifelong conditions involving "pervasive developmental disorder".

Until recently autism was defined to involve difficulty in three key areas, known as the "triad of impairments" (Wing and Gould, 1979):

1. Difficulties with social communication: language acquisition delay, and difficulty understanding and using speech, writing, body language, mood, gesture, and personal space (e.g. language, gestures, facial expressions and tone of voice);
2. Difficulties with social interaction: problems acquiring and using social skills which can result in isolation, difficulty processing emotional information, difficulty initiating social contact and adhering to social rules and thus difficulty sustaining relationships (e.g. recognising and understanding other people's feelings and managing their own);
3. Difficulties with social imagination: being unable to correctly distinguish the real from imaginary, finding it difficult to be reflexive, to inhibit behaviour, and to exhibit repetitive behaviours and obsessional interests (e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine).

In May 2013 the American Psychiatric Association (APA) revised its diagnostic manual, known as the Diagnostic and Statistical Manual (DSM), to create a fifth edition.

The key changes for autism are:

- The previous use of three domains of impairments has been reduced to two domains:
 1. Social communication and interaction.
 2. Restricted, repetitive patterns of behaviour, interests or activities.
- In DSM-5, the terms 'autistic disorder', 'Asperger disorder', 'childhood disintegrative disorder' and 'PDD-NOS' have been replaced by the collective term 'autism spectrum disorder'. All individuals who currently have a diagnosis on the autism spectrum, including those with Asperger syndrome, will retain their diagnosis. No one will 'lose' their diagnosis because of the changes in DSM-5.
- Sensory behaviours are included in the criteria for the first time, under the 'restricted, repetitive patterns of behaviours' descriptors.
- The emphasis during diagnosis will change from giving a name to a condition to identifying all the needs that someone has and how these affect their life.
- DSM-5 has introduced 'dimensional elements' which give an indication of how much someone's condition affects them. This will help to identify how much support an individual needs.

Everyone with autism experiences difficulties across these distinct areas, albeit the severity and presentation of difficulties can vary significantly and so an 'Autistic Spectrum' is talked of. As such there is an uniqueness to autism and how it presents in individuals. The word spectrum is used because some people with autism are able to live relatively 'unsupported' lives and others need a lifetime of specialist support. While some people with autism may have limited language skills, others have good language skills, but difficulty understanding.

It is common for people with autism to have unusually high or low sensitivity in one or more of their senses. People with autism often prefer routines and find changes to their routine difficult to manage.

Children, young people and adults with autism will vary enormously but they all share the two 'core' features of autism, these are persistent difficulties with social communication and social interaction and restricted, repetitive patterns of behaviour, interests, or activities. They also have significant strengths. These often include reliability, a good eye for detail, producing highly accurate work, an excellent memory for facts and figures, and the ability to thrive in a structured, well-organised work environment ([Research Autism](#)). Children and young people can experience some of a range of issues such as epilepsy, Attention Deficit-Hyperactivity Disorder (ADHD), gastro-intestinal problems, mental health issues, motor difficulties, sensory issues and sleep problems ([more information here.](#)) Beyond the health issues associated with autism there can be other aspects that affect the child or young person such as attending the right school and education, how this then turns into future employment opportunities, healthy lifestyle, independence and future relationships. Both for children, young people and into adulthood the family unit remains an important aspect of continuity and support though this is at times challenging for family members due to a range of issues.

To further add to the complexity of diagnosis, autism appears to change over time from child to adulthood, even in the same person, as suggested by the Medical Research Council (2001). A child may lack social imagination, which is evident by their lack of ability to 'pretend play', whereas in adulthood a lack of social imagination may show as a lack of interest in fiction and a fascination with facts (e.g. memorising insignificant dates)

The National Autistic Society report (2006), *make school make sense for me*, interviewed children and young people with autism to find out about their experiences of education and it suggested that possibly over 40 per cent of children with autism may have been bullied at school. Also, although 1 in 110 children has autism, there is no requirement for trainee or practising teachers to undertake any training in autism, and in the region of 25 per cent of children with autism may have been excluded from school.

Adults with autism face many challenges in life. Often they also have other co-occurring conditions such as learning disabilities or mental health problems. Those who have higher functioning autism or Asperger Syndrome feel they have a 'hidden' condition which is not easily recognised or understood by professionals or the public.

Turk (2010) suggests that many older people will be undiagnosed because autism only became formally recognised as a range of conditions in the late 1960s. The condition can also be masked by other co-occurring conditions such as a mental health problem, learning disability or attention deficit hyperactivity disorder (ADHD).

One of the key issues for adults with autism is that they risk falling into the gap between services for people with learning disability and mental health conditions, according to Bolton's JSNA (2012), so could struggle to receive the support they need. Autism is a developmental disorder and not a mental health problem. However they are more likely to receive support if

they also have a co-occurring condition such as a learning disability which has been identified in childhood or a mental health problem. However if an adult with autism does not receive the support they need for this condition they are more likely to develop a mental health problem. Low level support at the right time could prevent this arising.

Barnard et al (2001) suggested that:

- Many adults with autism cite employment as the single biggest issue or barrier facing them in particular the need for increased awareness of their needs among employment and benefits advisers.
- Research suggests that the number of people with autism in full-time employment is very low with the lower functioning end of the spectrum this falls to an estimated 2% rate of employment.
- The low numbers of adults with autism in employment not only leads to wasted potential, social exclusion and lack of personal fulfilment according to the National Autism Strategy (Department of Health, 2010) but also puts pressure on families supporting these adults and on Local Authorities.

Hendricks (2010) identified:

- Obtaining employment for people with autism is particularly difficult because of their unique communication and social impairments, and acknowledges the ongoing high unemployment rates amongst people with autism identified by the National Autistic Society in 2008.
- The interactional difficulties associated with autism accounts for the biggest vocational hurdle, and in her interviews with people with autism communication and social difficulties with supervisors and co-workers consistently emerge as a primary hindrance to job performance.

Beth Reid produced a report for the National Autistic Society (2006) (*Moving on up? Negotiating the transition to adulthood for young people with autism*) that suggested:

- Despite the fact that many people with autism have skills which could be valuable to employers, only around 15% of people with autism are in full-time employment. There is a lack of awareness and knowledge of autism among potential employers and Jobcentre Plus staff, which can result in poor decision-making and job outcomes for adults with autism
- There is a lack of sufficient knowledge and awareness of autism by those staff working in health, social care, benefits and employment services.
- The National Audit Office estimated that if such services identified and supported around 4% of the adults with high-functioning autism in their local area, they could become cost-neutral over time, as well as resulting in additional earnings and reduced expenses for individuals. Higher identification rates could increase these benefits further, potentially leading to net savings for the public purse.

A large proportion of the cost of supporting people with autism is accounted for by lost employment including potential increased self-esteem and social integration. This significantly impacts not only on the people with autism, and as Knapp (2007) contests also on wider society, and on the UK economy with he suggests the lifetime cost for someone with high-functioning autism being near to £3.1 million and £4.6 million for someone with low-functioning autism. This means that many adults with autism are dependent on benefits, and this under-representation also indicates that UK employers are not benefiting from the skills and talents adults with autism can offer in the workplace. (Department of Health, 2010)

National Autistic Society (2007) report by Laura Simons, *Think Differently, Act Positively-Public Perceptions of Autism*, highlighted the following:

- While the overall employment rate for disabled people is 48%, estimates at the time suggest that only 15% of all people with autism were in full-time paid employment. Other research suggested that only 12% of people with high-functioning autism are in full-time employment and 6% part-time.

Beardon and Edmonds (2007) report on the needs of those with Asperger Syndrome,

- 83% of individuals with Asperger Syndrome surveyed felt strongly that many of the problems they faced were as a direct result of others not understanding them
- Characteristics of autism such as the inability to understand social norms, increased likelihood of being socially misunderstood, obsessive interests, apparent lack of empathy, communication difficulties, and literal interpretation of language could all theoretically put people with autism at higher risk of becoming a victim of crime or offending themselves
- There are societal misconceptions about the exact characteristics of autism, and there are many negative reactions to the typical behaviour commonly associated with autism.

As a consequence of this lack of understanding people with autism are at high risk of social isolation and exclusion. The characteristics associated with autism mean that developing friendships and social networks can be very difficult and stressful. As a result, anxiety increases and individuals often either exclude themselves or find themselves excluded, and so have little contact with the outside world. It can also increase vulnerability and may lead to people being exploited and either being led to commit crime themselves or becoming a victim of crime. Equally the incidence of disability hate crime against persons with autism may well be severely under-reported due to their communication difficulties and failure to understand what is and what isn't the social norm. Those that do enter the system as victims are often deemed as not being a credible witness, leading to failures to prosecute

Bolman (2008) highlighted:

- Communication difficulties include difficulties understanding directions, inability to 'read between the lines', read facial expressions and tone of voice, asking too many questions and communicating in an inappropriate manner.
- Behavioural difficulties that might result from communication problems include tantrums, aggression, self-injury, property destruction, ritualistic behaviours or pica.

Dein and Woodbury-Smith (2010) conclude:

- Autism could also render someone highly vulnerable if they come into contact with the criminal justice system
- With the criminal justice system, police officers, probation services and courts being unaware of communication challenges – leading to overly heavy-handed responses to incidents.

A survey of adults with autism and their families, '[I Exist: The Message from Adults with Autism](#)', (2008) carried out by Mia Rosenblatt for the National Autism Society reported:

- People with autism are at high risk of bullying or harassment; over half of adults with autism who were surveyed by the National Autistic Society in 2008 reporting that they had been bullied or harassed as adults
- 63% of adults with autism surveyed did not have enough support to meet their needs, of those, 82% say that with more support they would be less isolated.
- Of those who do not have enough support, 79% said that with more support they would be able to do the things they want to do and 70% said that with more support they would be more independent.

- 92% of parents were either very worried or quite worried about their son or daughter's future when they are no longer able to support them
- Only 15% of adults with autism are in full-time paid employment
- 49% of adults with autism still live at home with their parents
- Of those adults who live on their own, 44% said that their families provide most of their support
- Over 69% of people with Asperger's Syndrome or high functioning autism said that they have experienced problems in accessing health and social care services

Recently published by Liverpool Public Health Observatory on behalf of Cheshire & Merseyside Public Health Intelligence Group is Learning disabilities and autism: A health needs assessment for children and adults in Merseyside and North Cheshire. This document ([viewed here](#)) provides supporting information to that covered above.

Autism: estimating numbers

Some suggested key elements:

- More prevalent in males than females ([National Autistic Society](#))
- No accurate figures are available of people who are known to services,
- There is a reported difficulty in determining a diagnosis of autism especially within adults. Studies in adulthood have shown that four out of five adults with autism find obtaining a diagnosis in adulthood difficult or not possible (Taylor & Marrable, 2011) and many will not have received a formal diagnosis (Brugha *et al.*, 2011). The estimated incidence of people on the spectrum is higher amongst people who do not have a learning disability than in those who do have learning disability

Brugha et al (2007) produced a report for the NHS Information Centre, *Autism Spectrum Disorder (ASD) in adults living in households throughout England, a report from the Adult Psychiatric Morbidity Survey 2007*, in which they suggest that:

- 1.0% of the adult population had autism with the rate higher in men (1.8%) than women (0.2%). This fits the profile found in childhood population studies as Baird (2006) and Baron- Cohen (2009).
- Autism was associated with a person's educational qualification, in that the rate was lowest amongst those with a degree or equivalent (0.2%) and highest among those with no qualifications (2.1%)
- People who were single were more likely to be assessed with autism. 4.5% of single men were assessed with autism.

Brugha et al (2012) reproduced this 2007 report as "*Estimating the prevalence of autism in adults: Extending the 2007 Adult Psychiatric Morbidity Survey*", (2012). Data from the [2007 Adult Psychiatric Morbidity Survey](#) has been combined with data from a new study of the prevalence of autism among adults with learning disabilities living in private households and communal care establishments in Leicestershire, Lambeth and Sheffield.

- Autism is common among people with a learning disability, whether they live in communal care establishments or in private households
- Overall prevalence of autism in England is 1.1% (compares with previous estimate of 1.0%) In other words, just over one in 100 adults in the population have autism.
- The rate is higher in men (2.0%) than women (0.3)
- The prevalence of autism increased with greater severity of learning disability/lower verbal IQ.

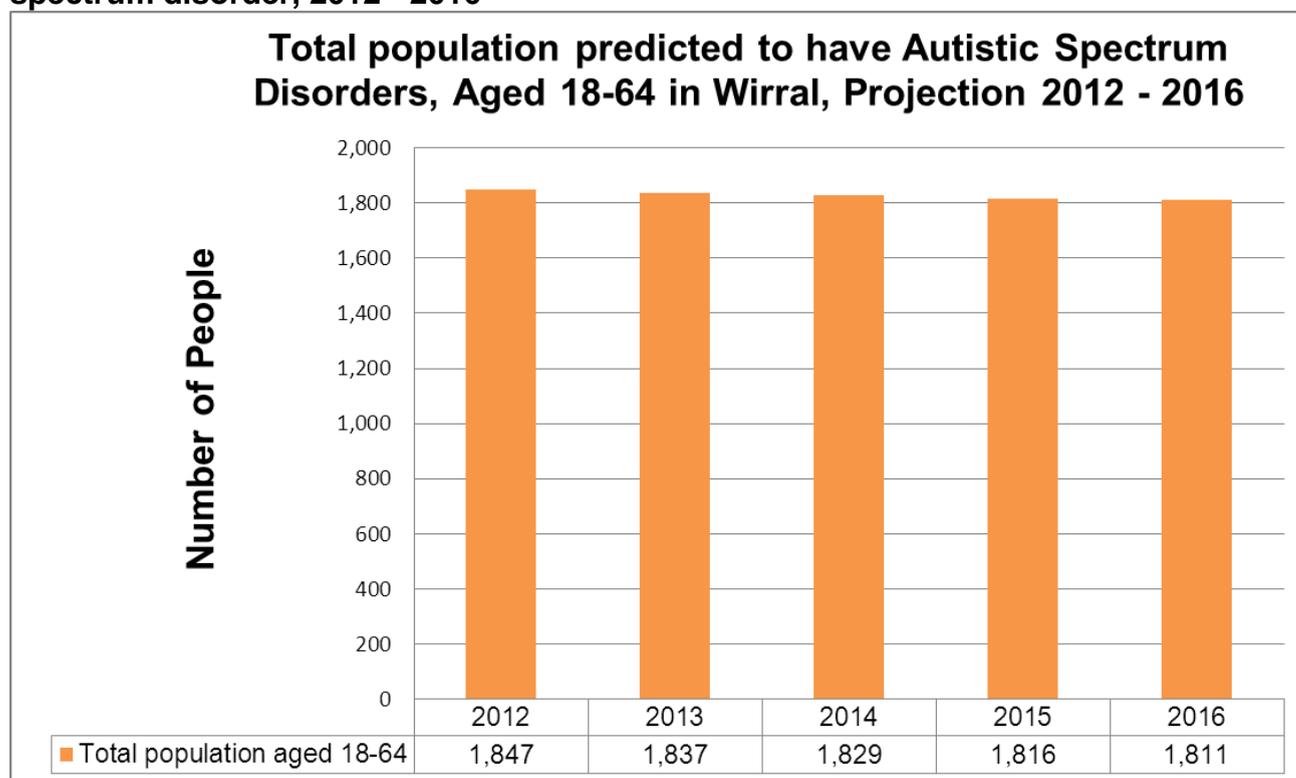
- Autism prevalence rate of adults with severe learning disability living in private households was 35.4%
- Autism prevalence rate of adults with a mild or severe learning disability living in communal care establishments was 31.0%

Wirral

As indicated above there are alternative methods used of estimating the number of people with autism in Wirral, such as PANSI and Brugha (2012) revised prevalence rate estimate percentages.

Estimated prevalence rates are provided by the [Projecting Adult Needs and Service Information](#) (PANSI) system. The PANSI system provides estimated population prevalence rates for adults aged 18-64 predicted to have autism based on the Office for National Statistics (ONS) population projections and prevalence research, which estimates the prevalence at 1% of the population (Brugha et al, 2007). Wirral's projected numbers for people predicted to have autism can be seen in figure 1 below.

Figure 1: Total number of people, aged 18-64, and predicted to have an autistic spectrum disorder, 2012 - 2016



Source: PANSI 2013 www.pansi.org.uk version 7.0 (Table produced on 10/06/13)

Notes: The information about ASD is based on *Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007* was published by the Health and Social Care Information Centre in September 2009.

The prevalence of ASD was found to be 1.0% of the adult population in England, using the threshold of a score of 10 on the Autism Diagnostic Observation Schedule to indicate a positive case. The rate among men (1.8%) was higher than that among women (0.2%), which fits with the profile found in childhood population studies.

The report *Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)*, Baird, G. et al, *The Lancet*, 368 (9531), pp. 210-215, 2006. found that 55% of those with ASD have an IQ below 70%.

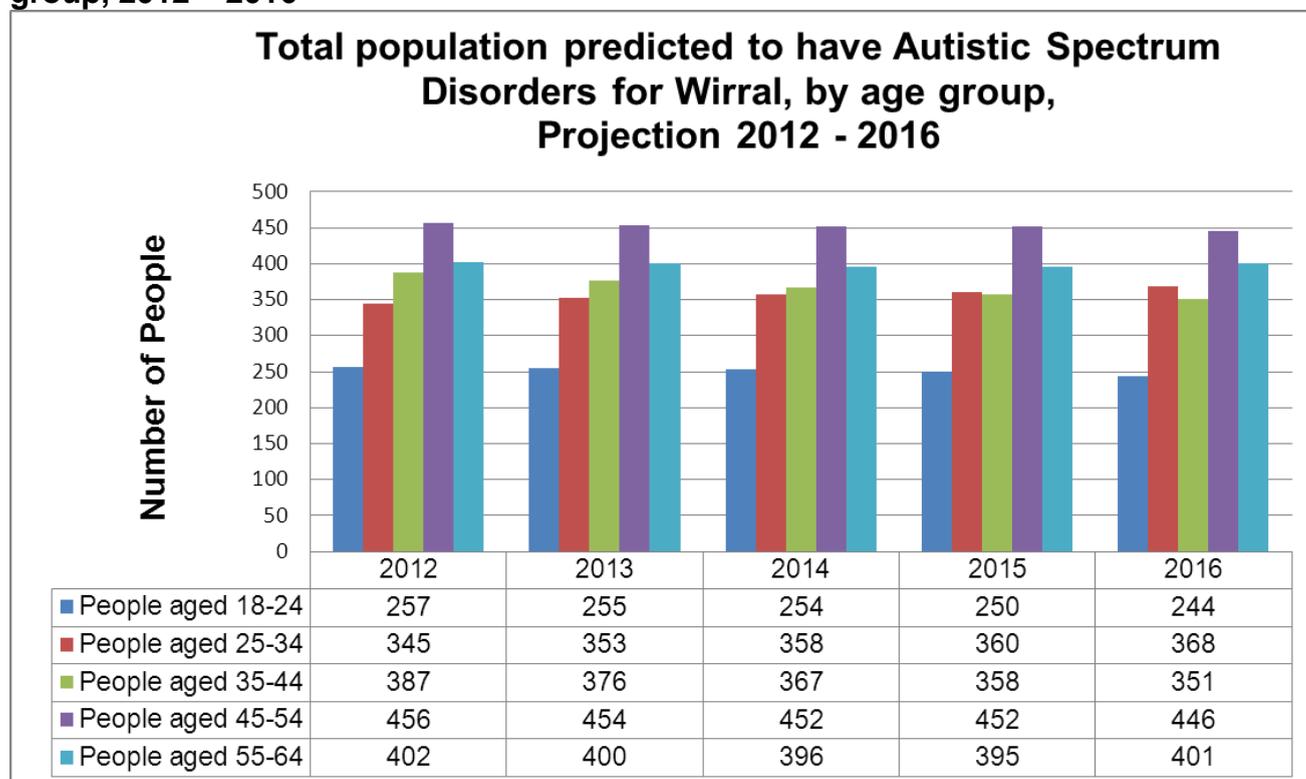
The National Autistic Society states that 'estimates of the proportion of people with autism spectrum disorders (ASD) who have a learning disability, (IQ less than 70) vary considerably, and it is not possible to give an accurate figure. Some very able people with ASD may never come to the attention of services as having special needs, because they have learned strategies to overcome any difficulties with communication and social interaction and found fulfilling employment that suits their particular

talents. Other people with ASD may be able intellectually, but have need of support from services, because the degree of impairment they have of social interaction hampers their chances of employment and achieving independence.'

The prevalence rates have been applied to ONS population projections of the 18 to 64 population to give estimated numbers predicted to have autistic spectrum disorder to 2020.

In figure 2 the predicted numbers by age group are suggested. In 2013 there are expected to be 1,837 people, aged 16 – 64 years, living in Wirral with autism.

Figure 2: People aged 18-64 predicted to have an autistic spectrum disorder, by age group, 2012 – 2016



Source: PANSI 2013 www.pansi.org.uk version 7.0 (Table produced on 10/06/13)

Notes – The information about ASD is based on *Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007* was published by the Health and Social Care Information Centre in September 2009.

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The prevalence rates have been applied to ONS population projections of the 18 to 64 population to give estimated numbers predicted to have autistic spectrum disorder to 2020.

Other approach to estimating prevalence numbers

Using Brugha et al (2012) revised population estimates of 1.1% (2.0% male and 0.3% female) as seen in table 3; it suggests that the number of people with autism living in Wirral is 2,103, as 1853 for males and 294 for females. These are proxy figures based on national prevalence estimates and do have some rounding applied.

Table 3: Estimated Wirral prevalence of Autism using Brugha (2012), in conjunction with 2013 population figures

Prevalence of Autism	Overall	Males	Females
Overall prevalence of autism (%)	1.1%	2%	0.3%
Wirral Population (Aged 18 to 64)	191,260	92,660	98,240
Wirral numbers of people with Autism (estimated)*	2,103	1,853*	294*

Source: Wirral Council, Public Health Intelligence Team, 2013

Notes: *Using Brugha (2012) estimated populations' percentages we have applied these to local 2013 population figures, these percentages may not total as they are subject to rounding

School population

In Table 4 below are the January 2013 Wirral School Census figures by key stage group by those without a special education need (SEN), those with school action, school action plus and a recorded special education need. This suggests that 22% of Wirral's school population (Reception to Year Eleven, or 4 to 16 years of age) has a special education need.

Table 4: Wirral school pupils by numbers with special education needs (SEN) as at January 2013 by Key Stage (KS)*

SEN provision	Reception/ KS1	KS2	KS3	KS4	Totals
No SEN	9453	10473	7965	5615	33506
School Action**	892	1752	1454	919	5017
School Action Plus***	505	1304	829	544	3182
Statement****	163	405	440	325	1333
Total number of pupils	11013	13934	10688	7403	43038
Number of pupils with reported SEN	1560	3461	2723	1788	9532
Proportion of SEN	14%	25%	25%	24%	22%

Source: Wirral Children and Young People Department, January 2013

Notes: * For definitions of Key Stage levels please view here

** School Action may be further assessment, additional or different teaching materials, different teaching methods and sometimes additional adult support. Individual Education Plans (IEPs) are used record the differential provision required.

***School Action Plus is the level of intervention for a child where the school requires external support (e.g. from an educational psychologist or speech and language therapist) to meet the needs of the child.

****A statement is the level of intervention where a child's needs require that the local authority sets out the support required and the local authority is required by law to ensure this support is then provided.

School population with primary and secondary diagnosis of autism

In Table 5 below we see the proportion of Wirral pupils who have a primary and secondary diagnosis of autism compared to other pupils over a five year period. This suggests that Wirral school pupils (Reception to Year Eleven, or 4 to 16 years of age), with a primary or secondary diagnosis of autism is currently 1.3%. This is similar, yet higher than, the 1.0% national prevalence estimate suggested by Brugha (2007) and (2012) and studies of children and young people for autism prevalence undertaken by Baird (2006) and Baron-Cohen et al (2009). This proportion of young people with a primary or secondary diagnosis has been increasing over this 5 year period from 1.0% to 1.3%, or a 39% increase in numbers from 473 to 654 in that five-year period. At the same time there has been a reduction in the number of pupils with School Action Plus or a Statement.

Table 5: Wirral school pupils with autism as primary and secondary diagnosis, between 2009 and 2013, as at July 2013.

ALL	2013	2012	2011	2010	2009
Pupils with primary SEN of autism					
School Action Plus	204	161	146	121	86
Statement	273	235	244	247	254
Pupils with secondary SEN of autism					
School Action Plus	33	35	25	20	17
Statement	144	130	113	112	116
Total number of pupils with primary or secondary diagnosis	654	561	528	500	473
Total number of pupils School Action Plus and Statemented	4871	5044	5269	5152	5086
Percentage of pupils with autism diagnosis in school SEN population (%)	13.4%	11.1%	10.0%	9.7%	9.3%
Total school population	48937	48940	48520	48925	49189
Percentage of pupils with autism diagnosis in school overall population (%)	1.3%	1.1%	1.1%	1.0%	1.0%

Source: Wirral Children and Young People Department, January 2013

Notes: *School Action Plus is the level of intervention for a child where the school requires external support (e.g. from an educational psychologist or speech and language therapist) to meet the needs of the child.

**A statement is the level of intervention where a child's needs require that the local authority sets out the support required and the local authority is required by law to ensure this support is then provided.

2011 autism figures could be understated, due to SEN data from one academy school not being available

Further options to consider when producing estimates

Emerson and Baines (2010) led the study for the Department of Health's Learning Disabilities Observatory that carried out a systematic review to estimate the prevalence of autism amongst adults with Learning Disabilities. The review led to the conclusion that the prevalence for adults who are likely users of social care services that have both learning disabilities and autism was likely to lie somewhere between 20% and 33%. In 2013, the estimated number of adults aged 18 to over 85 with a learning disability thought to be living in Wirral was 5,888 (PANSI, 2013). Using Emerson and Baines study conclusions, this would suggest that between 1,178 (20%) and possibly 1,766 (33%) of people estimated to have a learning disability could also have autism. This study also indicated that the prevalence of autism increased with greater severity of learning disability/lower verbal IQ.

Emerson and Baines (2010) also estimated the population prevalence rate for children and young people with autism. They took into account both Baird (2006) and Baron-Cohen et al (2009) and subsequently derived two estimates of the overall prevalence of autism for use in subsequent modelling. By using the ONS mid 2011 estimates for numbers of children and young people, birth to 18, and the upper estimate of 150 per 10,000 (1.5%) and a lower estimate of 100 per 10,000 (1%), suggests a figure between 676 and 1,014 overall prevalence of autism in Wirral (birth to 18 years of age).

Baron-Cohen et al (2009) study of Cambridgeshire school children set out to consider different methods to estimate the prevalence of autism-spectrum conditions. They estimated the prevalence to be 157 per 10 000, or 1.57% (including previously undiagnosed cases). Again with Wirral's population for children from birth up to 18 as 67,578 (ONS mid 2011 estimates) this could equate up to 1,061 children potentially with some form of autism.

Baird (2006) study suggested that the prevalence of autism and related spectrum disorders is

substantially greater than recognised before their work. Whether the increase was due to better ascertainment, broadening diagnostic criteria or increased incidence is unclear. Services in health, education, and social care should recognise the possible increasing numbers and needs of children with some form of autism, who constitute 1% of the child population. Wirral's population for children from birth up to 18 is 67,578 (ONS mid 2011 estimates) and so this could equate to 676 children potentially with some form of autism

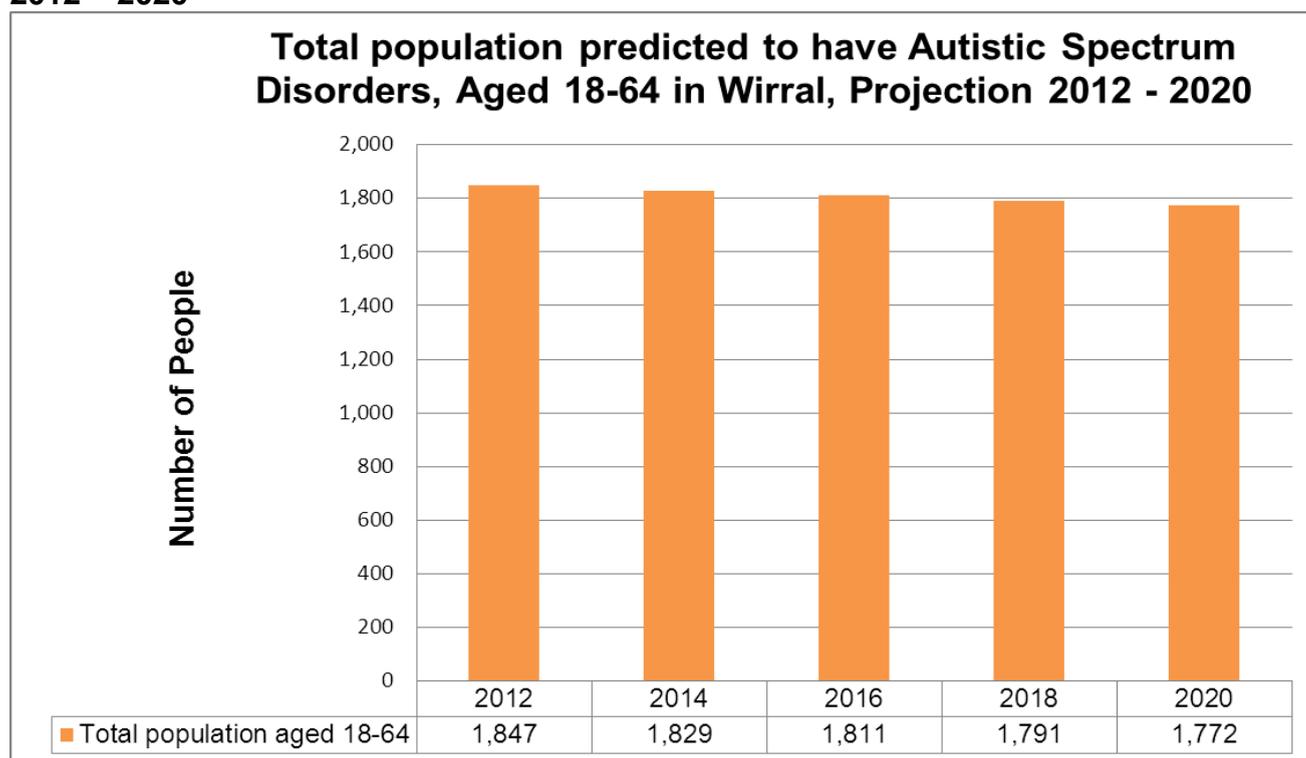
It is clear that the estimated prevalence rates for adults and children with autism can only be a very approximate guide to the actual numbers of people living in Wirral. The current local sources of information on the number of adults with autism, even for those with a diagnosis, are limited across a range of providers.

At present, for Wirral's Department of Adult Social Services, there is no requirement to hold data on clients with autism. However from April 2014 the local authority will be required to record for adults any primary support reason (this will be recorded at the assessment stage) and any other underlying health condition.

Trends

In Figure 6 the estimated prevalence numbers from PANSI by age group are shown. This suggests that there will be a reduction in numbers of people, aged 18 – 64 years, living in Wirral with autism from 1,847 in 2012, to 1,772 in 2020.

Figure 6: Wirral population aged 18 – 64 predicted to have autistic spectrum disorders, 2012 – 2020



Source: PANSI. 2013

Notes: *The information about ASD is based on Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007 was published by the Health and Social Care Information Centre in September 2009.*

The prevalence of ASD was found to be 1.0% of the adult population in England, using the threshold of a score of 10 on the Autism Diagnostic Observation Schedule to indicate a positive case. The rate among men (1.8%) was higher than that among women (0.2%), which fits with the profile found in childhood population studies.

The report Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP), Baird, G. et al, The Lancet, 368 (9531), pp. 210-215, 2006. found that 55% of those with ASD have an IQ below 70%.

The National Autistic Society states that 'estimates of the proportion of people with autism spectrum disorders (ASD) who have a learning disability, (IQ less than 70) vary considerably, and it is not possible to give an accurate figure. Some very able people with ASD may never come to the attention of services as having special needs, because they have learned strategies to overcome any difficulties with communication and social interaction and found fulfilling employment that suits their particular talents. Other people with ASD may be able intellectually, but have need of support from services, because the degree of impairment they have of social interaction hampers their chances of employment and achieving independence.'

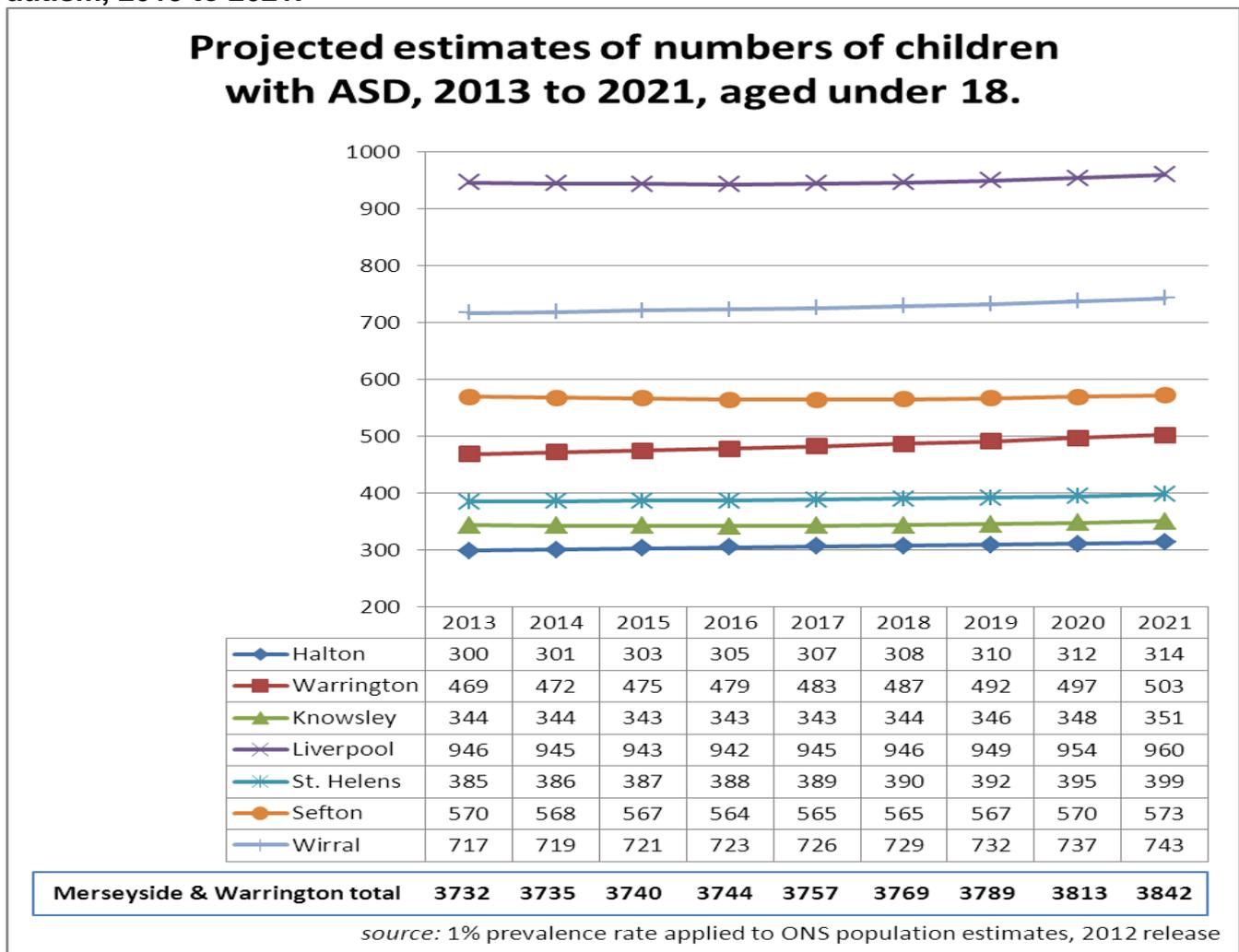
The prevalence rates have been applied to ONS population projections of the 18 to 64 population to give estimated numbers predicted to have autistic spectrum disorder to 2020.

The information about ASD is based on Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007 was published by the Health and Social Care Information Centre in September 2009.

The prevalence of ASD was found to be 1.0% of the adult population in England, using the threshold of a score of 10 on the Autism Diagnostic Observation Schedule to indicate a positive case. The rate among men (1.8%) was higher than that among women (0.2%), which fits with the profile found in childhood population studies.

In Figure 7 Cheshire and Merseyside Learning Disabilities and Autism health needs assessment (2013) provided population trend data for children and young people (under 18) across these areas. This suggests a slight increase for Wirral, from 717 in 2013, to 743 by 2021. This increase is in line with local views that numbers are rising in Wirral.

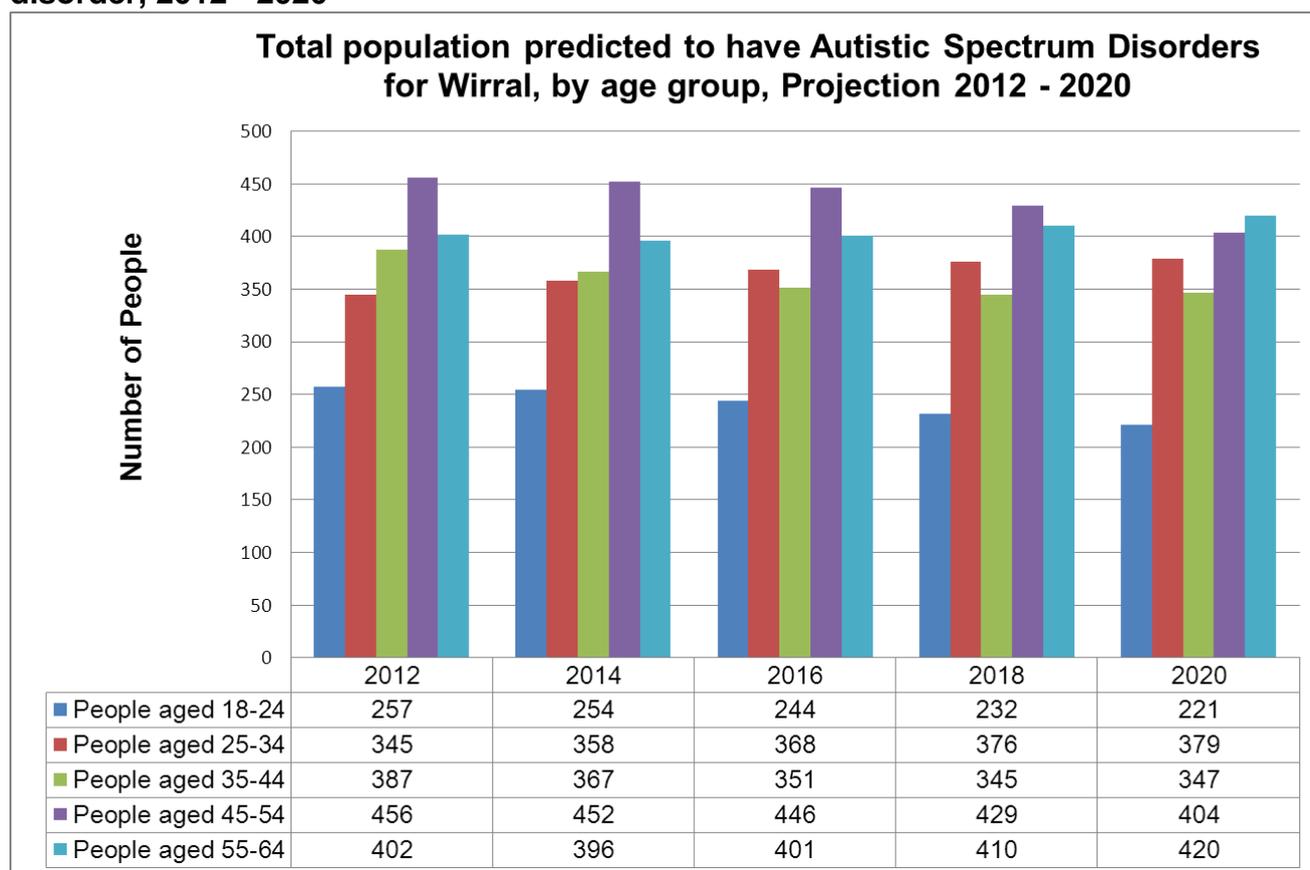
Figure 7: Cheshire and Merseyside Learning Disabilities and Autism Health Needs Assessment (2013) - Projected estimates of numbers of children aged under 18 with autism, 2013 to 2021.



Source: [Liverpool Public Health Observatory, 2013](#)

In Figure 8 below, the expected prevalence numbers of people, aged 16 – 64, with autism is further broken down into age bands. Over the period 2012 to 2020 it suggests a reduction of 14% in numbers of people aged 18 – 24 with autism, a reduction of those aged 45 – 54 by 11% but an increase of 4% in adults aged 55 – 64.

Figure 8: Total population, by age group, predicted to have an autistic spectrum disorder, 2012 - 2020



Source: PANSI. 2013

Notes: *The information about ASD is based on Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007 was published by the Health and Social Care Information Centre in September 2009.*

The prevalence of ASD was found to be 1.0% of the adult population in England, using the threshold of a score of 10 on the Autism Diagnostic Observation Schedule to indicate a positive case. The rate among men (1.8%) was higher than that among women (0.2%), which fits with the profile found in childhood population studies.

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The prevalence rates have been applied to ONS population projections of the 18 to 64 population to give estimated numbers predicted to have autistic spectrum disorder to 2020.

The decreases predicted are based upon population reduction rather than changing prevalence. Based on the PANSI model there is expected to be a small decrease of 4.07% in the total number of adults with autism, aged 18-64 years, in Wirral in the coming years from 1,847 in 2012 to 1,772 by 2020. It is difficult to estimate how many adults with autism are likely to require adult social care in the future because data is only routinely collected on numbers that are known to services.

Other tools used to estimate numbers of people with autism

Estimating local numbers of children with autism - Public Health England online tool

Public Health England provide an online tool that attempts to show modeled data for how many schoolchildren aged 7-15 with learning disabilities that can be expected to live in each region, local authority and ward in England ([view here](#)). The columns indicate the expected numbers of pupils with Severe Learning Difficulties; Profound and Multiple Learning Difficulties; Moderate Learning Difficulties; and Autistic Spectrum Disorder in each area. The number of school children studying in Wirral used for this tool does not reflect current pupil numbers.

Local Health profiles for Learning Disabilities (provided by Public Health England)

Public Health England Health profiles are numbers which help people who plan health services. They come as reports for local areas and the health profiles are for the areas of Local Authorities that run Adult Social Services. They are used by planners in health services and social services. They are also interesting for self-advocates and family carers. [You can view Wirral's 2011 profile for learning disabilities \(that includes estimates on some autism numbers\) here](#)

In summary...

- PANSI estimates suggest that approximately 1,847 adults aged 18 – 64 year olds currently living in Wirral. This will reduce to around 1,829 by 2014.
- PANSI estimates suggest a small overall reduction in the number of adults with autism by 4.07% by 2020
- Using Wirral's 2013 School Census data it suggests that 1.30% of Wirral school children have a primary or secondary diagnosis of autism and this is higher than the suggested national prevalence rate of 1.0%
- Using Brugha (2012) revised population prevalence estimates this sees Wirral having 2,103 adults with autism with 1,853 males and 294 females
- Using PANSI to estimate current Learning Disability numbers and then Emerson and Baines (2010) study, then there could be from 1,178 to 1,766 people living in Wirral who have a Learning Disability and autism.
- Emerson and Baines (2010) also provide more recent prevalence estimates of autism in children and young people (that take account of both Baird and Baron-Cohen et al) that suggest between 676 (1.0%) and 1,014 (1.5%) of children and young people with autism in Wirral (birth to 18 years of age)

Expectations

There have been a number of national drivers to direct the work to support people with Autism and these include:

[The Autism Act 2009](#) and the subsequent Statutory Guidance in 2010,
[Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England \(2010\)](#)
[Autism Act: Final Guidance for Local Authority's and NHS organisations on implementing 'Fulfilling and Rewarding Lives' \(2010\)](#)
[Fulfilling and Rewarding Lives: Evaluating progress against the Autism Strategy \(2011\)](#)
[NICE Guidelines: CG142 Autism: recognition, referral, diagnosis and management of adults on the autism spectrum \(June 2012\)](#)
[NICE Guidelines: CG128 Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum \(September 2011\)](#)
[NHS National Outcomes Framework \(2013/2014\)](#)
[Adult Social Care Outcomes Framework \(2013/14\)](#)
[Public Health Outcomes Framework \(PHOF\) 2013/14](#)
[Department of Health Review: Winterbourne View Hospital Final Report \(December, 2012\)](#)

What are the expectations?

Autism Act 2009 ([view here](#)) required:

- the provision of relevant services for the purpose of diagnosing autistic spectrum conditions in adults;
- the identification of adults with such conditions
- the assessment of the needs of adults with such conditions for relevant services;
- planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults;
- other planning in relation to the provision of relevant services to adults with autistic spectrum conditions;
- the training of staff who provide relevant services to adults with such conditions;
- Local arrangements for leadership in relation to the provision of relevant services to adults with such conditions.

Autism Strategy - [Fulfilling and Rewarding Lives \(2010\)](#), [Final Guidance \(2010\)](#) and [Evaluating progress against the Autism Strategy \(2011\)](#)

In addition to the Autism Strategy, the Department of Health published in 2011 guidance to NHS and social care organisations on evaluating progress against the Autism Strategy including key quality outcomes and service ambitions for local self-assessment.

Outcomes

- 1 - Adults with autism achieve better health outcomes
- 2 - Adults with autism are included and economically active
- 3 - Adults with autism are living in accommodation that meets their needs
- 4 - Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets
- 5 - Adults with autism are no longer managed inappropriately in the criminal justice system
- 6 - Adults with autism, their families and carers are satisfied with local services
- 7 - Adults with autism are involved in service planning.

Service ambitions

- 1 - Local authorities and partners know how many adults with autism live in the area
- 2 - A clear and trusted diagnostic pathway is available locally
- 3 - Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism

National Institute for Health and Clinical Excellence (NICE) guidelines:

NICE have published clinical guidelines for [adults with autism](#), and [children and young people with autism](#), that set out a model care pathway which should form the foundation for local commissioners to develop referral and care pathways in their areas.

NHS Outcomes Framework 2013/14 ([view here](#))

There are no specific outcomes for people with autism in the published NHS Outcomes Framework. However domains 1, 2, and 4 are relevant.

- 1 - Preventing people from dying prematurely
- 2 - Enhancing quality of life for people with long term conditions
- 4 - Ensuring that people have a positive experience of care.

Adult Social Care Outcomes Framework (ASCOF) 2013/14 ([view here](#)).

Again there are no specific outcomes for people with autism in the published ASCOF. However domains 1, 2, 3 and 4 would appear to be relevant.

- 1 - Enhancing quality of life for people with care and support needs
- 2 - Delaying and reducing the need for care and support
- 3 - Ensuring that people have a positive experience of care and support
- 4 - Safeguarding adults whose circumstances make them vulnerable and protecting them from harm

Public Health Outcomes Framework (PHOF) 2013/14 ([view here](#)).

The new Public Health Outcomes Framework introduces the overarching vision for public health, the outcomes and the indicators. Again there are no specific outcomes for people with autism in the published PHOF. However domains 1, 2, 3 and 4 would appear to be relevant.

- 1 – Wider determinants of health
- 2 – Health improvement
- 3 – Health protection

Whilst these outcomes are not intended to establish a new national dataset or central monitoring framework, they provide a clear and consistent basis for NHS organisations, local authorities and their local stakeholders to evaluate their progress. Data published locally can also be compiled to give a picture of national progress. A local self-assessment template setting out these outcomes and ambitions and elaborating them slightly, accompanied this new policy approach. (See page xx for last Wirral Autism self-assessment return)

Department of Health Review: Transforming care: A national response to the Winterbourne View Hospital Final Report (December, 2012) ([view here](#))

Easy Read version of the Department of Health Review: Transforming care: A national response to the Winterbourne View Hospital Final Report (December, 2012) ([view here](#))

Department of Health Review: Winterbourne View Review: Concordat: A Programme of Action. ([view here](#)),

Following the publication of the Department of Health Review, Transforming Care - “A National Response to Winterbourne View Hospital” and the associated “Winterbourne View Review: Concordat: A Programme of Action”, the Local Government Association (LGA) and the NHS Commissioning Board (NHS CB) established a two-year joint improvement programme that is expected to drive local leadership and transformation of the approach to supporting people with behaviour that challenges and those with complex needs.

National partners have committed to a programme for change to transform health and care services and improve the quality of the care offered to children, young people and adults with learning disabilities or autism who have mental health conditions or behaviour that challenges to ensure better care outcomes for them. This should result both in a movement away from the use of long stay, large-scale hospital services and also lead to real change in the attitudes and culture.

A series of commitments have been made that require local action planning and implementation across Local Authorities and the NHS so that a range of improvement activity takes place.

The **key recommendations** are:

- Health and Social Care commissioners will review all current hospital placements and

support everyone inappropriately placed in hospital to move to community-based support asap and no later than 1 June 2014;

- Every area has a locally agreed joint plan for high quality care and support services for people of all ages with challenging behaviour that accords with the model of good care;
- Areas should consider supporting this with pooled budget arrangements with local commissioners offering justification where this is not done;
- Improvements are required in the overall quality and safety of care;
- Accountability and corporate responsibility for the quality of care will be strengthened;
- Regulation and inspection of providers will be tightened;
- Future planning for this cohort of people should start from childhood.

The Winterbourne View Joint Improvement Programme (WVJIP) was established in December 2012 with the purpose of providing leadership and support to the transformation of services locally and based on the documents above. ([Link to WVJIP web content](#))

The strategic objectives of the WVJIP include:

- To support the transformation of commissioning and provision of support and services for people with learning disability, autism and/or challenging behaviour so that they are personalised, safe and local.
- To significantly reduce in the reliance on long term placements in Assessment and Treatment (A&T) Centres.
- Development of more locally based provision enabling people to remain closer to home throughout the pathway of their care.

Specific progress measures include:

- The completion of joint reviews of all people in learning disability or autism inpatient beds by June 2013
- A rapid reduction in the numbers of people in hospital or large scale residential care with people receiving personalised care and support in appropriate community settings by June 2014.

Local Stocktake

(Stocktake of progress reports can be viewed as [Full Report](#), [Executive Summary](#) and [Easy Read version](#))

In June 2013, the Winterbourne View Joint Improvement Team (WVJIP) asked local areas – specifically Local Authority Chief Executives, and Clinical Leads of Clinical Commissioning Groups (CCGs), to undertake a local stocktake and self- assessment of progress against key activities that support local delivery of Transforming Care and Concordat commitments.

The stocktake was a self-assessment of progress across a number of strategic and practical domains that will need to be in place to enable people with learning disabilities or autism, who also have mental health conditions or behaviours viewed as challenging, to live in local community settings rather than in hospital.

In October 2013 the Local Government Association and NHS England published the 'Stocktake of progress report'. (see above)

The report is an analysis of a questionnaire that covers all 152 health and wellbeing board areas, and is designed to enable local areas to assess their progress against commitments in the Winterbourne View Concordat, share good practice and identify development needs. The Stocktake report demonstrates that health and social care systems in local areas across the

country are universally engaged in, and working on the Concordat commitments, this report can be accessed via:

The stocktake provided:

- a strong basis for follow up lines of enquiry with localities
- a consistent sense of both the challenges in the system and of strengths / weaknesses to address these
- a good test of challenges set out in 'Transforming Care' and of how robust responses to those are being developed
- a sector led indication of what needs to be put in place – and where it might be targeted – to support localities to achieve sustainable change

As a next step, the Winterbourne View Joint Improvement Team are talking to localities and regions to develop appropriate and responsive improvement support.

Performance

[Improving Health and Lives Learning Disabilities Observatory](#) (2011) prepared a [preliminary report on extracting information from local Autism Self-Assessment Frameworks](#) (Copeland and Glover, 2012) which indicates that some authorities had begun to formalise service planning for people with autism but that there was still significant work required with the criminal justice system and to secure better health outcomes for adults with autism

In 2011 the Department of Health provided all local authorities in England with the means to assess their progress towards Autism Strategy goals. In December 2011, local authorities were invited to send copies of their assessment of their own position in relation to the issues raised to the Learning Disabilities Public Health Observatory for collation and wider publication. Wirral has completed this Autism Self-Assessment Framework for 2010/11. [This can be viewed via this link.](#)

The second national self-assessment: Adult Autism Strategy *Fulfilling and Rewarding Lives 2013.*

Following on from the 2010/11 baseline survey, a second self-assessment process has been conducted and the purpose was to:

- Assist Local Authorities and their partners in assessing progress in implementing the 2010 Adult Autism Strategy;
- Judge how much progress has been made since the baseline survey, as at February 2012
- Provide evidence of examples of good progress that can be shared and of remaining challenges

Wirral completed this return in September 2013 and the data submitted up to this point, will be used for the initial high-level national report expected to be circulated by Public Health England in October / November 2013. This report will show headline figures for each question and national response rates, but not local breakdowns at this initial stage.

[Other documents on IHAL – Wirral's Learning Disabilities Profile 2013](#)

What is this telling us?

Overview

Within Wirral there is a strong commitment across partners in health and social care to achieving sustainable change in the nature of treatment, care and support available to people with learning disabilities or autism, who also have mental health conditions or behaviours viewed as challenging.

As a partnership, we need to continue to develop in the areas of:

- Embed local governance arrangements to ensure that health and social care systems, alongside, housing, employment and the criminal justice service are universally engaged and working.
- Improve overall data collection e.g PANSI data indicates a prevalence in excess of 1,000 adults within Wirral who have a learning disability and autism. In respect of specific autism diagnosis recording, (unaudited) health and social care data would indicate that 53 individuals have been formally diagnosed since September 2011.
- Strengthen links between schools, health and social care (Adults and Childrens) to ensure that appropriate support and signposting is available to children and young people with a primary or secondary diagnosis of autism, their carers and families

Local views

People with disabilities including children and adults with autism, their families, and the general public are to be invited to a number of listening and consultation events that are being planned in Wirral in November and December 2013.

The results of this engagement will inform the work of the Wirral Disabilities Partnership Board, a later version of this JSNA Chapter and in turn local service planners and commissioners in their work.

National and local strategies

National

[The Autism Act 2009](#) and the subsequent Statutory Guidance in 2010,
[Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England \(2010\)](#)
[Autism Act: Final Guidance for Local Authority's and NHS organisations on implementing 'Fulfilling and Rewarding Lives' \(2010\)](#)
[Fulfilling and Rewarding Lives: Evaluating progress against the Autism Strategy \(2011\)](#)
[NHS National Outcomes Framework \(2013/2014\)](#)
[Adult Social Care Outcomes Framework \(2013/14\)](#)
[Public Health Outcomes Framework \(PHOF\) 2013/14](#)

Current activity and services

There is an incomplete picture of how children, young people and adults, with autism (both known and not known to services) in Wirral are accessing local services and activities. This places limitations on our local knowledge around need, experience and outcomes. However there is a range of service provision and providers available for people with autism.

It is the intention to provide an overview of the current local services and provision that is available. This will be included in a later version of the autism chapter.

Key inequalities and health issues

Some of the issues that people with autism face include:

- Prone to social and economic exclusion
- Services that are not available consistently; different adults with autism in the same area can have very different experiences
- Risk of severe health and mental health problems, homelessness, descending into crime or addiction for those without support.
- Although many adults with autism make successful and important contributions to their communities, the economy and their families, too many are dependent on benefits.
- There is more vulnerability to anxiety and depression in people with Autism.
- There is an incomplete picture locally around information, needs, experiences and outcomes for adults with autism who may also have mental health problems.

Emerson & Baines (2010) study highlighted a number of key health inequalities that encompass those people with a learning disability that in turn will affect some people with autism. These key health inequalities are:

- Higher levels of early mortality though life expectancy is increasing
- Variations in outcomes for cancer with higher levels for childhood leukaemia for those children with Down's syndrome but lower incidence patterns for a number of other cancers
- Respiratory and coronary heart disease are leading causes of death for people with LD
- Mental health problems and challenging behaviours are more prevalent among people with autism with the presence of psychiatric disorder marked for those adults with autism
- Epilepsy at higher levels than the general population
- Live with a range of sensory and sometimes physical impairments

In relation to autism in particular, [Research Autism](#), suggest there are a number of potentially corresponding health issues have been identified:

- **Epilepsy:** Although the majority of individuals with autism do not have epilepsy, between 20% and 30% of those with autism will suffer from epilepsy or seizures¹. Research suggests that those autism sufferers with more severe cognitive disability, motor planning problems and significant receptive language issues are more at risk of developing epilepsy. A person with autism is at greater risk of epilepsy if they also have some neurological conditions such as tuberous sclerosis or neurofibromatosis. There are two peaks for the onset of seizures: infantile spasms (often associated with learning difficulties) and in adolescence.
- **Attention Deficit Hyperactivity Disorder:** This appears to be the most common second diagnosis for autism of 6 – 12 year olds, with around 50% co-diagnosed with Attention Deficit-Hyperactivity Disorder (ADHD). It is estimated that between 10% and 40% of those with autism will have ADHD which will continue into adulthood.
- **Anxiety:** MacNeil et al (2009) found that more than 80% of children with autism had at least one anxiety disorder. Many young adults with Asperger syndrome have intense feelings of anxiety, an anxiety that may reach a level where treatment is required.

- **Mental Health** - Mental health problems appear to be common in people with autism, as well as their families and carers. For example Muris (1998) suggested that 84.1% of children with autism met the full criteria of at least one anxiety disorder Tantam (1991) indicated that 1 in 15 people with Asperger syndrome experience depression. Kim et al (2000) also found depression to be more common in children with autism than in other children. ([More information available here](#))
- **Self-harm:** Individuals with autism are also prone to self-harm. Self-harm may be a reaction to anxiety, an unpredictable or overwhelming situation or lack of control – as a way of controlling themselves and the reactions of those around them. In individuals with autism and additional severe learning difficulties (intellectual impairment), self-harm is likely to arise as a reaction to frustration or panic.
- **Sleep issues:** Children with autism commonly have problems with sleeping and these problems can remain into adulthood. As children, there are problems in getting to sleep, in sleeping in their own bed, in staying asleep and in waking early. This results in very little sleep for the child, and consequently in very little sleep for the family. As adults, people with autism frequently have problems sleeping and often exist on very little sleep (only 2 to 4 hours a night for some children and adults) but seem at the same time to be suffering from the symptoms of chronic sleep deprivation; adding to their problems of stress. ([More information available here](#))

Suggested key approaches to needs and good practice

[NICE Guidelines: CG142 Autism: recognition, referral, diagnosis and management of adults on the autism spectrum \(June 2012\)](#)

- The key interventions identified in the guidance for adults with autism are social support such as employment and education support, housing, social groups/social skills training which are likely to reduce isolation and access to early accurate diagnosis.
- Improvements of social support systems may reduce the likelihood of a person experiencing common mental health problems. There is a need to support people with autism to be as autonomous as possible.
- The evidence also indicates that the needs of carers and family need to be considered and appropriately addressed due to the nature of autism and the impact this can have on family and carers' health and wellbeing.

[NICE Guidelines: CG128 Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum \(September 2011\)](#)

- One of the key aspects suggested by the guidance would be the provision of a local pathway for recognition, referral and diagnostic assessment of possible autism. This could be managed through a local autism multi-agency group.
- This group could include staff from child health and mental health services, education, social care, parent and carer service users, and the voluntary sector. It is also suggested that a case coordinator be identified for every child or young person who is to have an autism diagnostic assessment.
- Any such group should consider any improvement to early recognition, awareness and the development of any local autism pathways for recognition, referral, diagnosis and transition of children and young people.
- The communication of the results from the autism diagnostic assessment should be considered, with appropriate consent, with other professionals so it can contribute to the child or young person's individual education plan and needs-based management plan.

[Social Care Institute for excellence \(SCIE\) Guide 43 \(Taylor & Marrable, 2011\)](#) suggests there are some key needs that should be addressed by commissioners when providing services:

- Greater autism awareness among social care workers needs to go hand-in-hand with in-depth knowledge of the individual with autism.
- Better understanding of autism in the social care sector can help people get a diagnosis of autism, and get timely, appropriate support after diagnosis.
- Staff need to make adjustments in their work, planning and communication with people with autism, and with each other, so that services can be more accessible.
- Commissioners of services need to be flexible and collaborative in meeting the needs of people with autism, especially those whose behaviour challenges services, and those with Asperger's Syndrome or high-functioning autism.
- People with autism need particularly good support during significant life changes.
- Personalised approaches can benefit people with autism, and professionals need to support them and their families to make the most of them.
- Support with social interaction and everyday living tasks can address some of the needs people with autism have, at relatively low cost.
- Carers of people with autism typically know them extremely well. Professionals should offer carers support in their own right, and work with them to provide the best possible services for people with autism

Department of Health (2010) guidance dictates that there must be a clear pathway to diagnosis and an appointed person in the Local Authority developing diagnostic services.

- All adults receiving a diagnosis of autism should be offered a community care assessment, regardless of where they are on the spectrum, and that all carers should be informed of their right to a carer's assessment.
- The national autism strategy also highlights (Department of Health, 2010) that health and social care are sectors where staff come into contact with adults with autism most frequently, and can be highly influential in determining the kind of support adults with autism receive, both through needs assessment processes and in terms of the actual care and treatment prescribed or provided. For these sectors the need for awareness training is great, not only to improve knowledge but to change behaviour of staff.

The 2009 National Audit Office survey and report of local authorities and their NHS partners to assess service provision for adults with autism, including: health, social care, education, benefits and employment support concluded that:

- Organisations that support people with autism need better awareness of the number of people with autism, so that services can be planned, delivered and monitored appropriately to meet the needs of this group.

The National Autistic Society (2009) recommends using tools such as keeping diaries, talking about anxiety, using relaxation techniques and getting support from other people with autism, for example through support groups, to help people become aware of what is making them anxious and to help them manage their anxiety. Delays in diagnosis can both impact on the family and give a higher chance of misdiagnosis with a mental health problem. This can cause expensive and inappropriate mental health interventions.

Attwood (2006) implies that cognitive behavioural therapy and applied behavioural analysis are two interventions that have shown positive effects for adults with autism. Cognitive Behavioural Therapy can be used to improve social skills as well as treat co-morbid common mental health problems such as depression in people with autism, providing it is adapted to the cognitive style of people with the condition

Other key suggestions

Employment

People with autism have difficulties with communication, social interaction and social imagination which can make finding jobs and retaining jobs problematic, particularly due to a propensity for other people to be unaware or misunderstand autism due to its 'hidden' nature.

Support to overcome these barriers includes Disability Employment Advisors who are often the key contact through local job centres for people with autism with regards to training, employment issues, legal frameworks and overcoming general difficulties when job seeking.

In addition to this, the Department of Work and Pensions (DWP) has an Access to Work programme aiming to help disabled people overcome work-related obstacles and to meet additional costs resulting from disability such as reasonable adjustments in the workplace, which is a legal requirement for all employers.

Hendricks (2010) does identify a number of strategies for success which are centred on supported employment such as supported employment to include job placement which is individualised and based on the person's strengths and interests and the support from supervisors and co-workers; training for the person with an autism in respect of communication, interpersonal skills and self-management of behaviours; and on the job support in times of difficulty.

Housing

The National Autism Strategy (Department of Health, 2010) states that the needs of adults with autism should be taken into account in local housing planning, design and allocation, in line with local priorities. Any support should be available for adults with autism who want to, or have to, live independently – both on an on-going basis and during the transition period into a new home. This will require adults with autism and their carers being given help to understand the options available to them, including the financial help they may be entitled to.

Social support

Services and support dedicated to adults with autism can play a pivotal role in enabling effective use of mainstream services, and can help adults with autism to live more fulfilling lives in society. Similarly, many user-led and voluntary support groups help adults with autism build friendships, share experiences and live independently. These play an important role in enabling adults with autism to develop a social life, build relationships meet others with autism without worrying about how they will be judged or viewed. Support groups can also provide an important setting for training in life skills and social skills, for example in cooking, dealing with money and bills and relationship advice.

Advocacy

Advocacy is a process of supporting and enabling people to express their views, to access information and services, to find out about options and make decisions, and to secure their rights. The nature of autism, particularly the propensity for an impaired ability to communicate, means that many people with autism need help to express their needs and promote their rights. This may be needed at any time in the life-course, for example during the transition from child to adult services, or when seeking housing or employment. Advocacy services are seen as extremely important for people with autism.

Key gaps in knowledge and services

- Lack of systematic recording of people known to services who have an autism diagnosis
- Numbers not known accurately – in population and in service
- The evidence base evaluating services for people with autism needs further development
- The extent of knowledge and skills held by the range of health or social care staff that work with people with autism is uncertain. This is likely have a significant impact on their service experience and meeting of support needs.
- Further understanding is required of the needs of people with autism from a range of backgrounds in particular minority ethnic and cultural groups, women and older people.
- A greater depth of content and views from service users (those diagnosed with autism and their carers)
- Understanding the experience of Wirral residents with autism in terms of local employment, housing and the criminal justice system

What is coming on the horizon?

Research is currently being undertaken by National Autistic Society into Autism and Ageing. It is suggested that current research and knowledge is to date limited in terms of autism in an older population. The outcomes of this work will be included in future updates of the JSNA.

Links

[National Autistic Society](http://www.autism.org.uk/) - (<http://www.autism.org.uk/>)

[Research Autism](http://researchautism.net/pages/welcome/home.ikml) - (<http://researchautism.net/pages/welcome/home.ikml>)

[National Institute for Health and Clinical Excellence \(NICE\)](http://www.nice.org.uk/) - (<http://www.nice.org.uk/>)

[Diagnosing, supporting and caring for adults with autism. Understanding NICE guidance: Information for people who use NHS services.](#)

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