



# Autism Needs Assessment

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## Introduction

### Policy Context

In 2010, a statutory duty was placed on the NHS and Local Authorities to ensure that services are in place to meet the needs of people with Autism Spectrum Conditions (ASC). This was done through the introduction of the Autism Act 2009<sup>1</sup> and the publication of the national autism strategy *Fulfilling and rewarding lives: the strategy for adults with autism in England*<sup>2</sup>. Statutory guidance for health bodies and local authorities was published later the same year<sup>3</sup>, together with a document *What this guidance means for adults with autism*<sup>4</sup>.

Alongside these documents, The National Audit Office published a report *Supporting people with autism through adulthood* in 2009<sup>5</sup>. This report highlighted two key areas where existing services could be improved and made more effective. These were better strategy and planning based on good information and raising levels of knowledge and awareness of ASC. Other Government reports have highlighted that adults with ASC are some of the most excluded people in society.

Publication by the National Institute for Health and Clinical Excellence (NICE) of *Clinical guidelines on the recognition, referral, diagnosis and management of adults on the autistic spectrum* in 2012<sup>6</sup> further supports the implementation of the national autism strategy. This document provides evidence based recommendations. More recently the Local Government Association (LGA) in association with NHS England published *Ensuring quality services*<sup>7</sup>, a core principles commissioning toolkit for those with learning disabilities and/or autism.

### Needs Assessment

This needs assessment has been undertaken on behalf of Business Transformation to inform Solihull Metropolitan Borough Council's Autism Strategy. Needs Assessment is a systematic review of issues facing a population in order to agree priorities and allocate resources to address issues and reduce inequalities.

### Aims

This needs assessment will attempt to inform the Autism strategy by:-

- Collect information where available on the prevalence of ASC in Solihull
- Determine where possible the number of people with ASC in contact with services
- Identify gaps in services and unmet need
- Determine priorities and make recommendations

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<sup>1</sup> HMSO 2009

<sup>2</sup> Department of Health March 2010

<sup>3</sup> Department of Health December 2010

<sup>4</sup> Department of Health December 2010

<sup>5</sup> National Audit Office 2009

<sup>6</sup> NICE 2012

<sup>7</sup> LGA 2014, Gateway reference 01197

## Autism Spectrum Conditions

NICE guidelines describe autism as a lifelong neurodevelopmental condition that is a spectrum of conditions which includes Asperger's Syndrome and childhood autism. Asperger's syndrome was first described in 1944 by a Viennese paediatrician Hans Asperger and not widely recognised until 1981 when Dr Lorna Wing coined the phrase. Thus older people are less likely to be diagnosed with the condition in childhood. People with Asperger's Syndrome generally have a higher IQ (>70) and often do not have coexisting learning difficulties.. However they are still affected by the difficulties common to all people with autism, illustrated in the diagram below and summarised as a "triad of impairments"<sup>8</sup> as illustrated in Figure 1 and summarised below.

Figure 1: Difficulties experienced by people with autism



© National Autistic Society

- Communicating socially, particularly using and understanding facial expressions, tone of voice and abstract language
- Recognising or understanding other people's emotions and feelings and expressing their own, making it more difficult to fit in socially
- Understanding and predicting other people's behaviour, making sense of abstract ideas and imagining situations outside their daily routine

Around half of people with autism also have a learning disability, often accompanied by an IQ of <70.

<sup>8</sup> Supporting people with autism through adulthood, NAO, 2009

Autism expressed in individual people may differ at various stages in their life course and the features may range from mild to severe and fluctuate in response to changes in circumstances or over time. Autism spectrum condition (ASC) is used in this document to describe people across the autistic spectrum.

Evidence from both the National Autistic Society and Research Autism suggests that people with ASC are vulnerable to mental health issues. Depression is common as are emotional difficulties such as social anxiety disorder. They are regarded as secondary to ASC as this develops first and the other conditions develop as a consequence.

### Other conditions associated with ASC<sup>9</sup>

- Attention deficit hyperactivity disorder (ADHD)
- Tourette's syndrome or other tic disorders
- Epilepsy
- Dyspraxia (a developmental co-ordination disorder)
- Obsessive compulsive disorder (OCD)
- Generalised anxiety disorder
- Bipolar disorder

### Classification

The International Classification of Diseases version 10 (ICD10) places Autism in pervasive developmental disorders (F84). "This group of disorders is characterized by qualitative abnormalities in reciprocal social interactions and patterns of communication and by a restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a pervasive feature of the individual's functioning in all situations".<sup>10</sup> This group includes childhood autism (F84.0), atypical autism (F84.1) and Asperger's syndrome (F84.5) amongst other e.g. Rett's syndrome. These codes are more likely to be seen on hospital inpatient records.

An alternative classification is the Diagnostic and Statistical Manual (DSM) IV created by the American Psychiatric Association similarly identified autism and Asperger's syndrome as two separate categories within pervasive developmental disorders. However DSM V now groups pervasive developmental disorders under one umbrella diagnosis of Autism Spectrum Condition. This classification is favoured by America and Australia.

The majority of people are registered with a General Practitioner (GP) and GPs are often the first point of contact with the NHS for those with autism. GPs use Read codes to record patient conditions but there is not a consistent Read code for autism but GPs may write in notes that patient has autism. Work is under way to look at the feasibility of introducing a consistent Read code for ASC<sup>11</sup>

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<sup>9</sup> NHS choices

<sup>10</sup> International Statistical Classification of Diseases and Related Health Problems, 10th revision, WHO 1992

<sup>11</sup> Think Autism; Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update, Her Majesty's Government 2014

## The Causes of Autism

What causes autism is not yet known but it is thought that several complex genetic and environmental factors are involved. Underlying conditions may also contribute to ASC<sup>12</sup>.

The exact cause is still under investigation. Most experts believe there is not one single cause but that it can be caused by several physical factors all of which affect brain development. Several genes are likely to be involved in some forms of autism but it is difficult to establish gene involvement because of the interaction of genes with environmental factors. However an early study by Kanner in 1943 on twins established that autism is highly inheritable. A more recent study has looked at foetal cortex development in pregnancy and discovered that children with autism were more likely to have focal patches of disrupted development in the six cortical layers when compared to children without autism.<sup>13</sup> Other studies have looked at parental obesity, gestational diabetes and advanced parental age and the link with autism. These conditions are thought to be significant risk factors but not causes. Further investigation is required in all areas of research.

Several studies have been carried out world-wide and these have established that there is no link between mumps, measles and rubella (MMR) vaccination. ASC is also not caused by the way someone is brought up or by their diet.

## Diagnosis of Autism Spectrum Conditions

As understanding of ASC increases, more early diagnoses are made. In the past understanding was limited so fewer adults have a formal diagnosis. Parents are usually the first to notice the symptoms of ASC when their children are about 2 -3 years old but in some cases ASC is not diagnosed until adulthood. The process of diagnosis may differ depending on where someone lives<sup>14</sup> as there isn't a standard way of diagnosing ASC but there are guidelines that professionals should follow<sup>15</sup> when diagnosing a child. Diagnosis in adults is more difficult and can be done in some areas by self-referral to services but is more often done through a GP referral. If an adult is in contact with another health professional for another condition they too could make a referral. Diagnosis for them often means that they gain understanding of why they find some things difficult but are good at others. Also they are often been able to access support and benefits for the first time.

## The prevalence of Autism Spectrum Conditions in Solihull

### National prevalence

Prevalence means the number of people with a health condition in a population at a particular time, usually expressed as a percentage. To get actual data on the numbers of people in the population who have ASC is very difficult because they may or may not be known to services and they may receive a lot of different services, the data from which is not held in a central database. Prevalence is therefore estimated using information published by the Health and Social Care Information Centre (NHSCIC) in 2009<sup>16</sup>. This survey estimated the national prevalence at 1.1% for those people aged 18-64. However the rate appears to be higher in males than in females (1.8% and 0.2%) respectively, but some researchers feel that ASC in females is under-diagnosed so prevalence could be higher.

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<sup>12</sup> NHS choices, [www.nhs.uk](http://www.nhs.uk)

<sup>13</sup> Courchesne et al , On line edition New England Journal of Medicine, March 27<sup>th</sup> 2014

<sup>14</sup> Diagnosis what to expect, National Autistic Society website [www.autism.org.uk](http://www.autism.org.uk)

<sup>15</sup> Clinical guidelines CG128, NICE, 2011

<sup>16</sup> Autism Spectrum Disorders in adults living in households throughout England: Report from the Psychiatric Morbidity Survey 2007, NHSCIC 2009

These prevalence figures fit the profile found in childhood studies. The split between those with ASC and possible learning difficulties (LD) and those with ASC and little or no LD (this group includes those with) Asperger's is thought to be 50:50<sup>17</sup>. These estimates are accepted by the National Autistic Society and reflect differences in service and eligibility criteria.

When the national prevalence rate is applied to the most up to date population data for Solihull (2012) it results in the following numbers.

*Table 1: Estimated numbers for people with ASC by age group*

	1-17			18-64			65+		
	with ASC			with ASC			with ASC		
	with ASC	+LD	inc.Asperger's no LD	with ASC	+LD	inc.Asperger's no LD	with ASC	+LD	inc.Asperger's no LD
persons	469	235	234	1331	666	665	454	227	227
males	396	198	198	1064	532	532	328	164	164
females	41	21	20	124	62	62	46	23	23

This means that there could be 2250 children and adults with ASC in Solihull. This figure will include those with and without a formal diagnosis and therefore with both met and unmet need. Research quoted by NICE suggests that for every 3 known cases of ASC there are 2 undiagnosed.

### Prevalence in primary care

In 2008 the National Audit Office commissioned a survey of GPs on the subject of ASC<sup>18</sup>. Of the patients seen in a 6 month period, 2.5% of children (<18), 1.4% of 18-64 year olds and 0.5% of patients aged 65 and over, had symptoms that indicated they may have ASC. None of these patients had a previous formal diagnosis of the condition. The overall prevalence measured in this survey of ASC appears to be slightly higher than previously thought and also seems to decrease with age.

There is some evidence<sup>19</sup> that estimates the prevalence of coexisting conditions e.g.

- 84.1% of children with ASC meet the criteria for at least 1 anxiety disorder. In Solihull this would equate to 394 children.
- In addition 10% children with Asperger's were diagnosed with Obsessive Compulsive Disorder (OCD) i.e. 23 Solihull children
- 1 in 15 with Asperger's syndrome experience depression which could be as many as 75 children and adults.

### Criminal Justice system

Richard Mills in a presentation on behalf of Research Autism and the National Autistic Society quoted a number of studies that estimated ASC in the offender population as between 2-4% which is higher than in the general population (1%)<sup>20</sup>. In the same presentation there are studies quoted as estimating that 15-20% of the Asperger's population are at increased risk of offending.

However the National Autistic Society on their website state " that there is no evidence of an association between ASC and criminal offending, in fact, due to the rigid way that many people with ASC keep to rules and regulations, they are usually more law abiding than the general population.

<sup>17</sup> Supporting People with autism through adulthood, NAO, 2009

<sup>18</sup> [www.nao.org.uk/wp-content/uploads/2009/06/0809556\\_gp.pdf](http://www.nao.org.uk/wp-content/uploads/2009/06/0809556_gp.pdf)

<sup>19</sup> Research Autism

<sup>20</sup> Richard Mills, presentation for Research Autism and National Autistic Society, 2012

People with ASC are more at risk as victims of crime rather than offenders<sup>21</sup>. This may be because specific vulnerability factors may increase an individual's risk. These include difficulties with communication, social interaction and some coordination problems. Their behaviour is sometimes seen as odd and this may draw unnecessary attention but in general ASC is a hidden disability.

The type of offences that people with ASC may "commit" may relate to social naivety i.e. because they want to make friend, they may be befriended by and become unwitting accomplices of, criminals. They could also be aggressive because there has been a change in their routine or environment which causes them anxiety and distress. Also because people with ASC adhere strictly to rules they may become agitated if others seem to break them e.g. kicking a car if it is illegally parked. In addition, many of those with ASC will not understand the implications of their behaviour and do not learn from past mistakes and may subsequently "re-offend".

The Public Health Outcomes Framework (PHOF)<sup>22</sup>, states that in 2012 there were 349/100,000 new entrants to the youth justice system in Solihull. This equates to 74 young people aged between 10 and 17, 3 of whom could have ASC.

Statistics from a Freedom of Information request (FOI) shows that the custody and probation caseload of those offenders who give Solihull as their home address was 482 in the community as at 31/12/11 and 135 in prison as at 31/03/12<sup>23</sup> meaning that there could be between 12 and 24 Solihull residents with ASC in contact with the justice system.

## People known to services

There is great difficulty establishing the actual number of people with ASC in Solihull, however Solihull is not alone in this as other areas also experience problems

### Children

The best data source for children with ASC is the annual school census which counts the number of children with statements of special educational need (SEN) and their primary type of need.

In January 2013 there were 179 primary school children, 179 secondary school children and 78 children in special schools recorded with SEN statements or at school action plus where the primary need is ASC. This is 12.5% of the total number of pupils compared to 10.4% for England and 11.1% for comparator authorities. This percentage has steadily increased since January 2008 when the value was 5.51%<sup>24</sup>.

The main primary need for statements in primary school children is moderate learning difficulties(23.7%), ASC is ranked 4<sup>th</sup> (11.9%); for secondary pupils the primary need is behavioural, emotional and social difficulties (19.7%), ASC is ranked 5<sup>th</sup> (12.1%); the primary need in special schools is moderate learning difficulties(38.5%), ASC is ranked 3<sup>rd</sup> (16.1%). Only special schools have a large proportion of pupils with severe learning difficulties (21.9%). The total number of children with ASC is therefore 436, close to the 0-17 estimate of 469 above. As mentioned previously, some pupils with learning difficulties as their primary need may also be autistic.

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<sup>21</sup> The National Autistic Society, Criminal Justice System and ASD, [www.autism.org.uk](http://www.autism.org.uk)

<sup>22</sup> PHOF, <http://www.phoutcomes.info/public-health-outcomes-framework#gid/1000041/pat/6/ati/102/page/0/par/E12000005/are/E08000029>

<sup>23</sup> <https://www.justice.gov.uk/downloads/.../foi.../foi-78049-annex-a.xls>

<sup>24</sup> PHE, Learning Disabilities Profiles, [www.ihal.org.uk/profiles](http://www.ihal.org.uk/profiles)



Chart 1: Pupils with statements of special educational need

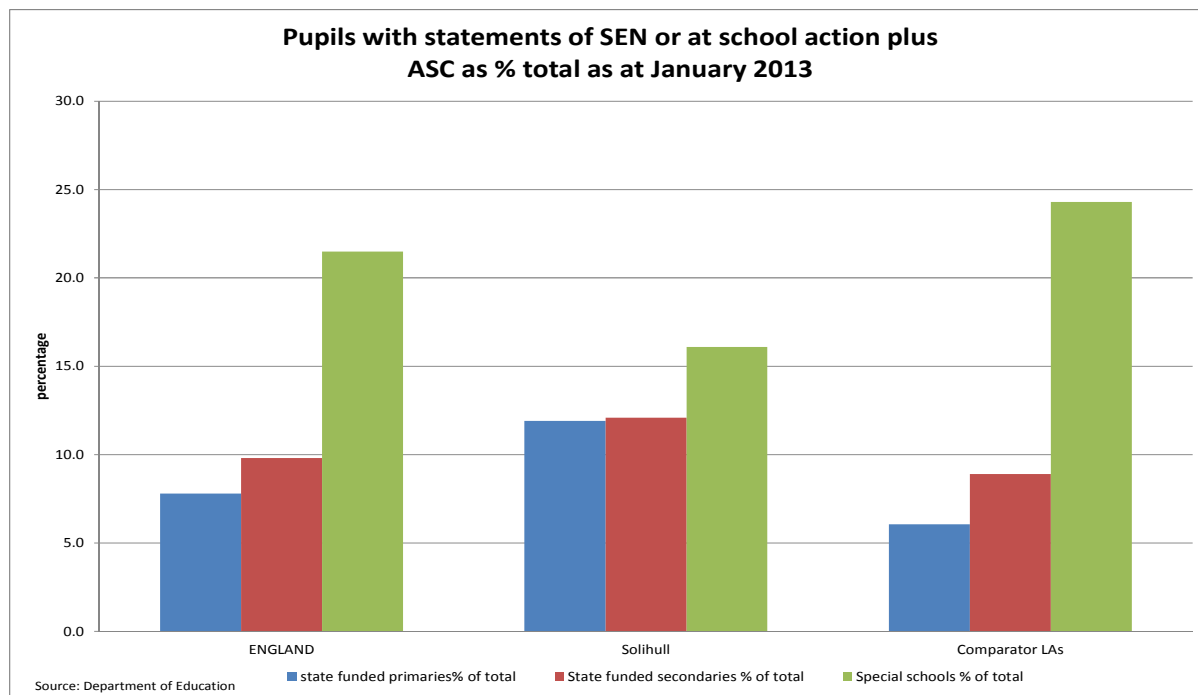
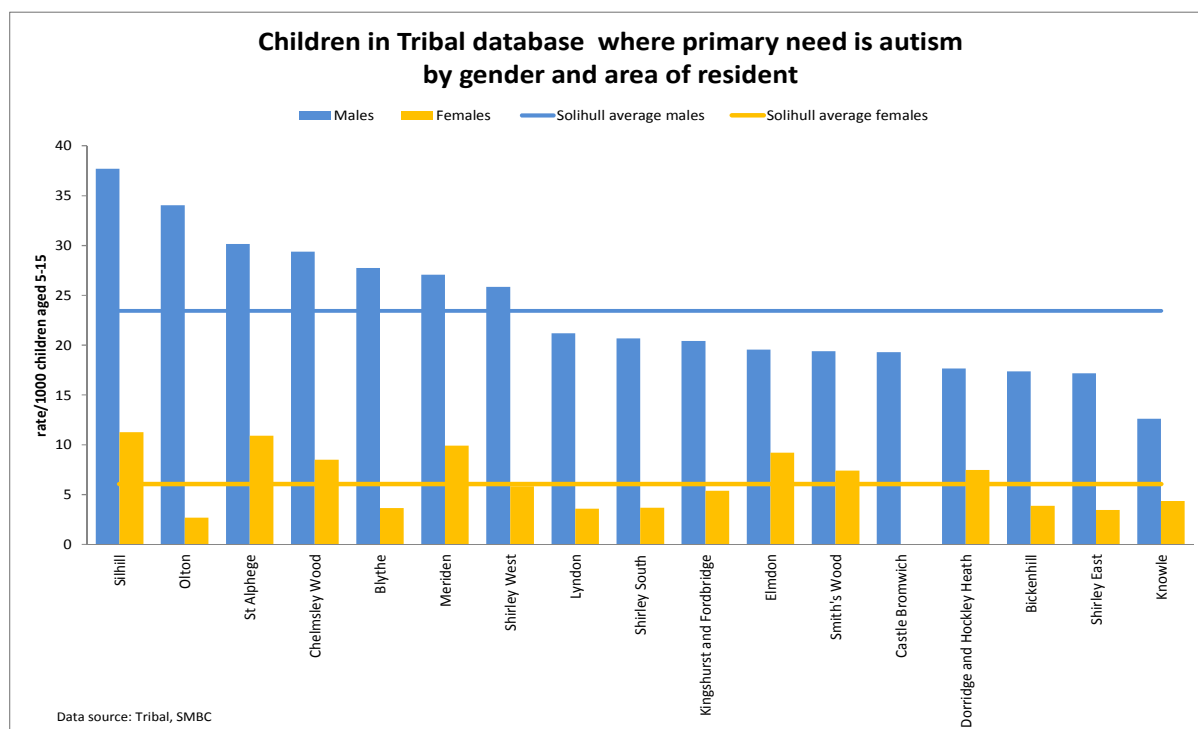


Chart 1 indicates that more children with ASC appear to be accommodated in mainstream school in Solihull than in England and comparator local authorities. There were also correspondingly fewer children with ASC in special schools than other areas. This may indicate more pupils with ASC without LD (possibly Asperger’s) in Solihull than in the comparator areas.

The local Tribal system records Information on where Solihull children with statements and ASC as a primary need, live. Chart 2 appears to show that there is no strong link with deprivation.

Chart 2: Area of residence of pupils with ASC



## Social Care Data

The CareFirst system at the council records residents who have been in receipt, as well as those who are currently receiving, social care services provided by the council. The numbers who have ASC by area are shown in Table 2.

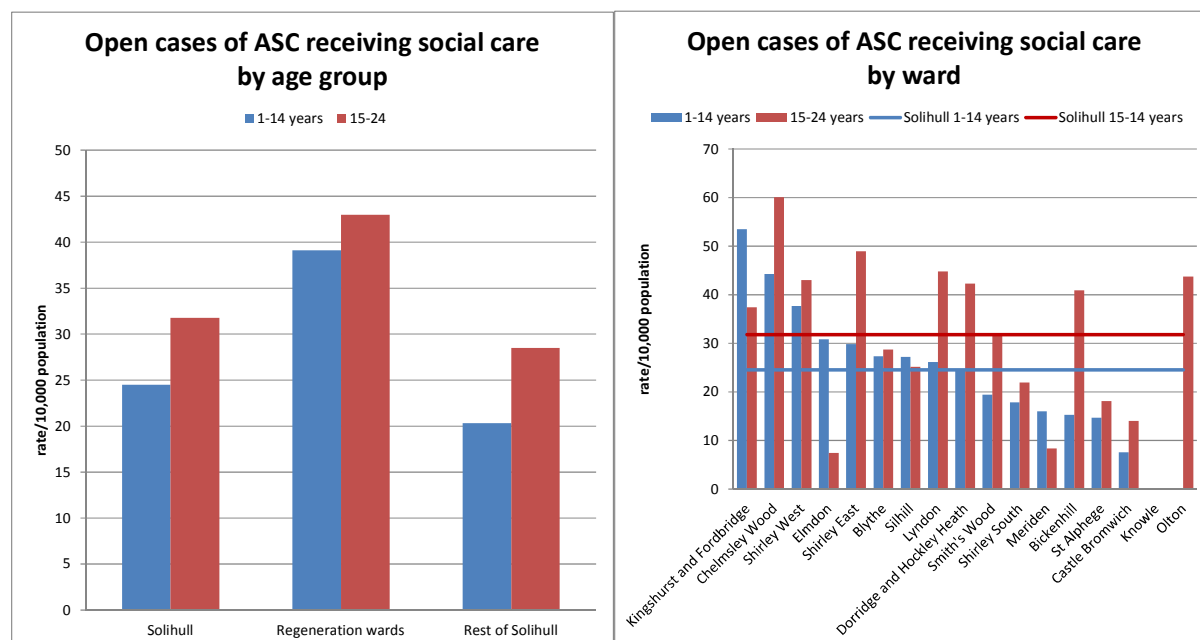
Table 2: Number s of children and young people with ASC on CareFirst<sup>25</sup>

Age group (years)	1-14		15-24		Total	
Area	NOT AN OPEN CASE	OPEN CASE	NOT AN OPEN CASE	OPEN CASE	NOT AN OPEN CASE	OPEN CASE
Solihull	114	84	82	78	196	162
Regeneration wards	63	30	36	24	99	54
Rest of Solihull	51	54	46	54	97	108

The number of children and young people with ASC who are no longer receiving social care is higher than those currently receiving care. The reduction is seen in those children and young people, particularly 1-14 year olds, resident in the regeneration wards (Chelmsley Wood, Kingshurst and Fordbridge and Smith’s Wood) whereas the number receiving care has increased slightly in the rest of Solihull.

When these numbers are converted to a rate it can be seen from the chart below that those aged 1-14 years with ASC receiving care in the regeneration area is approximately double that seen for the rest of Solihull. The rate of open cases for the 15-24 age group is higher than that for the 1-14 year olds for both the regeneration area and the rest of Solihull, but the regeneration area is a third higher than the rest of Solihull

Chart 3: Open cases on CareFirst as a rate



<sup>25</sup> J. Hill , SMBC

The ward rates show less of a link to deprivation but numbers are small so differences are unlikely to be statistically significant.

### *Solihull Specialist Inclusion Support Service*

A snapshot of ASC prevalence was established between September and November 2013 by the ASD operational group as part of a bench marking exercise<sup>26</sup>. The results were:-

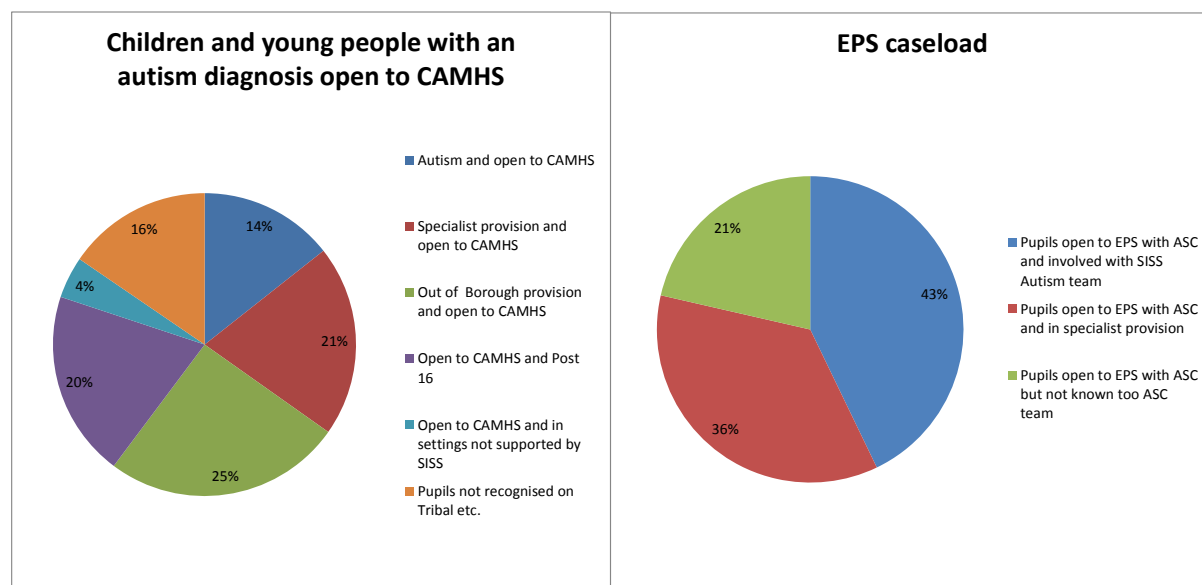
<b>Number of Children with a diagnosis of ASC in Solihull known to:-</b>	
SISS ASD team – non traded service working with children of statutory school age with a diagnosis of ASD only	526
SISS under 6 team	20
Educational psychology service (EPS)	14
CAMHS	181

Children known to the Meadow Centre Service are not included in the above table as these children are mainly awaiting diagnostic assessment.

There is considerable overlap between the children identified through SISS and those on the caseload of CAMHS and EPS. The records for each service have not been cross-matched but the ASD operational group have taken the SISS caseload, including SISS under 6 as being the most accurate number of children diagnosed with ASC in the borough i.e. 546<sup>27</sup>

### *Child and Adolescent Mental Health Services (CAHMS and Educational Psychology Service (EPS)*

Chart 4 CAMHS and EPS



A high number of children and young people with an ASC diagnosis present to CAMHS with a number of co-morbid difficulties, the largest of which is Attention Deficit Hyperactivity Disorder (ADHD), followed by anxiety and then depression. It is difficult to discharge these individuals as there is no Tier 2 services for families. Children who are on medication that GPs are reluctant to prescribe also stay on caseload.

<sup>26</sup> Information provided by Shirley Heatherington, ASD operational group

<sup>27</sup> Information provided by Shirley Heatherington, ASD operational group

There is also no service for children and young people who have mild or moderate learning difficulties unlike those with severe learning difficulties who can access life long support. This situation is made worse by the fact that when families are in crisis and in need of support, there is no option to dip on and out of services when needed.<sup>28</sup>

### *NHS – Hospital admissions data<sup>29</sup>*

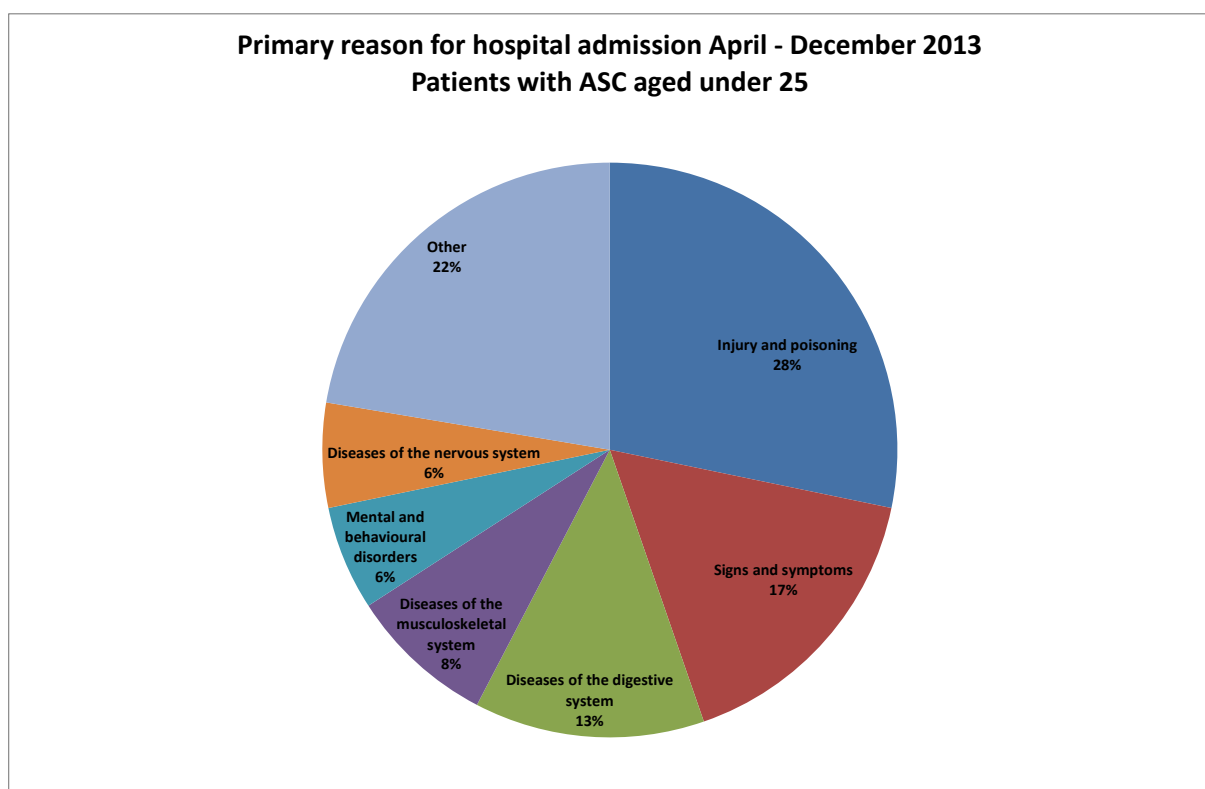
Between April and December 2013 there were 86 hospital spells for children and young people (aged under 25) where ASC is recorded in one of the supplementary diagnostic codes.

The primary causes of admission are shown in chart 5. The admission rate for the south of the borough was 9.9/10,000 population and the north 24.4/ 10,000 i.e. an admitted patient is 2.5 times more likely to be from the north

The largest causes of admission are covered by diagnoses in the chapter for injury, poisoning and other consequences of external causes. The majority are injuries (2/3rds) and the rest, poisonings. This perhaps supports the view that those with ASC do not fully understand the consequences of their actions and are therefore “accident prone”.

The second largest causes of admission are covered by the chapter for symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified such as unexplained nausea and vomiting, fever and chest pain. The Other category is an accumulation of chapters where admissions for each chapter are less than 5.

*Chart 5: Primary reason for admission patients aged under 25*



<sup>28</sup> Information provided by Shirley Heatherington, ASD operational group

<sup>29</sup> Local SUS data + ONS mid year population estimates

## Adults

### Social care

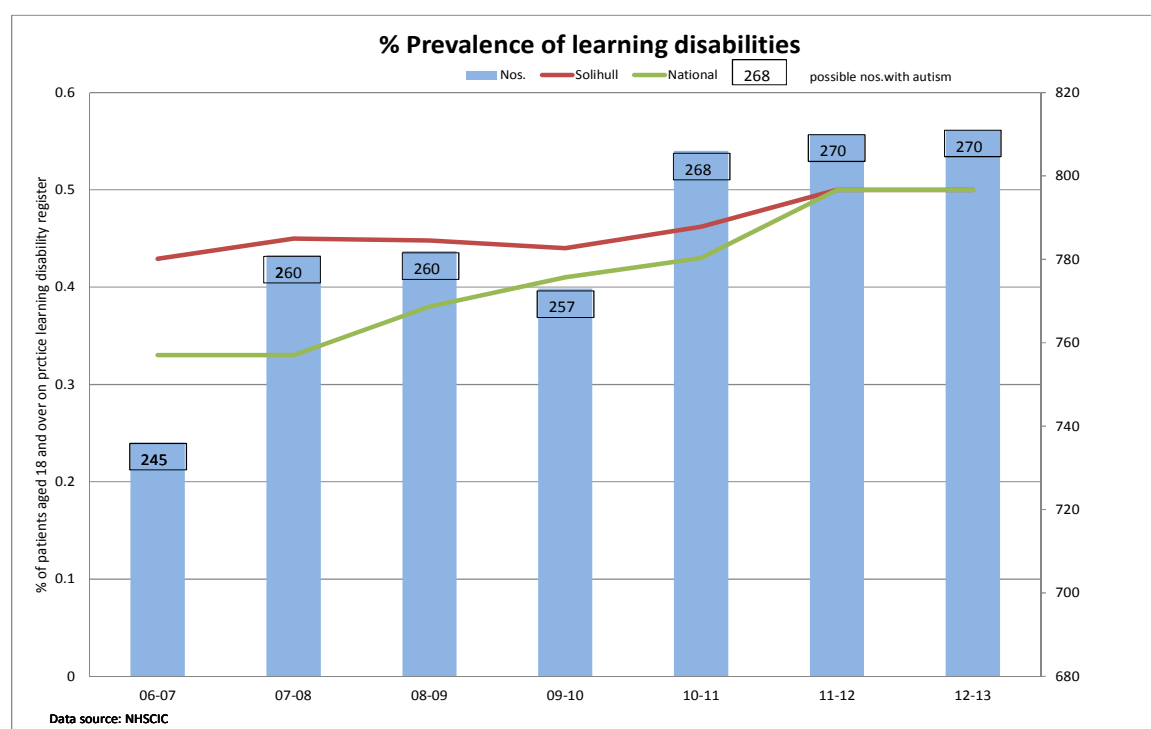
According to the data recorded on CareFirst there are only 12 people aged 25+ that have ASC and who are currently receiving social care. This compares to 9 who were previously receiving care. This is a lot lower than those seen for younger age groups and shows the effect of increased awareness and diagnosis. These numbers convert to a rate of <1/10,000 population and this is a fraction of the expected population from prevalence studies.

### Primary care

General practices maintain a number of registers of patients with certain conditions for the Quality and Outcomes Framework (QOF) payment system. Unfortunately ASC is not one of these conditions but learning disabilities (LD) is.

Chart 6 shows the % prevalence of LD for people aged 18 and over and numbers on the registers over time. National prevalence models underestimate the prevalence of LD so the national reported rate exceeds the expected rate by 7%<sup>30</sup>. Expected values have not therefore been included in Chart 6. In Solihull, the expected value is 0.21% of but actual prevalence is more than double that at 0.5%.

Chart 6: QOF practice registers



The chart also shows that Solihull prevalence has increased over time and was higher than national prevalence but is now the same. Between a fifth and a third of these patients are also likely to have ASC<sup>31</sup> and estimated figures for ASC at a third of LD are also included on the chart. These however are only a small proportion of adults thought to have ASC. Information on the actual number of patients with ASC could be collected through a specific search of each GP database.

<sup>30</sup> NHS comparators, [www.nhscomparators.nhs.uk](http://www.nhscomparators.nhs.uk)

<sup>31</sup> Learning Disabilities Observatory, [www.ihal.org.uk](http://www.ihal.org.uk)

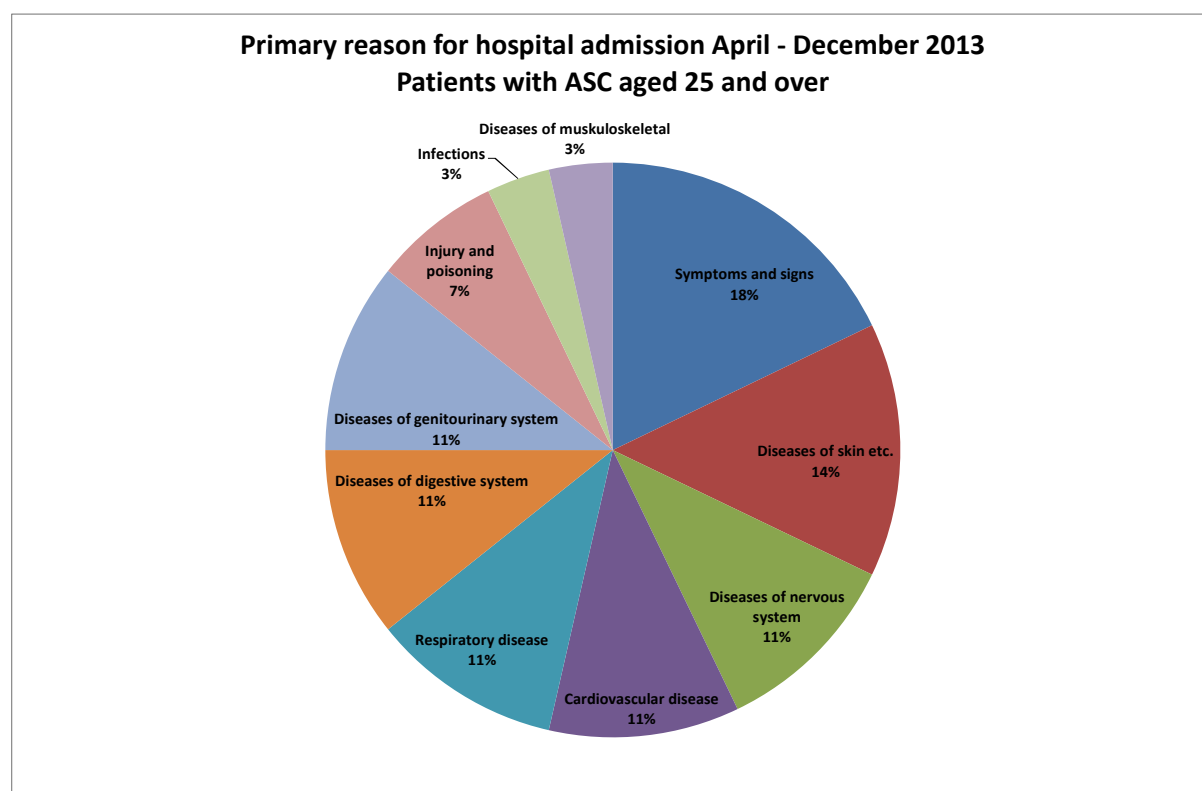
There appears to be a link with deprivation and learning disability as the rate for North Solihull practices is approximately twice that seen for practices in the South. This may also imply a link with deprivation and ASC for adults or it could be greater recognition and diagnosis of LD in some areas.

### *NHS – Hospital admissions data*

Between April and December 2013 there were 28 hospital spells for people aged 25 and over where ASC is recorded in one of the supplementary diagnostic codes. This is a smaller number than that seen for those aged under 25. The primary causes of admission are shown in chart 7. The admission rate for the south of the borough was 1.3/10,000 population and the north 4/10,000 i.e. ~3 times more likely to be admitted from the north.

Primary reasons for admission vary more widely for people with ASC aged 25 and over than for those aged under 25. The largest cause of admission is covered by the chapter for symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified such as fainting and collapse and chest pain. The second largest cause is diseases of skin and subcutaneous tissue and covers such conditions as cellulitis and ingrowing toenails. Numbers covered by this chapter in the under 25 age group are small and are accumulated into the “other” category.

*Chart 7: Primary reason for admission 25 and over*



### *Criminal justice system*

No one asked in Solihull were aware of any system that could provide information on the actual numbers of people in touch with the justice system who had a diagnosis of ASC. As far as they were aware no system records this information.

People with ASC can be both a victim of crime and an offender, the latter often through deliberate exploitation by others<sup>32</sup>. Prevalence of autism in the offender population is thought to be between

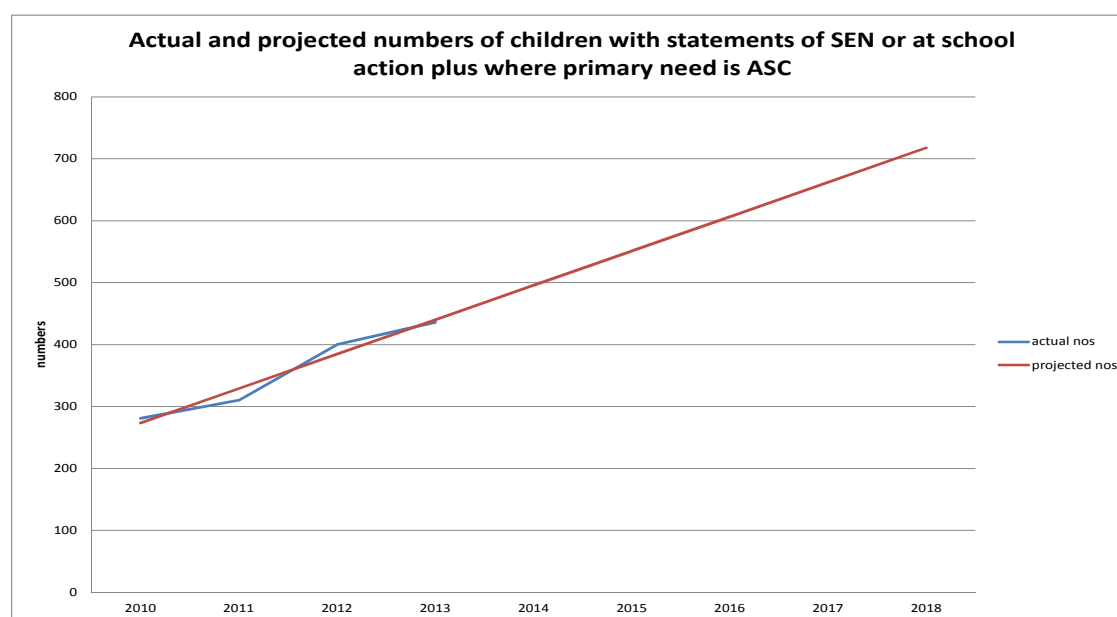
<sup>32</sup> Richard Mills, Presentation on behalf of Research Autism, June 2012

2-4%, compared to 1% in the general population. Also 15-20% of people with Asperger's are at increased risk of offending. The reasons for this are not well understood but until better records are kept awareness raised, progress is difficult<sup>33</sup>.

## Future numbers

Data on the number of children with current diagnosed ASC is presented in the previous section. If the Department of Education numbers for the last 4 years for children with statements or at School action plus, whose primary need is autism are projected forward 5 years, then by 2018 there could be over 700 children with diagnosed ASC. As recognition of ASC increases and if awareness is raised amongst professionals, numbers could be even higher.

Chart 8:



The Projecting Adult Needs and Service Information System (PANSI)<sup>34</sup> projects the number of people predicted to have ASC aged 18-64 up to 2020. From Table 2 it can be seen that overall numbers for both males and females increases slightly (~2%) over this period but there is more variation between age groups and gender (see Chart 1 below) but these numbers reflect the underlying population structure.

Table 3: Projected numbers of males aged 18-64 with ASC

Males in Solihull predicted to have ASC by age and gender predicted to 2020						%
	2012	2014	2016	2018	2020	inc/dec
male 18-24	151	149	144	139	133	-12
male 25-34	194	203	214	221	229	18
male 35-44	234	221	218	216	220	-6
male 45-54	274	277	277	272	261	-5
male 55-64	221	221	227	238	248	12
<b>Total males aged 18-64</b>	<b>1074</b>	<b>1071</b>	<b>1080</b>	<b>1086</b>	<b>1091</b>	<b>2</b>

<sup>33</sup> As above

<sup>34</sup> [www.pansi.org.uk](http://www.pansi.org.uk)

Table 4: Projected numbers of females aged 18-64 with ASC

Females in Solihull predicted to have ASC by age and gender predicted to 2020	2012 2014 2016 2018 2020					%
						inc/dec
female 18-24	16	16	16	15	15	-6
female 25-34	23	24	24	25	26	13
female 35-44	28	27	26	26	27	-4
female 45-54	32	33	33	32	31	-3
female 55-64	26	25	26	27	29	12
<b>Total females aged 18-64</b>	<b>125</b>	<b>125</b>	<b>125</b>	<b>125</b>	<b>128</b>	<b>2</b>

A similar system projects needs and service information for older people, Projecting Older People Population Information System (POPPI)<sup>35</sup>. This system however does not make any reference to ASC only the number of older people with learning disability (LD). Research indicates that ~ 1/3<sup>rd</sup> of people with LD may also have ASC, therefore the predicted numbers up to 2020 are:-

Table 5: Projected numbers of older people with ASC

	No. of older people in Solihull predicted to have ASC							% inc
	2012	2013	2014	2015	2016	2018	2020	
<b>65-74</b>	155	160	165	168	171	174	169	9
<b>75-84</b>	92	93	94	95	95	100	109	19
<b>85+</b>	37	39	41	41	43	47	49	33
<b>Total</b>	283	292	299	305	309	320	327	15

## Treating autism spectrum condition

There is no cure for ASC but a range of specialist education and behavioural programmes/interventions can improve skills particularly in children. There are many different interventions for ASC but any intervention should focus on important aspects of development e.g.

*Communication skills* – such as how to start conversations

*Social interaction skills* – such as the ability to recognise and understand other peoples feelings and respond to them

*Cognitive skills* – such as imaginative play

*Academic skills* – such as the traditional skills a child needs to progress with education i.e. reading writing and maths

Treatment of ASC often includes a team of specialists working together and the team may include a paediatrician, a psychologist, a psychiatrist, a speech and language therapist and an occupational therapist. This approach is facilitated in Solihull by the Solihull Specialist Inclusion Support Service (SISS)

<sup>35</sup> www.poppi.org.uk



Special diets, chelation therapy, hyperbaric oxygen therapy and neuro-feedback are amongst treatments that are NOT recommended for ASC, as there is little or no evidence that these approaches work.

## Services

### Children with ASC

#### *Solihull Specialist Inclusion Support Service*

SISS offers multidisciplinary support to children and young people aged (0-19 years) with special educational needs and disabilities (SEND). The service is made up of 6 specialist teams<sup>36</sup>:-

- Communication and learning difficulties (CLD)
- Emotional , social and behavioural difficulties (ESBD)
- Autism
- Sensory and physical impairment (SPI)
- Special educational needs under 6 (SENU6)
- Speech, language and communication disorders (SLCD)

SISS provides support in schools, nurseries, early years settings and homes. Approximately 1 in 6 children receiving services through SISS are pre-school.

#### *Oaklands Special School and Pupil Referral Unit (PRU)*

It is proposed that the above school is closed at the end of August 2014 and a new Academy established in its place. This new academy, known as Northern House School (Solihull) will cater for the needs of children from across Solihull aged 4-16 with statements of special educational needs including ASC.

The PRU for secondary aged pupils permanently excluded pupils will also close at the same time but it is envisaged that these pupils will be accommodated through an agreement between the existing North Solihull Secondary schools.

#### *The Meadow Centre*

The centre is part of Heart of England Foundation Trust (HoEFT) and offers services for children and young people aged 0-18 years and their families<sup>37</sup>. The Meadow Centre provides multidisciplinary assessment advice and support for children with significant and complex medical, developmental and/or social needs. This also extends to their families.

The service is organised into 3 teams:

- The team for younger children up to 6 years of age, with complex medical and/or developmental needs including difficulties that may indicate the possibility of an Autism Spectrum Condition.
- The team for older children aged 7 years to 18 years with difficulties that indicate the possibility of an Autistic Spectrum Condition.
- The Children's Disability Team is a team of social workers working with severely disabled children up to 18 years old. This team provides additional family support, information, care packages, access to short breaks and child protection services.

There are currently waiting lists for this service.

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<sup>36</sup> [www.solihull.gov.uk](http://www.solihull.gov.uk)

<sup>37</sup> [www.heartofengland.nhs.uk/the-meadow-centre/](http://www.heartofengland.nhs.uk/the-meadow-centre/)

## Support groups

### *SASSI (Solihull Autism Spectrum Support and Information)*

SASSI is an Autism Support Group for parents/guardians of children and young people with ASC<sup>38</sup>. It offers a social opportunity for people to talk to other parents in the same situation as well as approach a variety of professionals informally. They meet once a month in the evening in a school hall and there is usually a formal talk on topics suggested by parents. In addition there are fund raising activities and social events for both children and adults.

### *Solihull Parent Partnership Service<sup>39</sup>*

This organisation offers a free, impartial and confidential service that enables parents/carers to make informed choices about their child's education by offering advice, information and support to make these decisions.

### *Signpost Inclusion<sup>40</sup>*

Signpost Inclusion hold regular drop-in parent support groups, specifically for parents who have children with additional needs. The groups provide an opportunity to spend time with other people who share similar experiences. Parents meet in a relaxed and friendly setting to share ideas and offer emotional and practical support to each other. An autism specific support group meets once a month, during the day.

### *Autism-friendly screenings at Cineworld*

In partnership with the social care provider, Dimensions, Cineworld host an autism-friendly screening once a month to cinema goers, where lighting is kept on, volume levels are reduced, there are no advertisements or trailers and customers can bring in their own food.

## Adults with ASC

Some people with ASC do not have their condition diagnosed and others do not have it recognised until they have reached adulthood. Treatment of adults is similar to that for children but the programmes offered may be slightly different i.e.

- *Social learning programmes* to help them cope in social situations
- *Leisure activity programmes* where those with ASC can take part in leisure activities (games, exercise, going to the cinema) with a group of people
- *Skills for daily living programmes* - help for those with problems carrying out daily activities such as eating and washing

Such programmes are delivered at day/drop in centres in Solihull such as Park View and Bacon's End for those adults who also have a learning disability. More opportunities for leisure, physical activity and work are listed in the Solihull Care Directory<sup>41</sup> and include SoLO (Solihull Life Opportunities) and Newlands Bishop Farm (Family Care Trust) - a working and training environment.

If adults are diagnosed with ASC they can access certain benefits such as Personal Independence Payment (PIP) which they can then use to buy care or pay for a range of activities.

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<sup>38</sup> [www.solihullsassi.co.uk](http://www.solihullsassi.co.uk)

<sup>39</sup> [www.solihullparentpartnership.co.uk](http://www.solihullparentpartnership.co.uk)

<sup>40</sup> [www.signpostinclusion.org.uk](http://www.signpostinclusion.org.uk)

<sup>41</sup> [www.solihullcaredirectory.co.uk/Home.aspx](http://www.solihullcaredirectory.co.uk/Home.aspx)

Diagnosis could also mean that they can live in different types of housing with support depending on their level of need ; such as residential or supported housing (either with other people or alone) , or may have help to stay independent. The level of need is assessed by Social Services and agreed with the person and their carer.

Many people with ASC find it difficult to get a job because the workplace may be unpredictable or it is difficult to get to, but in the right environment and job they can thrive because they are often accurate, reliable and have a good eye for detail. A 2012 survey of adults with ASC conducted by the National Autistic Society found that only 10% had current employment support. Work Choice from the Department of Work and Pensions (DWP) provides specialist support to people with disabilities whose work needs are not met by other programmes. Specialist support programmes result in significantly higher rates of employment and higher employee satisfaction when compared to generic disability employment services<sup>42</sup> and commissioning of such schemes are recommended by NICE guidelines. Within Adult Social Care the STEPS scheme helps people with learning disabilities and/or autism to find employment or voluntary work.

Solihull Adult Social Care/Clinical Commissioning Group also commission Autism West Midlands to lead and support ASPIre Adult Support Group. The group meets monthly and provides an opportunity to meet and learn from others about their condition. The meetings consist of an opportunity to discuss an autism-related topic followed by a chance to socialise.

## Recommendations

- Raise awareness of environmental risk factors for autism pre-conception
- Increase awareness and understanding of ASC amongst frontline professionals so that barriers to access of services is removed
- Use of autism alert cards by relevant services (e.g. CSJ)
- Develop and improve systems that can record data on autism and enable the systems to talk to each other so that a complete picture of a person's needs is gained
- Manage transition from children's to adult services
- Ensure that identification and diagnosis of ASC in adults leads to an assessment of need for relevant services
- Ensure equal take up of services by people from ethnic minorities and cultural groups, women and older people with ASC
- Help adults with ASC to get into and stay in work

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<sup>42</sup> Supporting people with autism through adult hood, NAO, 2009