



BELS
Barnet Education
& Learning Service



Barnet Autism Position Statement

Recommendations from the Leading Edge Group



1. Being Autistic

Being Autistic is a lifelong difference impacting the way individuals communicate, interact and process information, including sensory information.

Being Autistic brings positives as well as challenges, and for Autistic people to reach their potential it is essential that they are supported appropriately.

Autistic people have a range of strengths but can also experience difficulties and may have additional support needs. Some have learning disabilities, additional mental health needs and other co-occurring conditions¹. In Barnet we aim to match support to the needs of the individual.

There is no 'cure' for being Autistic. Most Autistic advocates and their allies argue that resources should be used to improve the lives of Autistic people, not to change them.

Only Autistic people understand what it is like being Autistic. Professionals across all disciplines should endeavour to be educated and informed by Autistic people.

It is important that professionals engage with and listen to, people with lived experience. That means Autistic people and their families and those that are important to them.



¹ National autistic society



2. Terminology

In Barnet, identity-first language ('Autistic person' rather than 'person with autism') will be used throughout in accordance with preferences stated by the Autistic community².



Many Autistic people find the term Autistic Spectrum Disorder (ASD), or Autism Spectrum Condition (ASC) “over medicalised” and negative. We recognise that medical diagnosis currently requires that the term Autistic Spectrum Disorder (ASD) be used.

The terms 'Autistic', 'Autistic experience' or 'autism' or whichever is preferred by the individual, should be used³.

Positive accurate descriptions of autism support individuals and their families to accept their diagnosis, acknowledge its advantages and recognise their support needs.

Therefore, we encourage professionals to qualify what the diagnosis means using descriptors written by Autistic people and based on research co-produced with the community.

² Kenny et al. 2016

³ How to talk about Autism



3. Functioning Labels

Historically, Autistic people have been described using the “functioning labels” High and ‘Low Functioning, based on cognitive skills often measured by standardised IQ tests⁴. Standardised IQ tests were not designed to measure autistic cognition and are therefore misleading.

Many Autistic people, their families, people important to them and professionals find these labels inaccurate, misleading, and offensive.

The abilities of some people have been historically underestimated and misunderstood because they are non-speaking. The support needs of others are not understood because they are academically able.

We recommend that accurate descriptions of the individual’s strengths, difficulties and their support needs/profiles are used, rather than “functioning labels”.



⁴ <https://www.spectrumnews.org/news/iq-scores-not-a-good-measure-of-function-in-autism/>



4. Presentation and Identity

Autistic individuals have unique profiles and presentations. It is important to understand the individual, their family, culture, gender identity and sexuality.

Some people will actively hide or “mask” being Autistic.

Masking, which is also called camouflaging or compensating, is a social survival strategy. Some people will attempt to hide being Autistic at a significant cost to their wellbeing.

Unique profiles and presentations of being Autistic and masking have been associated with misdiagnosis and underdiagnosis of individuals.

It is now recognised that girls and women have been significantly underdiagnosed and that their experience is often misunderstood.

Varied presentation and masking are also prevalent amongst boys/ men and non-binary people and can lead to underdiagnosis and misdiagnosis.

Some Autistic people’s needs are overlooked because they mask or do not conform to a stereotypical description of autism.

The experience of Autistic people of colour/Black, Asian and minority ethnic people⁵ can differ significantly, and their experience is under-represented in research. Also, experience related to diagnosis is varied. For example, one recent study⁶ reported the prevalence in Black pupils was higher than that of the average of all school age pupils in state schools while the lowest was in Gypsy/Roma/Travellers⁷.



⁵ [Survey finds ‘BAME’, ‘BME’ and ‘Ethnic Minority’ not representative - NHS - Race and Health ObservatoryNHS – Race and Health Observatory \(nhsrho.org\)](#)

⁶ Roman-Urrestarazu A, van Kessel R, Allison C, Matthews FE, Brayne C, Baron-Cohen S. Association of Race/Ethnicity and Social Disadvantage With Autism Prevalence in 7 Million School Children in England. *JAMA Pediatr.* Published online March 29, 2021. doi:10.1001/jamapediatrics.2021.0054

⁷ [Tackling inequalities faced by Gypsy, Roma and Traveller communities - Women and Equalities Committee \(parliament.uk\)](#)



5. Strategies, support, interventions, and services should be individualised and personalised

There is no universal way to work with Autistic people. There is no “one-size fits all” approach.

Each Autistic person is a unique individual with unique abilities and needs. The most effective interventions are tailored to meet the unique characteristics of each individual.⁸

How to design strategies, support, interventions, and services in a tailored way to meet the unique needs, abilities, and characteristics of Autistic people:

- Work in partnership and collaboratively with Autistic people, families/those that are important to them, professionals, and educational settings to create support and strategies.
- Utilise strengths and interests⁹ that are an important element of ¹⁰Autistic cognition, rather than focusing on perceived weaknesses and absence of skills.
- Build local expertise and communities of practice, drawing upon multi-disciplinary expertise but place the Autistic person at the centre of considerations¹¹.
- Anxiety and stress are frequently experienced by Autistic people. Interventions and strategies should not increase anxiety. Support should be available to reduce and prevent stress and anxiety. A variety of strategies



⁸ Research Autism, 2015

⁹ Damian Milton

¹⁰ <https://www-sciencedirect-com.libproxy.ucl.ac.uk/science/article/pii/S1364661321000899>

(Research paper Francesca Happé, Will Mandy et al. 2021)

¹¹ Damian Milton



should be offered which include the Autistic persons views and those of their parent/carers.

- Ongoing support should be available to help Autistic children and young people to manage anxiety and stress.
- Sensory differences and difficulties are prevalent amongst Autistic people. Sensory needs should be recognised, and changes should be made in the environment to improve accessibility and reduce discomfort and distress.
- Social communication can look different amongst Autistic people. It is beneficial to develop mutual understanding so that Autistic people and non-Autistic people understand each other, rather than promoting only one style of social communication.
- Not all Autistic people develop reliable speech. Access to effective communication systems is essential to support well-being, academic achievement, autonomy, and access to medical support.



6. We do not recommend supporting the use of:

- Approaches based on solely behaviourist principles.
- Approaches that aim to make the individual be or appear “less Autistic”.
- Approaches that prohibit the use of harmless effective stress relief e.g., stimming, or that promote masking (see below). Stimming is a self-regulatory behaviour. Many stims are comforting and have a positive outcome. Where stimming is harmful to the individual or other this should be addressed

Stimming, or self-stimulatory behaviour includes arm or hand-flapping, finger flicking, rocking, jumping, spinning, or twirling, head-banging and complex body movements (and many more).

It includes the repetitive use of an object, such as flicking a rubber band or twirling a piece of string, or repetitive activities involving the senses (such as repeatedly feeling a particular texture).

(National Autistic Society)

- Diets to ‘treat’ the characteristics of being Autistic (e.g. social communication or sensory and repetitive behaviours).
- We follow the NICE guidelines that the following interventions **should not** be used for the ‘treatment’ of autism¹²:
 - Neurofeedback
 - Auditory integration training
 - Omega-3 fatty acids
 - Secretin
 - Chelation
 - Hyperbaric oxygen therapy

¹² [Recommendations | Autism spectrum disorder in under 19s: support and management | Guidance | NICE](#)



- We also recommend that Autistic people and their families/caregivers/people important to them are cautious and learn how to spot fake and potentially harmful ‘treatments’ for autism¹³.

From Damian Milton’s recommendations:

“...right from the start, from the time someone came up with the word ‘autism’, the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced”

(Williams, 1996: 14) Source: Damian Milton



- We do not use dangerous restraint methods. Forced seclusion should be seen as a disciplinary offence.
- Rather than focusing on perceived weaknesses and absent skills, utilise strengths and interests.
- Building local expertise and communities of practice, drawing upon multi-disciplinary expertise, but places the neurodivergent person at the centre of considerations.

¹³ Fake and harmful autism 'treatments' - NHS (www.nhs.uk)

7. Recommendations

- We recommend that professionals and parents and carers have access to information and regular training about the different presentations of autism.
- Autistic people should not be compelled or encouraged to mask.
- School's anti-bullying policies should recognise that autistic people are at significant risk of being bullied. This can contribute to the "need" for individuals to mask and hide being Autistic.



<https://www.purpleella.com/>

“The mask I use to hide my autism is for your comfort not mine. It causes me overstimulation, exhaustion and a deep sense that who I am underneath isn't good enough. Before I perfected my mask I was too much, or too little. Too much on my noisy days, too bouncy and intense. Too little on the days when I can barely communicate and just want to sit silently. Autistic people sometimes mask, do you really need us to do that?”

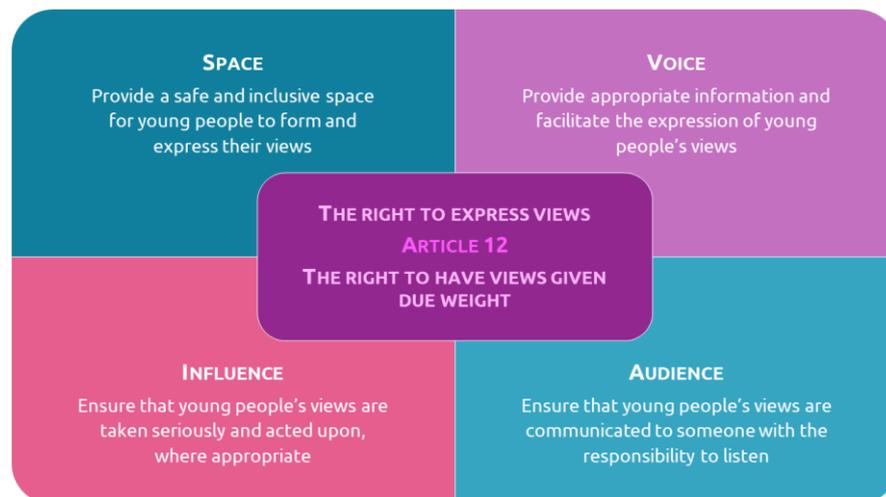
Purple Ella



8. Positive about Autism

We recommend:

- Early intervention and support for children and young people is crucial. The earlier medical and educational services become involved the better the outcomes for Autistic children and young people.
- Seek the views of Autistic children, young people, and adults by creating a safe space and facilitating the use of appropriate materials. Listening to their views and honouring Autistic children, young people and adult voices by ensuring that their views are taken seriously and acted upon.



The Lundy Model of Child Participation

- All staff working with Autistic children and adults have regular positive realistic and up-to-date training about Autistic experience.
- That training from Autistic trainers is made available to professionals and families.
- That schools are supported to run assemblies and events developing understanding, acceptance and celebrating Autistic identity regularly.
- That there is support and training for families about Autistic experience.
- That there are Barnet-based cultural events celebrating being Autistic/Autistic experience.



9. Support

In Barnet we aim to match support to the needs of the individual.

Preschool children are supported by the Barnet early Autism Model (BEAM) Team¹⁴.

In Barnet support is provided at mainstream schools, special schools, and specialist autism resourced provisions (ARPs) in mainstream primary and secondary schools.

Mainstream schools, colleges and ARPs are supported by the Autism Advisory Team¹⁵.

¹⁴ <https://www.barnetlocaloffer.org.uk/pages/home/information-and-advice/early-years/barnet-early-autism-model-beam>

¹⁵ <https://www.barnetlocaloffer.org.uk/organisations/27110-autism-advisory-team-lb-barnet?term=Autism+advisory+team>