

5. Needs Assessment

5.1 National figures (and local projections based on these)

Estimates of the prevalence of ASC in the UK differ depending on the source and have varied over time as diagnostic categories have changed. The National Autistic Society currently estimates that around 1 in a 100 people are on the spectrum. For Leeds this would mean a current figure of 6450 adults with ASC based on an adult population in July 2009 of 645,314 (Leeds GP registered population aged 18+).¹

This figure is backed up by the The Psychiatric Morbidity Survey (2007) “Autism Spectrum disorders in adults living in households throughout England”² which found that 1.0% of the adult population had ASD. The rate was higher in men (1.8%) than women (0.2%).

¹ <http://www.autism.org.uk/about-autism/some-facts-and-statistics/statistics-how-many-people-have-autism-spectrum-disorders.aspx>

² http://www.ic.nhs.uk/webfiles/publications/mental%20health/mental%20health%20surveys/APMS_Autism_report_standard_20_OCT_09.pdf

The absolute numbers were small (so they need to be treated with caution) but the figures indicate:

- People who were single were more likely to be assessed with ASD than people of other marital statuses combined. This was evident among men: 4.5% of single men were assessed with ASD.
- ASD was associated with educational qualification. The rate was lowest among those with a degree level qualification (0.2%) and highest among those with no qualifications (2.1%).
- Likelihood of a positive assessment for ASD varied with tenure and the level of deprivation in the local area. Those living in accommodation rented from a social landlord were the most likely to have ASD. This was strongly evident among men: 8.0% of men in social housing were identified with ASD.
- Being of low predicted verbal IQ was also associated with presence of ASD.
- There was no indication of any increased use of treatment or services for mental or emotional problems among people with ASD.

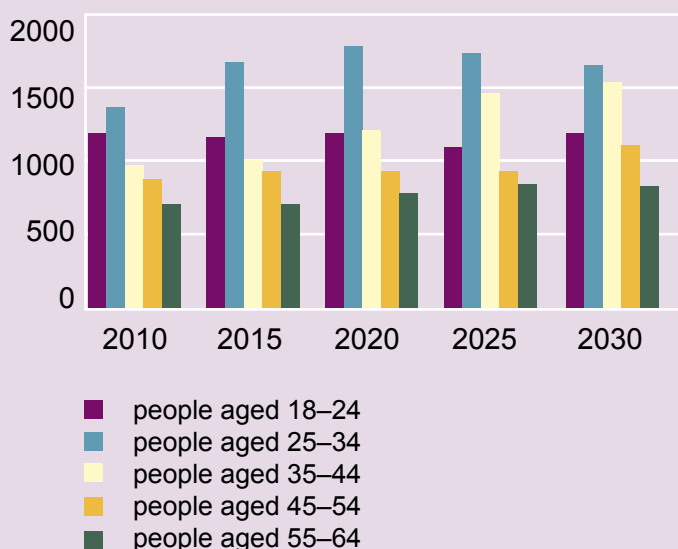
PANSI is a web based information system which collates demographic information to project future need. This table shows the PANSI³ estimates and projections for ASC in Leeds for 2010 up to 2030 (using a Leeds population figure of 536,900 for age 18-64):

	2010	2015	2020	2025	2030
Numbers of people with ASC in Leeds	5392	5793	6090	6352	6641
% increase on 2010 fig.		7%	13%	18%	23%

(NB the age range here is 18-65; the figures in the first paragraph are 18+)

The PANSI projections for Leeds, categorised by age groups, are set out graphically below:

People aged 18–64 in Leeds predicted to have ASD projected to 2030 (with or without a learning disability)



It is not clear whether the pattern of distribution by age group is a reflection of prevalence or of imperfect current information projected into the future.

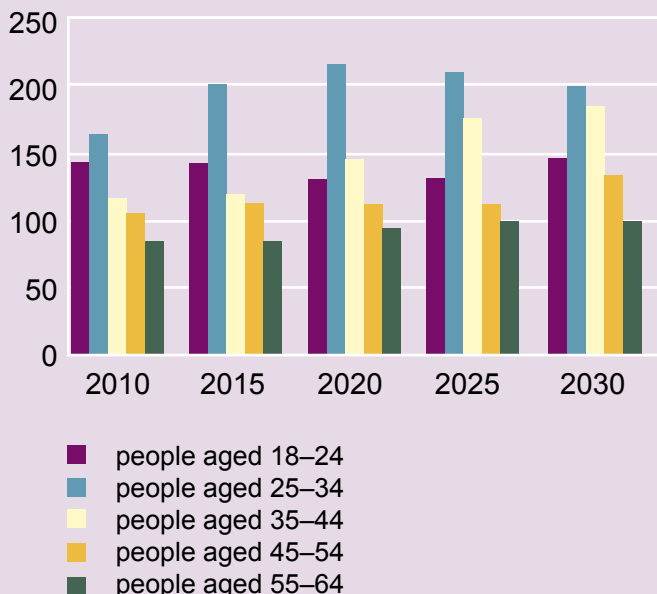
5. 1.1 People with ASC and another condition.

Adults with ASC and a Learning Disability

12% of people with ASC are estimated to also have a learning disability (defined as IQ less than 70). The table below from the Leeds Learning Disability Needs Assessment (based on the PANSI data) sets out the projections from 2010 to 2030. It is anticipated that there will be a steady rise in the increase of people with this type of disorder as mortality rates decrease and life expectancy rises.

	2010	2015	2020	2025	2030
Numbers of people with ASC with a learning disability in Leeds	647	695	730	762	797
% increase on 2010 fig.		7%	13%	18%	23%

People aged 18–64 in Leeds predicted to have ASD with a learning disability



³ <http://www.pansi.org.uk/>

Likelihood of a co-occurring mental health problem

There is limited evidence for this but one set of figures assembled from a number of pieces of research suggest that the overlap between autism and other conditions is substantial:

- ADHD (30-45 %)
- Intellectual Disability (30-80%)
- Depression (4-38%)
- Anxiety Disorders (11-76%)
- Obsessive-Compulsive Disorder (25-50 %)
- Schizophreniform Disorders (7-35%)
- Bipolar Affective Disorder (3-9%)
- Catatonia/Movement disorders (4.5-20%)
- Specific Reading/Writing difficulties ⁴

Coleman and Gillberg (2011) found that nearly all children diagnosed with autism also have another condition.

The implication of these figures is that many people with autism will be using other services where their needs arising from their autism may, or may not, be recognized.

Other co-occurring problems

There is a 20-30% likelihood that people with autism will have epilepsy. (<http://www.autism.org.uk/about-autism/related-conditions/epilepsy.aspx>)

5.1.2 Discussion

The predicted figure of 1% people with ASC-approximately 6,500 adult people in a city the size of Leeds - seems to be widely accepted now. There are however a number of unknowns: the major one in terms of a needs assessment is people's level of need. Autism is a spectrum with the implication that some or

many people on the spectrum will cope with life with minimal support. We are awaiting some DH commissioned research which will indicate what proportion of the 1% of people will have (in social care terms) eligible needs.

There is increasing concern that women on the spectrum may not be diagnosed at a rate that reflects their need – this might imply that a diagnostic system more attuned to women might both diagnose more people but also that services might need to pay more attention to women's needs.

The Leeds Education figures suggest a relatively low number of diagnoses of Asian children relative to other ethnic groups in the city; there is some evidence that this isn't restricted to Leeds.

Both of these areas together with the indication about social class in the psychiatric morbidity study (above) give an indication that planning for future services would need to be sensitive to possible specific gaps in information.

5.2 Local Figures

Information about people in Leeds with ASC is patchy. This is reflected in other areas of the country, it reflects lack of diagnoses, and also limitations of recording systems, for example the Adult Social Care system does not have a possible category of autism (as yet). It is almost certain that the figures below will be an underestimate of people who are being supported or who are known to services. At the time of writing (July 2011) we are awaiting more information from various sources which are listed at the end.

⁴ "Autism Spectrum Disorders: Presentations and Co-morbidities in Adults" Royal college of psychiatry website. Ronan Mullaney (Presentation)

5.2.1 Children and Young People

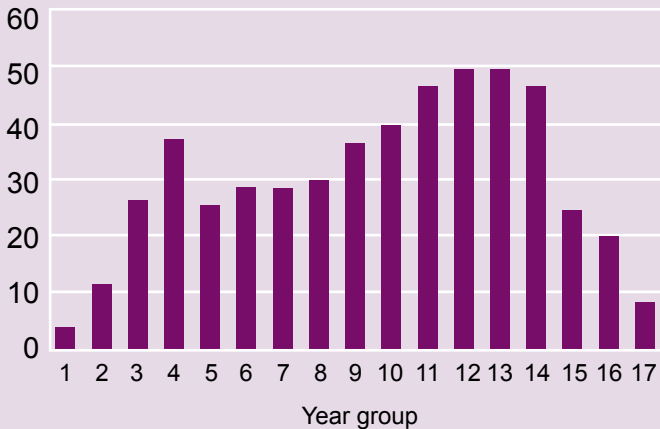
Education Leeds Data 2011

a) **Overall figures:** 507 children aged 3-18 are categorised as having ASD on the 2011 School Census records. 475 (94%) have ASD as a primary SEN need. This means 0.3% of the under 18 Leeds population (152,400).

This data is likely to be an underestimate as it includes only children with a statement or with school action plus. Children with a higher cognitive ability or with less marked autistic needs may not be recorded here.

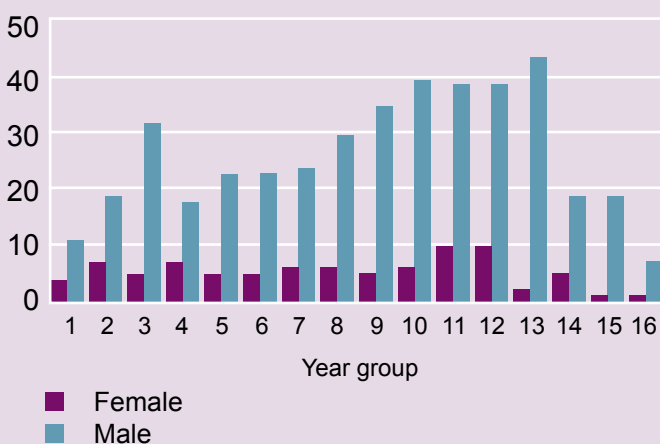
NB: when comparing with transitions figures note that the figures on the bottom axis are school year not age.

Number of pupils with autistic needs (2011 School Census data)



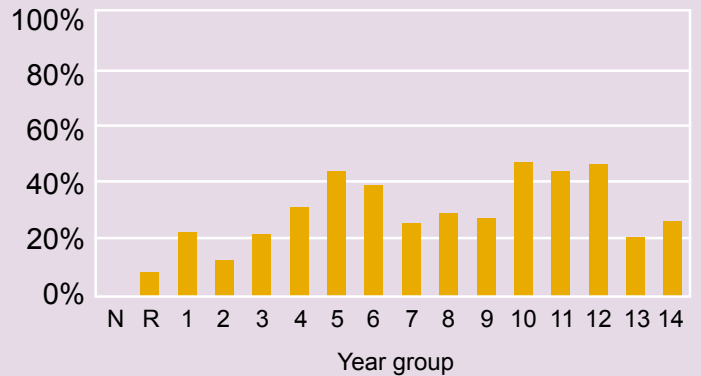
b) The same data, broken down by gender:

ASD pupils by year group, by gender



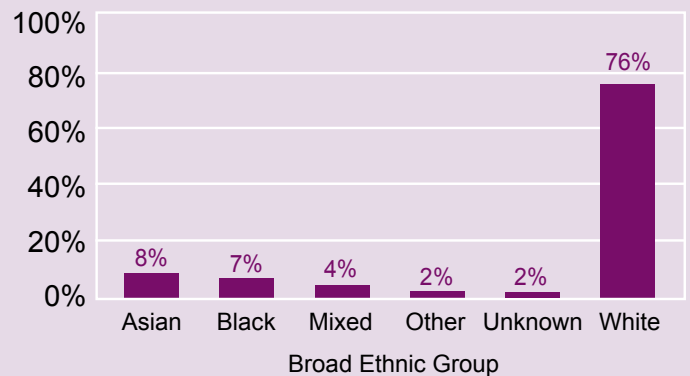
c) this chart shows the percentage of children and young people with an additional need recorded: (this may indicate those children with learning disabilities as well – although the additional need could be something else).

Percentage of children with ASD with an additional need recorded



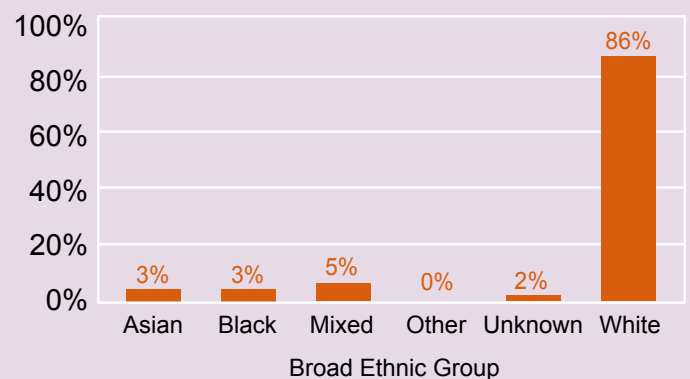
d) chart based on ethnicity of primary age children (using broad categories):

Ethnicity of primary children with ASD



e) chart based on ethnicity of secondary age children, (using broad categories):

Ethnicity of secondary children with ASD



Proportions of children with ASC in different ethnic groups approximate to the proportion in the overall population except for children from an Asian background where markedly fewer children are diagnosed. This is more noticeable in secondary age children so more information would be necessary to establish if levels of diagnoses are rising to reflect the norm.

1.2 Further and Higher Education Data

Leeds University: 39 students with an ASC diagnosis + a further 10 (approx) with ASC and another issue.

Leeds Metropolitan University: 29 students with an ASC diagnosis.

Leeds City College: Approximately 40 students with an ASC diagnosis (verbal report).

These numbers will vary from year to year – they are very low using the 1 in 100 proportion as a bench mark. This would give expected figures of approximately 300 for each establishment. Under diagnosis and under declaration will contribute to this. Presumably other possible factors are lack of progression through the educational system – the figures are also compatible with the finding in the Psychiatric morbidity study that the prevalence rate was lowest amongst those with the highest educational qualifications.

1.3 Transitions Data:

The transitions service is a social work team for disabled children aged between 14 and 25. The team works with disabled young people who are already known and receiving social care support and services. Its aim is to help children and families negotiate the major change from children’s to adults’ services. They are likely to support children with more intensive needs so it is not surprising that the numbers are lower per year group than the Education Leeds figures.

There are 55 young people in the transitions team with ASC aged 15-23 the majority of whom will also have learning disabilities.

Age	Number of people
Age 14	2
Age 15	10
Age 16	27
Age 17	14
Age 18	1
Age 23	1

5.2.2 Adult Services

Adult Social Care

People with ASC could be supported by learning disabilities care management, mental health social work or area offices

Learning disabilities are supporting about 600 people with a dual diagnosis of learning disabilities and autism – (Learning Disabilities Joint strategic needs assessment). This is consistent with the population based estimates for the city.

The other areas are less clear. 31 people are funded from the Mental Health budget in a range of accommodation and community supports. We are undertaking a snap shot picture to establish how many people with ASC are supported by area teams so this information will be available later this year. In the future Autism will be an option on ESCR (the social care recording system) so gradually information retrieval should improve.

Health

Autism is to be put on the GP audit as a category from July so we should gradually have more information about GP's understanding of the number of people on their books with ASC.

Currently people without learning disabilities who seek diagnosis are referred to Sheffield – 20 people have been diagnosed this year.

Provider information

The accommodation and day support provision on the Existing Services list (part 6) is funded by adult social care so their figures will be included within the social care figures.

Asperger's groups

These groups support about 30 people on the spectrum who may not overlap with the people supported by social care.

Further Information

We are awaiting information from the following sources:

- 1) Results of GP Audit
- 2) NHS data from Public Health Analysts
- 3) Adult Social Care Information – Area Offices
- 4) Leeds City College information
- 5) Forensic: prison/probation

Summary and Discussion

For a number of reasons the Leeds figures are incomplete. We will continue to gather information and to update this document as more information is gathered.

The figures above are likely to be more accurate for people with concurrent learning disabilities and for younger people. This probably reflects the pattern of existing services and a more established diagnostic system in children's services.

As noted above actual Learning Disabilities/ASC figures are comparable with predicted ones but there is a large gap between expected non Learning Disabilities /ASC people and actually supported ones.

There are likely to be a number of reasons for this:

- poor recording of autism – we are supporting more people than we at present know about
- some people on the spectrum will have a low level of need and won't have used (or been able to access) services
- multiple issues mean that some ASC people will be being supported in different services eg mental health ones.
- equally some older people will never have been diagnosed so they and others will be unaware that they are on the spectrum

Predictions of possible future need for services

These figures are as stated above very incomplete. It is however clear that there are a significant number of younger adults or children near to entering adult services with a need for high level services. Given the gap between the predicted numbers of people on the spectrum and the ones we know about there also are quite possibly a number of undiagnosed adults with a need or wish for lower level support who may be seeking diagnosis or support in the near future.