A Needs Assessment for People with Autistic Spectrum Condition in Sheffield 2014

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Contents

1 Introduction....4
1.1 Aim....4
1.2 Scope....4
1.3 Policy context....4
1.4 Future development of the ASC Joint Strategic Needs Assessment (JSNA)....5
2 Autism Spectrum Conditions (ASC)....5
2.1 Definition....5
2.2 Diagnosis....7
2.3 Co-occurring conditions....9
2.3.1 Learning Disabilities....9
2.3.2 Epilepsy....9
2.3.3 Mental illness....9
3 People with ASC in Sheffield....10
3.1 Estimated Prevalence....10
3.1.1 Adults....10
3.1.2 Ethnicity....11
3.1.3 Children....12
3.1.4 ASC and Learning Disability....12
3.2 Local Data on Prevalence....13
3.2.1 School Age Children....13
3.2.2 Health and Social Care clients and Learning Disabilities Case Register Clients 19
3.3 Projected trends....21
4 Issues for People with ASC, local 'voice'....22
4.1 Health Care....22
4.2 Housing....23
4.3 Employment and employment services....24
4.4 Universal services....25
5 Key Findings....25
6 Recommendations: Strategic Priorities....25

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1 Introduction

1.1 Aim

This assessment aims to describe the population level view of the prevalence of autistic spectrum condition (ASC) in Sheffield. This will support the work of the Autism Strategy Implementation Group to consider the implications for the strategic commissioning of services, and will form part of the overall joint strategic needs assessment for the city.

1.2 Scope

In Sheffield we are able to identify the prevalence of ASC within the learning disabled population through the well-established Case Register. We also have an existing strategy to meet the social and clinical needs of this population https://www.signpostsheffield.org.uk/partnership-plans/our-plans/ASC which is delivered through a commissioned clinical pathway. Some of this knowledge is reflected in the paper. However, it is recognised that the needs of people on the autistic spectrum who do not have learning disability are less visible in the city. This paper will establish some estimate of the size, characteristics and needs of this population.

While the paper will describe what is known in respect of ASC within our school age population, it will not examine the needs of children in detail as this work will be covered in a forthcoming needs assessment for the Children's, Young People and Families (CYPF) Portfolio into the needs of children with complex conditions. It should be noted that the term autistic spectrum disorder (ASD) is in common usage within children's services, and in the CYPF report referred above. The terms ASC and ASD are therefore both used here and are considered interchangeable for the purposes of this report. The main findings and recommendations from this work are summarised in Sections 5 and 6. The detailed findings are discussed in sections 3-4.

1.3 Policy context

The first ever strategy for improving the lives of adults with ASC in England was published on 3 March 2010.The strategy set out a number of key actions and recommendations for central Government as well as for local authorities, the NHS and Jobcentre Plus, focusing on five key areas:

- increasing awareness and understanding of ASC
- developing a clear and consistent pathway for diagnosis
- improving access to the services and support people need to live independently within the community
- employment
- enabling local partners to develop relevant services to meet identified needs and priorities

In December 2010, the Government published statutory guidance for local councils and local NHS bodies setting out what they have to do to ensure they meet the needs of adults with ASC in England. In response, the Sheffield Clinical Commissioning Group (SCCG) commissioned a diagnostic and post diagnostic service, to be delivered by a multi-disciplinary team, in line with NICE guidance. The service began in autumn 2013.

The statutory guidance requires that going forward; services are commissioned on adequate population data. This paper begins to bring this together as part of the local JSNA. It is recognised by the Department of Health that there is a lack of data sources available to LAs in respect of people with autism. National actions to address this have been agreed (DH 2014)[1]. A national cross governmental working group will be set up in 2014 to report on available data to support LAs, and the Royal College of GPs will consider the feasibility of introducing a code for autism within primary care recording by 2017.

1.4 Future development of the ASC Joint Strategic Needs Assessment (JSNA)

This document represents the starting point for the ASC element of the Sheffield JSNA. Work will continue in response to strategic and commissioning requirements as they develop. For example, the JSNA will be informed by the emerging work from CYPF mentioned above, and by the emerging data from new ASC diagnostic service. Needs data have been requested by Sheffield Clinical Commissioning Group (SCCG) as part of the specification and contract for this new diagnostic and post diagnostic service and this will be a specific focus of work. In the longer term the work will be supported by any outcomes from the supporting work streams at national level described above.

2 Autism Spectrum Conditions (ASC)

2.1 Definition

Autism Spectrum Conditions are complex lifelong conditions defined in the ICD-10 (WHO 2007) and DSM-V (American Psychiatric Association 2013). It is ICD-10 that is of most relevance in England.

Some people have severe autism and require a lot of specialist support; others exhibit some mild characteristics, although the impact can be devastating under certain conditions, and live largely independent lives. Therefore autism is often referred to as a spectrum condition. This paper will refer to the condition as ASC, and include the full spectrum such as high functioning autism, Asperger's Syndrome and atypical autism (see table 1 below). However, the term 'spectrum' should not be misunderstood. An intellectually high functioning adult with autism is no less autistic than an intellectually lower functioning adult; the impact of the autism within their environment can be just as severe as with any other individual on the spectrum (Beardon et al, 2013)[2].

The conditions are characterised by impairments and difficulties in three main areas: social interaction, social communication and social imagination, known as the triad of impairments.

Social interaction:

- Problems in acquiring and using social skills

[1] DH, Think Autism. Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update, 2014.

[2] Beardon L., Chown N., West Midlands Adult Autism identification Pathways, Sheffield Hallam University 2013.

- Difficulty processing social and emotional information
- Often unable to initiate social contact so can become very isolated
- Alternatively, craving social contact but initiating it inappropriately and unable to work out social rules
- Difficulty forming and sustaining friendships/relationships.

Social Communication:

- Delay of language acquisition, or in some cases can be mute. However, people with Asperger's Syndrome appear to develop language at a normal rate but may still not use language in a socially appropriate way
- Difficulties interpreting, understanding and using speech, body language, intonation, mood, gesture, personal space, writing and visual symbols.

Social imagination:

- Have difficulties with social imagination, and therefore find it difficult to empathise with others and distinguish real from imagined
- Find it difficult to:
  - initiate actions without prompting;
  - inhibit behaviour;
  - switch their attention;
  - reflect on learning/experiences.
- Exhibit inflexible repetitive behaviours and rituals and have an obsessional interest.

People with ASC also often have hyper and hypo sensitivity to sensory stimulus involving any one or more of the senses. Sensory sensitivities can also include vestibular functioning and proprioception, affecting a person's overall sense of body position, spatial awareness and movement. These sensitivities can be significantly debilitating for many people. Often difficulties are hidden, there being no obvious physical indication of the presence of a disability.

The term "spectrum" is used as there are significant variations between individual cases, including the severity and presentation of the triad of impairments such as differing IQ levels; sensory difficulties and general functional abilities. All people with an ASC, regardless of IQ level, experience difficulties to a greater or lesser extent in relation to the triad of impairments. People with ASC and an IQ level of 70 or above are often considered to be on the "higher functioning" end of the spectrum. However, this is not necessarily the case due to many still experiencing significant difficulties with social interactions, social communication and behaviour that can make them particularly vulnerable. A small, but significant number, of people with an IQ above 70 require intensive care and support. Further explanation of the subgroups is given Figure 1 below.

Although subgroups exist, their use may not be considered helpful in some cases. For instance, a child diagnosed with "Autistic Disorder" may later present as an adult with symptoms closer to Asperger's Syndrome or High Functioning ASC. The condition appears to change over time, as do the abilities of the person with the condition.

Figure 1 Autistic Spectrum Conditions

Autistic Spectrum Condition	Description
Autistic Disorder (also known as Classic Autism or Kanner's Autism)	Autistic Disorder is considered to be at the severe end of the Autistic Spectrum. It is characterised by the presence of the "triad of impairments", which include impairments in: (1) social interaction abilities; (2) communication abilities; (3) presence of repetitive, stereotyped behaviours. Onset is also before the age of 3 years. The presentation of the disorder is different across individuals depending on their developmental level and chronological age.
Asperger's Syndrome (AS)	Asperger's Syndrome is also characterised by the presence of the triad of impairments, however there is no delay in the development of language and IQ is in the average to above average range (IQ≥70). Difficulties in motor skills and co-ordination are often present.
Pervasive Developmental Disorder – Not Otherwise Specified (*Also referred to as "Atypical ASC-ICD-10)*	This diagnosis is given if the criteria for another autistic disorder is not met (i.e. one of the triad of impairments may not be present or it is difficult to determine whether onset was before age 3).
High Functioning Autism (HFA)	High Functioning ASC is not currently recognised by the ICD-10, but is nevertheless referred to in the literature. Those with High Functioning ASC also present with the triad of impairments and language delay in childhood, but are found to have IQ levels in the normal range (IQ≥70). Adults with HFA present similarly to those with Asperger's Syndrome.

From Rowenhusrt S. (2010) NHS Westminster and Westminster City Council (adapted from ICD-10, Diagnostic Statistical Manual IV and the National Autistic Society website)

2.2 Diagnosis

Identification of ASC is the first step towards accessing effective support, and is particularly important for adults whose condition has not previously been recognised. Their life may have been affected by a sense of not fitting in, of not understanding the way they respond to situations or why social settings may be difficult (DH, 2010).

The term 'autism' was first introduced 70 years ago (Kanner, 1943)[3] .The diagnostic criteria have continued to develop over this period. The ICD-10 and the DSM-V are based on a qualitative analysis against a set of behavioural criteria:

[3] Kanner, L. 1943, Autistic disturbances of affective contact, Nerv Child, vol. 2, pp. 217-250

- Early emergence of the condition (before 3 years of age)
- Qualitative impairments in social interaction
- Qualitative impairments in communication (and imagination)
- Restricted and repetitive interests in activities

A range of tools have developed to support the process of diagnosis. Nice Clinical Guideline 142 suggests that for adults with possible autism, who do not have a moderate or severe learning disability, the Autism-Spectrum Quotient – 10 items (AQ-10) is used to determine whether the need for a comprehensive assessment is indicated.

It should be noted, and is of key significance, that access to reliable diagnosis for adults has been extremely difficult. There are several influencing factors: the lack of awareness in the community and amongst professionals; challenges in diagnosis with someone who has communication difficulties; variable presentation of ASC between individuals and in the same individual across time; the reliance on early childhood information; risks of misdiagnosis; the high cost of diagnosis.

Misdiagnosis and late diagnosis are significant problems faced in particular by people on the higher functioning end of the spectrum. Misdiagnosis can involve a number of psychiatric conditions including schizophrenia and obsessive compulsive disorder, leading to ineffective treatment and possible deterioration of the ASC (Fitzgerald & Corvin, 2001)[4] . The most effective interventions and strategies are those that start at an early age (Howlin, 1998)[5] .

It is now likely that children are more readily identified and referred for diagnosis due to their frequent contact with health and education professionals during early years, and the increasing awareness of ASC amongst these professionals. However, there will be adults with Asperger's Syndrome or High Functioning ASC, having not been identified in childhood, who do not realise they have a diagnosable condition. Late diagnosis for adults is complicated by the need for early developmental information from their parents/family.

As the condition may change over time in an individual (2.2. above), particularly during development into adulthood when aspects may intensify, access to ongoing assessment is important to reduce the risk of greater isolation.

2.3 Co-occurring conditions

An understanding of co-occurring conditions is important to promote the most effective management of all the conditions involved and will assist in identification of people who may be undiagnosed. It is known that a number of conditions occur at an increased rate in people with ASC compared to the general population. Some conditions are extremely rare. The more common are noted overleaf.

[4] Fitzgerald, M. & Corvin, A 2001, Diagnosis and differential diagnosis of Asperger syndrome, Advances in Psychiatric Treatment, vol. 7, pp. 310-318

[5] Howlin, P. 1998, Practitioner review: psychological and educational treatments for autism, Journal of Child Psychology and Psychiatry, vol. 39, pp. 307-322

2.3.1 Learning Disabilities

Fombonne (2005)[6] reported that 30% of people with have normal to above average intelligence (IQ^- 70), 30% have mild to moderate learning disability and 40% have serious to profound learning disability. The increased prevalence of ASC amongst people with learning disability is discussed in more detail below, as well as local knowledge of prevalence.

2.3.2 Epilepsy

Epilepsy is a condition in which the affected person has seizures or periods of loss of consciousness. It is the second most common neurological condition in the UK. A number of studies have looked at the association between ASC, epilepsy and levels of IQ. Amiet et al (2008)[7] , using meta-analysis found that 21.5% of people with ASC and a learning disability also had epilepsy, whereas 8% of those with ASC and no learning disability had epilepsy. Females with ASC were found to be at higher risk of epilepsy than males. This suggests there may be potential for people with undiagnosed ASC to be found within epilepsy services.

2.3.3 Mental illness

There is evidence to suggest that people with ASC are more likely to have a mental health problem, in particular depression and anxiety. Estimates of prevalence of common mental health problems in this population vary from 16% to 35% (Brugha et al 2001)[8] . The presence of ASC could mask the appearance of a mental health problem, given a person's limitations in expressing emotions. Conversely, the expression of autistic traits may be misinterpreted as symptoms of mental illness.

3 People with ASC in Sheffield

3.1 Estimated Prevalence

There is no exact count kept of people in the population with ASC, although information on children is more comprehensive than adults, but it is possible to establish estimates based on epidemiological surveys. The limits around estimates should be noted. The European Commission (2005)[9] highlights the problems associated with establishing prevalence rates for ASC, such as likely inconsistencies of definition over time and between locations.

3.1.1 Adults

The latest prevalence studies of ASC indicate that 1.1% of the adult population (aged 18+) in England may have ASC. This represents approximately 450,000 adult cases of

[6] Fombonne E. Epidemiology of autistic disorder and other pervasive developmental disorders Journal of Clinical Psychiatry, 2005, Vol. 66(Suppl. 10), pp. 3-8 2005

[7] Amiet, C., Gourfinkel-An, I. Tordjman, A. et al. 2008, Epilepsy in autism is associated with intellectual disability and gender: Evidence from a meta-analysis, Biological Psychiatry, vol. 64, no. 7, pp. 577-582

[8] Brugha, T. S., Jenkins, R., Taub, N., et al. 2001, A general population comparison of the Composite International Diagnostic Interview (CIDI) and the Schedules for Clinical Assessment in Neuropsychiatry (SCAN). Psychological Medicine, vol. 31, pp. 1001–1013.

[9] European Commission (2005) *Some elements about the prevalence of Autism Spectrum Disorders (ASD) in the European Union.* European Commission, Health & Consumer Protection Directorate- General http://ec.europa.eu/health/ph_information/dissemination/diseases/autism_1.pdf

ASC nationally. The study of adults was published in two parts by the NHS Information Centre, (Brugha et al, 2009)[10] and (Brugha et al, 2012)[11] .

Based on these studies the estimated prevalence in Sheffield amongst adults, and by gender, is indicated below (Figure 2):

Figure 2

Sheffield
Estimated Prevalence of autism among adults aged 18 years and over

Sex	ONS Mid 2012 Population Estimate	Estimated Prevalence Rate (%)*	Prevalence Estimate
All	443,374	1.1	4,877
Men	217,266	2.0	4,345
Women	226,108	0.3	678

*Brugha, T. et al. (2012) Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey. Leeds: NHS Information Centre for Health and Social Care.
Available to dow nload at http://w w w .hscic.gov.uk/pubs/autism11

The estimated prevalence of ASC in adults by gender varies across studies, but consistently indicates a greater proportion of males than females. Fombonne at al (2011)[12] found a mean of 5.5 males to 1 female in their research review. Baird et al (2006)[13] found a male to female ratio of 3.3:1 for the whole spectrum in their sample. The Adult Psychiatric Morbidity Survey, as studied by Brugha et al (2009)[14] looked at people in private households, and found a prevalence rate of 1.8% male compared with 0.2% female, a ratio of 9:1. However, when they extended the study to include those people with learning disabilities who had been unable to take part in the APMS in 2007 and those in communal residential settings, they found that the rates for females were much closer to those of the males in the learning disabled population (Brugha et al., 2012)[15] . The estimated rates from this study have been applied to Sheffield in Figure 2 above.

There is considerable debate whether these estimates reflect true incidence by gender, an under-diagnosis of females or whether in fact females, in particular with HFA,

[10] Brugha, T. et al (2009) *Autism spectrum disorders in adults living in households throughout England: report from the Adult Psychiatric Morbidity Survey, 2007*. Leeds: NHS Information Centre for Health and Social Care. Available to download at http://www.hscic.gov.uk/catalogue/PUB01131 [Accessed 20/09/2013].

[11] Brugha, T. et al. (2012) *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey*. Leeds: NHS Information Centre for Health and Social Care. Available to download at http://www.hscic.gov.uk/pubs/autism11 [Accessed 20/09/2013]

[12] Fombonne, E., Quirke, S. and Hagen, A. (2011). Epidemiology of pervasive developmental disorders. In Amaral D.G., Dawson G. and Geschwind D.H. eds. (2011) *Autism spectrum disorders*. New York: Oxford University Press, pp. 90 – 111. Available from the NAS Information Centre.

[13] Baird, G. et al. (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet*, 368 (9531), pp. 210-215.

[14] Brugha, T. et al (2009) Op.cit

[15] Brugha, T. et al. (2012) Op cit

develop better coping strategies and therefore are not recognised. The National Autistic Society noted the need for further exploration of how ASC affects males and females differently. Their survey of around 3,000 people with ASC and 5, 500 carers found that it was harder for females to get a diagnosis and that they were more likely to be mis-diagnosed (Bancroft et al 2013)[16] . Only one-fifth of females with Asperger's syndrome or higher functioning ASC had been diagnosed by the age of eleven, compared to half of males.

There are no data to indicate that the prevalence of ASC differs across age groups. However it is likely that there are significant differences in the number of people with a diagnosis due to the relatively recent advances in understanding of autism. Also, because of the strong association between ASC and learning disability (LD), and the reduced life expectancy of people with LD, areas with younger demographic profiles would be expected to have an increased number of people with LD and ASCs. It is not possible to model this effect. Brugha (2009) analysed the findings from the APM Survey by broad age bands and found a slight downward trend with increasing age appeared to be evident but this was not significant.

3.1.2 Ethnicity

It is not possible, from the current research base, to determine with any confidence whether there are differences in prevalence between ethnic groups in the general population. However, as noted in Brugha (2012)[17] when extending the estimate of population prevalence to include people with LD, the sample was drawn from a population known to have a higher proportion of ethnic minorities than in England as a whole. On limiting the study to the white population only, the prevalence estimate did not change significantly, suggesting that ethnicity was not of significance in this sample.

3.1.3 Children

Emerson and Baines (DH, 2010)[18] have reported that the range of estimates of prevalence of ASC lies in the range of 30-160 per 10,000 children, two of the most recent studies they refer to are described below. They acknowledged that prevalence has increased over time and suggested that the current consensus is that this rise is the result of: (1) improved methods for the detection of ASC; (2) a broadening of the concept of ASC, especially in relation to children with near normal or normal non-verbal intelligence. It therefore remains unclear whether there have been any changes in underlying prevalence.

A study of 56,946 children in South East London by Baird et al (2006)[19] estimated the prevalence of ASC in children aged 9 to 10 years at 38.9 per 10,000 and that of other ASCs at 77.2 per 10,000, making the total prevalence of all ages 116.1 per 10,000.

[16] Bancroft K, Batten A, Lambert S, Madders T (2013) *The way we are: autism in 2012.* The National Autistic Society. London. http://www.autism.org.uk/get-involved/50th-birthday/survey-report.aspx

[17] Brugha, T. et al. (2012) Op cit

[18] Emerson, E. and Baines, S. (2010) *The estimated prevalence of autism among adults with learning disabilities in England*. Stockton-on-Tees: Improving Health and Lives.
Available to download at http://www.improvinghealthandlives.org.uk/projects/autism [Accessed 10/05/2013]

[19] Baird, G. et al. (2006) Op cit

A survey by Baron-Cohen et al (2009)[20] of ASC-spectrum conditions using the Special Educational Needs (SEN) register alongside a survey of children in schools aged 5 to 9 years produced prevalence estimates of ASC-spectrum conditions of 94 per 10,000 and 99 per 10,000 respectively. The ratio of known to unknown cases is about 3:2. Taken together, a prevalence of 157 per 10,000 has been estimated to include previously undiagnosed cases.

Taking into account these studies, alongside prevalence as recorded by the Department for Education among 7 to 15 year olds, Emerson and Baines suggest rates of 1% (lowest) and 1.5% (highest) for purposes of modelling.

Analysis of these predicted rates and Sheffield Schools data is given in 3.2.1 below.

3.1.4 ASC and Learning Disability

Research findings on the proportion of people with ASC spectrum disorders who also have learning disabilities (IQ less than 70) vary considerably as they are affected by the method of case finding and the sample size.

Emerson and Baines (2010)[21] in their meta-analysis of prevalence studies found a range of children with ASC who also had learning disabilities from 15% to 84%, with a mean of 52.6%. Combining prevalence estimates of ASC and of learning disability for children, Emerson and Baines also calculated a prevalence of ASC in children with a learning disability (IQ less than 70) of 30%.

The adult prevalence study, by Brugha et al. (2012)[22] , found between 31% and 35.4% of adults with a learning disability have ASC. They also found a steady increase in the prevalence of ASC as a person's level of intellectual functioning decreased, which is in line with previous learning disabilities studies (Bhaumik et al 2008[23], Cooper et al 2007[24]) and the general population (Brugha et al 2009)[25] . The authors note that neither the method used in the 2012 study to predict verbal IQ, nor the correspondence of verbal IQ with general intelligence, have been validated for use specifically among people with ASC, so may influence the validity of the findings.

3.2 Local Data on Prevalence

[20] Baron-Cohen, S. ,Scott, F.J. , Allison, C., Williams, J., Bolton, P., Matthews, F.E. and Brayne, C. (2009) Prevalence of autism-spectrum conditions: UK school-based population study. The British Journal of Psychiatry, 194 (6), 500-9.

[21] Emerson, E. and Baines, S. (2010) *The estimated prevalence of autism among adults with learning disabilities in England*. Stockton-on-Tees: Improving Health and Lives.
Available to download at http://www.improvinghealthandlives.org.uk/projects/autism [Accessed 10/05/2013]

[22] Brugha, T. et al. (2012) Op cit

[23] Bhaumik S, Tyrer F, McGrother C, Ganghadaran SK. Psychiatric service use and psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research* 2008;52:986-95.

[24] Cooper SA, Smiley E, Morrison J, Williamson A, Allan L. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *British Journal of Psychiatry* 2007;190:27-35.

[25] Brugha, T. et al. (2009) Op cit

3.2.1 School Age Children

There are stages of support available to children with special educational needs. Stage 1, 'school action' involves additional help within the school; stage 2, 'school action plus' (S+) would involve input from a specialist in addition e.g. a speech therapist; the third stage, following an assessment, a 'statement of special educational needs' (SEN) is given.

In 2014 there were 1201 children know to the education services with a primary need for SEN/S+ of Autistic Spectrum Disorder, which formed 12.8% of all SEN/S+ primary needs. This number has shown a steady increase year on year and overall a 50% increase in numbers between 2009 and 2014.

The figures below illustrate the recent increase in diagnosis of ASC in school age children since 2009 (Figure 3 to). This has been a consistently increasing proportion of the children in SEN/School action plus. It is possible that this reflects a change in diagnostic practice rather than an underlying change in the symptoms experienced. It is of note that the numbers of children with severe learning disability also increased in this period, and the numbers identified with behaviour, emotional and social difficulty reduced. It is also apparent that prevalence amongst school age children rose steadily over this period, and that the majority of the increase was evident in boys. Overall, prevalence of 15 per 1000 in 2013 is high when compared with the rate we may expect from the epidemiological research. This may indicate that we have a relatively good level of diagnosis in children and young people.

Figure 3

Sheffield School Children Trends in Primary Needs (SEN plus School Action +), 2009 to 2014

Primary Need		2009	2010	2011	2012	2013	2014
ASD	Autistic Spectrum Disorder	800	822	921	1029	1107	1201
	% of total	8.1	8.0	9.3	10.3	11.9	12.8
SPLD	Specific Learning Difficulty	1335	1452	1350	1386	1233	1112
MLD	Moderate Learning Difficulty	2555	2518	2245	2057	1645	1509
SLD	Severe Learning Difficulty	338	353	367	383	384	367
PMLD	Profound And Multiple Learning Difficulty	115	127	88	81	109	98
BESD	Behaviour, Emotional And Social Difficulty	2006	1921	1735	1652	1497	1514
MSI	Multi Sensory Impairment	2	3	0	0	1	3
SLCN	Speech, Language And Communication Needs	1834	2127	2202	2466	2428	2572
VI	Visual Impairment	90	101	105	115	109	120
HI	Hearing Impairment	264	322	332	349	332	335
PD	Physical Disability	239	237	256	246	226	241
OTH	Other	303	286	270	268	263	290
	Total	9881	10269	9871	10032	9334	9362

Data Source: PAS Team, CYPD, SCC . Note: includes nurseries. PHIT 10/2/14, updated to 2014 16/6/14

Figure 4

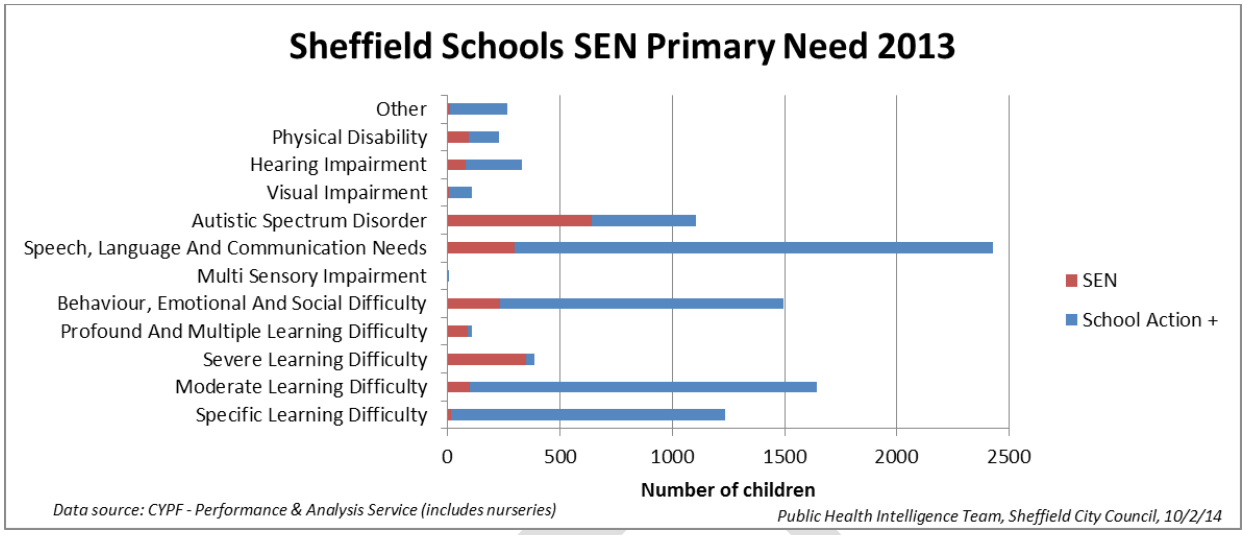
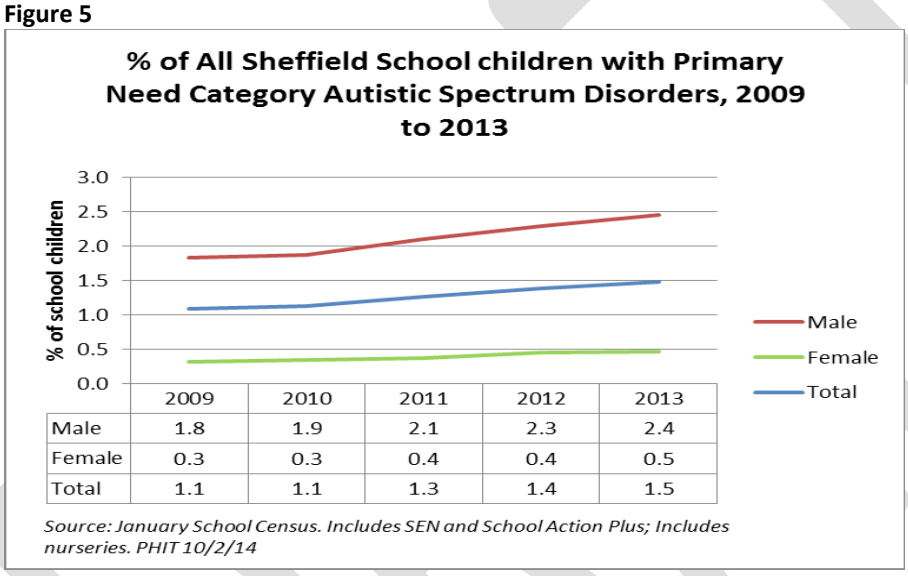


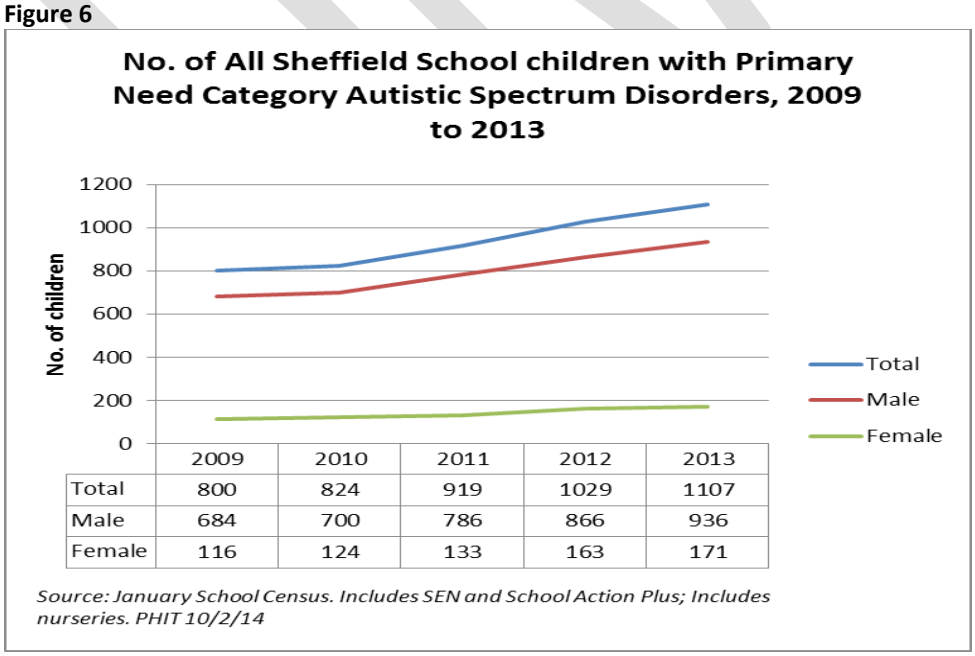
Figure 5



	2009	2010	2011	2012	2013
Male	1.8	1.9	2.1	2.3	2.4
Female	0.3	0.3	0.4	0.4	0.5
Total	1.1	1.1	1.3	1.4	1.5

Source: January School Census. Includes SEN and School Action Plus; Includes nurseries. PHIT 10/2/14

Figure 6



	2009	2010	2011	2012	2013
Total	800	824	919	1029	1107
Male	684	700	786	866	936
Female	116	124	133	163	171

Source: January School Census. Includes SEN and School Action Plus; Includes nurseries. PHIT 10/2/14

Figure 7 shows local prevalence according to the age groups applicable to the epidemiological studies. The predicted rates of autism by Baird et al (2006) and by Baron-Cohen et al (2009) have been applied to the 2013 population and compared with the number of children identified locally in Sheffield schools with ASD.

Figure 7

School Action Plus (P) and Statement of SEN (S) with the primary need category 'ASD' - Autistic Spectrum Disorder.

Sheffield Prevalence compared to Various Predicted Prevalances

Age at start of school year	2009	2010	2011	2012	2013	Total No. all children in Jan Census 2013	Local Rate per 10,000
School Action Plus (No. of children)							
5 to 9	84	104	139	177	198		
9 and 10	35	37	56	58	62		
7 to 15	130	168	205	255	294		
Statemented (SEN) (No. of children)							
5 to 9	229	190	230	221	216		
9 and 10	104	100	111	109	124		
7 to 15	453	458	497	515	526		
Total (No. of children)							
5 to 9	313	294	369	398	414	29,179	**142**
9 and 10	139	137	167	167	186	10,760	**173**
7 to 15	583	626	702	770	820	49,347	**166**

Prevalence Estimates				
Age at start of school year	**Estimated rate**		**Condition**	**Estimated number in Sheffield 2013**
9 and 10	38.9	per 10,000	Autism	42
	77.2	per 10,000	other ASCs	83
	116.1	per 10,000	All ASCs	125
Source: Baird et al (2006)				
5 to 9	94	per 10,000		274
	99	per 10,000		289
	157	per 10,000	estimate to take into account undiagnosed children	458
Source: Baron-Cohen et al (2009)				

We find above a local prevalence in 9 and 10 year olds of 173 per 10,000 in 2013, compared to an estimate (Baird et al 2006) of 116.1. Looking at children aged 5 to 9, the local rate identified in 2013 is 142. Baron-Cohen et al (2009) indicated a prevalence of 157, taking into account an estimate of undiagnosed cases. The overall prevalence in 7 to 15 year olds locally is 166 in 2013, compared to 150 suggested by Emmerson and Baines as the highest rate for purposes of modelling. Local data suggest we have relatively high levels of identification of ASD in children, and relatively few as yet undiagnosed cases in 5 to 9 year olds. The ongoing trends should be monitored to establish whether rates begin to plateau.

illustrates a differential increase in autism being identified according to ethnicity (31.1% change since 2009 in the white British population compared with 145.7% BME). Considering identification of ASC within ethnic groups as a rate per 1000 population, it can be seen that the rate has increased across all groups. The rate has increased most

rapidly in the Asian and the 'Other' groups (although small numbers within the 'other' group mean this may not be significant). The rate within the Asian group remains below average (12.1 compared to 15.7). The highest rate over the last 3 years has been in the mixed population, rising to 19.0 in 2014.

Figure 8

School Action Plus (P) and Statement of SEN (S) with the primary need category ASD' - Autistic Spectrum Disorder. Sheffield Schools by Ethnicity. All Schools, 2009 to 2014

Ethnicity	Number						% change since 2009	Rate per 1,000 population					
	2009	2010	2011	2012	2013	2014		2009	2010	2011	2012	2013	2014
White British	671	674	733	795	844	880	31.1	12.2	12.5	13.8	15.1	16.1	16.9
Irish	3	5	3	3	2	3	0.0	18.8	29.2	18.6	20.4	15.2	22.4
White Eastern European	1	0	0	3	4	4	300.0	2.0	0.0	0.0	2.8	3.3	2.8
White Other*	9	12	10	15	13	17	88.9	9.5	12.7	10.8	13.2	8.6	8.1
Total White	**684**	**691**	**746**	**816**	**863**	**904**	**32.2**	**12.1**	**12.4**	**13.6**	**14.8**	**15.7**	**16.2**
White and Black Caribbean	21	22	28	32	40	44	109.5	12.3	12.5	15.7	17.1	20.5	21.7
White and Black African	1	3	2	4	6	8	700.0	3.2	8.5	5.1	8.9	11.7	13.9
White and Pakistani	4	2	3	4	6	5	25.0	16.4	7.4	10.0	12.3	16.2	13.0
White and Any Other Asian Background	7	8	9	10	7	13	85.7	12.8	13.2	14.0	13.9	8.9	15.2
Any Other Mixed Background	9	11	20	21	22	25	177.8	10.6	12.2	19.7	19.5	20.1	21.8
Total Mixed	**42**	**46**	**62**	**71**	**81**	**95**	**126.2**	**11.4**	**11.8**	**15.0**	**16.0**	**17.2**	**19.0**
Indian	6	4	5	12	12	15	150.0	17.4	11.3	12.8	28.0	26.1	33.0
Pakistani	17	21	33	42	44	57	235.3	3.3	3.9	6.0	7.5	7.7	9.6
Bangladeshi	6	6	9	10	14	20	233.3	7.6	7.4	10.6	11.6	16.1	22.1
Any Other Asian Background	3	6	4	10	10	11	266.7	3.3	6.6	4.3	8.0	8.5	9.0
Total Asian or Asian British	**32**	**37**	**51**	**74**	**80**	**103**	**221.9**	**4.4**	**5.0**	**6.7**	**9.1**	**9.7**	**12.1**
Caribbean	12	9	15	20	19	17	41.7	19.0	14.6	25.0	34.7	33.6	30.5
Somali	6	8	9	8	10	19	216.7	4.7	6.3	7.3	6.4	7.9	15.2
Other Black African	7	16	19	24	26	29	314.3	5.8	12.5	14.3	16.6	17.1	17.0
Any Other Black Background	5	1	2	2	3	4	-20.0	15.7	2.9	5.5	4.8	6.3	8.5
Total Black or Black British	**30**	**34**	**45**	**54**	**58**	**69**	**130.0**	**8.7**	**9.7**	**12.8**	**14.7**	**15.2**	**17.3**
Chinese	0	0	1	1	1	1	100.0	0.0	0.0	3.0	2.9	2.8	2.6
Yemeni	2	3	5	5	7	10	400.0	2.2	3.1	4.8	4.7	6.3	8.7
Any Other Ethnic Group	5	4	7	7	14	12	140.0	5.8	4.1	6.8	6.7	13.0	11.1
Total Other Ethnic Groups	**7**	**7**	**13**	**13**	**22**	**23**	**228.6**	**3.4**	**3.1**	**5.4**	**5.3**	**8.6**	**8.8**
Refused	1	2	3	1	1	1	0.0	5.4	10.6	15.2	4.7	4.2	3.8
Information not yet obtained	4	4	0	0	2	2	-50.0	7.9	20.0	0.0	0.0	12.0	8.4
Not recorded	0	1	1	0	0	0	0.0	0.0	3.9	4.2	0.0	0.0	0.0
Total Refused/not obtained	5	7	4	1	3	3	-40.0	7.1	10.9	6.4	2.1	6.6	5.0
GRAND TOTAL	**800**	**822**	**921**	**1029**	**1107**	**1197**	**49.6**	**10.9**	**11.2**	**12.6**	**13.9**	**14.8**	**15.7**
White British	**671**	**674**	**733**	**795**	**844**	**880**	**31.1**	**12.2**	**12.5**	**13.8**	**15.1**	**16.1**	**16.9**
BME (all except White British)	**129**	**148**	**188**	**234**	**263**	**317**	**145.7**	**6.9**	**7.6**	**9.3**	**10.9**	**11.6**	**13.0**
% of all Pupils with Primary Need 'ASD' (SEN and School Action Plus)													
White British	83.9	82.0	79.6	77.3	76.2	73.5							
BME (all except White British)	16.1	18.0	20.4	22.7	23.8	26.5							

Source: CYPD, SCC, January School Census which includes all state-funded (academy or LA) schools but will not include children with statements of SEN maintained by Sheffield LA but placed in independent or out-of-city schools. (Public Health Intelligence team, SCC, 16/06/14)

** includes Gypsy/Roma and travellers of Irish heritage*

3.2.2 Health and Social Care clients and Learning Disabilities Case Register Clients

Sheffield's Learning Disability Case Register enables detailed information to be extracted about the learning disabled population in Sheffield. Inclusion on the register is optional but coverage is estimated to be 90-95%. Sheffield Health and Social Care Trust also hold the Insight database of clients using mental health services.

Figure 9 provides a picture of the Sheffield learning disabled population registered population and the numbers with ASCs (n=1020). The proportion of people on the register with ASC falls with increasing age. This could be a reflection of the increasing awareness of ASC amongst professionals as discussed above, resulting in increased diagnosis in the younger population. The relatively high proportion of children with learning disability (under 18s) with a diagnosis of ASC (55.2%), compared to the research (see 3.1.4 above), suggests that Sheffield has a relatively high rate of diagnosis in children, and possibly reflects the relatively comprehensive data available for this population in Sheffield compared to other localities due to the existence of the case register.

Figure 9

Sheffield Case Register

Active Case Register Clients December 2013

Area	Sex	Age Group			Grand Total
		under 18	18 - 64	65+	
Sheffield	Male	606	1501	128	**2235**
	Female	260	950	127	**1337**
	Total	**866**	**2451**	**255**	**3572**
Clients with Pervasive Developmental Disorders (F84) Case Register recorded diagnosis Dec 13, Sheffield only					
Age Group		under 18	18-64	65+	**Total**
Sex	Male	374	423	7	**804**
	Female	104	108	4	**216**
	Total	**478**	**531**	**11**	**1020**
As Percentage of Active Register Clients, Dec 2013					
	Male	61.7	28.2	5.5	**35.9**
	Female	40.0	11.4	3.1	**16.2**
	Total	**55.2**	**21.7**	**4.3**	**28.5**

Data source: SHSC

Notes:

1. F84 Pervasive Developmental Disorders (includes ASC, Asperger's and Rett's syndromes)
2. Recorded at any time on Insight or Case Register and who have used SHSC services during 2012/13.

Figure 9 also indicates an overall ratio of 4: 1, male to female, of people on the register with ASC. This is within the range that may be expected from the research, and therefore may indicate under identification of these conditions in women, in common with other localities. There is a higher relative ratio for females over 65 but numbers are

too small to attach significance to this. In addition, a number of people with ASC are known to SHSC through the Insight recording system, related to mental health services. These people are detailed in Figure 10 overleaf.

Figure 10

Clients with Pervasive Developmental Disorders (F84) on SHSC Insight database, December 2013					
Age Group		under 18	18-64	65+	**Total**
Sex	Male	3	101	2	**106**
	Female	0	25	1	**26**
	Total	**3**	**126**	**3**	**132**

It can be seen that a relatively small number of people with ASC are known to mental health services, and they are represented at a ratio of 4:1 male to female. Consideration of Adult Social Care data brought the same group of clients to light, so is not represented separately here.

Figure 11 shows the ethnicity profile for people with pervasive development disorder on the Case Register or Insight services and using SHSC services during 2012/13 (n= 1044). While a distribution across the ethnic profile is indicated here, in line with the research, it can be seen that the proportion of non-white clients increases in the under18 age group. This reflects the information from the schools register, and it should be noted that this population will primarily reflect children and young people with a learning disability.

Figure 11

ETHNICITY AGE AND SEX														
Clients with Pervasive Developmental Disorders (F84) (includes autism, Asperger's and Rett's syndromes), using SHSC or Case Register recorded Services during 2012/13														
Detailed Ethnic Group		Female				Male				Total				
		Age Group				Age Group				Age Group				% of total
		under 18	18-64	65+	Total	under 18	18-64	65+	Total	under 18	18-64	65+	Total	
A0	White - British	84	106	3	193	311	380	7	698	395	486	10	891	85.3
B0	White - Irish			1	1		2		2	0	2	1	3	0.3
C0	White - Other White	1			1	3	2		5	4	2	0	6	0.6
D0	Mixed - White and Black Caribbean	2	3		5	10	6		16	12	9	0	21	2.0
E0	Mixed - White and Black African	1	1		2	2	2		4	3	3	0	6	0.6
F0	Mixed - White and Asian				0	2	1		3	2	1	0	3	0.3
G0	Mixed - Other Mixed	3			3	12	4		16	15	4	0	19	1.8
H0	Asian - Indian				0	4	1		5	4	1	0	5	0.5
J0	Asian - Pakistani	5	1		6	12	12		24	17	13	0	30	2.9
K0	Asian - Bangladeshi	1			1	4	1		5	5	1	0	6	0.6
L0	Asian - Other Asian	2			2				0	2	0	0	2	0.2
M0	Black - Caribbean	2	1		3	6	4		10	8	5	0	13	1.2
N0	Black - African	1			1	9			9	10	0	0	10	1.0
P0	Black - Other Black				0	5	1		6	5	1	0	6	0.6
PA	Black - Somali				0	1	1		2	1	1	0	2	0.2
R0	Other - Chinese		1		1				0	0	1	0	1	0.1
S0	Other - Any Other Ethnic Group	3			3	6	2		8	9	2	0	11	1.1
SF	Other - Yemeni	1			1	2			2	3	0	0	3	0.3
Z0	Not Stated	1			1	4	1		5	5	1	0	6	0.6
	GRAND TOTAL	**107**	**113**	**4**	**224**	**393**	**420**	**7**	**820**	**500**	**533**	**11**	**1044**	**100.0**
	Broad Ethnic Group													
	White	**85**	**106**	**4**	**195**	**314**	**384**	**7**	**705**	**399**	**490**	**11**	**900**	**86.2**
	Mixed	**6**	**4**	**0**	**10**	**26**	**13**	**0**	**39**	**32**	**17**	**0**	**49**	**4.7**
	Asian or Asian British	**8**	**1**	**0**	**9**	**20**	**14**	**0**	**34**	**28**	**15**	**0**	**43**	**4.1**
	Black or Black British	**3**	**1**	**0**	**4**	**21**	**6**	**0**	**27**	**24**	**7**	**0**	**31**	**3.0**
	Other Ethnic Groups	**4**	**1**	**0**	**5**	**8**	**2**	**0**	**10**	**12**	**3**	**0**	**15**	**1.4**
	Not Known	**1**	**0**	**0**	**1**	**4**	**1**	**0**	**5**	**5**	**1**	**0**	**6**	**0.6**

Data source: SHSC

Notes:

1. F84 Pervasive Developmental Disorders (includes autism,
2. Recorded at any time on Insight or Case Register and who have used SHSC services during 2012/13.

3.3 Projected trends

In the absence of known numbers, estimated rates as calculated in Brugha et al 2009 i.e. 1.0%, have been applied in the PANSI database to ONS estimates of the 18 to 64 male and female population to give expected numbers predicted to have autistic spectrum disorder (Figure 12). This projection will be helpful in indicating how well we progress in identifying our population with ASC through the future provision of an adult diagnostic service. Uplift to a rate of 1.1% has been applied across the 18-64 age group to reflect the findings of Brugha et al 2012 (Figure 13). When the prevalence found in local school children of 1.5% is applied to the age group 18-24 and 1.1% to the age group 25+ then the predicted figures increase again as shown in .

Figure 12 Autistic spectrum disorders

People aged 18-64 predicted to have autistic spectrum disorders, by age and gender, projected to 2020, Sheffield.

Autistic spectrum disorders	2012	2014	2016	2018	2020
People aged 18-24	812	833	827	808	784
People aged 25-34	769	806	852	902	934
People aged 35-44	724	698	686	680	692
People aged 45-54	707	730	739	730	710
People aged 55-64	547	549	569	598	626
Total population aged 18-64	3,559	3,615	3,671	3,717	3,746

Figures may not sum due to rounding. Crown copyright 2012. Population projections published 28 September 2012, are interim 2011-based. http://www.pansi.org.uk

Figure 13

Sheffield predicted Autism Numbers at 1.1% prevalence

Autistic spectrum disorders	2012	2014	2016	2018	2020
Total population aged 18-64 uplifted to reflect 1.1% prevalence	3,904	3,956	4,009	4,051	4,078

Applied to ONS mid2011 based population projections

Figure 14

Sheffield predicted Autism Numbers at 1.5% prevalence in ages 18-24, and 1.1% in ages 25+ (The 1.5% reflects the rate found in Sheffield School children)

Autistic spectrum disorders	2012	2014	2016	2018	2020
Total population aged 18-64 uplifted to reflect 1.1% prevalence	4,226	4,283	4,334	4,368	4,385

Applied to ONS mid2011 based population projections

4 Issues for People with ASC, local 'voice'.

4.1 Health Care

People with ASC report that not being able to get a diagnosis of ASC causes anxiety and frustration. Misdiagnoses cause mental health difficulties and problems for people.[26] There are examples of people receiving late diagnoses (e.g. when people are aged over 40). Yet some people believe that obtaining a diagnosis creates better recognition and treatment under the Equality Act. It enables people to access appropriate services and is cost-effective – e.g. for mental health inpatient services.[27] People with ASC have highlighted that GPs may lack knowledge about ASC and ASC services to refer patients to seek a diagnosis.

People with ASC highlight difficulties accessing and using universal health services. A pathway between health services is seen as desirable but there is disagreement about whether a 'flagging' system which identifies a person's ASC to health services is suitable. A range of training is needed for health staff – e.g. tiered according to role and involvement with people with ASC – but some difference of opinion about the effectiveness of on-line courses.[28]

[26] consultants, 13.12.11 and 15.03.12, citing Luke Beardon and Genevieve Edmonds, 2008 ASPECT consultancy report: Sheffield: The Autism Centre

[27] Ibid

[28] and family carer representatives, 30.01.12

In principle, people believe health services should provide quiet areas for patients with ASC, although there is a feeling that this might be impractical or disproportionate. Simple guides for services to provide adaptations, and access to professionals who can advise about ASC, would be beneficial.[29]

People with ASC believe that Community Mental Health Teams cannot offer ASC specific services (e.g. CBT that is Aspergers-specific, or sensory integration therapy) – although much of this is available for children. There is seen to be a lack of join-up between services and regret that professionals in adult services do not do similar roles to those in children's services.[30]

People with ASC can respond a-typically to pain or physiological symptoms, and may have communication difficulties, all of which can lead to undiagnosed conditions or differences in treatment. Specialist ASC support is needed for professionals who provide health services. There is a view that addressing a person's ASC and co-occurring conditions is more effective than seeking to make health services ASC-appropriate.

GPs may not see enough patients with ASC to develop an effective knowledge or empathy, or may not seek support. It is difficult to monitor the quality and application of annual health checks for people with ASC who also have a learning disability.[31]

People believe there is a need to increase ASC awareness amongst GPs and other professionals. There have been concerns that people may require severe and enduring mental health problems before being referred for diagnosis, or receiving a local diagnosis.[32] People have previously pointed to difficulties accessing a diagnosis in Sheffield.

4.2 Housing

There is some perception that there is not enough ASC appropriate accommodation in Sheffield. This view is shared amongst families of people with ASC who are currently living out of Sheffield. Sensory issues – caused by buses, main roads and noise in adjoining properties – impact on people and are not taken into account.[33]

One feeling expressed is that people with ASC are thought to be over-sensitive and not to be taken seriously if there is a genuine noise nuisance. People are often not equipped to fight their case or get out of the situation, therefore their health and wellbeing deteriorates.[34] Some people feel that adaptations and assistive technology may be needed to address sensory and other problems. The views and advice of people with

[29] Ibid
[30] Ibid
[31] Autism self-assessment Framework, Department of Health, 2012
[32] Ibid
[33] Autism self-assessment Framework, Department of Health, 2012
[34] consultant, 29.03.12

ASC, families and specialist providers should be sought.[35] The Equality Act needs to be applied more effectively.[36]

People with ASC and family members have highlighted the need to support individuals and families as nearly half of people with ASC continue living in the family home.[37] This arrangement may not be suitable for the person with ASC. Family carers worry about living arrangements for their relatives with ASC in the future.[38] People with ASC can have limited choice about where they live. Difficulty making and maintaining relationships can hamper the ability of people with ASC to share accommodation. The wrong housing environment can lead to anxiety and difficulties for people with ASC and, in some cases, challenging behaviour.[39]

People feel the creation of longer leases for people with ASC renting is desirable but difficult to influence.[40] Landlords, and professionals supporting people to find housing, need greater ASC awareness.[41] It is felt that housing officers have an important role but are currently not recognising the needs of people with ASC.[42]

4.3 Employment and employment services

People with ASC bring many skills and benefits to the workplace – e.g. focus and diligence, pride in the job, independent and unique thinking and attention to detail. ASC awareness-raising with employers is regarded as essential – e.g. through work placements or a campaign. People report that the attitude of employers and work colleagues impacts significantly on the ability of a person with ASC to work. Buddying schemes are perceived positively. Many people with ASC need meaningful activity, particularly if they are unable to work. Support is needed with functions that enable people with ASC to work – e.g. social interaction, sensory issues, independent travel, time-management.

The important role of large employers in providing guidance and consistent support – from human resources and occupational health, etc. – has been raised. People with ASC need to know who to approach in the workplace for support. People believe a culture is needed where employees with ASC and managers feel able to raise issues about the employees' ASC. Support for managers and employers is essential – e.g. reasonable adjustments could be hints and tips rather than major changes. Support for people with ASC to plan ahead and anticipate change is important – e.g. change of line manager.

People report that government employment schemes do not benefit people with ASC as much as they could. They are time-limited, but on-going support in the workplace may

[35] Family carer representatives, 31.01.12
[36] consultants, 13.12.11 and 15.03.12
[37] Family carer representatives, 31.01.12, citing Good Practice in Supporting Adults with autism: Guidance for community and support services, Ben Higgins
[38] Autism self-assessment Framework, Department of Health, 2012
[39] Family carer representatives, 31.01.12
[40] consultant, 31.01.12
[41] Family carer representatives, 31.01.12
[42] Autism self-assessment Framework, Department of Health, 2012

be needed. Alternatively, people may not know of their existence and the way they could fund ASC-specific support.

4.4 Universal services

People with ASC describe the condition as affecting every aspect of their life. Coping with a housing disrepair can severely impair the functioning of a person with ASC at work.[43] Accessing buildings and workplaces with bright halogen and overhead lighting can be difficult.[44]

People with ASC report a perception that the range of appropriate support services in Sheffield is inadequate.[45] A lack of information causes anxiety and risks people missing out on opportunities.

The issue of people with ASC going through the transitions process, and who need information, has been highlighted in particular.[46]

5 Key Findings

1. There has been a rapid increase in identification of children with ASD since 2009.
2. The average rate of ASD amongst school children at 1.5% is high compared to predicted prevalence, and has implications for population rates going forward.
3. There is a more rapid rate of increase in identification in children from BME communities than in the White British population, and rates within ethnicities vary.
4. As expected, identification of adults (aged 18-64) with ASC is low, less than 700 from a probable total of 3,900. Identification in the 64+ age group is lower still.
5. The gap between people identified and predicted levels should narrow as children with a diagnosis move into adulthood and the adult diagnostic service has an impact.

6 Recommendations: Strategic Priorities

Notes for discussion

[43] consultant,
[44] consultant, letter to planners May 2013
[45] ASC and family carer representatives, 30.01.12 and second autism self-assessment exercise, Department of Health, 2013
[46] Family carer representatives, 31.01.12