

Autism

What does this mean?

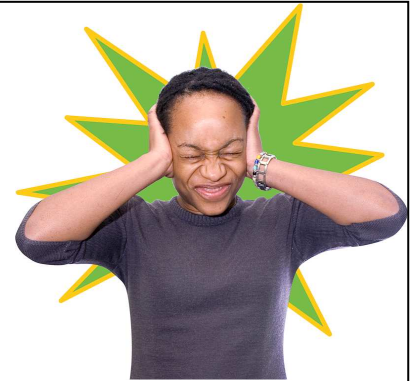
Autism is a lifelong developmental condition that affects how a person communicates with, and relates to, other people. It also affects how people make sense of the world around them.

It is a spectrum condition, which means that, while people with autism will all share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives, whilst others who may also have a learning disability will require a lifetime of individualised support.

Many people with autism will also experience under or over sensitivity to sounds, taste, touch, smells, lights or colours.

Asperger Syndrome is a form of autism. People with the condition generally have average or above average intelligence. They will have fewer problems with speech, but difficulties in processing and understanding information. The three main areas of difficulty for people with autism are sometimes known as the 'triad of impairment', these are:

- Difficulty with social communication
- Difficulty with social imagination
- Difficulty with social interaction



Why is this important?

People with autism are amongst the most socially vulnerable and excluded members of our society.

It has been hard to raise awareness about autism.

Many parents report that their children are seen as naughty. Adults with the condition report that they are frequently misunderstood.

People with autism experience multiple health inequalities, including reduced access to employment, poor access to good housing and increased rates of bullying and harassment.

When accessing health and social care services people with autism experience discrimination and inequalities. This is due to a lack of awareness and understanding, inappropriate communication, poor access to services and a lack of service provision relevant to their needs.

In 2009 the Autism Act became law. As the first piece of single disability legislation it required the government to produce an Autism Strategy. In 2010, the government produced "Fulfilling and Rewarding Lives: the strategy for adults with autism in England". Following the current government published statutory guidelines for Local Authorities, the NHS and Foundation Trusts. These documents set out the plan for Autism Services and guidelines for delivery of improved outcomes for adults with autism.



What do we know about people with autism in England?

Research carried out in 2007 suggests that people with autism constitute 1% of the general population. The National Autistic Society suggests that 50% of adults with autism will also have a learning disability.



Autism Facts ¹

- Autism doesn't just affect children. Children with autism grow up to be adults with autism.
- Autism is a hidden disability. You can't always tell if someone has it.
- Autism is incurable but with the right support at the right time can make a tremendous difference to peoples' lives.
- Over 40% of children with autism have been bullied at school.
- Over 50% of children with autism are not in the kind of school their parents believe would best support them.
- One in five children with autism have been excluded from school, many more than once.
- Nearly two-thirds of adults with autism in England do not have enough support to meet their needs.
- At least one in three adults with autism experience severe mental health difficulties due to a lack of support.
- Only 15% of adults with autism in the UK are in paid full-time employment.
- 51% of adults with autism in the UK have spent time with neither a job nor access to benefits. Of those, 10% have been in this position for 10 years or more.
- 61% of those without work say that they want to work.
- 79% of those on Incapacity Benefit say that they want to work.

What is the picture in Bristol?

We do not know exactly how many people with autism are currently living in Bristol, however the Local Joint Strategic Needs Assessment (JSNA), identifies it as an area that requires greater consideration.

The most current source of information is the Department of Health, who have used a report from the Health and Social Care Information Centre to estimate prevalence.

At present, it is estimated that there are 3,124 adults with autism living in Bristol and that this figure will rise to over 4,000 by 2030.

According to the National Autistic Society 50% of this group will also have a learning disability.



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What is happening in Bristol to support people with Autism?

- Avon and Wiltshire Partnership have developed a specialist service called the Bristol Autism Spectrum Service. This team provide diagnosis and short-term post-diagnostic support. The team are also available to support other Health and Social Care Teams in their work with adults with autism. The Bristol Autism Spectrum Service can be contacted by calling 01275 796 200
- Bristol City Council are producing a local Autism Strategy which will influence and steer service commissioning and design
- During 2011 Bristol LINK have held two Autism specific events. The first of these events was for adults with autism to share their experience of Health and Social Care services in the city. The second event shared the information gained from people with autism with Commissioners, Service Managers within the Local Authority and PCT.
- The National Autistic Society currently operate a Helpline service which offers Advice and Information. The helpline can be contacted on 0845 070 4004.
- People First, a self advocacy organisation provide support for adults with autism and a Learning Disability.
- Bristol Learning Difficulties Partnership Board has representation from all stakeholder groups and is the main strategic forum for commissioning, planning and developing services for people with autism and a learning difficulty. The board oversees the implementation of Valuing People in Bristol. Government funding attached to this board has recently paid for carers of people with Autism to become skilled in delivering Autism Awareness training for health and social care staff.



How to support people with autism*

- Explain at every stage what you are about to do, what will happen next and why.
- Give the person enough time to understand the information you are sharing and wait a few seconds for a response if it's not given immediately.
- Questions should be clear and direct, using language that is easy to understand and pictures wherever necessary. Do not rely on the person to pick up on the meaning of your questions.
- People with autism may take what you say literally. Avoid words with a double meaning and humour that could be misunderstood.
- Maintain a routine – familiarity is often important to some people with autism.
- Social difficulties may include a lack of eye contact, unusual body language, talking at inappropriate moments, or inappropriate topics.
- Repetitive behaviours may be a coping mechanism and therefore should be respected.
- Environment is important. Some people with autism are particularly sensitive to light, movement, sounds, smell, and touch. Help alleviate any anxiety by keeping the immediate environment calm.
- Always consider the person's behaviour in terms of his or her autism, even if it becomes challenging.
- Ask the person and/or parent, carer or advocate what support they might need.

*Adapted with kind permission from the Estia Centre

Footnoted References

1. Rosenblatt, M (2008). *I Exist: the message from adults with autism in England*. London. The National Autistic Society Fulfilling and Rewarding Lives: the strategy for adults with autism in England (Department of Health, 2010)
2. Batten, A et al(2006). *Autism and Education: the reality for families today*. London: The National Autistic Society. p31 Exist: the message from adults with autism in England (The National Autistic Society, 2008)
3. Redman, S et al (2009). *Don't Write Me Off: Make the system fair for people with autism*. London: The National Autistic Society.

References for Content

- *Fulfilling and Rewarding Lives: the strategy for adults with autism in England*, (Department of Health, 2010).
- *I Exist: the message from adults with autism in England*, (The National Autistic Society, 2008).
- *Don't Write Me Off: make the system fair for people with autism*, (The National Autistic Society, 2009)
- *Autism and Education: the reality for families today*, (The National Autistic Society, 2006)

Further Reading

- *Valuing People; a New Strategy for Learning Disability for the 21st Century*, (Department of Health, 2001).
- *Independent Living Strategy*, (Department of Health, 2008).
- *Valuing Employment Now: real jobs for people with Learning Disabilities*, (Department of Health, 2009).
- *Supporting People with autism through adulthood*, (National Audit Office, 2009).

Further Information Contact Details

- Avon National Autistic Society, tel: 07825227026 or email: avon@nas.org.uk
- National Autistic Society, Bristol branch, tel: 0117 9047682 or email: NASBristolBranch@nas.org.uk

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