

Autism

Autism is a lifelong developmental disability that affects children, adults and their families. The exact causes are still not known but research shows that genetic factors are important. The spectrum of autistic conditions covers a wide range. It varies from profound severity in some through to subtle problems of understanding in others of average or above average intelligence. Autism often occurs with other learning difficulties.

People with autism have a disability characterised by a triad of impairments as follows:

- absence or impairment of two-way social interaction
- absence or impairment of comprehension and use of language and non-verbal communication
- absence or impairment of true flexible imaginative activity, with the substitution of a narrow range of repetitive, stereotyped pursuits

The term 'autism' is used here to describe all diagnosis on the autism spectrum, including classic autism, Asperger syndrome and high-functioning autism.

Other conditions sometimes associated with autism may include attention deficit hyperactivity disorder (ADHD), or learning difficulties such as dyslexia and dyspraxia. People with autism may also experience high or low sensory sensitivity, resulting in unusual reactions to their surroundings.

Autism leads to related problems which may include:

- resistance to change
- obsessive or ritualistic behaviour
- high levels of anxiety
- lack of motivation
- inability to transfer skills from one setting to another
- vulnerability, and susceptibility to exploitation
- depression
- challenging behaviour
- self-injury

Legal duties

The adult autism strategy¹ and statutory guidance² set out legal duties for local authorities and health services on the actions they need to take to meet the needs of adults with autism living in their area.

Where the guidance says that local authorities *should* do something, this means that they have to do it by law, unless they can show a good reason why not. The guidance itself states that "*lack of sufficient resource would not necessarily constitute a good reason*".

The guidance is divided into 4 sections:

- Training of staff who provide services to adults with autism
- Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services
- Planning in relation to the provision of services to people with autism as they move from being children to adults
- Local planning and leadership in relation to the provision of services for adults with autism

¹ Department of Health (2010). Fulfilling and Rewarding Lives: the strategy for adults with autism in England

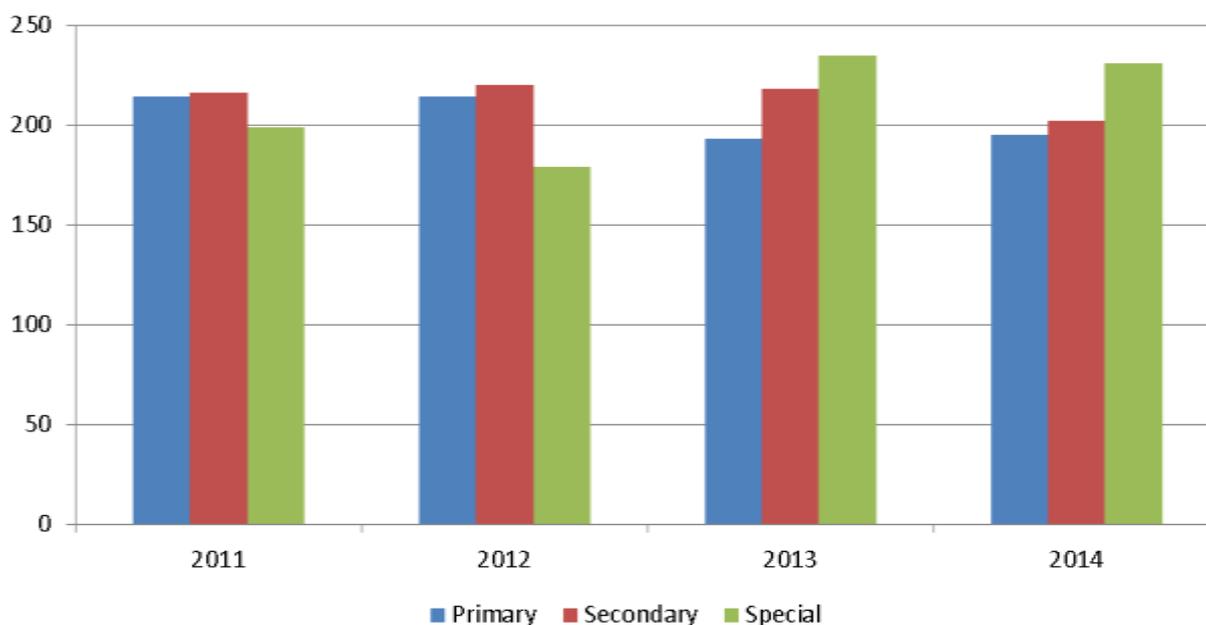
² Department of Health (2010). Implementing Fulfilling and Rewarding Lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy

Growth in population

The National Autistic Society estimates that around 700,000 people may have autism in the UK, or more than 1 in 100 of the population. Based on the estimated national prevalence for autism this suggests that there are currently just over 7,500 people in Devon with autism, including around 1,500 children and young people aged 0 to 18.

In 2014 there were 637 children and young people attending Devon schools recorded with Special Educational Needs (SEN) statements whose primary need was autism, equivalent to 18.7% of the statemented population. It was the second most common primary need among statemented pupils after behaviour, emotional and social difficulty.

Children and Young People with a Statement of SEN where the primary need is autistic spectrum disorder by school sector in Devon 2011-2014:



Source: DfE School Census – Analysis of Needs Type by Outcome Stage

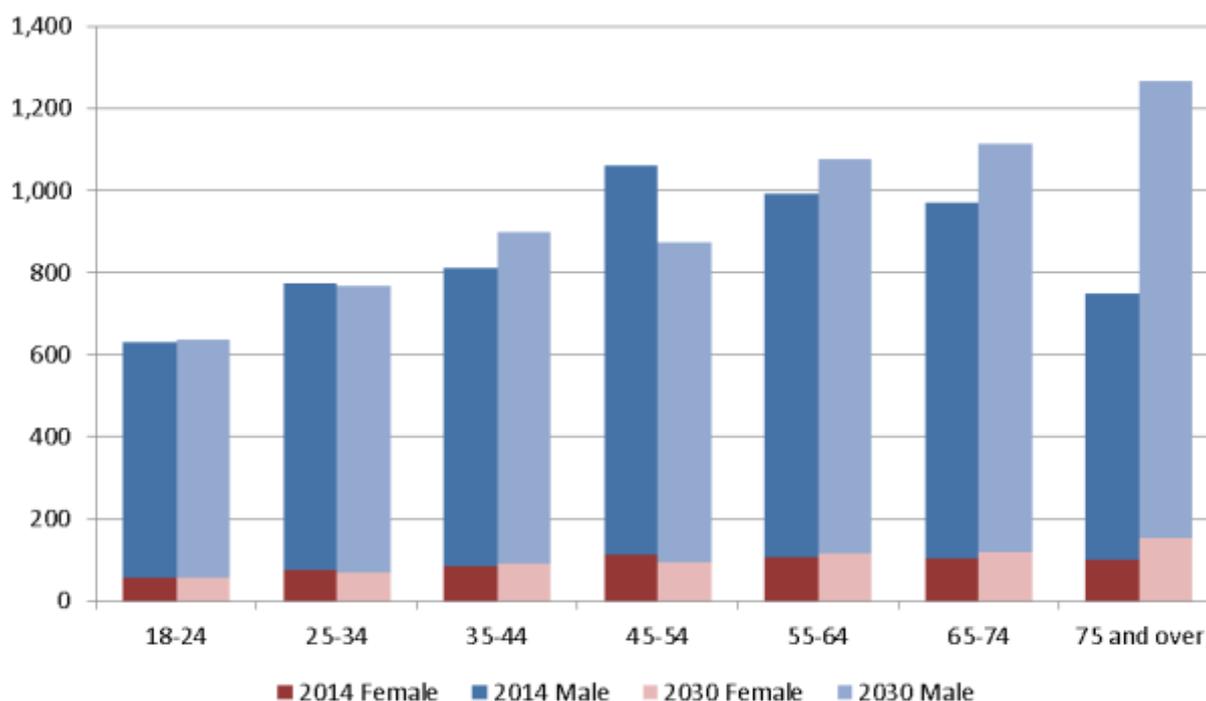
Note: This includes both LA Schools and Academies. Does not include Nurseries, All-through Schools and DPLS

Since 2012, there has been a 2% increase in the number of SEN statements in Devon schools where the primary need is autism. A larger proportion of placements for children and young people with autism are in mainstream schools in 2014 (63%) than in special schools (37%).

In addition to those with a statement, in 2014 there were 174 children and young people at SAP (School Action Plus) with a primary need of ASD, equivalent to 3% of the population at SAP and was the 7th (out of 12) most common primary need among pupils at SAP in Devon.

Data collected by CSET (County Special Education Team) for all children and young people who live in Devon or that we are responsible for shows slightly less (626 in 2014) SEN Statements where the primary need is autism than the Census figures for Devon schools quoted above. The difference is due to pupils crossing the border to/from Devon schools. This suggests that we have a slightly higher number of pupils with SEN statements for autism attending Devon schools from outside of the County than we have attending schools outside of Devon.

The number of adults predicted to have autistic spectrum disorders in Devon 2014 – 2030:



Source: Institute of Public Care (IPC) www.pansi.org.uk version 8.0 and www.poppi.org.uk version 9.0. Crown copyright 2014

The total number of people aged 18-64 with autistic spectrum disorders in Devon is predicted to stay fairly steady from 4,268 in 2014 to 4,254 in 2030, representing a 0.3% decrease³. There is a 38.5% increase predicted for the 65 and over age group from 1,718 in 2014 to 2,379 in 2030. These figures might be a slightly low estimate. The forecasts use a prevalence rate for ASD of 1.0% of the adult population in England (men 1.8%, women 0.2%), based on studies published in 2007. A new study suggests the rates may be nearer 1.1% (men 2%, women 0.3%)⁴.

The predicted little change in the numbers of adults aged 18-64 with autistic spectrum disorders in Devon is also challenged by the School Census data which indicates an overall increase in statements for pupils with autism leading to an eventual comparable increase in the number of adults with autism.

Autism appears to be more common among boys than girls. This could be because of genetic differences between the sexes, or that the criteria used to diagnose autism are based on the characteristics of male behaviour. However, understanding of this is far from complete, and this will remain the case until we know more about the causes of autism⁵.

What are the needs of the population?

Learning Disabilities

People with autism can have different 'degrees' of learning disability, which can affect all aspects of their life, from studying in school to learning how to wash themselves or make a meal. Some people will be able to live fairly independently - although they may need a degree of support to achieve this - while others may require lifelong, specialist support.

³ IPC (Institute of Public Care) online prediction tool – Projecting Adult Needs and Service Information. Available at www.pansi.org.uk

⁴ The Health and Social Care Information Centre, 2012. Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey. Available at <http://www.ic.nhs.uk/statistics-and-data/collections/mentalhealth/mental-health-surveys/estimating-the-prevalence-of-autism-spectrum-conditions-in-adults-extending-the-2007-adultpsychiatric-morbidity-survey>.

⁵ The National Autistic Society. Available at <http://www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction/gender-and-autism/autism-why-do-more-boys-than-girls-develop-it.aspx>

Research carried out by the Learning Disabilities Observatory estimates that between 20% and 33% of adults known to Councils with Social Services Responsibilities as people with learning disabilities also have autism⁶. The number of adults in the population who have both learning disabilities and autism (including those who do not use specialised social care services) is likely to be much higher.

Mental Health

People with ASDs are particularly vulnerable to mental health problems such as anxiety and depression, especially in late adolescence and early adult life⁷. At least one in three adults with autism experience mental health difficulties due to a lack of support.

Health Access

Reasonable adjustments – equalities duties

Education and Transition

Education can do a lot to improve the long-term opportunities of people with autism. Children and young people with autism and Asperger syndrome are entitled to extra help in early years settings, school, college and university – as well as at times of transition, when they move from one education setting to another.

Employment

It has been estimated that only 15% of individuals with autism are in paid employment despite the fact that many of these people have an average or higher IQ. 61% of those out of work say they want to work and 79% of those on Incapacity Benefit say they want to work⁸. They just haven't had the right support and opportunities to make their ambitions a reality.

Criminal Justice System

Research suggests that people with autism are potentially overrepresented within the criminal justice system.

Ethnic Minorities

The prevalence of autism is thought to be the same across all ethnicities but individuals and families from BME backgrounds who are affected by autism have told the National Autistic Society that they often have to battle to receive appropriate support from their communities and local authorities.

A report published by the National Autistic Society on Autism, Education and Ethnicity⁹ found that children with autism from black and minority ethnic (BME) communities experience discrimination on two fronts – their disability and their ethnicity. This isolates them from the education system that should provide opportunities for success. Some excellent practice exists but sadly this is still an exception. The neglect of BME families by researchers, professionals and service providers is unacceptable and must be addressed with urgency.

What works?

- Training Models
- Autism Partnership Group structures and best practice model

⁶ Improving Health and Lives: Learning Disabilities Observatory. The Estimated Prevalence of Autism among Adults with Learning Disabilities in England - Eric Emerson & Susannah Baines

⁷ Tantam & Prestwood, 1999

⁸ Redman, S et al (2009). *Don't Write Me Off: Make the system fair for people with autism*. London: The National Autistic Society

⁹ Missing out? Autism, Education and Ethnicity: the reality for families today – Clare Corbett and Prithvi Perepa, 2007.

Available at <http://www.autism.org.uk/about-autism/our-publications/reports/our-policy-and-research-reports/missing-out.aspx>

What is currently being done in Devon?

Specialist Autistic Spectrum Condition (ASC) Diagnosis Service is currently in place in Devon and Plymouth. Referral rates per month range from 5-20 for either autism or ADHD, with an average of 13 assessments per month.

The ASC Service is developing well and providing good support throughout the assessment process

Service user/carer groups are becoming established and have positive feedback

Recommendations for commissioning

1. A lead joint commissioner in the area
2. Develop a Devon based Autism Partnership Group
3. Ensuring everybody has access to a diagnostic service that follows NICE Standards
4. Mainstream services made accessible for people with autism
5. Commissioning of care services for people with autism

Further information

Local documents and resources (hyperlinks)

National documents and resources

- [National Autistic Society website](#)

Data downloads

Version control

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Next update due:

Please note: This document was created using the recommended new structure and layout for the Devon Joint Strategic Needs Assessment 2011.