

The Overlap of Disordered Eating, Autism and ADHD: Future Research Priorities as Identified by Adults with Lived Experience

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Abstract

The focus of mental health research in emerging fields should be driven by the priorities of people with lived experience. Autism and ADHD are childhood-onset neurodevelopmental conditions that are associated with a range of negative outcomes, including increased risk for eating disorders. The evidence base for how best to support neurodivergent individuals who experience disordered eating is still in its infancy, but research suggest existing clinical approaches are not currently fit for purpose. In this Position Paper, through community consultation with autistic people and people with ADHD who have experienced disordered eating, we present a comprehensive ranked list of research topics that those with lived experience prioritise. These priorities could be clustered into two overarching areas: 'Improving Outcomes' and 'Identifying Causal Mechanisms'. Within the Improving Outcomes theme, topics focused on improving treatment, the need for neurodiversity training in clinical services and the identification and minimization of unintended adverse effects of psychological intervention. Within the Identifying Causal Mechanisms theme, topics focused on the identification of risk factors and better understanding of the impact of autistic/ADHD neurocognitive profiles as potential contributors to eating disorder vulnerability. The final Top 10 Research Priorities are contextualized, in terms of how they compare to the existing literature on the overlap between autism/ADHD and eating disorders, and concrete suggestions are given for how to implement these research priorities as testable hypotheses. Research informed by these priorities will build necessary understanding of the reasons behind the increased risk for eating disorders in neurodivergent people, and how to best support those affected to live positive and fulfilling lives.

Background

Autism and ADHD are common childhood-onset neurodevelopmental conditions¹⁻³ which frequently co-occur^{4,5} and are being increasingly diagnosed in the UK.^{6,7} Currently, both autism and ADHD are associated with poorer outcomes, in terms of people's wellbeing and functioning;⁸⁻¹³ with perhaps the most shocking marker of disadvantage being the premature mortality associated with both conditions.^{14,15} Better understanding of the factors that drive these poor outcomes would allow more effective support for neurodivergent people and enable them to lead more positive and fulfilling lives.

One factor that likely drives many negative outcomes associated with autism and ADHD is high rates of co-occurring mental health problems,^{16,17} including eating disorders.^{18,19} Systematic reviews report on average a four-fold increase in the prevalence of autism¹⁸ and 2.5 increase in ADHD prevalence¹⁹ in eating disorder populations. Outpatient samples of adults with neurodevelopmental diagnoses (primarily autism and ADHD) are characterised by an increased prevalence of eating disorders.²⁰ This overlap extends beyond diagnostic categories; associations between disordered eating and autistic/ADHD traits are also present in nonclinical samples.^{21,22} Eating disorders are associated with a range of adverse medical and psychiatric consequences,^{23,24} and

have one of the highest mortality rates in comparison to other psychiatric illnesses, with 1 in 5 individuals with anorexia who die, doing so by suicide.²⁵

Despite the fact that eating disorders are common in people with autism and/or ADHD, and it is clear that eating disorders are dangerous and damaging conditions, current clinical support for neurodivergent people with disordered eating is not fit for purpose. In anorexia nervosa, autistic traits are associated with a more severe clinical presentation on admission to inpatient care,²⁶ and a diagnosis of autism is associated with more negative treatment outcomes.^{27,28} Cognitive remediation therapy (CRT) appears not to be effective in patients with anorexia who have high autistic traits,²⁹ and autistic women with anorexia feel their needs are not being met by standard eating disorder treatments³⁰ and rate clinical services for eating disorders as less beneficial.³¹ Despite a similar overlap with eating disorders as to autism, far less is known about the impact of ADHD symptoms on eating disorder presentation and treatment effectiveness. One study showed baseline ADHD symptoms may influence eating disorder treatment outcomes indirectly through increasing eating disorder symptom severity.³² Another found baseline ADHD symptoms were predictive of non-recovery one year later in adult females, but this was only true of patients with loss of control over eating, bingeing, or purging, and effects were largely driven by inattentive rather than hyperactive-type symptoms.³³

One constraint on the provision of good-enough services for autistic people/people with ADHD with eating disorders is the lack of a knowledge base to guide service development and improvement. Therefore, research is urgently needed to improve outcomes for neurodivergent people who experience disordered eating. It is paramount to involve stakeholder voices at this crucial juncture, so that the focus of research within this emerging field can be driven by the needs of those with lived experience. The aim of this manuscript is to present a list of research priorities for the topic of disordered eating in individuals who are autistic and/or have ADHD, derived through a collaborative process with individuals with lived experience. These topics can act as a comprehensive guide for researchers in this emerging field, and ensure future research funding and projects are in line with community priorities.

Community Consultation

To identify the priorities of individuals with lived experience, we used a two-step, iterative process of consultation and collaboration, incorporating a broad-range online survey with an in-depth online workshop (see Figure 1 for a schematic of the project). This dual approach was selected to encourage participation from a diverse group of individuals (to mirror the heterogeneity of both neurodivergent and eating disorder presentations and experiences) as it allowed us to collect contributions from open-survey text boxes, and detailed live discussions. We followed the principles outlined by the James Lind Alliance (<https://www.jla.nihr.ac.uk/>), a non-profit initiative designed to bring relevant groups together to identify and prioritise issues relevant to health research funders. We sought to recruit people who either identify as being autistic or having ADHD who had experience (past or present) of disordered eating to give their views on future research priorities. We chose to allow those who self-identify as having

autism/ADHD to also take part to increase the inclusivity and representativeness of the group sampled, but also in recognition of the fact that many neurodivergent people do not hold a formal diagnosis when they first present to clinical services.³⁴

The survey and workshop both received ethical clearance from the King's College London Research and Ethics Committee (LRS/DP-22/23-39270) and informed consent was collected from all participants before they took part in the research project. The online survey asked autistic people and people with ADHD who had experienced disordered eating (defined as only eating certain foods, not eating for a long period of time, and/or feeling out of control while eating) what they felt might be risk or protective factors for different forms of disordered eating, which types of informal (e.g., friends/family/community groups) and formal (e.g., clinical services) support are were helpful or unhelpful, and which topics researchers should focus on in the future.

Seventy-one people completed the survey. This included a range of ages (age brackets endorsed ranged from 18-24 to 45-54), gender identities, ethnicities and education levels (see Table S1 for full demographics), although the majority of the sample were female (78%), White (82%) and had an undergraduate degree or higher (72%). All participants confirmed they identified as neurodivergent and had experienced disordered eating. 62% of the sample either had a diagnosis of autism or identified as being autistic, and 62% of the sample either had a diagnosis of or identified as having ADHD, and all had lived experience of disordered eating (this included anorexia, bulimia, binge eating disorder, Other Specified Feeding and Eating Disorder; OSFED, and Avoidant Restrictive Food Intake Disorder; ARFID, see Table S1 for proportions).

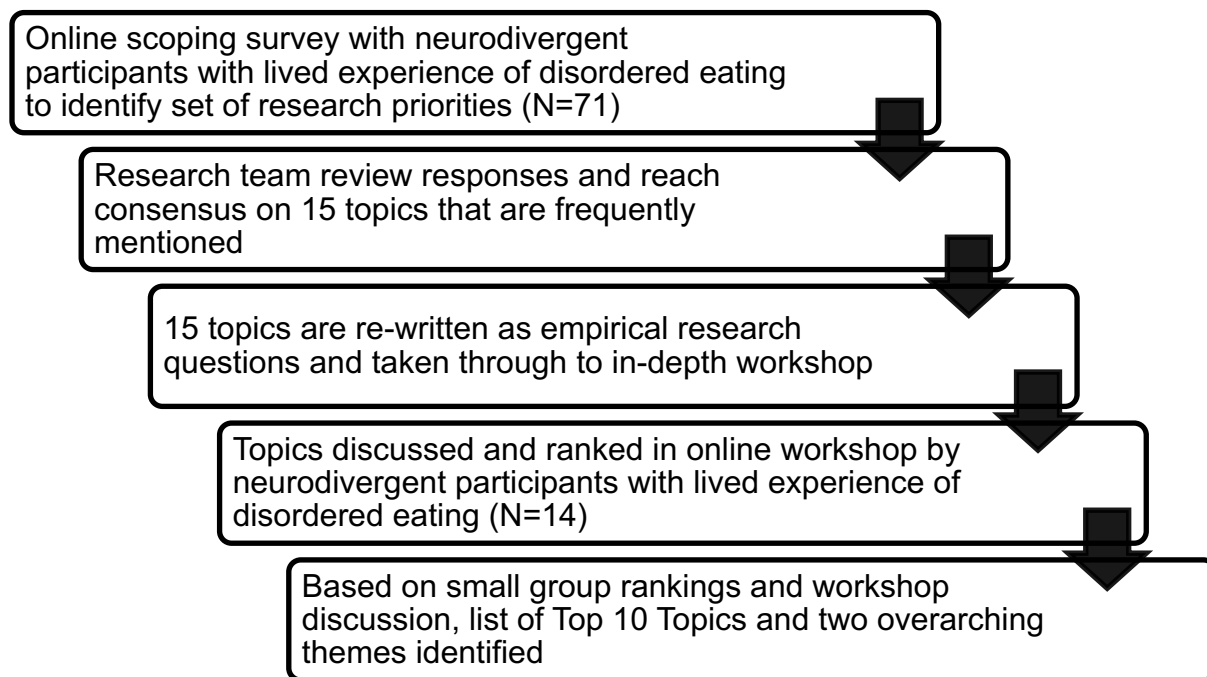


Figure 1. Schematic of Project Protocol to Identify Research Priorities

Two of the authors (J.K., V.C.L.) separately reviewed the open-text responses from the online scoping survey and identified topics that were mentioned frequently across participants. These were then reduced through discussion with all co-authors and consensus was reached on a list of 15 possible topics, which were re-written as concise research questions (e.g., ‘Is there a link between sensory sensitivities and disordered eating?’), and taken through to the in-depth workshop (see Figure 2 for the final list of research questions). This workshop was facilitated by an external company with extensive experience of engagement projects.

The workshop was designed to encourage participants to think about the list of possible priorities in a variety of ways and with reference to different groups in the population that the topic of disordered eating in neurodivergent people would be relevant to. This allowed us to build an in-depth understanding of why different topics might be seen as more or less important, including consideration of how different stakeholder types might have different priorities. The different stakeholder types were chosen through group brainstorming at the beginning of the workshop. These were 1) people with lived experience, 2) the general public (including friends and family of people with lived experience), 3) service providers (including clinicians and social care workers) and 4) people in power (including policy makers, researchers, politicians). Participants then completed a series of small group exercises where they were asked to discuss and rank topics in order of importance for these different stakeholder types, and think about the potential impact different research topics could have in terms of changing attitudes, people’s ability to act, and people’s wellbeing. Each group then selected their top five topics (although most groups selected six), ranked in order of priority. The session ended with a final discussion with the entire group based on the information fed back from the small group discussions. Fourteen people attended the workshop, and as before, this included a range of ages, gender identities, ethnicities, and education levels (see Table S2 for full demographics). All participants confirmed they identified as neurodivergent and had experienced disordered eating. 86% of the sample either had a diagnosis of autism or identified as being autistic and 50% of the sample either had a diagnosis of ADHD or identified as having the condition, and all had lived experience of disordered eating (this included anorexia, bulimia, binge eating disorder, OSFED and ARFID, see Table S2 for proportions).

Research Priorities

See Figure 2 for a visual summary of how different topics were ranked in priority for different societal groups and in terms of potential for impact, and Table 1 for the final list of ranked Top 10 Priorities. The Top 10 Priorities can be summarized by two overarching themes of ‘Improving Outcomes’ and ‘Identifying Causal Mechanisms’. Topics will be discussed in relation to these themes below.

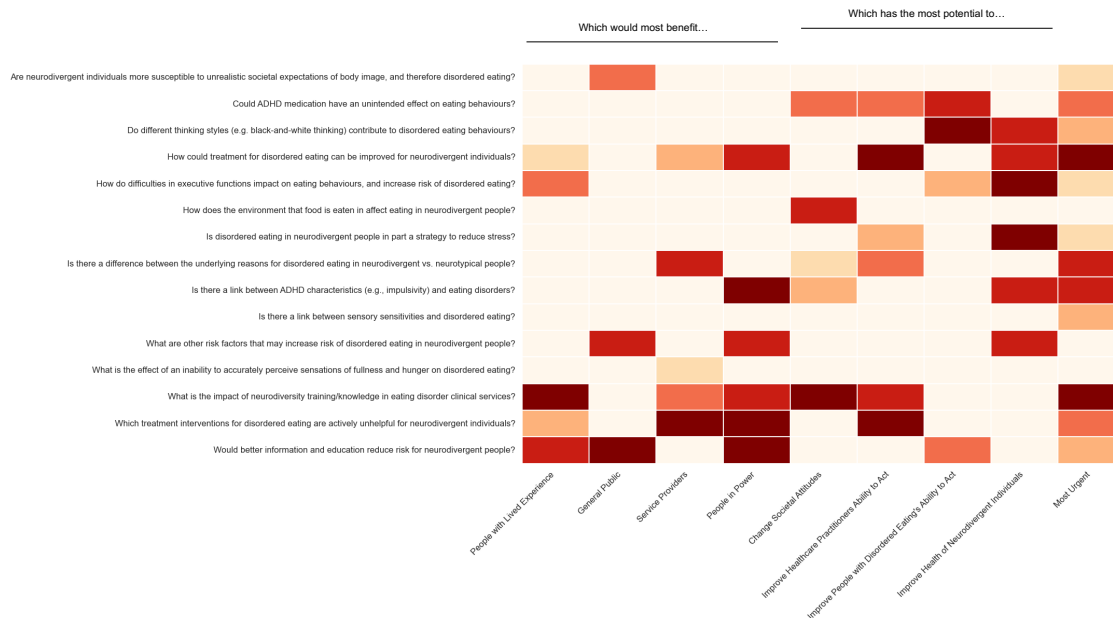


Figure 2. Heatmap Depicting Relative Importance of Different Research Topics for People with Autism and/or ADHD and Experience of Disordered Eating.

Note: Darker colours indicate topics were rated as more important by those with lived experience

Priority 1. Improving Outcomes

In general, research priorities relating directly to improvement of clinical services were ranked most highly. They were also ranked as most beneficial for people with lived experience, and most urgent (see Figure 2). This sits in contrast to the fact that the majority of funding, at least for autism, supports projects investigating basic science and causes and risk factors, rather than intervention and service development³⁵ (similar analyses have not yet been conducted for ADHD). From the questions, we identified two distinct strands of clinically focused future research priorities.

Subtheme 1: Improving Clinical Services

This subtheme relates to Questions ‘How could treatment for disordered eating can be improved for neurodivergent individuals?’ (Ranking 1), ‘What is the impact of neurodiversity training/knowledge in eating disorder clinical services?’ (Ranking 3), and ‘Which treatment interventions for disordered eating are actively unhelpful for neurodivergent individuals?’ (Ranking 4).

In the workshop, the most important topic for participants was how could treatment for disordered eating in neurodivergent people be improved. Some important work has been done to these ends; in the UK, the PEACE pathway has been developed to adapt eating disorder treatment for autistic individuals (<https://www.peacepathway.org/>). However, there are no agreed clinical guidelines, and there is not yet an evidence base

on the effectiveness of adapted treatment in autistic populations, and little to no work has been done adapting treatment for people with ADHD. Addressing these knowledge gaps should be a top priority for researchers going forward.

The flip side of the coin to improving treatment is the minimization of harm due to unintended treatment consequences. The understanding of what was unhelpful, or potentially harmful, was seen as most important for the groups of 'service providers' and 'people in power' and was ranked as having the most potential to improve a healthcare practitioner's ability to act. We have kept it separate from the question pertaining to improving treatment as we feel it requires a different focus to answer empirically (e.g., systematic collection of information on adverse effects). Workshop participants felt that it was vital that harm was clearly defined, ideally in collaboration with members of the neurodivergent community, as some forms of harm may not be immediately obvious to neurotypical individuals (e.g., encouraging masking of neurodivergent behaviours and characteristics). The potential harms of non-pharmacological interventions are routinely overlooked by professionals - a review of 82 National Institute for Health Research (NIHR) funded trials for psychological interventions found not one of the psychological interventions listed the occurrence of an adverse event, and available criteria for what are considered adverse events was inappropriate.³⁶ There is evidence that autistic people are more likely than non-autistic people to experience deterioration following psychological therapy, despite receiving more high-intensity treatment sessions,³⁷ which could in part be due to standard psychological interventions not always being appropriate for neurodivergent people.

The question pertaining to neurodiversity training ('What is the impact of neurodiversity training/knowledge in eating disorder clinical services?') is in line with reports that clinicians often feel lacking in knowledge of how to best support autistic clients,³⁸ and that autistic women see a lack of professionals knowledge as a barrier to accessing treatment for eating disorders.³⁹ Systematic reviews have highlighted a lack of education as a driver of lack of access to primary care in ADHD⁴⁰ and qualitative work found limitations and inaccurate misconceptions in physicians' understanding of ADHD in the UK, especially in women.⁴¹ A clear next step is to develop and evaluate a co-produced, systematic, and evidence-based neurodiversity training program for health providers, especially those working in the domain of eating disorders.

Subtheme 2: Improving Psychoeducation/Preventative Medicine

This subtheme relates to the Question 'Would better information and education reduce risk for neurodivergent people?' (Ranking 6). We felt it was useful to separate this from research focusing on intervention/training, because this theme focused on preventing disordered eating from becoming clinically relevant, rather than treating an eating disorder that has already developed. Furthermore, this theme focused on developing psychoeducational materials for people with lived experience and thus empowering them to understand potential triggers and potentially maladaptive patterns of eating.

From the workshop discussion, it was mentioned that psychoeducational resources should focus not only on knowledge (e.g., of neurodivergent profiles and eating disorder symptoms), but also acceptance and understanding of people's neuro-identity. There is some initial evidence that psychoeducation that emphasises the strengths and not just the difficulties associated with autism,⁴² or includes modules on acceptance of living with ADHD⁴³ can be beneficial, although this needs more rigorous examination, and potentially extension to include information about strategies to maintain healthy eating behaviors. For newly diagnosed neurodivergent people, community-led support may be especially welcome, as has been found for autism.⁴⁴

Priority 2. Identifying Causal Mechanisms

Subtheme 1: Identification of Risk Factors

This subtheme relates to the Questions 'What are other factors that may increase risk of disordered eating in neurodivergent people?' (Ranking 2) and 'Is there a difference between the underlying reasons for disordered eating in neurodivergent vs. neurotypical people?' (Ranking 5).

Qualitative research with autistic women with anorexia suggested that commonly assumed motivations such as weight and shape concerns, were less relevant than other factors.^{30,45} Instead, a variety of 'non-traditional' factors were present, many of which saw restrictive eating as a coping mechanism to manage distressing experiences and emotions (many of which stemmed from the difficulties associated with living as an autistic person in a neurotypical society). In the current workshop, although not listed as a Top 10 Priority, the idea of disordered eating as a response to stress in neurodivergent people was ranked as having high potential to improve the physical and mental health of neurodivergent individuals. This appears an important topic of focus - the next step would be to build on existing qualitative work by empirically testing the link between stress and disordered eating in neurodivergent and neurotypical populations, along with more extensive investigation of the relevance of 'traditional' risk factors for disordered eating in neurodivergent populations. Understanding whether there are differences in the underlying risk factors for disordered eating requires statistical comparison of the relative strength of associations between a given risk factor and disordered eating in neurodivergent as compared to neurotypical populations (i.e., interaction models), ideally within a longitudinal design to strengthen causal inference. Low hanging fruit could include analysis of existing cohort studies which have measurements of autistic/ADHD diagnosis, stressors and eating behaviours (e.g., Avon Longitudinal Study of Parents and Children (ALSPAC), Millennium Cohort Study (MCS), Norwegian Mother, Father and Child Cohort Study (MoBa)). The outcomes of this line of research will directly impact the design of prevention and intervention strategies. Indeed, the lack of relevance of traditional risk factors may explain why treatment outcomes for autistic people with eating disorders are less positive as current interventions are potentially not addressing the underlying mechanisms.

Table 1. Final List of Ranked Priorities for Future Research

Ranking	Question
1	How could treatment for disordered eating can be improved for neurodivergent individuals?
2	What are other factors that may increase risk of disordered eating in neurodivergent people?
3	What is the impact of neurodiversity training/knowledge in eating disorder clinical services?
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 vs. 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 executive functions impact on eating behaviours, 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 behaviours?

Note: In the two instances where topics had equivalent total ranking scores, their relative importance in terms of benefit and potential to change was used to determine which topic should be ranked higher

Subtheme 2: The Role of the Autistic/ADHD Neurocognitive Profile

This subtheme relates to the Questions ‘Is there a link between ADHD characteristics (e.g., impulsivity) and eating disorders?’ (Ranking 7), ‘How do difficulties in executive functions impact on eating behaviours, and increase risk of disordered eating?’ (Ranking 8), ‘Is there a link between sensory sensitivities and disordered eating?’ (Ranking 9) and ‘Do different thinking styles (e.g. black-and-white thinking) contribute to disordered eating behaviours?’ (Ranking 10). These questions all involve the idea that the cognitive profiles associated with autism and ADHD may increase vulnerability for disordered eating. The focus on cognitive functioning differentiated these topics from those searching for other risk factors (which may be externally located).

Qualitative interviews with autistic women find some overlap in our currently identified neurocognitive risk factors, for example, differences in sensory experience, social relations, difficulties with interpreting and regulating emotions, and more rigid thinking styles,⁴⁵ and sensory difficulties, and organizational difficulties impacting the ability to

shop for and cook food.³⁰ To our knowledge, no study has yet asked people with ADHD about their experience of disordered eating, or the factors they think may have contributed to any difficulties experienced. This would be a fruitful line for future research in order to generate more specific testable hypotheses that are grounded in individual's lived experience.

In terms of quantitative research, there are some reports of a link between sensory sensitivities and restrictive eating,^{46,47} and executive functioning and disordered eating,^{48,49} but whether these factors can account for the increased risk for eating disorders in autistic/ADHD populations requires further exploration (see ⁵⁰ for an example of mediation models that can delineate to what extent associations between autistic traits and disordered eating are driven by childhood selective eating). Better tools to objectively measurement of relevant domains of neurocognitive functioning (e.g., cognitive flexibility, see ⁵¹ for an example) in a manner that relates to the real-life difficulties people experience, combined with prospective longitudinal designs, would aid in this line of research.

Concluding Remarks

This work presents a comprehensive and detailed research agenda, fully grounded in and guided by the priorities of people with lived experience of autism and/or ADHD and disordered eating. Although we acknowledge that the current sample cannot be considered fully representative, both in terms of demographics, and verbal abilities (a significant subgroup of autistic people have few to little words), we feel that this collaborative approach is an important step towards truly co-produced research, where those with lived experience are seen as active partners. What is required is to continue this collaborative approach is each stage of the research cycle, for example, in formulating specific research hypotheses, selecting appropriate measures to capture domains of interest and interpreting results of analyses. These types of collaborative projects are integral to building and maintaining trust between research and lived experience communities, which is key to conducting relevant and respectful research. We hope this is a useful resource to guide researchers working in the field of disordered eating and neurodivergence, and highlights to funders the research priorities of people with lived experience. Uptake of these priorities and further collaborative research has the potential to understand why autistic people and people with ADHD are more vulnerable to disordered eating and how best to support those who need it. This will promote positive outcomes for neurodivergent individuals and ensure they are able to live happy and healthy lives.

Contributors

VCL contributed to the conceptualisation, funding acquisition, methods, data curation, visualisation, supervision, writing, reviewing, and editing of this Position Paper, and wrote the original draft. JK, MH and WM contributed to the conceptualisation, methods, writing, reviewing, and editing. JK also contributed to project administration, data collection and data curation.

Declaration of interests

All authors declare they have no conflicts of interest.

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The Overlap of Disordered Eating, Autism and ADHD: Future Research Priorities as Identified by Adults with Lived Experience

Supplementary Material

Table S1. Demographics of Online Survey Sample

	N	Percentage
Gender Identity		
Male	6	8.5%
Female	55	77.5%
Non/binary	3	4.2%
Prefer not to say	2	2.8%
Prefer to self-describe	5	7.0%
Age		
18-24	22	31%
25-34	23	32.4%
35-44	17	23.9%
45-54	9	12.7%
Ethnicity		
White	58	81.7%
Asian (Indian, Pakistani, Bangladeshi)	4	5.6%
Mixed (two or more ethnic groups)	7	9.9%
Other (Arab or any others)	2	2.8%
Highest level of education completed		
Completed primary school	1	1.4%
Completed secondary school	13	18.3%
Graduate or professional degree	27	38.0%
University Bachelor's degree	24	33.8%
Vocational or similar	5	7.04%
Prefer not to say	1	1.4%
Endorsed diagnosis		

Autism ⁺	44	62.0%
ADHD ⁺	44	62.0%
Anorexia	27	38.0%
Bulimia	13	18.3%
Binge eating disorder	19	26.8%
OSFED	7	9.9%
ARFID	11	15.5%

+ 27% endorsed both autism and ADHD

Table S2. Demographics of Workshop Sample

	N	Percentage
Gender		
Male	3	21.4%
Female	7	50.0%
Non/binary	3	21.4%
Prefer to self-describe	1	7.1%
Age		
18-24	1	7.1%
25-34	3	21.4%
35-44	7	50.0%
45-54	3	21.4%
Ethnicity		
White	12	85.7%
Asian (Indian, Pakistani, Bangladeshi)	1	7.1%
Mixed (two or more ethnic groups)	1	7.1%
Highest level of education completed		
Completed secondary school	1	7.15%
Graduate or professional degree	6	42.9%
University Bachelor's degree	4	28.6%
Vocational or similar	3	21.4%
Endorsed diagnosis		
Autism ⁺	12	85.7%
ADHD ⁺	7	50.0%
Anorexia	3	21.4%
Bulimia	2	14.3%
Binge eating disorder	5	35.7%
OSFED	2	14.3%
ARFID	3	21.4%

+36% endorsed both autism and ADHD