

# Researchers establish what the neurodivergent community would like from research on disordered eating

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New research from the Institute of Psychiatry, Psychology & Neuroscience (IoPPN) at King's College London and Birkbeck,



University of London, has worked with members of the neurodivergent community to establish what they would like to see prioritized in future research on disordered eating.

"The overlap of disordered eating, autism and ADHD: future research priorities as identified by adults with lived experience" was <u>published</u> in *The Lancet Psychiatry*.

The researchers hope that a more collaborative approach to studies in this field has the potential to create a greater understanding of why <u>autistic people</u> and people with ADHD are more vulnerable to disordered eating and how best to aid those who need support.

A total of 71 neurodivergent (either autistic and/or with ADHD) adults who had experienced disordered eating responded to an <u>online survey</u> asking about their suggestions and preferences for future research in the field.

A list of recurrent themes from this survey was then taken through to an in-depth workshop with a different group of 14 neurodivergent adults who had also experienced disordered eating. Priorities were thought about from various different angles and in terms of their potential for impact. From this workshop, researchers collated a list of the top 10 research priorities, ranked by order of importance:

- 1. How can treatment for disordered eating be improved for neurodivergent individuals?
- 2. What are other factors that can increase risk of disordered eating in neurodivergent people?
- 3. What is the effect of neurodiversity training and knowledge in clinical services for eating disorders?
- 4. Which treatment interventions for disordered eating are actively unhelpful for neurodivergent individuals?



- 5. Is there a difference between the underlying reasons for disordered eating in neurodivergent people compared with neurotypical people?
- 6. Would better information and education reduce risk for neurodivergent people?
- 7. Is there a link between ADHD characteristics (e.g. impulsivity) and eating disorders?
- 8. How do difficulties in <u>executive functions</u> affect eating behaviors and increase risk of disordered eating?
- 9. Is there a link between sensory sensitivities and disordered eating?
- 10. Do different thinking styles (e.g. black-and-white thinking) contribute to disordered eating behaviors?

Researchers sorted the list into two overarching themes, each with two subgroups:

### **Priority 1: Improving clinical outcomes**

Participants identified that research relating to the improvement of services was the most urgent <u>priority</u>.

### **Subtheme 1—Improving clinical services**

Clinical services for the treatment of eating disorders often aren't set up to accommodate the needs of neurodivergent individuals, and this can make treatment and support less effective.

Despite some progress being made in this area following the development of the PEACE Pathway, there are currently no clinical guidelines that have been agreed upon, and there has been little research conducted into the effectiveness of adapted treatments in autistic



populations.

Thus, many of the top ranked priorities asked about how services could be improved and identifying and minimizing potential harms caused by unsuitable treatments.

# **Subtheme 2—Improving psychoeducation and preventive medicine**

Another key priority was on the availability of educational resources for neurodivergent people. While participants were clear that outcomes needed to improve, they also expressed that <u>preventative measures</u> and information that could help people prior to developing a clinical diagnosis could also be helpful and would empower neurodivergent people to understand their own eating behaviors.

## **Priority 2: Identifying causal mechanisms**

A second priority that became apparent through the project was the participants' desire to understand the causal mechanisms linking neurodivergence with disordered eating.

Researchers broke this priority into two further subthemes:

#### **Subtheme 1: Identification of risk factors**

Historically, it was assumed that autistic women with anorexia were motivated by weight and body shape, based on explanatory models from neurotypical people. However, this may not be true in neurodivergent people, such that many mechanisms we think (and therefore target during treatment) lead to eating disorders may not be relevant for neurodivergent people.



One potential factor that often comes up in neurodivergent people is that patterns of disordered eating may represent a response to the stress of living in a neurotypical world as a neurodivergent person.

Researchers suggested an avenue of research could be to test the link between stress and disordered eating in both neurodivergent and neurotypical populations to help inform the design of prevention and intervention strategies.

## Subtheme 2: The role of autistic and ADHD neurocognitive profiles

Participants asked several questions based around the idea that the cognitive profiles associated with autism and ADHD could increase someone's vulnerability to disordered eating.

Current evidence suggests that there are links between sensory sensitivities and restrictive eating, and between executive functioning and disordered eating, but whether these factors can account for the increased risk for eating disorders in autistic and ADHD populations isn't yet clear.

Dr. Virginia Carter Leno, the study's senior author said, "Experiencing disordered eating is related to a variety of negative health outcomes, and it's important that services are able to meet the needs of all service users requiring treatment.

"Eating disorder services need to recognize that the needs of neurodivergent service users may be different to neurotypical people, and more research is needed to better understand the drivers of disordered eating in neurodivergent people.



"Our study has worked with a range of people with lived experience to help identify what they feel needs to be the highest priorities for future research in this area. We hope this list will act as a resource to ensure that future research in the field is informed by the experience and priorities of those with lived experience."

**More information:** Johanna Keller et al, The overlap of disordered eating, autism and ADHD: future research priorities as identified by adults with lived experience, *The Lancet Psychiatry* (2024). DOI: 10.1016/S2215-0366(24)00186-X

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