

# **Autism**

# Position Statement March 2025

# **Summary**

The British Dietetic Association's (BDA) Autism Specialist Sub-Group aims to promote excellence in nutrition and dietetic practice in supporting health and wellbeing in autistic children, young people and adults.

At least 1% of us are autistic (1). Autistic people experience stigma, health inequalities and poorer life outcomes (2). Autistic people die up to 15 years earlier than non-autistic people, are twice as likely to die from any nutrition-related cause, and are nine times more likely to die by suicide (3).

#### These issues are preventable. We all have a responsibility for redressing the balance.

This position statement was written by Zoe Connor, Paediatric Dietitian and Resource Officer of the BDA Autism Specialist Sub-Group and reviewed by all members of the committee. It sets out guidance for improving dietetic practice focused on inclusion and anti-discrimination of autistic people in line with the BDA Code of Professional Conduct (4), Health and Care Professions Council professional standards (5), and various UK governmental guidance (2) including the Autism Act (England) 2009, the Autism (Amendment) Act (Northern Ireland) 2022 (6), the Learning/intellectual disability and autism: transformation plan (Scottish Government) 2021 (7), and the Code of Practice on the delivery of autism services (Welsh Government) 2021 (8).

This statement is primarily aimed at the nutrition and dietetic workforce (comprising of student nutritionists and dietitians, apprentices, support workers, assistants, nutritionists and dietitians). It may also be of interest to other health and care professionals, commissioners and the wider public to highlight the need for dietitians to be involved in the provision and planning of all services that support autistic people.

#### Recommendations for the nutrition and dietetic workforce

- 1. Be neurodivergence-affirming. This involves:
  - Examining your own knowledge, skills and biases related to supporting autistic individuals and seek out training and supervision to fill any knowledge and skill gaps.
  - b) Adjusting services to maximise accessibility to autistic people—this is best done by consulting with their autistic service users.
  - c) Ensuring that communications are accessible, inclusive, and respectful of autistic people—this includes social media posts, media articles, diet sheets, information videos etc.
- 2. Actively tackle discrimination towards autistic people from colleagues, services, and institutions.

# **Background**

#### **Autism**

1-3% of us are autistic, many suspect the true figure is much higher (1). Autism encompasses the diagnosis 'autistic spectrum disorder' (9,10) and similar diagnoses that previously fell under the autistic spectrum umbrella e.g. Aspergers syndrome.

Autism is defined by autistic scholar Dr Nick Walker as:

"a genetically-based human neurological variant. ... Autism produces distinctive, atypical ways of thinking, moving, interaction, and sensory and cognitive processing. One analogy that has often been made is that autistic individuals have a different neurological "operating system" than non-autistic individuals.... Despite underlying neurological commonalities, autistic individuals are vastly different from one another. Some autistic individuals exhibit exceptional cognitive talents. However, in the context of a society designed around the sensory, cognitive, developmental, and social needs of non-autistic individuals, autistic individuals are almost always disabled to some degree – sometimes quite obviously, and sometimes more subtly." (11)

# **Neurodiversity and neurodivergence**

**Neurodiversity** is "the diversity of human minds, the infinite variation in neurocognitive functioning within our species", we are all therefore neurodiverse (12). **Neurodivergence** is

however a term that encompasses the 15-20% of people whose neurotype differs from those who are **neurotypical** (i.e. the prevailing norm) (13). **Neurodivergence includes autism** and a variety of other conditions such as but not limited to attention deficit hyperactivity disorder (ADHD), epilepsy, bipolar, depression, anxiety, downs syndrome, acquired brain injury (ABI), developmental trauma, dementia, dyslexia, intellectual disability (also known as a learning disability).

Many autistic people are **multiply neurodivergent**: up to 70% also have ADHD (14), up to 50% have anxiety disorders, and up to 45% have post-traumatic stress disorder (PTSD) (15). Up to 30% of autistic people also have an intellectual disability. 20% of autistic people speak few or no words (but may communicate in other ways) (15).

#### **Health inequalities**

Improving the health and wellbeing of autistic children and young people (CYP) and adults is a priority worldwide (16). Autistic people have an increased risk of many preventable nutrition-related conditions including vitamin and mineral deficiencies, dyslipidaemia, hypertension and type 2 diabetes; and die up to 15 years younger than the general population (3,17–19).

# **Barriers to accessing care**

Reduced access to prompt and appropriate health care contributes to the inequalities experienced by autistic people. 74% of autistic adults experience difficulties in accessing health care, and 88% feel that health professionals fail to understand their health needs (20). 24% of autistic people and their families are unable to access feeding, nutrition and dietary help via the NHS and of those who do, 77% don't find it useful (21).

Autistic adults identify various difficulties in accessing care: being unsure if symptoms warrant help, difficulty making appointments by telephone, not feeling understood, difficulty communicating and uncomfortable waiting room environments (22).

#### **Suicide**

Preventing suicide in autism is a public health priority. Autistic adults are nine times more likely to die from suicide than non-autistic adults. Autistic children are 28 times more likely to think about or attempt suicide (23). Late-diagnosed autistic women are a high-risk group. Red flags for suicide risk are different in autistic people and **disclosure of suicidal thoughts should always be taken seriously** even if the person doesn't seem otherwise depressed. The following have been preliminarily identified as useful to suicide prevention:

promoting **feelings of belonging, connectedness, and self-worth**. Risks are feeling socially disconnected and feeling like a burden (24).

## Intersectionality

Intersectionality refers to the additional, and often multiplied, disadvantage that people with multiple marginalised identities face (25,26).

#### Gender and sexuality

At least three times more boys than girls receive autism diagnoses. This ratio is decreasing as recognition of differing gender presentations grows (27). Autistic people are more likely to be trans or non-binary/agender/gender fluid than non-autistic people, and more likely to be gay or bisexual or otherwise non-heterosexual (28). Trans autistic people are more likely to be depressed or anxious than cis autistic people (29).

#### Race/ethnicity

Levels of autism are consistent across different ethnic groups however rates of diagnosis differ across groups in the UK—reflecting barriers to recognition and access to diagnosis. Early diagnosis and support are more often missed in children whose families don't speak English as a first language. Children from Asian families and Traveller/Roma families have lower rates of diagnosis. Families of children from Black and minority ethnicities report difficulty accessing diagnosis and support. Experiences of Black and minority ethnic group autistic adults are poorly researched (30).

## Diet, nutrition and eating behaviours

Standard government healthy eating advice and nutritional requirements apply to autistic people. However, many autistic people have eating differences that can be barriers to eating a varied diet. Many dietary and diet-related problems are more common in autistic people than in non-autistic people, including:

- Feeding problems in young children (five times more common than in non-autistic children) (31)
- Feeding and eating disorders such as anorexia nervosa and avoidant restrictive food intake disorder (ARFID). Up to half of ARFID patients may be autistic (32) and up to a third of those with anorexia nervosa (33,34).
- Gastrointestinal problems (four times more common) (35)
- Diabetes (type 2 only)
- Hyperlipidaemia in adulthood (twice as common) (37)
- Food allergy or intolerance (twice as common) (38)

Around four in five autistic children and young people have eating differences—most commonly limited food preferences, hypersensitivity to food textures, accepting only one brand of a preferred food, pocketing food without swallowing, and pica (32).

Autistic people are at higher risk of nutrient deficiencies. Numerous cases of limited diets leading to scurvy and severe nutrient deficiencies, blindness and near death have been published (39,40). The judiciary report into the death of autistic seven-year-old Alfie Nicholls in 2021 in Manchester highlighted that he died of undiagnosed ARFID and related malnutrition (41).

Eating differences leading to imbalanced diets are likely to contribute to the increased prevalence of dietary problems alongside the physical toll that stress, anxiety, and trauma can take on the body. Eating differences are typically driven by sensory perception differences (42,43), executive functioning differences and cognitive rigidity (44).

#### **Neurodivergence-affirming practice**

Being neurodivergence affirming (or neurodiversity affirming, ND affirming or neuro affirming) involves seeing neurodivergence through a 'strength-based' lens, as a brain difference, rather than something that needs 'fixing'. It is aligned with the social model of disability, i.e. that a disability results from societal barriers, rather than a person's impairment or difference.

Neurodivergence-affirming practice promotes the self-esteem and agency of autistic or otherwise-neurodivergent people (45–50). Being neurodivergence affirming is key to making services more inclusive and reducing health inequalities. For example, neurodivergence-affirming care might involve:

- Avoiding ableism (discrimination in favour of non-disabled people i.e. non-autistic people).
- Avoiding approaches that are harmful to autistic people.
- Being trauma-informed.
- Creating inclusive services for all.
- Accommodating a variety of communication styles and modes.
- Embracing and validating difference (including eating differences where they don't cause harm).
- Encouraging unmasking (i.e. being themselves), stimming (various self-stimulation activities like rocking, fidgeting), not insisting on eye contact or indeed face-to-face contact.
- Exploring the unique strengths and needs of each autistic individual.

- Indicators (e.g., in emails, websites, name badges) that you are neurodivergence-affirming.
- Listening to and amplifying the voices of autistic people as experts by lived experience.
- Reasonable adjustments.
- Understanding differing sensory needs to ensure sensory safety.
- Use of preferred language

Neurodivergence-affirming dietetic support in clinical practice involves accommodating eating differences wherever possible whilst also avoiding diagnostic overshadowing i.e. dismissing feeding problems as 'just autism'. Effective management of eating problems in autistic people is likely to need interdisciplinary individualised multi-modal support for underlying psychological, social and medical issues, as well as for executive functioning, oro-motor and sensory processing differences.

### Reasonable adjustments

Autistic people are entitled to reasonable adjustments under the Equality Act 2010 (England, Wales, Scotland) and the Disability Discrimination Act 1995 (Northern Ireland) i.e. services should take steps to ensure autistic people can use the same services as non-autistic people (51). Best practice is to design services flexibly and offer everybody adjustments autistic service users might need e.g., providing a list of possible adjustments to choose from in advance. Caregivers and family members of autistic people, or non-autistic service users may also be autistic and need their own accommodations. Examples are:

- Clear, unambiguous information.
- Clear information about what a meeting will involve in advance.
- Flexibility in timing, location, and length of meetings (as a rule allow at least double time and double the number of episodes for autistic people).
- Flexibility in mode of meetings e.g. video or phone calls, emails, texts, face-to-face, home visits.
- Supporting verbal information with written/visual information.
- Awareness of changes to the environment to meet sensory needs e.g. a quiet waiting room, dimmed lighting, frequent breaks.

# **Preferred language**

Language matters, studies have linked use of person-first language to increased self-harm in autistic people (52). Preferred language of the majority of autistic people is in the table below (53,54).

Do say/use	Don't say/use (unless an autistic individual
	expresses these are their preferred terms)
Autistic person, being autistic (identity-first	Person with autism, having autism, (person-
language)	first language), being 'on the spectrum'
Infinity rainbow 'autistic pride' symbol	Puzzle pieces as an autism symbol
Autism as a normal part of neurodiversity	Autism as a disorder
Differences e.g., sensory differences,	Deficits or disorders e.g. sensory disorder,
communication differences	communication disorder
Specifying individual support needs	High/medium/low functioning
	Mild/severe autism
	Growing out of autism
	'Everyone is a bit autistic'
A neurodivergent person. Autism is an	A neurodiverse person (we are all
example of neurodivergence.	neurodiverse).

# **Summary**

This position statement supports guidance from across the four nations that aims to improve the lives of autistic people and sets out mandatory training in autism for health professionals and other public service providers (6–8,55).

The nutrition and dietetic workforce have an important role in supporting the health and wellbeing of autistic people through evidence-based and neurodivergence-affirming support for eating and drinking difficulties, as well as in training others that support autistic people. All workers must ensure they are adequately trained to best support autistic people, address poor satisfaction with existing care, and raise concerns when needs are not met.

The nutrition and dietetic workforce should be proactive in promoting neurodivergence-affirming, trauma-informed, inclusive and equitable care and services for all, whether that is within policy, research, management or front-line health.

#### **Useful links**

• BDA Autism Specialist Sub-Group

# Training frameworks (setting out what health professionals should know)

- Core capabilities frameworks for supporting autistic people and/or people with a
  learning disability (relevant to those working in any sector and all staff working across
  health and social care)
- National autism training framework Wales
- NHS Education for Scotland autism training framework

# Reasonable adjustments

- NHS guidance on accessible digital content
- Beyond reasonable adjustment: autistic-friendly spaces and Universal Design
- Dos and don'ts for digital accessibility

# **Training**

- NHS England autism training directory
- NHS Education for Scotland autism resources (free for all)
- Oliver McGowan mandatory training on autism and learning disabilities (e-learning component free for all)

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This document has been prepared by the committee of the BDA Autism Specialist Sub-Group, some of whom are autistic. We recognise that language preferences are evolving. We welcome feedback on this document: <a href="mailto:autism@bda.uk.com">autism@bda.uk.com</a>. The statement is due to be reviewed by March 2027.