

# Autism

## Introduction and background

This report is one of the recent POSTnotes produced by the Parliamentary Office of Science and Technology. POSTnotes give a comprehensive overview on a given topic. This POSTnote deals with various aspects of autism and how it affects people's lives. It is extensively referenced, with 131 sources listed at the end of the report.

## Key points

### Autism: definition, diagnosis and prevalence

- Autism is a lifelong developmental condition that affects the way that a person interacts with and experiences the world around them. It is clinically defined by difficulties in social interaction and communication, and the presence of restrictive or repetitive behaviours and interests.
- The way in which autistic people process their environment can lead to areas of strength or difficulty, that vary between individuals and may not be immediately obvious. For example, autistic people can have: strong attention to detail; above average technical or creative skills; character strengths, such as honesty or loyalty; sensory processing differences, including over-and-under sensitivity; difficulty predicting what is going to happen next; and difficulty knowing or understanding what other people think and feel.
- Autism varies widely and is often referred to as a spectrum. However, the spectrum is not linear – autistic people cannot be defined as more or less autistic. Different features of autism vary from individual to individual as well as over the course of a person's lifetime. Furthermore, their autism may manifest itself differently in different environments.
- A review of the research revealed that the estimated global prevalence of autism is 1.04 per cent, equivalent to 700,000 autistic people in the UK. Recent UK estimates suggest that the diagnosis of autism in children is around 1.6 per cent. Autism is thought to be 3 times more common in men than in women. Researchers have suggested that it might be underdiagnosed in adults, females, gender-fluid and non-binary people, and in those from ethnic minorities.
- Clinical observation of behaviour and a person's developmental history are used to diagnose autism. The earliest age at which a diagnosis of autism can be made is currently 2, although there may be signs earlier than this. The average age of diagnosis in the UK is around 4.5 years. There is currently no biological test for autism.
- Concerns about an autism diagnosis are most often raised by parents, but may also be raised by health visitors, GPs or other practitioners, and education staff. There are screening tools for children and adults which may be useful for recording areas of concern; they cannot, however, provide a diagnosis.
- The autism strategy recommends that GPs refer individuals or families to a specialist autism team, who will conduct assessments (including questionnaires, interviews, or observations across home, school or work), and provide support (including information about autism and intervention options).
- Sometimes, a diagnosis of autism can be delayed by what is known as social camouflaging, whereby an individual uses tactics to mask their condition in order to fit in. Women in particular have noted that the effort of camouflaging has a detrimental effect on their mental health.
- NICE recommends that for children and adults a diagnostic assessment for autism be started within 3 months of referral. However, only 18 per cent of local authorities in England reported meeting this target in 2018. UK surveys suggest that the average waiting time between raising concerns with a health professional and receiving a diagnosis is 3.6 years for children, and over 2 years for adults.
- Autism is thought to be caused by a combination of genetic and environmental factors and it can run in families. The precise cause is unknown; there is no one particular gene which is known to be affected in all autistic people, nor does having a particular genetic variant mean that someone is autistic. Rates of autism are slightly higher in children with older parents and in cases where a mother has had gestational diabetes or infection during pregnancy.
- Although there has been considerable research investment in the UK to identify the causes of autism, the autistic community themselves do not see this as a research priority. When the UK autism research charity Autistica asked people with autism about their priorities, the top 3 areas were improving mental health outcomes, language and communication interventions and provision of adult social care.

### Co-occurring conditions

- There are a number of conditions which are found to be more prevalent in autistic people than in the general population.
- Research suggests that 70 per cent of autistic people have a mental health condition, and that 40 per cent have 2 or more. They are up to 4 times more likely to have anxiety, and twice as likely to have depression. Research has shown that they are also more vulnerable to negative life

experiences, which may also impact mental health. Compared to the general population, autistic people report having a lower quality of life.

- Autism is one neurodevelopmental condition which is often linked to others. These include general learning disabilities (affecting between 15% and 30% of autistic people), specific learning difficulties (such as dyslexia and attention-deficit hyperactivity disorder), and other conditions such as epilepsy. Delays in language development are common in people with autism, and up to 30 per cent of autistic people are non-speaking (completely, temporarily, or in certain contexts).
- Other health issues which are more common in autistic people are sleep problems, gastrointestinal problems and catatonia (abnormality of movement and behaviour).
- Autistic people have earlier mortality; a 2016 study based on the whole population of Sweden found that the average life expectancy of a non-autistic person is 70.2 years, compared to 53.9 years for an autistic person without learning disability, and 39.5 years for an autistic person with learning disability.
- Suicide is the main cause of early mortality amongst autistic people. A large UK study in 2014 found that 66 per cent of autistic adults without a learning disability had contemplated suicide, compared with 17 per cent of non-autistic adults. Research has suggested that 14 per cent of autistic children experience suicidal thoughts, compared with 0.5 per cent of non-autistic children. Research has also linked persistent social camouflaging to increased risk of suicide.

### Interventions and support

- Interventions to help autistic people include pharmaceuticals to manage and treat co-occurring conditions, learning materials or technologies to support communication, and support for families and carers. NICE guidelines state that pharmaceuticals should not be used to treat the core features of autism. Furthermore, research has suggested that many interventions currently available to autistic people are not effective.
- The treatments for medical conditions that co-occur with autism include medication for managing attention difficulties and sleep problems. Regarding treatments for mental health problems, research suggests that whereas group-based cognitive behavioural therapy is effective for anxiety in autistic children, individual therapy may be more appropriate for other age groups.
- Transitions can be difficult for autistic people who may require additional support when moving from education into employment or from childhood into adolescence. Research has shown that one-to-one interventions can provide timely support and that befriending schemes, such as those offered by the National Autistic Society can also help.
- Service providers recognise the need to provide families with information and support. Local authorities have a duty to provide respite options for disabled children and their families, such as after school play schemes, overnight stays, or longer breaks.
- The Preschool Autism Communication Trial (PACT) aims, by means of group training over several months, to provide parents with a positive perception of autism, and skills to support communication with their child. Research has shown that PACT training has a long-term positive impact on child development. Another approach is the EarlyBird parent-training program offered by the National Autistic Society, although it has limited research evaluation to date.

### Legislation, policy and guidance

- In England, the Autism Act (2009) placed a duty on the government to meet the needs of autistic adults by producing an Autism Strategy and statutory guidance for local authorities. Progress in implementing the Autism Strategy's recommendations is partly monitored by the Autism Self-Assessment Framework. Survey responses for the 2018 framework report show that in 5 of the 8 assessed areas there have been falls in ratings compared to 2016.
- Economic analyses have suggested that the total cost of autism can be reduced by providing effective support for autistic people and their families, including improved access to education and employment and treatment of co-occurring conditions. In the UK, annual health checks are currently being developed for autistic people to increase detection of health conditions, thereby reducing early mortality. The Department of Health and Social Care has announced £1.4million of government funding to develop a new training package on learning disability and autism for health and social care staff.
- Public Health England has reported that autistic people and those with learning disabilities are more likely to be inappropriately prescribed medications which affect psychological functioning than the general population, and at higher dosages. The NHS has launched a campaign to reduce this over-prescribing.
- The Royal College of General Practitioners' Autistic Spectrum Disorders Toolkit provides guidance for practitioners to support autistic people and their families. Other useful resources include Autism Alert cards and the Know your Normal toolkit, developed by the organisation Ambitious about Autism.
- Preliminary data have suggested that autistic children are up to 3 times more likely than children without special educational needs and disabilities (SEND) to be excluded from school.
- Across the UK, educational support for children and young people with autism is provided on a basis of needs (such as learning, communication, behaviour and sensory needs).
- Research has suggested that autistic people have the lowest employment rates of all disability groups. In the 2018 autism self-assessment framework, employment showed the least improvement since 2016.
- Research suggests that tailored support for people with autism can reduce pre-university anxiety and improve graduate employment. The Department of Work and Pensions and the Autism Alliance has produced an Autism and Neurodiversity Toolkit for employers, which promotes awareness and understanding of autism and other neurodevelopmental conditions in the workplace.
- It is estimated that autistic people are up to 7 times more likely than the general population to be involved in the criminal justice system, as a victim, a witness or a defendant. Researchers have recommended that autism training be provided to all frontline police officers and other staff such as the public prosecution services.
- In 2019, an all-party parliamentary group report on autism flagged up a number of priorities expressed by autistic people and other stakeholders. These included training, led by autistic people, to be delivered across sectors, including social care and education as well as establishing well-resourced specialist autism teams in each local authority.

The full document can be downloaded from:

<https://post.parliament.uk/research-briefings/post-pn-0612/>