



## IHPE Position Statement: Autism

### KEY INFORMATION

1. **Autism** is estimated to affect 1% of people globally. According to the World Health Organisation this is approximately 1 in 160 people. There is a lack of accurate prevalence data in many countries, particularly low- and middle-income ones.
2. Globally there is currently said to be a 1:4 ratio between males and females. Girls and women may present differently, and their autism is less likely to be recognised. There is also under-recognition in children from **ethnic minorities**. In the UK the numbers of people identified as autistic are increasing exponentially, especially in females and adults.(Russell *et al.*, 2021) About 4 in 10 people in the UK with autism also have learning difficulties.
3. '**Autism** is a lifelong developmental disability which affects how people communicate and interact with the world.'(National Autistic Society) As difficulties are not always visible externally, autism can be a **hidden disability**.
4. Autism is one form of **neurodiversity**. Variations in brain function exist which lead to different ways of thinking and behaving.
5. Autism can be associated with **strengths in learning and retaining information** for long periods of time and in visual, spatial, and auditory processing. Autistic people are often systemisers, adept at paying attention to detail, and may excel in maths, science, music, or art.
6. Autism is often misunderstood to comprise a spectrum of severity. However, '**spectrum**' refers to the wide variation in **both** the type and severity of difficulties people experience. These include combinations of behaviours which differ considerably from person to person and begin in early childhood.
7. Children and young people with autism are disproportionately at **risk of exclusion** from school, compared to other pupils.

8. The **Diagnostic and Statistical Manual of Mental Disorders (DSM-5)** lists diagnostic criteria under Autistic Spectrum Disorder (ASD), which now includes Asperger's syndrome. Previously Asperger's was listed separately to refer to those with autism without intellectual disability. Severity is determined by the level of support needed to enable people to function in daily life. Characteristics assessed include:
  - social communication/interaction behaviours
  - restrictive/repetitive behaviours
  - under or over-sensitivity to sound, smells, light, taste, touch and/or temperature.
9. Autism is associated with higher levels of **mental ill health** including anxiety, depression and eating disorders. These can arise from the negative experiences of living with autism, including meeting societal demands, and are frequently under-recognised or under-acknowledged. Coping with the Covid-19 pandemic has been especially challenging for autistic people.
10. Public Health England has reported that people with autism, a learning disability, or both, are being prescribed antipsychotics, antidepressants, anxiolytics, anticonvulsants, and/or sedative medication without appropriate clinical justification. **Overuse of psychotropic medicines** exposes people to unnecessary adverse effects such as tiredness, feeling 'drugged up,' and weight gain, which can have a negative impact on both mental and physical health.
11. Many **causes** have been proposed over the years but understanding of causation is incomplete. Studies have shown a strong genetic link, although other factors influence the expression of autism in daily life.
12. Only '16% of autistic people and their families in the UK think the public **understand autism** in a meaningful way.'(National Autistic Society) Globally levels of awareness can be very much lower, and autism is often **stigmatised**.
13. Only 22% of adults in the UK with autism are in any kind of employment.(Office of National Statistics)
14. **Support for parents** is crucial:
  - to understand autism and their children's' needs
  - access resources
  - protect their own mental health.
15. The IHPE is aware that there are debates about the **appropriate language** to use in discussing this subject, some individuals and organisations prefer 'autistic people' whereas others prefer 'people with autism'.

# STATEMENT

## General Points

1. The IHPE recognises the lack of agreement on preferred terminology. Given the dominant use of the terms 'autism' and 'autistic,' and a strong preference of autistic people for the use of 'autistic' these two terms will mainly be used in the statement. When referring to specific documents and contexts the statement adopts the terminology used in them.
2. The IHPE recommends that autism should be accepted as a **difference** rather than a pathological disorder to be treated. Greater use of the terminology **autistic spectrum condition** and/or **neurodiverse/neurodiversity** and the cautious use of the word disability, are therefore recommended.
3. There needs to be broader education in all countries to **raise awareness and understanding** of autism and its potential strengths and difficulties. Discrimination towards autistic people must be challenged.
4. **Inequalities** in identifying and supporting autistic children and adults must be addressed. These apply to gender, ethnicity, and geography, both national and international. Support is needed to expand the development of assessment and support structures in most low- and middle-income countries.
5. The **UK Autism Strategy** (July 2021) has been updated and extended to cover children and young people. The strategy is wide ranging and welcomed but implementation must be adequately resourced. It will be important to monitor the achievements in line with stated goals for each of the next 5 years. <https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026>.
6. **Autism awareness training** should be made available for education, health, social care, police officers, and other professionals.
7. **Adequate funding** is required to ensure that service provision can meet need. Any post-Covid cuts in resources for all people with additional needs, including autism, must be challenged.
8. **Environments** need to take in the needs of neurodivergent as well as neurotypical people. Everyone has a responsibility to gain an understanding of autism and the adjustments which can be made to ensure environments are 'autism friendly,' taking into account **sensory difficulties** such as lighting, noise and odours, which can cause considerable discomfort.
9. **Autistic self-advocacy** needs to be encouraged across ages and settings. Autistic people, and their families, should be involved in any consideration of provision of services, as they are the experts.
10. Inability to attend work or school due to fatigue, anxiety and/or challenging behaviours may result from **hidden internal difficulties**. It is therefore essential for **individual needs** to be understood and **nurturing space** given

for them to be communicated, including the involvement of parents or carers who can observe traits in children in the home environment.

### **Health Promotion and Health Care**

11. The IHPE recommends **increased training** for all professionals working with children and young people, to enable them to identify autistic traits, including sensory processing difficulties, which can be detected as early as 2 years of age. Health visitors have a crucial role and additional resources could increase their capacity to screen specifically for autism alongside developmental checks.
12. GPs, health visitors, educational and clinical psychologists, teachers, and other professionals need to recognise children who may be autistic as early as possible. **'Masking'** or **'camouflaging'** as a barrier to identifying both autism and any associated distress needs to be recognised and children promptly assessed and supported.
13. A **person-centred approach** to both diagnosis and management is recommended.
14. When children are diagnosed/identified as autistic the support needs of the **whole family** need to be met and carers introduced to local services and support groups. There are concerns about an institutional culture of 'parent blame,' and there is a need to work with and **support parents** <https://cerebra.org.uk/research/institutionalising-parent-carer-blame/>.
15. The IHPE recommends further research into **mindfulness** as a support for families of neurodiverse children.
16. **Psychotropic medicines** need to be used with caution, over-medication avoided, and regular reviews undertaken. See 'stopping over medication of people with a learning disability, autism or both.' (NHS England 2021, STOMP)
17. **The health inequalities** experienced by autistic people must be addressed.
18. The full adoption of the concept of **health promoting settings** (Thompson *et al.*, 2019) should ensure that autism is recognised and provided for. Accessible approaches need to be adopted in specific interventions, including healthy eating and physical activity.
19. **Expansion of access to creative arts** is needed, including music, art, writing and drama therapy. For example, projects such as those offered by the National Theatre, involving actors who define themselves as neurodivergent and with performances adapted to meet neurodivergent needs.
20. **Playgrounds** need to include sufficient opportunities for all children and not rely entirely on equipment that demands turn taking which can be difficult for autistic children.

## Education and Autism

21. Schools should have an **inclusive ethos** and a focus on what is in the **best interests of each individual**, with support and adaptation, rather than separation and isolation of autistic individuals. Further research is needed into the circumstances and outcomes of exclusions from school.
22. There is no 'one size fits all' in enabling autistic children and young people to achieve their potential. To flourish in mainstream education at secondary level many will need **additional support** for this **special educational need**; for example, in moving around the environment, access to quiet spaces, tools to aid coping with lesson changes throughout the day and **funded in-class support**.
23. The IHPE, in collaboration with experts in education, recommends moving to an **assets-based** approach for every child, identifying strengths, rather than the use of the current deficit model, which focusses on difficulties.
24. **Specialist units or personalised home education** may be preferred options for part of, or the whole school day, focussing on individual strengths, needs and with flexible pacing. A **flexible schooling approach**, or part-time attendance, may help to maintain connection with the education system, reducing the need to resort to full time Elective Home Education (EHE). Any changes to EHE should continue to allow for flexibility and prioritise mental health.  
<https://committees.parliament.uk/publications/6974/documents/72808/default/>.
25. **Attendance pressure** can make it difficult for schools to support families adequately. The rights of adults to be 'signed off sick' from work by their GP should equally apply for school children. There needs to be awareness of how school can be a traumatic environment for autistic children  
<https://inews.co.uk/news/real-life/carrie-david-grant-tylan-hollyoaks-autism-children-spectrum-aspergers-1162962>. The description '**school attendance barriers**' is preferred to more frequently used '**school refusal**'.

## Workplace

26. Workplaces need to recognise the **strengths** which autistic people can bring to the workplace, should adopt **inclusive policies**, and make reasonable adjustments to enable full functioning.
27. Full attention needs to be given to increasing the percentage of autistic adults who are in full or part time paid **employment**. Country-specific targets need to be set.
28. The recommendations in the **National Strategy for England**, UK (2021) on employment of autistic people need to be adopted, funded and progress measured. These are widely applicable.
29. The Autism Society in the UK offers guides and **online training** for employers and support materials for autistic people in the workplace:  
<https://www.autism.org.uk/advice-and-guidance/topics/employment/>

## **Criminal Justice System**

30. Autism can increase **vulnerability** to becoming a victim or witness of crime and police officers must consider whether any unusual behaviour may result from neurodiversity. A concise, informative guide can be found here: <https://www.autism.org.uk/advice-and-guidance/topics/criminal-justice/criminal-justice/professionals>.
31. Informed, inclusive procedures must be in place when approaching autistic offenders, to **prevent further harm**. In court appearances, access to an intermediary may be needed to ensure a level playing field for all.
32. In health promotion provision in custodial settings the **needs of autistic prisoners** need to be recognised and provided for.

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## **General Reading**

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## **Further Resources and Organisations**

Australian charity with a mission for the autistic community to be included, embraced, and valued.

<https://reframingautism.org.au/about-us/>

Campaign for policy change for autistic children and young people.

<https://www.ambitiousaboutautism.org.uk/what-we-do/policy-and-campaigns/position-statements>

Courses offered by the British Psychological Society.

<https://www.bps.org.uk/news-and-policy/three-adult-autism-awareness-e-learning-modules-relaunched>

Events, animations, webinars, books.

<https://thegirlwiththecurlyhair.co.uk/>

Global non-profit organisation, raising awareness and support for Autism communities, including in Africa, Armenia, and Pakistan.

<https://www.icare4autism.org/about-us>

Independent Provider of Special Education Advice (IPSEA,) for young people with SENDs.

<https://www.ipsea.org.uk/>

On-line community for autistic young people.

<https://www.spectrumgaming.net/about-us>

Registered charity supporting home educating parents in England and Wales.

<https://www.educationotherwise.org/>

Support and resources for parents of children who are struggling in school.

<https://notfineinschool.co.uk/>

Support, advice, and services for children with autism.  
<https://www.childautism.org.uk/>

Support, education and change for girls.  
<https://autisticgirlsnetwork.org/>

Parent-led resources and information.  
<https://www.specialneedsjungle.com/>

The All-Party Parliamentary Group on Autism (APPGA.)  
<https://www.autism.org.uk/what-we-do/campaign/england/how-we-work-with-parliament/all-party-parliamentary-group>

The Autism Society of America, including national position statements.  
<https://www.autism-society.org/public-policy/national-position-statements/>

The Centre for Personalised Education.  
<https://www.personalisededucationnow.org.uk/>

The National Autistic Society, UK.  
<https://www.autism.org.uk/>

The Special Educational Needs and Disabilities Information Advice and Support Services (SENDIASS) for parents, carers, and young people.  
<https://www.kids.org.uk/sendias>

United Nations articles on autism.  
<https://news.un.org/en/tags/autism>

Workshops and resources for autistic children, their families, and schools.  
<https://www.jodiesmitten.co.uk/>

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