

Autism



Autism affects the way that someone engages with the world around them. A cross-government adult autism strategy, *Think Autism*, was published in 2014. This note provides an overview of policy issues that are relevant to autistic people and their families.

What is autism?

Autism is a lifelong developmental condition that affects the way that a person interacts with and experiences the world around them.^{1,2} Throughout this note, the term “autistic” will be used, as preferred by a small majority of the autistic community.³ Autism is clinically defined by difficulties in social interaction and communication, and the presence of restrictive or repetitive behaviours and interests.^{4,5} While autism is often characterised by social difficulties, non-autistic people can also have difficulty knowing or understanding what autistic people think or feel.^{6–11}

The way that autistic people process their environment can lead to areas of strength or difficulty, that vary between individuals and may not be immediately obvious.^{12–14} For example, autistic people can have:

- Strong attention to detail^{15–18}
- Above average technical¹⁹ or creative skills^{20,21}
- Character strengths, such as honesty and loyalty^{22,23}
- Differences in sensory processing, including over- and under-sensitivity^{24–27}
- Difficulty predicting what is going to happen next^{28–30}
- Difficulty knowing or understanding what other people think or feel^{31–33}

Overview

- Autism affects at least 1% of the population, although it is likely that this is underestimated, particularly in non-males.
- Autism frequently co-occurs with other conditions, including mental health conditions, learning disability, and epilepsy.
- A range of interventions are available for autistic people, which include treatment of co-occurring conditions, support with communication, and providing support for parents and families.
- The Autism Act (2009) and relevant strategies have increased autism awareness, but autistic people continue to be disadvantaged in areas including health outcomes, education, employment, and the criminal justice system.

Autism varies widely and is often referred to as a spectrum. However, this spectrum is not linear³⁴ - it is not possible to line autistic people up in order of being more or less autistic.¹ Instead, there is a constellation,^{1,35} as different features of autism vary from individual to individual,^{36,37} as well as over the lifespan.^{38–40} How an autistic person appears in a particular environment may not be representative of how they appear in other environments.¹

Prevalence

A review of the research found that the estimated global prevalence of autism is 1.04%,⁴¹ equivalent to 700,000 autistic people in the UK.^{42,43} Recent UK estimates suggest that the diagnosis of autism in children is around 1.6%.^{44,45} Autism is thought to be three times more common in men than women.⁴⁶ Researchers have suggested that autism may be under-diagnosed in adults,¹³ females,⁴⁷ gender-fluid and non-binary people,⁴⁸ and those from ethnic minorities.⁴⁹

Diagnosis

Autism is identified through clinical observation of behaviour, and developmental history.⁵⁰ The earliest age at which autism can be diagnosed is currently 2 years,⁵¹ although indicators that a child might be autistic can appear earlier.^{52–56} The average age of childhood autism diagnosis in the UK is around 4.5 years.⁵⁷ There is currently no biological test for autism.³⁴

Box 1: The autism community - research priorities

UK autism research charity Autistica asked autistic people, their families, and professionals, what areas and topics autism research should address.⁸⁶ In 2016, they identified the following ten research areas, in order of priority for the autism community:

- Improving mental health outcomes
- Language and communication interventions
- Provision of adult social care
- Interventions to reduce anxiety
- Supporting the best education, life, and social outcomes across the lifespan
- Supporting parents and families to better understand autism
- Diagnosis of autism in adulthood
- Person-centred support for autistic employees
- Understanding sensory processing
- Service delivery to meet the needs of autistic people

Concerns about an autism diagnosis are primarily raised by parents, but may also be flagged by health visitors, GPs or other practitioners, and education staff.^{58,59} Screening tools are available for children^{56,55} and adults⁶⁰ that may be useful for recording areas of concern but cannot provide a diagnosis.^{55,56,61} The autism strategy recommends 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).

Recognition and diagnosis of autism can be delayed due to social camouflaging, which is the conscious or unconscious masking of behaviours or traits so that an individual may appear non-autistic.⁶²⁻⁶⁴ It is a behaviour that autistic people, particularly those without learning disability, may use in order to "fit in."⁶⁴⁻⁶⁶ Autistic people, particularly women, have reported that camouflaging can have a profoundly negative impact on mental health.⁶⁵⁻⁶⁸

NICE recommends that a diagnostic assessment for autism be started within 3 months of referral, for both children and adults.^{5,69} However, only 18% of local authorities in England reported meeting this target in 2018.⁷⁰ 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,⁵⁸ and over 2 years for adults.⁵⁹

Causes

Autism can run in families,⁷¹⁻⁷³ and is thought to be caused by a combination of genetic and environmental factors.⁷⁴⁻⁷⁷ The precise cause is unknown; there is not one particular gene that is known to be affected in all autistic people, nor does having a particular genetic variant mean that someone is autistic.^{78,79} Rates of autism are slightly higher in children with older parents,^{80,81} and in cases where a mother has had gestational diabetes or infection during pregnancy.⁸²

There has been substantial research investment in the UK to identify causes of autism.^{83,84} The autism community feel that research should be aligned with their priorities,⁸³⁻⁸⁵ which currently do not include research into causes (Box 1).

Co-occurring conditions

NICE estimates that around 70% of autistic people have an additional condition, which is "often unrecognised".^{5,69} The main conditions that co-occur more frequently in autistic people compared with the general population include:

- **Mental health conditions.** Research suggests that 70% of autistic people have a mental health condition, and that 40% have two or more.⁸⁷⁻⁸⁹ Autistic people are up to four times more likely to have anxiety,⁹⁰ and twice as likely to have depression.⁹¹ Research has shown that autistic people are more vulnerable to negative life experiences, which may also impact mental health.^{88,92} Compared to the general population, autistic people report having a lower quality of life.^{93,94}
- **Neurodevelopmental conditions.** These are caused by differences in early brain development, and affect the way that a person processes information, thinks, or learns. Autism is one such condition, and it is common for autistic people to have other neurodevelopmental conditions.⁹⁵ These include general learning disabilities (affecting between 15% and 30% of autistic people⁹⁶⁻⁹⁸), specific learning difficulties (such as dyslexia and attention-deficit hyperactivity disorder⁹⁹), and other conditions such as epilepsy.¹⁰⁰ Delays in language development are common in autism,³⁵ and up to 30% of autistic people are non-speaking (completely, temporarily, or in certain contexts).
- **Other conditions.** Other health conditions, such as sleep problems,¹⁰¹ gastrointestinal issues¹⁰² and temporary immobility or catatonia.¹⁰³

Health inequalities

Research has consistently found increased rates of many physical and mental health conditions in autistic people relative to non-autistic people.^{104,105,98} A study based on the whole Swedish population 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.¹⁰⁵

Suicide is a leading cause of early mortality amongst autistic people.^{105,106} A large UK study found that 66% of autistic adults without a learning disability had contemplated suicide, compared with 17% of non-autistic adults.¹⁰⁷ Research has suggested that 14% of autistic children experience suicidal thoughts, compared with 0.5% of non-autistic children.¹⁰⁸ Preliminary research has also linked persistent social camouflaging to increased risk of suicide.⁶⁸

Interventions and support

There is consensus amongst autistic people and researchers that the goal of an intervention should be to help an autistic person reach their full potential, and provide the skills required to do so.^{1,109} Interventions currently available to autistic people and their families include pharmaceuticals to manage and treat co-occurring conditions,^{105,110,111} learning materials or technologies to support communication,¹¹² and support for families and carers.¹¹³ NICE guidelines state that pharmaceuticals should not be used to treat the core features of autism.^{5,69} Some autism interventions can cause long-term

physical and mental harm.^{114,115} Research has suggested that many interventions currently available to autistic people are not effective.^{109,112,116,117}

Interventions for co-occurring conditions

Providing support and treatment for conditions that co-occur with autism can improve quality of life.^{93,94} Treatments for medical conditions that co-occur with autism are available, such as medication for managing attention difficulties¹¹⁸ and sleep problems.¹¹⁹ Service providers and autistic people believe that treatments for mental health problems need to meet the needs of autistic people.^{69,120–122} Research suggests that group-based cognitive behavioural therapy is effective for anxiety in autistic children,¹²³ but individual therapy may better suit other ages.^{110,124}

Individual support

Autistic people can require additional support around periods of support for social or hormonal transitions, such as between education and employment,^{125–127} or during puberty¹²⁸ and menopause.¹²⁹ For adults, research has suggested that one-to-one mentoring could provide targeted and timely support, such as helping someone to find a job.¹³⁰ Other approaches include befriending schemes, which can provide social support. The National Autistic Society offer befriending and mentoring schemes for children and adults.¹³¹

Support for families and caregivers

Autism can have a significant impact on family life.¹¹³ Service providers recognise the importance of providing carers of autistic children with a good understanding of autism and appropriate support for families.¹¹³ Local authorities have a duty to provide a range of respite options for disabled children and their families, such as after school play schemes, overnight stays, or longer breaks.¹³²

The Preschool Autism Communication Trial (PACT) aims to provide parents with a positive perception of autism, and skills to encourage communication with their child, through group training over several months. Research has shown that parent training via PACT has a long-term positive impact on child development, including social skills.^{133,134} Other approaches include the EarlyBird parent-training program offered by the National Autistic Society, which has limited research evaluation to date.^{135,136} Other family support groups are currently in development.^{137–139}

Legislation and policy

Autism covers many areas of legislation and policy, and each of the devolved nations has a different approach (Box 2). For a summary of policies related to autism across the UK, see the House of Commons Library briefing paper.¹⁴⁰ The Autism Act (2009)¹⁴¹ is the first individual disability-specific legislation in England.¹⁴⁰ The Act put a duty on the government to meet the needs of autistic adults by producing an Autism Strategy and statutory guidance for local authorities.¹⁴⁰

In England, progress in implementing the Autism Strategy's recommendations for service provision is partly monitored by the Autism Self-Assessment Framework. Survey responses are

Box 2: Policies for autistic people across the UK

Each of the devolved administrations are responsible for setting their own policies about service provision for autistic people.¹⁴⁰ The following either make specific provisions for autistic people or are particularly relevant to their needs.

UK-wide legislation

- Mental Capacity Act (2005). Aims to protect people who may lack the mental capacity to make their own decisions on treatment
- Equality Act (2010). Specifies reasonable adjustments be provided across services, including education and the workplace

England

- Mental Health Act (1983). Covers the assessment, treatment and rights of people with a mental health disorder
- Children and Families Act (2014). Particularly section 3 on special educational needs and disabilities

Scotland

- Scottish Strategy for Autism (2011), and Scottish Government priorities for 2018-2021^{142,143}
- Children and Young People Act (2014) and Education Act (2016)
- Adults with Incapacity Act (2000) and Mental Health Act (2015)

Northern Ireland

- Mental Health Order (1986) and Mental Capacity Act (2016)
- Autism Act (2011) and autism strategy (2013-2020)¹⁴⁴
- Education Act (2014)

Wales

- Welsh Autism Spectrum Disorder Strategic Action Plan (2008), and corresponding strategy for 2018-2021^{145,146}

published by Public Health England, and the most recent assessment was completed in 2018 by 92% of authorities.⁷⁰ The 2018 report showed that five of the eight assessed areas (service planning, staff training, diagnosis, provision of social care, and employment) had seen falls in ratings across England, compared with the 2016 report.⁷⁰

A report from the All-Party Parliamentary Group on Autism found that only 8% of autistic people and 5% of family members felt that health and care services had improved since the Autism Act.¹⁴⁷ While the Act has increased awareness of autism, many autistic people continue to have poor outcomes across health, social care, employment, and the criminal justice system.¹⁴⁷

Provision of services for autistic people

Autism places a large cost on services, and economic analyses have suggested that this cost can be reduced by providing effective support for autistic people and their families.^{148,149} This includes improving access to education and employment and treating co-occurring conditions.^{106,150}

Physical and mental health services

The Think Autism strategy: governance refresh (2018)¹⁵¹ and the NHS Long Term Plan (2019)¹⁵² both highlight the need to reduce early mortality in autistic people. In the UK, annual health checks are currently being developed for autistic people to increase detection of health conditions.¹⁵³ According to a recent report, a high proportion of people who are segregated

Box 3: Accessible and autism-friendly public spaces

There are many ways to increase public understanding of autism and provide inclusive spaces for autistic people. Example initiatives include:

- In 2017, the Houses of Parliament received an Autism Friendly Award.¹⁹² The parliamentary website provides information for autistic people visiting parliament for recreation and business.¹⁹³
- The “Please offer me a seat” campaign by Transport for London can help autistic people who struggle with sensory aspects of public transport.¹⁹⁴ Autistic people and their families may be eligible for a Blue Badge to access disabled parking spaces.¹⁹⁵
- Businesses such as cinemas and supermarkets can provide an Autism Hour by dimming lights and turning off music.¹⁹⁶
- Sensory or quiet rooms can provide a space for autistic people to manage sensory overload.¹⁹⁷

or detained in mental health institutions are autistic.¹⁵⁴ The NHS aims to reduce the number of autistic people in mental health hospitals, and improve mental health support for autistic people in the community.¹⁵² In 2019, the Department of Health and Social Care announced £1.4million of government funding to develop a new training package on learning disability and autism for health and social care staff, which would cover topics such as making reasonable adjustments and adapting communication styles.^{155,156}

There is a concern that medications that affect psychological functioning, such as anti-psychotics, are over-prescribed among autistic people.¹⁵⁷ Public Health England reported that autistic people and those with learning disabilities are more likely to be inappropriately prescribed these medications than the general population, and at higher dosages.^{158,159} The NHS launched a campaign to reduce over-prescribing in this group.^{160,161}

Research has shown that GPs¹⁶² and psychiatrists¹⁶³ self-report a lack of confidence in providing care for autistic patients. The Royal College of General Practitioners’ Autistic Spectrum Disorders Toolkit¹⁶⁴ provides guidance for practitioners to support autistic people and their families. Autism Alert cards inform people that someone is autistic and can be useful in medical or community settings.^{165,166} A group of autistic young people at Ambitious about Autism developed the Know Your Normal toolkit, which may help some autistic people identify and communicate changes in their health and well-being.^{167,168} There is consensus among stakeholders that understanding the health and social care needs of autistic older adults is an emerging area of priority.^{169–171,129}

Education

Autistic children and young people often need educational support, which works best when it is personalised to the individual.¹⁷² Autistic people can require additional support during transition between educational stages,^{125,127} including into further or higher education.¹⁷³ Across the UK, educational support is provided on a basis of needs (such as learning, communication, behaviour and sensory needs), and autism cuts across all of the main areas.¹⁷⁴ Preliminary data have suggested that autistic children are up to three times more likely than

children without special educational needs and disabilities (SEND) to be excluded from school.^{175,176}

The Children and Families Act (2014) and accompanying SEND code of practice (2015) aim to establish a multi-agency, person-centred system for addressing the needs of children and young people with SEND, with an emphasis on preparation for adulthood.¹⁷⁷ This includes Education, Health and Care plans for children with more complex needs. An inquiry from the Education Committee highlighted that many families continue to face barriers in accessing education provision and services,¹⁷⁸ and that there is variation in the extent of person-centred provision.^{156,172} In 2019, the government announced a review to evaluate and address implementation of these SEND reforms.¹⁷⁹

Employment

Research has suggested that autistic people have the lowest employment rates of all disability groups.^{126,147,180,181} In the 2018 autism self-assessment framework, employment showed the least improvement since 2016.⁷⁰ In 2019, the government made a commitment to record the number of autistic people in employment across the UK via the Labour Force Survey.¹⁸² Many autistic people can and do work,¹⁸⁰ but face barriers in employers’ understanding of autism and lack of reasonable adjustments.^{181,183} The Department of Work and Pensions and the Autism Alliance produced an Autism and Neurodiversity Toolkit,¹⁸⁴ which promotes awareness and understanding of autism and other neurodevelopmental conditions in the workplace. Research suggests that tailored support can reduce pre-university anxiety¹⁷² and improve graduate employment.¹⁸⁵

Criminal justice system

It is estimated that autistic people are up to seven times more likely than the general population to be involved in the criminal justice system, as a victim, a witness or a defendant.^{186–189} Poor understanding and accommodation of autistic people’s needs can cause negative experiences in the justice system.^{187,190} Researchers have recommended that autism training be provided to all frontline police officers and other staff such as the public prosecution services.¹⁴⁷ The custody environment could be adapted to better meet the sensory needs of autistic people – such as, providing a quiet area, and use of communication aids.¹⁸⁹

Access and inclusion

Stakeholders recognise the importance of including autistic people and their families in delivering policies and services for autistic people,^{83,85,156} and increasing understanding of autism amongst the general public (Box 3). Further recommendations from stakeholders¹⁴⁷ to improve outcomes for autistic people include:

- Establishing well-resourced specialist autism teams in each local authority.¹⁴⁷ One model that worked well in Scotland was a comprehensive One Stop Shop for diagnosis, information, and support for autistic people of all ages, support needs, and their families.^{121,191}
- Training, which is led by autistic people, be delivered across sectors, including social care and education.¹⁵⁶

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