



# postnote

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## AUTISM

**Autism affects how a person communicates, socialises and interprets the world. This can lead to wide ranging difficulties in every day life including forming relationships and living independently. Recent evidence that autism is more prevalent than previously recognised has put pressure on service providers and highlighted the need to train professionals to improve awareness of autism. This POSTnote describes autism and autism research, and considers policy approaches.**

### What is autism?

Autism is one of a group of conditions that make up the autism spectrum. For the purpose of this POSTnote the term 'autism' is used to refer to all conditions on the autism spectrum, including Asperger syndrome. As autism affects social interaction and communication it has implications for how individuals participate in everyday life. Autistic<sup>1</sup> people often interpret situations differently from non-autistic people and struggle with new, unpredictable and ambiguous environments. This affects how they manage in a range of situations and settings such as schools, hospitals, shops, on public transport and in the workplace.

### Identification

As there is no clear biological marker of autism it is behaviourally defined. The diagnostic criteria are:

- impaired social interaction, plus;
- impaired social communication, plus;
- a restricted range of interests and behaviours.

Autism can be identified in early childhood. Reports suggest that some parents are aware of differences in the first two years of life. In some cases autism is now diagnosed before the age of 3 years. However, many diagnoses, particularly of Asperger syndrome, take place later in childhood or in adulthood. Diagnostic services are scarce in some areas and access to such services can become increasingly difficult as individuals enter adulthood and have less contact with education and other services.

### Prevalence

Recent estimates suggest that 1% of the population falls on the autism spectrum, approximately 600,000 people in the UK.<sup>2</sup> This is higher than previously thought. However, there is consensus among informed parties that any apparent increase in prevalence is largely due to increasing awareness of the condition and changes in diagnostic practices. The 1% figure was based on a study of children<sup>2</sup> and it is widely assumed that this applies to the whole population. However, there has been no robust survey of the number of autistic adults.

#### Box 1. Autism, learning disability & mental health

Many autistic people have additional learning disabilities and/or mental illnesses (most commonly depression and anxiety). To some extent learning disability and mental illness in autistic individuals can be supported in the same way as in non-autistic individuals. However, staff training is essential so that knowledge of autism can be used to guide services and treatments, and misdiagnosis can be avoided. For example, in some cases autism has been misdiagnosed as schizophrenia. This can lead to the inappropriate prescription of powerful drugs.

### Variation across the autism spectrum

There is much variation in autism:

- the manifestation of autism can change with age, as patterns of atypical behaviour and impairments become more or less marked over time;
- actual capacity in any one individual may fluctuate at different times and in different circumstances;
- the severity of autistic characteristics varies widely across the autism spectrum (see Table 1).

For example, some autistic people have severe learning disabilities (see Box 1), little language ability and display challenging behaviour, including self-harm. Others are of average or above intellectual ability, use language fluently and show great knowledge or skill in specific areas. Table 1 gives examples of extreme behaviours in autism. However, an individual can fall anywhere in between the extremes for each characteristic shown in the table.

**Table 1. Variation in behaviour across the autism spectrum<sup>3</sup>**

	Presentation can range:	
	from...	...to
<b>Key characteristics:</b>		
Social interaction	Aloof and indifferent	Makes one-sided approaches
Social communication	No communication	Spontaneous but repetitive, one-sided
Repetitive behaviour/activities	Simple, bodily directed (e.g. face tapping, self injury)	Verbal, abstract (e.g. repetitive questioning)
<b>Other characteristics:</b>		
Formal language	No language	Grammatical but long winded, repetitive, literal interpretations
Responses to sensory information (oversensitivity, insensitivity)	Very marked	Minimal or no unusual responses
Unusual movements (hand flapping, tiptoe walking)	Very marked	Minimal or absent
Special skills (drawing, rote memory)	None	One skill at a high level, very different from other abilities

**Possible causes of autism**

Considering the complex nature of autism, a single cause is unlikely. The charity Autism Speaks was set up in 2004 to raise funds for research into the causes of autism; further research of this kind has been identified as a priority (Box 2).<sup>4</sup>

**Genetics**

Autism affects approximately three times as many males as females. Taken together with studies looking at families and twins, this suggests that autism has a genetic component.<sup>5</sup> It is likely that a number of genes are involved. However, the exact mechanism by which genes are implicated in autism is unclear and is an important focus for future research. In addition, future studies aim to determine how genes interact with environmental factors in autism.

**Biology of the brain**

Progress in identifying brain differences between the brains of autistic and non-autistic people has been slow and findings are inconsistent.<sup>5</sup> Nevertheless there is evidence suggesting that in autism:

- brains are larger and heavier and there are differences in the cells of some brain regions;
- there is reduced activity in areas associated with the processing of social and emotional information, and planning and control of behaviour;
- there are differences to some signalling molecules in the brain such as serotonin.

**Cognition**

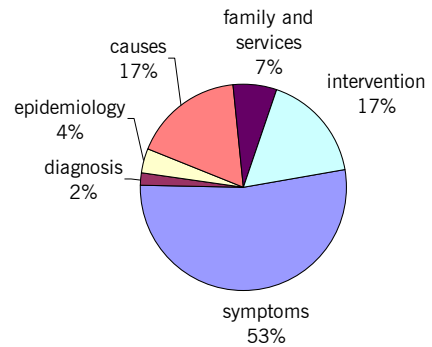
Three psychological theories have been used to explain aspects of autistic behaviour (the first two are consistent with reduced activity in brain areas, see above):

- autistic people have difficulty in understanding the mental states of others, for example that others can have different beliefs, knowledge and points of view to oneself;
- some autistic individuals have difficulties planning and controlling behaviour;

**Box 2. Priorities for research**

There is a strong research base investigating autism in the UK. A review has summarised the breakdown of research funding from government and charity bodies.<sup>4</sup> The majority of projects funded between 1996 and 2000 focused on symptoms, including brain differences, mental processes and behaviour. In comparison, 17% focused on genetic and environmental causes and 17% on interventions; the report highlighted both of these areas as priorities for future research.

**Figure 1. Breakdown of autism research funding in UK**



- a different style of processing information in the environment allows some autistic individuals to be particularly good at processing fine detail. These theories highlight the uneven profile of strengths as well as weaknesses that can be observed in autism.

**Interventions**

It is generally agreed that no single intervention will suit all autistic people, and that any intervention can have negative as well as positive effects. A range of interventions have been developed. Examples include those based on behavioural methods, education-based approaches and non-verbal communication systems. Pharmacological interventions have also been used with some success to treat depression and anxiety in autism, although they do not treat autism itself. There is insufficient evidence about which autism interventions will be effective and why. Therefore, research on interventions has been identified as a priority (Box 2).<sup>4</sup>

Choosing an intervention can be a difficult task as there are many different options available, they can be costly, and it is often difficult to determine which interventions will best suit an autistic person. The Research Autism website<sup>6</sup>, launched in 2007, can guide decisions by:

- providing clear information about different interventions and what they involve;
- summarising the research that is available in a clear and user-friendly way.

**Issues**

Autism is a disability under the Disability Discrimination Act. According to this legislation, organisations must make reasonable adjustments to include autistic individuals; under the Disability Equality Duty all public bodies must promote the equality of autistic individuals. As autism affects social communication and interaction,

social inclusion, for instance in leisure activities, is a particular challenge.

The range of ability and disability in autism means that individuals and their families have diverse needs. Their primary needs will change with age from early childhood and educational services, to support in adulthood, for example with employment. In addition, most will need financial and other support throughout their lifespan (for example respite, see Box 3).

### **Box 3. Respite and short breaks**

Irrespective of severity or age, autism places significant strains on daily life and short breaks are invaluable so that the autistic person can have time away from their home, and their family or carers can have some respite. People have a right to request an assessment of need from their Local Authority (LA), but a lack of appropriate facilities means that this may not always be provided. In 2007 the Government pledged £280 million for short breaks for families with disabled children, including autism. However, funding is also needed for the households of autistic adults. Interested parties agree that short break programmes should be specially tailored to account for some of the difficulties associated with autism, such as adjusting to different environments.

### **Service provision for children**

The needs of autistic children are targeted to some extent by general health, social and educational policy. There is little autism-specific policy and this has an impact on the ability of autistic children and their families to access services. In particular, difficulty accessing mental health<sup>7</sup> and short break<sup>8</sup> services (see Box 3) have been highlighted. The government has produced some specific information to guide service provision for autistic children.

#### *Information for local service providers*

The DH's National Service Framework for children, young people and maternity services was first published in 2004. Alongside this the DH has published a chapter that describes an idealised patient journey for an autistic child that can be used at the local level to guide services. A survey by the All-Party Parliamentary Group on Autism<sup>9</sup> found that few local authorities were using the autism chapter but among the minority who were, it was used to establish autism-specific provision.

#### *Information for parents*

As part of the Early Support programme, the Department for Children, Schools and Families (DCSF) and DH have published information for parents of preschool children either awaiting diagnosis, or with a diagnosis of autism.<sup>10</sup> This provides information about childcare, financial help, education, and health and social services.

#### *Education*

The government acknowledges the need for a range of educational provision to meet the needs of autistic children. Autistic children attend a range of schools. A survey of NAS members showed that irrespective of the

setting, it is expertise in autism that is important to parents.<sup>11</sup> Charities such as the NAS agree that LAs should provide a range of school places and that mainstream schools can be suitable for many children as long as they receive appropriate additional support (see Box 4).

### **Box 4. Autism and Special Educational Needs**

To receive maximum support in school, children must have a statement of Special Educational Need (SEN). The SEN code of practice stipulates a statutory maximum of 26 weeks between the LA receiving a request and issuing the final statement. It is a legal requirement for the LA to arrange the special educational provision specified in a statement of SEN. Many autistic children have a statement of SEN. However, in a recent survey the NAS found that 31% of children with a statement do not receive all the support outlined in it, particularly speech and language therapy and social skills programmes.<sup>11</sup>

#### *Information for schools*

According to recent estimates one in five autistic children have been excluded from school<sup>11</sup> and many leave school with no formal qualifications. The Department for Education and Skills (DfES, now DCSF) and DH produced good practice guidance on autism for LAs, which included information for schools. The government has also funded the Autism Education Trust to help shape future educational provision.

Autism charities, such as TreeHouse and the NAS, and other interested parties, agree that further training on autism is needed in schools. This is supported by a National Union of Teachers survey, in which 76% said that lack of professional development in this area was a barrier to teaching autistic children.

Autism expertise would help ensure that these children can deal with the social demands in both classroom and playground in order to have a positive experience of school. The DCSF has launched an Inclusion Development Programme, which will include professional training about SEN - autism will be the focus of the next stage. It is hoped that this will lead to greater awareness of autism in schools.

#### *Transition*

Autistic people struggle to process social and other information from the environment. To cope with this, individuals rely on structure, routine and rules. Thus, transition and change - such as moving from primary to secondary school, from school into adulthood, or between different living arrangements - can be particularly difficult for autistic individuals. In 2007 a joint DfES (now DCSF) and HM Treasury report<sup>8</sup> was published and included £19m for a Transition Support Programme for young disabled people. The NAS suggests that this is an important first step, but sees further attention to the careful planning of services to guide smooth transitions as a matter of priority.<sup>12</sup>

### Service provision for adults

In 2008 the NAS launched the 'I Exist' campaign to highlight and address the gap between the support that autistic adults need and what they actually receive. During their survey 47% of parents and carers of autistic adults with a learning disability told the NAS that a lack of understanding of autism was a barrier to their son or daughter receiving support.

There is no existing government policy that relates specifically to autistic adults. However, in 2006 the DH commissioned a document summarising policies relating to autistic adults to aid social care and health service provision at the local level.<sup>13</sup> There is consensus amongst clinicians, researchers and the voluntary sector that providing for autistic adults should be a priority for future policy. Issues of particular importance are access to appropriate health care, mental health services, social care, adult education, housing, and employment (below).

#### Accessing services

Autism crosses traditional public service boundaries such as health, education and social welfare. This provides a challenge for local service providers who must make sure that individuals don't fall between service gaps (see Box 5 for an example of good practice). Where autistic adults access services this is usually via mental health or learning disability teams, but services are less accessible for those that do not have significant additional mental illnesses and/or learning disabilities (see Box 1).

#### Box 5. The Liverpool Asperger Team

Autistic individuals that have average and above intellectual ability (for example Asperger syndrome or high functioning autism) are particularly at risk of falling through service gaps. In response to this the Liverpool Asperger Team was set up in 2002, funded by Liverpool Primary Care Trusts and Liverpool City Council. The multidisciplinary team provides co-ordinated services such as assessment, diagnosis and intervention along with specialist knowledge, information and advice. The Liverpool Asperger Team is often cited as an example of good practice.<sup>13</sup>

As part of the 'I exist' campaign the NAS found that 60% of autistic adults had difficulty receiving services. Government policy<sup>13</sup> recommends the following strategies for promoting access to services: pooling resources, joint working protocols, joint training and sharing expertise.

#### Employment

A recent report suggests that few autistic adults are employed. Also, of the £25 billion annual cost of autism to society, 36% can be accounted for by lost employment.<sup>2</sup> In some cases employment may not be appropriate. However, even among individuals of high intellectual ability, most have difficulty sustaining employment. Without employment individuals are likely to experience less independence and social interaction, suffer from low self-esteem and to claim more benefits. Support including access to information and communication technology can help some autistic adults find employment (see Box 6).

#### Box 6. Supporting employment

The NAS runs Prospects, an employment scheme for autistic clients, which is partly funded by the Department for Work and Pensions. An independent evaluation<sup>14</sup> of the scheme showed that over an eight year period Prospects found employment for approximately 68% of their clients. Further, although finding jobs for individuals was relatively costly, this cost was largely offset by a reduction in benefit claims, and gains in tax and National Insurance. Despite the success of Prospects, there are few schemes of this kind. Further schemes would enable a greater number of individuals to work rather than receive income-related benefits.

### Overview

- Approximately 1% of the population are on the autism spectrum.
- Autism primarily affects social interaction and communication, which has implications for how individuals react to a wide range of situations.
- More research is needed into causes and constructive interventions.
- Variation across the spectrum means that autistic people and their families need to be able to choose from a wide range of support services.
- Training of professionals and raising awareness is of primary importance to ensure that autistic people have access to appropriate services.

#### Endnotes

- 1 We use this term throughout, for discussion of this issue see Sinclair, J, [http://web.svr.edu/%7Ejisincla/person\\_first.htm](http://web.svr.edu/%7Ejisincla/person_first.htm)
- 2 Knapp, M et al, *The economic consequences of autism in the UK*, Foundation for People with Learning Disabilities, 2007
- 3 Adapted from Baird, G et al, *The British Medical Journal*, vol 327 (2003), pp 488-493
- 4 Charman, T & Clare, P, *Mapping autism research: Identifying UK priorities for the future*, The National Autistic Society, 2004
- 5 *Review of Autism Research: Epidemiology and Causes*, Medical Research Council, 2001
- 6 [www.researchautism.net](http://www.researchautism.net)
- 7 *The National Service Framework for Children, Young People and Maternity Services*, Department of Health, 2004
- 8 *Aiming High for Disabled Children: Better Support for Families*, HM Treasury / Department for Education and Skills, 2007
- 9 Yuille, R, *Policy into practice: Implementation of the National service framework for children, young people and maternity services by local authorities*, The National Autistic Society, 2007
- 10 [www.earlysupport.org.uk](http://www.earlysupport.org.uk)
- 11 *Make school make sense*, The National Autistic Society, 2006
- 12 Reid, B, *Moving on up?* The National Autistic Society, 2007
- 13 *Better Services for People with an Autistic Spectrum Disorder*, Department of Health, 2006
- 14 Howlin P et al, *Autism*, vol 9 (2005), pp 533-549

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