

# BODYWHYS

The Eating Disorders Association of Ireland

## **Submission - Autism Innovation Strategy**

Founded in 1995, Bodywhys – The Eating Disorders Association of Ireland - is the national voluntary organisation supporting people affected by eating disorders and their families. We provide a range of non-judgemental listening, information, and support services, as well as school talks, training, literature, and webinars. Other aspects of our work include developing professional resources and collaborating with social media companies to respond to harmful online content. Bodywhys is the support partner to the HSE's National Clinical Programme for Eating Disorders (NCP-ED). Bodywhys welcomes the opportunity to address the Autism Innovation Strategy.

### **Eating disorders and autism**

There is a significant relationship between autism and eating disorders.<sup>1,2,3,4</sup>

Estimates from the Pathway for Eating disorders and Autism developed from Clinical Experience (Peace Pathway) in the United Kingdom suggest that 35% of people experiencing eating disorders may be autistic.

In March 2021, Bodywhys and the Psychological Society of Ireland (PSI), delivered a live webinar 'Autism and Eating Disorders Across the Lifespan',<sup>5</sup> which over 300 people attended.

Bodywhys receives support requests from both autistic people experiencing eating disorders and family members. Anecdotal feedback from a survey undertaken by Bodywhys in partnership with AsIAM in April 2022 suggests that autistic people

experiencing eating disorders and their families can experience a number of challenges, including a lack of joined up thinking, feeling excluded from services, a lack of meaningful and specialised services, feeling passed on from one service to another, a lack of knowledge and understanding amongst clinicians and that traditional eating disorder treatments may be less effective when someone is autistic.

Suggested strategies from survey respondents include support for those unable to support themselves, support for parents and carers, tailored and designed to a person's needs and circumstances, that a person feels listened to and heard, experienced and accessible staff, good communication from services, collaboration between services, education of professionals and practitioners and not using preconceived understandings of autism.

Whilst Bodywhys can play a role in responding to some aspects of people's support needs, and raising awareness, a comprehensive approach to autism and eating disorders is needed in the Irish context.

It is essential:

- That autistic people experiencing eating disorders and their families can access healthcare services where staff have dual understanding and expertise
- That communication between autistic people and treatment providers is flexible and adaptive
- That clinicians working in eating disorder services are supported to receive autism-specific training
- That general practitioners (GPs) are informed about the link between autism and eating disorders
- That eating disorder treatment modalities are adapted to encompass the needs of autistic people
- That treatment settings such as inpatient care are adapted to reduce sensory barriers or potential sensory overload
- That services collaborate and don't exclude individuals due to an autism diagnosis

- That professional research is conducted to capture the experience of autistic people living in Ireland who are experiencing eating disorders and that the research process, from design to completion, includes autistic people

Bodywhys recommends:

## Language

- That communication about, and with autistic people, uses identity first language in keeping with preference of most of the autistic community, advocacy organisations and recently, clinical and diagnostic professional groups.<sup>6,7</sup>

## Services

- That the design of services includes input from a breadth of autistic people across the lifespan, including for example girls, women and older autistic adults

## End of submission

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<sup>1</sup> Tchanturia, K. (Ed) (2021) *Supporting Autistic People with Eating Disorders: A Guide to Adapting Treatment and Supporting Recovery*. London: Jessica Kingsley Publishers

<sup>2</sup> Fisher Bullivant, F. & Woods, S. (2020) *Autism and Eating Disorders in Teens: A Guide for Parents and Professionals*. London: Jessica Kingsley Publishers

<sup>3</sup> Brede, J., Babb, C., Jones, C. et al. (2020) "For Me, the Anorexia is Just a Symptom, and the Cause is the Autism": Investigating Restrictive Eating Disorders in Autistic Women. *Journal of Autism and Developmental Disorders*, 50, 4280–4296.

<sup>4</sup> Babb, C., Brede, J., Jones, CRG. et al. (2021) 'It's not that they don't want to access the support... it's the impact of the autism': The experience of eating disorder services from the perspective of autistic women, parents and healthcare professionals. *Autism*, 25(5), 1409-1421.

<sup>5</sup> Available from <https://www.youtube.com/watch?v=-XDvVmJdUT8>

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<sup>6</sup> National Institute for Health and Care Excellence (NICE) (2011, updated December 2017). Autism spectrum disorder in under-19s: Recognition, referral and diagnosis. 2021 surveillance of autism. Clinical Guideline (CG 128, CG142 and CG170).

<sup>7</sup> Psychological Society of Ireland (2022) *Professional Practice Guidelines for the Assessment, Formulation, and Diagnosis of Autism in Children and Adolescents, 2nd Edition*. Dublin: Psychological Society of Ireland.