Beat
Eating disorders

NOT DESIGNED FOR ME

Transforming Eating Disorder Support for Autistic People

"It's 'complex' is all we ever heard, but both the eating disorder and the autism are intrinsically linked. However, no one knows how to deal with it."

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EXECUTIVE SUMMARY

There are approximately 3.5 million people in the UK (around 5-6%) likely living with an eating disorder. Autistic people are twice as likely to have an eating disorder than people who are not Autistic. This report highlights that far too many Autistic people with eating disorders are being failed by a healthcare system that is highly variable in its consideration of Autistic people's experiences and needs.

Traditionally, most eating disorder support has been designed around assumptions that people communicate and experience the world in a neurotypical way. Additionally, Autistic people face delayed or missed recognition of autism, misinterpretation or misunderstanding of their needs, a lack of reasonable adjustments, and treatment approaches that do not fully consider nor understand how Autistic characteristics can interact with eating disorder behaviours. Similarly, eating disorders are often missed where autism is recognised because eating difficulties are attributed to an autism diagnosis.

In comparison, autism-affirming care involves recognising Autistic people as experts in their own experiences, taking the time to ask about and understand individual needs and preferences, adapting communication, environment and treatment, anticipating transitions, and assessing the impact of care using outcomes meaningful to the person.

While there is a growing recognition of the overlap between autism and eating disorders it is apparent that a sharp lack of autism-affirming care leads to harm and has a real impact on the personal, social, educational, and work lives of Autistic people with eating disorders and their families and friends. It leads to delayed recovery, repeated relapses, increased use of restrictive interventions, avoidable admissions, family breakdowns, loss of trust in the healthcare system, and trauma caused by inappropriate care.

We also acknowledge the significant pressures services continue to face, across recruitment, retention, funding and resourcing. This sits within a wider context of eating disorders research having long been severely underfunded, all of which play a role.

To better understand these experiences, Beat conducted a survey of over 800 Autistic people with lived experience of eating disorders, alongside carers, families and loved ones. The survey explored experiences of diagnosis, accessing treatment, adaptations, support, and people's perspectives on what would improve care. This survey found that 56% of Autistic people with eating disorders didn't have their treatment adapted because of their autism, while only 39% of carers said they received support for themselves.

Alongside the survey, this report brings together academic evidence, innovations in research, examples of service development, and resources, and coordinates expertise from clinicians, policy makers, academics, and experts by experience. It also sets out the legal frameworks, guidelines, and specifications that stipulate requirements to provide reasonable adjustments, and the professional duty of care to ensure confidence in working with Autistic people.

The findings from this work highlight several key challenges:

- **Autism and eating disorders are often recognised late, if at all.** Many people reported autism being explored after their eating disorder treatment, while others were still waiting for assessment upon discharge without appropriate adaptations having been made. Similarly, Autistic people with a diagnosis described challenges in their eating disorder being recognised. Barriers to recognition for both included masking, diagnostic overshadowing, and assumptions about what autism and eating disorders look like.

- **Access to eating disorder care is inconsistent and fragmented.** Respondents described delays to support being related to diagnosis, service provision, geographical location, and Body Mass Index (BMI) being used as an inappropriate criterion for access. For respondents who already had a diagnosis of autism and/or other diagnoses at the point of accessing eating disorder support, some people experienced being turned away. Ineffective coordination between services meant Autistic people or their carers were responsible for coordinating their care, with 86% of Autistic people reporting at least one other condition. Some described turning to costly private treatment to receive support that they could not access through NHS services.

- **Autism-affirming adaptations are not consistently available.** Where there were examples of autism-affirming care, such as adjustments to communication, sensory needs, the treatment environment, and treatment approaches, many respondents described these as being dependent upon an individual clinician, rather than being embedded consistently in an individualised way across services.

- **Carers often carry a heavy burden.** Many carers described having to advocate for their loved one to receive the help they needed and found themselves coordinating care across a complicated healthcare system without adequate support. Many neurodivergent families also felt blamed for the challenges they were facing.

- **There is an urgent need for better evidence, professional understanding, and co-produced approaches to eating disorder treatment.** It's clear that Autistic people and carers need to be meaningfully involved in shaping research, services, training, and improvements to eating disorder care across the UK.

These findings highlight the gap between what good autism-affirming care should look like and the experiences of many Autistic people receiving eating disorder care. There are already examples of national policy demonstrating that change is possible, such as Scotland's National Specification for the Care and Treatment of Eating Disorders, which reflects many of the recommendations in this report. This shows how national plans can set clear expectations for services, while highlighting the importance of ensuring that these commitments are consistently implemented in practice.

When care for an eating disorder is autism-affirming, people describe feeling understood and seen, and that treatment feels more effective. This is a consistent message through the multiple

perspectives included in this report, including through PEACE (Pathway for Eating disorders and Autism developed from Clinical Experience), which is a clinical pathway that has consistently demonstrated impact, and the Eating Disorders and Autism Collaborative, both of which this report builds on.

In addition to personal benefits, there is also a strong economic argument for providing autism-affirming care through possible outcomes such as the reduction of unnecessary interventions and the length of inpatient admissions, and prevention of crises. For example, findings from the implementation of PEACE at an adult inpatient eating disorder unit saw a reduction in the average inpatient stay for Autistic patients from 19 to 13 weeks. Estimated cost-savings were approximately £22,837 per patient, and approximately £275,000 per year for the service as a whole.

The recommendations outlined in this report therefore focus on the following:

- Improving the identification of autism and autistic traits, and access to eating disorder care
- Providing autism-affirming care
- Ensuring joined-up care
- Supporting staff
- Improving data collection and the evidence base

While not the focus of this report, accessible adaptations and flexible service provision that does not assume 'one size fits all' can also benefit those who are not Autistic or those for whom traditional treatment models are not appropriate.

Autistic people should be able to access support for an eating disorder that is designed with their needs in mind. The challenges described here and in this report are not due to Autistic needs being 'too complex' as many Autistic people report being told, nor are they inevitable outcomes of being Autistic. Change is both necessary and achievable. Beat's recommendations aim to ensure that Autistic people with eating disorders can reliably access and receive equitable care that recognises their needs, values their experiences, prevents avoidable barriers, and supports meaningful individual recovery.

RECOMMENDATIONS

Bringing together lived experiences, academic research, clinical expertise, and policy documents that are described in this report, Beat recommends the following:

Improving identification and access to care

1. Services should routinely consider autism during eating disorder assessment and throughout treatment (and conversely, eating disorders in an autism assessment). This should include routinely using autism screening tools alongside clinical judgement.

    a. Where autism (or an eating disorder) is suspected or identified, there should be a timely discussion to explore potential next steps, and referrals to appropriate pathways for diagnosis, assessment, and post-diagnostic support.

    b. Autism-affirming support and reasonable adjustments should be available based on identified needs, regardless of whether someone has a formal autism diagnosis, including for people who self-identify as Autistic. Services should avoid requiring a formal diagnosis before considering or implementing appropriate adjustments.

    c. Services should consider barriers to recognition, including masking, diagnostic overshadowing, assumptions about who is likely to be Autistic, and differences in Autistic presentation. This should include considering both autism and eating disorders when assessing people with eating difficulties and avoiding assumptions that disordered eating is simply part of being Autistic. Services should also explore an individual's profile where they present with a known autism diagnosis.

2. Autistic people with eating disorders should be able to access timely treatment.

    a. Access to timely treatment should be regardless of weight, diagnosis, age, presentation, location, or personal characteristics.

    b. Services should recognise and address inequalities that may affect identification, access to care, treatment experiences, and outcomes.

3. Services should take an intersectional approach to assessment, formulation, and treatment.

    a. Services should recognise how different aspects of a person's identity, lived experience, life stage, and co-occurring conditions may interact with their eating disorder, presentation, support needs, and experience of care.

    b. Staff developing formulations and treatment plans should have the knowledge and skills to consider these factors appropriately.

Providing autism-affirming care

4. Services providing care to people with eating disorders should provide person-centred, autism-affirming care as standard, that is suitable for Autistic people.

a. Appropriate, personalised adaptations to communication preferences, sensory and environmental needs, and treatment approaches should be included within care plans.

b. Adaptations should consider sensory differences (including those related to taste, smell, texture, sound, sight, and other sensory experiences), differences in recognising or responding to internal bodily signals such as hunger and fullness, food preferences, communication needs and differences, and the ways autism may influence eating behaviours and patterns and a person's experience of having an eating disorder.

c. Co-occurring mental and physical health conditions and disabilities should also be considered, including how they may affect the experience of being Autistic with an eating disorder.

5. Treatment and care plans should be developed collaboratively with the person with the eating disorder (and carers where appropriate), starting from an assumption of capacity and recognising the importance of autonomy, choice, and shared decision-making.

a. Plans should reflect individual priorities, communication preferences, support needs, and preferences around language and identity.

b. Plans should be shared in an accessible format and reviewed regularly throughout treatment to ensure they continue to meet the person's needs, including through the use of tools such as communication passports.

Ensuring joined-up care

6. Eating disorder, autism, and other relevant services should establish clear communication pathways, agreed processes for joint working, and named points of contact to prevent avoidable gaps and delays in treatment.

a. These arrangements should be regularly reviewed to ensure they are meeting the needs of Autistic people with eating disorders.

b. Where more than one service is involved, clear responsibilities for care across providers should be set out in treatment plans, understood by all services involved, and communicated to person with the eating disorder.

7. Transitions to and between different services (such as moving from children and young people's services to adult services or from inpatient to community care) should be planned well in advance, with transition planning beginning at least 6 months before planned transitions where possible.

a. Planning should consider the individual needs of Autistic people, including reasonable adjustments to the transition process, taking into account time needed to process information.

b. Transitions should involve shared decision-making with the patient (and carers where appropriate), be clearly communicated to everyone involved, and include ongoing support throughout the transition period.

8. Families, carers and loved ones should be recognised for the caring role they provide and routinely offered information, support and opportunities to be involved in decisions about treatment, balanced by the wishes of the Autistic individual, in line with guidance.

a. This should include recognition and support for carers who are also neurodivergent. Information and support should be accessible and autism-affirming, taking into account individual communication preferences.

Supporting staff

9. Staff providing treatment and care to patients with eating disorders should receive regular and up-to-date training in autism-affirming care that builds on statutory training. This may be internally delivered or through a national provider.

a. Training should be co-produced with people with lived experience of autism and eating disorders, and clinicians and researchers.

b. Training should include Autistic presentations, communication and sensory needs, treatment adaptation, masking and diagnostic overshadowing, how autism and eating disorders can interact, reasonable adjustments, awareness of co-occurring conditions, and practical approaches to adapting assessment and treatment to meet individual needs.

10. Services should appoint 'Autism-affirming care leads' within their teams who can bring together different perspectives, evidence, and lived experiences, and lead on ensuring the right support is available.

a. These leads should have appropriate knowledge, protected time, and organisational support to influence practice and service development.

b. Insights and improved data collection should be used by commissioners and providers to meet the needs of local populations and reduce inequalities in access to care.

c. This role should complement, rather than replace, responsibility across the whole service for providing autism-affirming care.

Improving data collection and the evidence base

11. Researchers and services should be supported and funded to strengthen the evidence base for autism-affirming eating disorder recognition, treatment, and service models.

a. Research should be co-produced with Autistic people with lived experience of eating disorders, and families, carers and loved ones.

b. Approaches should be evaluated and published, so that models which deliver the best outcomes can be identified and promoted for adoption.

c. This should include longer-term follow-up data, economic evaluation, outcomes that are meaningful to Autistic people, and carer outcomes, and be used to inform service development, improvements, and future research priorities.

12. Research funders should continue to support networks for autism and eating disorders that bring together lived experience, clinical expertise, and up-to-date research evidence, such as the Pathway for Eating Disorders and Autism (PEACE) and the Eating Disorders and Autism Collaborative (EDAC). These networks offer opportunities to inform and share evidence, develop good practice, facilitate collaboration, reduce variation in care, and support the implementation of vital autism-affirming approaches across the UK.

1. INTRODUCTION

The report

This report focuses on the experiences of Autistic people with eating disorders and their families and friends. It brings together lived experiences, academic research, examples of good practice in different services, presents projects building our understanding of this topic, and outlines a UK wide policy context. This insight is used to make recommendations to professionals, services, funders, and policy makers.

It highlights where current systems are not meeting people's needs and sets out recommendations for improving recognition, access, treatment, clinical services, and support for Autistic people experiencing eating disorders and their carers. We understand that this may be particularly difficult to read for Autistic people and their families and friends. If you or a loved one is currently struggling to access treatment, we have outlined some next steps and resources to support you the appendices.

This report covers all eating disorders covered in ICD-11.

The scale of the overlap between autism and eating disorders

Autism is a lifelong neurodivergence that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. Autism is highly heritable. You are born Autistic and are Autistic for life. It is a spectrum condition which means that, while all Autistic people share differences from non-Autistic people in how they think, feel, and communicate, Autistic people are all different and have their own unique combination of characteristics (1-4). More than one in 100 people are Autistic and there are at least 700,000 Autistic adults and children in the UK (5). Autism is not caused by life experiences, personal circumstances, or parenting style.

Autistic people are at higher risk of developing an eating disorder, although autism or autistic traits are not always the reason an Autistic person develops disordered eating. There is no one factor responsible; eating disorders are multifaceted and develop due to a number of factors.

At least 3.5 million people are likely living with an eating disorder in the UK (6), and Autistic people are disproportionately affected, often experiencing additional barriers to recognition, treatment, and recovery compared with non-Autistic people. Self-identifying Autistic people from one study were reported to be twice as likely as non-Autistic peers to experience eating disorders (7). Recent systematic reviews estimate that around 29% of people with anorexia nervosa meet diagnostic criteria for autism, while approximately 16% of people with ARFID are Autistic (8,9). Research also indicates autistic traits among people with bulimia nervosa and binge eating disorder are elevated, while it is difficult to produce a prevalence figure for OSFED given the heterogenous nature of this diagnosis (10).

Much like each individual's experience of being Autistic is different, as are the ways autism may interact with eating disorders. Differences in communication, sensory processing, thinking styles, routines, emotional awareness, and awareness and experience of the body can influence how eating difficulties develop, present, are maintained, and are understood (11-15). There is no single Autistic experience, and the interaction between autism and eating disorders varies significantly. Similarly, some differences in eating patterns represent

preference and not disordered eating, not all Autistic individuals have eating disorders and vice versa.

For some individuals, these experiences may contribute to avoidant/restrictive food intake disorder (ARFID), where food avoidance or restriction is not driven by concerns about weight or shape, but instead by factors such as sensory sensitivities, fear of aversive consequences (such as choking or vomiting), or a lack of interest in eating. Understanding these different drivers is crucial, as similar eating behaviours can have different underlying causes and require different approaches to assessment and support.

An academic literature review is included in Appendix 2 and further describes research on the overlap between autism and eating disorders.

Challenges

> *"For me, being autistic has made it much harder to access support, as it has made it harder for me to go to places such as the GP in the first place, and, once there, I feel that being autistic has meant that my eating disorder is not taken as seriously and is simply treated as a symptom of autism rather than a serious problem in itself."*

Autistic people report experiencing social challenges, stigma, minority stress, and exhaustion associated with masking or camouflaging (i.e., attempting to hide or change behaviours to conform to perceived socially acceptable expectations) of their autistic traits (16-21), whilst navigating a world that is often designed around neurotypical ways of communicating and being. These experiences may contribute to vulnerability to eating difficulties. In addition, some Autistic people may have a co-occurring intellectual disability, which can further influence how eating disorders present, how someone communicates their experiences, and the support they need.

Where food restriction occurs, the reasons behind this can vary considerably between individuals. For some Autistic people, eating difficulties may be linked to sensory experiences, including sensitivities to smells, tastes, textures, or the predictability of food. Others may experience alexithymia (22) (difficulty recognising and describing emotions) or differences in interoception (difficulty recognising internal body signals), making it harder to identify hunger, fullness, emotions, or distress (13). High arousal levels through emotional and/or sensory overload can also displace eating.

Research also highlights that Autistic people often experience barriers to recognition and diagnosis. Autism can be missed due to masking, gender-based stereotypes (23) cultural inequalities (24) differences in presentation, or because clinical support focuses mainly on eating disorder symptomology without considering the wider context, like autism. Long waiting times for an autism assessment can also mean that people may not have access to a formal diagnosis for a substantial amount of time. This can make it harder to access appropriate support and can result in Autistic needs being overlooked, misunderstood, or attributed solely to the eating disorder or another mental health condition. This is despite a diagnosis not being needed to make the appropriate adaptations. These challenges can work both ways, with eating disorders also being missed or overlooked within autism services, and an increased awareness is needed across

settings. Findings from our survey found that where people needed or were receiving care from more than one service, care was particularly fragmented. This has also been highlighted by the UK All-Party Parliamentary Group on eating disorders (25).

Delayed recognition of autism can contribute to delays in accessing appropriate support. Where treatment is accessed, outcomes are often poorer than outcomes for non-Autistic people, which can be due to difficulties receiving support that is appropriate and effective. Autistic children and young people are significantly more likely than their non-Autistic peers to require treatment beyond standard outpatient family-based therapy, while Autistic people are also disproportionately represented among those receiving nasogastric tube feeding under restraint.

In recent years, awareness of autism and eating disorders has increased, including through innovative pathways and projects that are described in this report. However, experiences of care remain stagnant in comparison to people who aren't Autistic, with many Autistic people and their carers continuing to experience significant gaps.
More research is also needed to better understand how autism and eating disorders interact, which approaches best support Autistic people with eating disorders, and how these can be implemented consistently across the UK.

Policy and guidelines

It is of critical importance that existing laws across the UK stipulate the legal requirement for health and social care organisations to make it as easy as possible for Autistic people to use health services as it is for people who are not Autistic. This is an established anticipatory duty, which means services and organisations must proactively take steps to remove barriers Autistic people face.

There are multiple guidelines, frameworks, and ongoing pieces of work that align with the recommendations outlined in this report, such as the National Specification for the Care and Treatment of Eating Disorders in Scotland. A more detailed policy context can be found in the Appendix 1.

The need for change

This report emphasises the fundamental need for eating disorder support, autism services, and broader healthcare services to better understand the relationship between autism and eating disorders, recognise when autism may be influencing a person's eating difficulties, and ensure care is adapted to meet individual needs throughout their treatment journey. There is also an urgent need for more research to improve understanding of the experiences and needs of Autistic people with eating disorders, and that helps services provide accessible, effective, timely and equitable support.

There is also a real opportunity to improve support for Autistic people with eating disorders and their families and friends through what we do already know. This includes implementing and building on PEACE, a clinical framework that has set the foundations for demonstrating impact in supporting Autistic people with an eating disorder. It also includes using existing resources and practical guidance on autism-affirming adaptations and principles.

These challenges are not due to a lack of commitment from professionals. Rather, they reflect systemic issues, including gaps in training, guidance, service design, and resource. However, they do result in many Autistic people not receiving care that considers their unique experiences or meets their individual needs. Change is urgently

needed to ensure that autism-affirming care is embedded and consistently provided for anyone seeking or receiving support for an eating disorder in the UK.

A note on terminology

We use identity-first language ("Autistic people"), reflecting the preferences of many people within the Autistic community, feedback from Autistic people who contributed to this report, and the approach taken by Beat. We use a capital 'A' in "Autistic" to reflect the views of people who see being Autistic as an important part of their identity, culture, and community, rather than solely a medical diagnosis. We recognise that language preferences vary and respect individuals' choices about how they describe themselves. In direct quotes, language reflects that used by the individual.

Where we refer to carers, this can mean anyone who supports someone with an eating disorder in a personal capacity; parents, partners, siblings, grandparents, other family members, friends, or otherwise.

Where we refer to the term 'recovery', we recognise that this can mean different things to different people. Recovery is not a linear, one-size-fits-all experience or journey. As such, it is important to take a person-centred approach to the concept and work with the individual towards treatment outcomes that are meaningful for them (26).

2. SURVEY

To better understand the experiences of Autistic people with eating disorders and those who support them, Beat conducted a survey exploring experiences of diagnosis, accessing support, treatment experiences, reasonable adjustments, and priorities for improving care. The survey was advertised through Beat's social media accounts, websites, professional contacts, and email communications, inviting people with lived experience and those who support them to share their experiences.

The survey was developed collaboratively by Beat with input from people with lived experience and was informed by existing evidence relating to autism and eating disorders. The survey included questions for both Autistic people with lived experience of eating disorders and carers supporting someone Autistic and with an eating disorder.

The survey was open to people living in the UK and collected responses on:

- autism identification and diagnostic experiences
- experiences of accessing and receiving care and support
- reasonable adjustments and adaptations
- carer experiences
- co-occurring conditions
- suggestions for improving services and support

A total of 859 responses were received, including 541 responses from Autistic people with lived experience of eating disorders and 318 responses from carers.

Quantitative survey responses were used to identify key patterns and themes within the data, including responses relating to diagnosis experiences, treatment access, adaptations, and co-occurring conditions. Qualitative responses were analysed using thematic analysis to identify recurring themes and shared experiences across responses.

Several consistent themes emerged, which highlight that many of the challenges Autistic people with eating disorders face are not due to individual needs being 'too complex' to treat, but because systems and services are highly variable in supporting Autistic experiences and needs. Taken together, these findings offer valuable insight into the experiences of Autistic people with eating disorders and their carers, demonstrating the urgent need to improve care, remove avoidable barriers, and ensure services are better equipped to meet the needs of Autistic people affected by eating disorders.

Open text responses and quotations from the survey have also been used throughout this report to demonstrate the experiences of those directly affected and inform recommendations for change.

Age

Respondent ages varied. Table 1 shows the age distribution across all survey respondents, including those with direct experience of an eating disorder, and ages of the people that carer respondents told us about.

Age	Lived experience of an eating disorder respondents, n (%)	Carer respondents; age of loved one
15 and under	9 (2%)	94 (37%)
16-18	71 (16%)	72 (29%)
19-21	72 (16%)	36 (14%)
22-30	151 (34%)	27 (11%)
31-40	60 (13%)	5 (2%)
41-50	52 (12%)	4 (2%)
51-60	28 (6%)	5 (2%)
61-70	6 (1%)	3 (1%)
71-80	-	1 (<1%)
Prefer not to say	1 (<1%)	4 (2%)

Table 1. Age of survey respondents

Eating disorder type

Respondents were asked which eating disorder(s) they or their loved one had experienced. The eating disorders selected by each group are shown in Table 2.

Eating disorder type	Lived experience of an eating disorder respondents (n)	Carer respondents (n)
Anorexia Nervosa (AN)	347	179
Avoidant-Restrictive Food Intake Disorder (ARFID)	120	123
Bulimia Nervosa (BN)	100	19
Other Specified Feeding or Eating Disorders (OSFED)	91	23
Binge Eating Disorder (BED)	87	18
Other	36	32
Pica	10	12
Rumination-regurgitation Disorder	10	7

Table 2. Type of eating disorder experienced

Autism diagnosis

Respondents were asked about whether they or their loved one had received an autism diagnosis. Responses are shown in Table 3. Open-text responses from those selecting 'Other' indicated that most of these respondents were in the process of seeking or waiting for an autism assessment or diagnosis. Some reported that an assessment or diagnosis had been declined due to factors such as not being weight restored or service restrictions.

Autism diagnosis status	Lived experience of an eating disorder respondents, n (%)	Carer respondents, n (%)
Received a professional autism diagnosis	335 (63%)	225 (70%)
Had not received an autism diagnosis	109 (20%)	39 (12%)
Other	91 (17%)	54 (17%)
Total	535 (100%)	318 (99%)*

*Table 3. Autism diagnosis status. *Percentages may not total 100% due to rounding.*

Co-occurring conditions

Respondents were asked whether they had any other diagnosed conditions. The majority (355, 83%) reported having at least one other diagnosed condition, while 72 (17%) reported having no other diagnosed conditions. The most commonly reported conditions were anxiety and depression. Further detail on other diagnosed conditions is provided later in the report.

Other diagnosed condition	Respondents with lived experience of an eating disorder, n
Anxiety	201
Depression	181
No other diagnosed condition(s)	72
Total	535 (100%)

Table 4. Other diagnosed conditions reported by respondents with lived experience of an eating disorder

Eating disorder treatment

Respondents were asked whether they or their loved one had received treatment for their eating disorder. Responses are shown in Table 5. The majority of open text responses for 'other' also indicated being rejected support or waiting for treatment.

Treatment received	Respondents with lived experience of an eating disorder, n (%)	Carer respondents, n (%)
Yes	307 (68%)	193 (66%)
No	101 (22%)	55 (19%)
Other	43 (10%)	46 (16%)
Total	451 (100%)	*294 (101%)*

*Table 5. Eating disorder treatment received *Percentages may not total 100% due to rounding.*

Treatment setting

Respondents were asked where they or their loved one had received eating disorder treatment. Respondents could select more than one option, so totals exceed the number of respondents. The settings selected are shown in Table 6.

Treatment setting	Respondents with lived experience of an eating disorder, n	Carer respondents, n
Outpatient	275	97
Inpatient	142	62
Day patient	66	7
Other	36	59

Table 6. Settings in which eating disorder treatment was received

Timing of autism diagnosis (if received)

Respondents who reported that they or their loved one had received an autism diagnosis were asked when this occurred in relation to eating disorder treatment. Responses are shown in Table 7. Open-text responses highlighted prominent themes about autism assessment and diagnosis being long waiting lists and autism assessments being delayed until eating disorder symptoms had improved.

Timing of autism diagnosis	Respondents with lived experience of eating disorder, n (%)	Carer respondents, n (%)
Before eating disorder treatment	81 (22%)	63 (25%)
During eating disorder treatment	103 (28%)	83 (33%)
After eating disorder treatment	135 (37%)	55 (22%)
Other	46 (13%)	48 (19%)
Total	365 (100%)	249 (99%)*

*Table 7. Timing of autism diagnosis *Percentages may not total 100% due to rounding.*

Eating disorder treatment adaptations

Respondents were asked whether their eating disorder treatment had been adapted because they or their loved one was Autistic. Responses are shown in Table 8. The majority of open-text responses from those that selected 'Other' indicated that respondents felt treatment was insufficiently or partially adapted.

Treatment adapted because of autism	Respondents with lived experience of an eating disorder, n (%)	Carer respondents, n (%)
Yes	69 (22%)	46 (21%)
No	174 (56%)	101 (46%)
Other	68 (22%)	72 (33%)
Total	311 (100%)	219 (100%)

Table 8. Eating disorder treatment adaptations

Carer support

Carers were asked whether they had received support themselves in relation to their loved one's eating disorder. Responses are shown in Table 9. Open-text responses from those selecting 'Other' highlighted receiving limited support, or support via charities.

Carer respondents support received	n (%)
Yes	92 (39%)
No	92 (39%)
Other	51 (22%)
Total	235 (100%)

Table 9. Support received by carers

3. WHAT NEEDS TO CHANGE

The challenges noted here are not inevitable consequences of being Autistic. They occur because research into eating disorders has been consistently underfunded, and misconceptions and stereotypes persist, which means services have not been funded or set up to consistently recognise, understand and respond to Autistic needs.

Eating disorder care needs to move towards a model where autism is recognised, understood, and supported as part of standard practice. Autistic people should not be expected to adapt themselves to services that were not designed with their needs in mind.

This section summarises the key findings from Beat's survey and explores how these insights can be translated into practice to improve the recognition, access, treatment, and support available to Autistic people with eating disorders and their carers. Themes that emerged have been used to form subsections. Drawing on survey findings, lived experiences, evidence, and examples of good practice, each subsection highlights why change is needed and concludes with Beat's recommendations for creating more autism-affirming eating disorder services and support.

3.1 Improving identification and access to care

3.1.1 Why this matters

Autism is often recognised late, missed entirely, or misunderstood within eating disorder support and services. Many Autistic people described receiving eating disorder care for years prior to identification of their autism, whilst others were still waiting for assessment when their eating disorder treatment came to an end.

The Eating Disorders Clinical Research Network (EDCRN) aims to standardise information collected in eating disorder services and found that of the first 500 adult patients enrolled in the Network, 37% (n=185) scored above the screening threshold on the AQ-10 (28). While high AQ-10 scores aren't the same as an autism diagnosis, this finding highlights the importance of routinely assessing for Autistic traits within eating disorder services alongside other factors (demographics, co-occurring conditions). High AQ-10 scores were seen across eating disorder diagnostic groups.

Yet, identification alone is not enough. A formal autism diagnosis should not be required in order for someone to receive autism-affirming support. This is positively made clear in the National Specification for the Care and Treatment of Eating Disorders in Scotland. Considering the significant barriers and delays that many Autistic people face when seeking assessment, it is important that services consider individual needs as standard and make adaptations wherever they are required to meet individual needs.

Earlier recognition and support could improve experiences of accessing and receiving eating disorder treatment, reduce distress, prevent traumatic experiences, and ensure treatment is adapted to the individual's needs, thereby facilitating effective engagement. This can include routine use of standardised,

validated autism screening tools for all people presenting for eating disorder support such as the AQ-10 or Social Responsiveness Scale (SRS) alongside clinical input (28,29). These can usefully flag traits that may need to be taken into account, highlight the importance of considering reasonable adjustments, and contribute to a personalised formulation of the eating difficulties. NHS England's guidance on autism and eating disorders (30) provides further information on screening for autism in the context of eating disorders and disordered eating, and a report from Autistica (31) provides information on the screening tools available and their supporting evidence.

However, screening tools should not be the only approach used to identify autistic traits, as some questionnaires may not resonate with all Autistic people, and therefore clinicians should consider broader indicators such as masking and sensory sensitivities, lengthy nasogastric (NGT) feeding, and paradoxical effects of medication (30, 31).

3.1.2 Autism and eating disorders can be missed, misunderstood, and misdiagnosed

Where autism was recognised, the journey to receiving a diagnosis was described as long and difficult. For many, autism was identified only after their eating disorder treatment had ended, while others were still waiting for assessment at the time of completing the survey. Thus, many people spent significant periods of time receiving support without their Autistic needs being recognised. Misdiagnosis can also occur between different eating disorders, for example, people receiving a diagnosis of Anorexia Nervosa instead of ARFID.

"We are three years into the illness/ recovery and it's only the last few months Autism has been mentioned of being something she has."

"I think professionals need a greater understanding of how these conditions can look when combined. I was diagnosed with ASC at 24, but had struggled with food and control issues for a decade prior. I feel if either of my conditions were considered in context, I could have received better, more comprehensive support earlier."

"...the treatment I was given for my eating disorder was traumatic and prolonged my illness."

Some respondents felt that professionals missed their autistic traits because they did not match common assumptions about autism and how it presents. This was particularly highlighted by women and girls, who described being overlooked or due to masking, differences in presentation, and stereotypes that autism primarily affects boys and men.

Others described experiencing diagnostic overshadowing, where Autistic characteristics were interpreted as symptoms of an eating disorder or another mental health condition. Conversely, where there is an existing autism diagnosis, this could be interpreted as part of someone's autism rather than an eating disorder that needs support.

"[Clinicians] labelled autism as 'behavioural' and 'personality traits', even though she didn't meet diagnostic threshold for EUPD."

"Was originally diagnosed with Borderline Personality Disorder which I strongly disputed and always felt I wasn't listened to."

"I am diagnosed with mixed anxiety and depressive disorder but I feel that this was a misdiagnosis and the symptoms were actually due to struggling with undiagnosed autistic traits."

Behaviours that were part of respondent's Autistic experience, such as sensory sensitivities, preference for routines, difficulty with unpredictability, communication differences, or difficulties communicating emotions were sometimes understood only through the lens of the eating disorder. Similarly, intense autistic responses to overwhelming situations were misinterpreted as a result of mental health conditions.

Many people described the emotional impact of repeatedly feeling misunderstood within services. For example, a significant number of respondents disclosed feeling shame, hopelessness, exhaustion, trauma, and isolation when treatment failed to recognise their Autistic needs. Some felt they weren't taken seriously because their eating disorder symptoms were described away due to them being Autistic, and others described masking throughout treatment. These experiences resulted in a lack of trust in services and, for some, made engaging with treatment even more challenging. These misunderstandings across different domains and their impact are echoed in research (32), and together, these experiences can influence treatment outcomes.

"They [clinicians] said they didn't realise I was autistic…they just thought anorexia made me cognitively impaired, when I was like this before developing the illness. They made me feel ashamed."

Fundamentally, it is a legal requirement for services to provide reasonable adjustments (33, 34), and that professionals also have a duty of care to ensure confidence in identifying the possibility of autism. As stated in the Royal College of Psychiatrists report, 'The psychiatric management of autism in adults', "Therapies applied without awareness of the autism can be harmful or, at the least, ineffective." (35, p.43). Services should therefore have processes that enable staff to recognise when autism may be relevant, explore this sensitively with the person, and identify and implement reasonable adjustments without making support dependent on a formal diagnosis.

This work is also broader than preventing crises, it is also about early intervention preventing deterioration. Autistic people should be supported with earlier recognition of harmful eating patterns and support before diagnostic thresholds are met. This support should be integrated in schools, universities, primary care, and other relevant settings.

Examples of what this could look like in practice

- Asking about diagnosed, suspected, or self-identified autism at assessment and revisiting this during treatment, including through appropriate screening.
- Recognising that an eating disorder diagnosis in addition to existing autism diagnosis is important for informing clinical support and intervention.
- Looking beyond traditional stereotypes of autism by recognising that Autistic people may mask their differences or present differently across genders, cultures, sexualities, ages, and levels of intellectual ability.
- Avoiding making assumptions and instead, asking the individual about any differences in communication, sensory experiences, routines, and social interaction during eating disorder assessment, rather than focusing only on eating disorder symptoms.
- Remembering that Autistic people may feel misunderstood, blamed, or viewed as unwilling to engage with treatment, when they may instead be experiencing barriers that services have not recognised, and considering this if treatment appears ineffective.
- Providing autism-affirming adaptations where required, rather than waiting for a formal autism diagnosis.
- Providing a clear route to autism assessment and post-diagnostic support.

3.1.3 Understanding autism and eating disorders together

Understanding the interaction between autism and eating disorders is essential to ensuring people receive appropriate and effective support.

When autism is not properly understood or recognised, eating disorder treatment may unintentionally focus on changing autistic traits and behaviours without understanding why they occur or what someone may be communicating through their behaviour. Some Autistic people may eat specific and limited range of foods due to sensory preferences; they may eat in specific or categorised ways due to autistic preferences for routine and continuity; or they may eat small quantities of food due to differences in recognising fullness or hunger.

Understanding the interaction between autism and eating disorders is therefore essential. Without this understanding, Autistic people can feel misunderstood, blamed, or viewed as unwilling to engage with treatment, when they may instead be experiencing barriers that services have not recognised. This was reflected in the survey responses, where many respondents described instances of being told they are "difficult", "challenging", or "uncooperative". This led to feelings of shame, frustration, isolation, and losing trust in professionals that require trust for treatment to be effective. Some described masking throughout treatment as a result of feeling unsafe, whilst others felt they were not listened to or taken seriously once their autism was recognised.

> *"Binaries aren't helpful! My issues are both sensory and body image and self-worth related, to acknowledge one element and not the other is really unhelpful!"*

Another respondent explained that autism should not be viewed as something to remove or change, but as part of understanding the person's needs and experiences.

Given themes on not being heard or included in decisions about treatment, it is also crucial

that if the possibility of autism is considered, services should first discuss this with the individual (and their carers if appropriate) prior to making a referral for an autism assessment. This allows for time to adjust if needed, as well as factor that some people may not want to pursue a diagnosis at the current time, but that this does not mean they cannot benefit from adaptations.

Examples of what this could look like in practice

- Exploring why a behaviour occurs without assumptions or biases; remaining curious and open-minded, and listening without judgement.
- Exploring whether behaviours such as food restriction, avoidance, or distress around meals may relate to sensory experiences, predictability, communication differences, or emotional processing.
- Considering how autism and the eating disorder may influence each other, rather than attempting to separate them completely.
- Developing formulations that not only consider eating disorder symptoms, but also how to work with individual Autistic experiences.

3.1.4 Barriers to timely and equitable care

Many respondents described significant barriers to accessing eating disorder support. These included delays related to service availability, eligibility criteria, weight thresholds, diagnosis requirements, geographical variation, and whether someone's presentation fitted existing pathways.

These challenges are not unique to Autistic people, however, Autistic people reported being unable to access appropriate treatment because their needs did not fit existing service pathways. This was particularly highlighted by people with ARFID, people seeking support as adults, and those whose presentations did not align with traditional expectations of eating disorders.

"After being diagnosed with ARFID, when trying to access treatment, I was deferred to charities…which support Autistic people, but are not in any way an eating disorder treatment."

Others described needing to seek private treatment because suitable NHS support was unavailable, inequitable, or because eating disorder treatment waiting times were too long.

"The NHS by this time said they had given me all their resources and I was wasting it, but I was lucky to receive help from a private healthcare profession who did try different approach."

"The NHS care was so poor we were forced to fund private counselling, we are not a wealthy family and funding this significantly impacted on the family."

Autistic people may also face additional barriers related to other aspects of their identity, including gender, ethnicity, disability, sexuality, and socioeconomic background. Research led by Dr Kai Thomas on improving awareness, understanding, and support for eating disorders in Autistic, ADHD, and trans and gender diverse populations (as described in Appendix 3) highlights that eating disorders cannot be fully understood through any single aspect of a person's identity. Findings from the

project so far highlight that neurodivergent trans and gender diverse people described their eating disorders as ways of coping with a range of challenges, including social exclusion, sensory overwhelm, gender dysphoria, experiences of stigma and discrimination, and concerns about safety and belonging. A lack of awareness could make accessing treatment more difficult, particularly when there have been previous negative treatment experiences.

Work from the National Autism Society (37) on autism in racialised communities has explored why people are not receiving the appropriate support or diagnoses. This included people reporting assumptions from professionals due to a lack of cultural competence and humility, which can lead to a dismissal of families' views. Language barriers and the inaccessibility of services can make these challenges more difficult, particularly when considered alongside potential previous experiences of racial discrimination (38).

As noted in findings from a research project taking an anthropological approach to eating disorders (see Appendix 3.3) participants also explained their eating disorders emerged at the intersection between the challenges of living with autism in a non-accepting society; a range of adverse experiences, such as bereavement, bullying, family breakdown or abuse; multiple mental health and chronic physical conditions; reflections on and challenges with gender identity; and life transitions, such as leaving home and enrolling at university.

What is important is that eating disorders and autism do not sit in isolation from different aspects of someone's identity or wider societal inequalities, such as food insecurity. Rather than simply supporting people to consider these intersecting factors, clinicians should be aware of the potential intersections of identity with autism and eating disorders, including as part of assessing and formulating drivers of eating disorder behaviours.

Examples of what this could look like in practice

- Offering eating disorder assessments based on need, rather than relying solely on BMI or weight thresholds.
- Providing autism-affirming support whilst people wait for assessment.
- Reviewing referral criteria and waitlists e.g., to identify any groups that may be excluded from care or wait longer for care
- Improving pathway accessibility by removing barriers – physical, digital, cultural, financial, and communication e.g., through approaches such as language translation, plain English, pictures, or gestures, easy to use digital tools, flexible service hours, and flexible contact routes.

Beat therefore recommends:

Improving identification and access to care

1. Services should routinely consider autism during eating disorder assessment and throughout treatment (and conversely, eating disorders in an autism assessment). This should include routinely using autism screening tools alongside clinical judgement.

a) Where autism (or an eating disorder) is suspected or identified, there should be a timely discussion to explore potential next steps, and referrals to appropriate pathways for diagnosis, assessment, and post-diagnostic support.

b) Autism-affirming support and reasonable adjustments should be available based on identified needs, regardless of whether someone has a formal autism diagnosis, including for people who self-identify as Autistic. Services should avoid requiring a formal diagnosis before considering or implementing appropriate adjustments.

c) Services should consider barriers to recognition, including masking, diagnostic overshadowing, assumptions about who is likely to be Autistic, and differences in Autistic presentation. This should include considering both autism and eating disorders when assessing people with eating difficulties and avoiding assumptions that disordered eating is simply part of being Autistic. Services should also explore an individual's profile where they present with a known autism diagnosis.

2. Autistic people with eating disorders should be able to access timely treatment.

a) Access to timely treatment should be regardless of weight, diagnosis, age, presentation, location, or personal characteristics.

b) Services should recognise and address inequalities that may affect identification, access to care, treatment experiences, and outcomes.

3. Services should take an intersectional approach to assessment, formulation, and treatment.

a) Services should recognise how different aspects of a person's identity, lived experience, life stage, and co-occurring conditions may interact with their eating disorder, presentation, support needs, and experience of care.

b) Staff developing formulations and treatment plans should have the knowledge and skills to consider these factors appropriately.

What these recommendations mean to me – lived experience perspectives

"I just wish Autism was far more considered than it is. If clinicians are constantly asking "why?"; why isn't this patient getting better, why aren't they fitting into a neat diagnostic box, why are their symptoms so different, why do they experience such an array of difficulties? Then services need to start considering neurodivergence more and keeping it at the heart of their work. Being caught up in a web of services and misdiagnoses is so painful because you are constantly left feeling like you never fit in and therefore will never get the right support or get better."

"....I found this did apply to me during certain parts of treatment, I had a clinician who listened to me explain how I was doing directly before we looked at weight or how I had gotten ready for my appt etc. It made me feel more heard and understood which built a better client-therapist relationship, making therapy feel safe. I benefited more from this rather than in the past leaving appointments feeling frustrated or invalidated."

"I had this recommendation implemented into my treatment with adult services through Specialist Supportive Clinical Management as it was a more collaborative treatment taking on board a holistic view. Often with eating disorders, it is about more than just food, I found this approach enabled me to address other factors that may be contributing. My formula felt more like 'me' rather than an eating disorder."

3.2 Providing autism-affirming care

3.2.1 Why this matters

Autism-affirming care means recognising that autism is an important part of a person's identity and experience, while ensuring that treatment meets their individual needs as an Autistic person. Every Autistic person is unique, with different needs and strengths, so will require different adaptations. Importantly though, autism-affirming care is not just about adapting existing treatment. Individual formulation is essential to understanding the person in consideration of their autism, their eating disorder, and the relationship between the two.

Autism does not explain every aspect of an eating disorder, but it does give insight into how specific traits and characteristic may be driving and maintaining an eating disorder, and how a person's Autistic experiences, communication, support needs, and engagement may interact with eating disorder treatment.

"Health professionals need to understand that the Autistic brain works differently to a neurotypical brain and therefore traditional treatments may not work."

"Having an eating disorder is horrible whether you're autistic or not, but being squashed into the one-size-fits-all "treatment" plan is both alienating and demotivating."

Recognising that behaviours may communicate unmet needs, rather than unwillingness to engage, is a vital part of supporting Autistic people to engage meaningfully in treatment. This requires services to take responsibility for creating environments

where Autistic people can communicate their needs and access appropriate support, rather than placing the responsibility solely on individuals to adapt to services that may not meet their needs. For example, involving Autistic people in developing and reviewing their formulations, where appropriate, can support shared understanding and help ensure that their needs, experiences and preferences are accurately reflected throughout their care. Clinical documentation should use clear, respectful and non-stigmatising language, acknowledging that these records can shape how their experiences are understood by others involved in their care.

Embedding such approaches within care as standard is an important part of ensuring that autism-affirming care is available consistently across eating disorder treatment and should be personalised and informed by the individual's formulation, recognising that adaptations that are helpful for one person may not be appropriate or helpful for another. Further, autism-affirming care should not depend on individual clinicians' knowledge or expertise, specialist services, or where someone lives. This means ensuring that staff are appropriately trained to understand and respond to the needs of Autistic people, and that reasonable adjustments are identified and implemented as part of routine care. This should include consideration of Autistic people with intellectual disabilities, recognising that support may need to be further adapted to ensure treatment is accessible and appropriate for people with a range of communication, cognitive and support needs.

A consistent message shared by respondents was that eating disorder treatment was often based on a "one size fits all" approach. Many described services that expected Autistic people to adapt to existing treatment models, rather than adapting care around the person.

"It is horrendous seeing the person you care for seemingly making no progress with their eating disorder because the treatment given to them doesn't take account of their autism."

Autistic people should not have to mask, suppress their needs, or experience distress in order to access effective eating disorder care.

3.2.2 Autism-affirming adaptations that helped

One of the strongest themes from the survey was that autism-affirming adaptations were often inconsistent and frequently depended on individual clinicians rather than being embedded across services.

However, some respondents described positive experiences where clinicians adapted their approach, took time to understand their needs, and worked collaboratively with them. Calm, predictable, low-pressure, relationship-based approaches that prioritised trust and flexibility were cited as improving their experience and outcomes of care. However, other respondents described receiving the same treatment approach regardless of their autism diagnosis or support needs.

"My therapist helped me in situations where I felt overwhelmed because of sensory overload, such as dining rooms and restaurants, and helped me to work out how to better manage those types of situations. This helped me to differentiate when I was struggling with sensory overload and when my eating disorder was bothering me."

"For my son it was learning to trust one doctor and not see different people all the time. Once he trusted a doctor he was able to respond to treatment."

Respondents described a wide range of adaptations that could make eating disorder treatment more accessible and effective, including:

Communication

- Clearer and more predictable communication, including written information alongside verbal discussions
- Alternative ways of communicating e.g., writing instead of talking
- Advance notice of treatment sessions and of any changes to plans, noting that these should be avoided where possible
- A communication passport (38) to document the person's unique communication styles, preferences, and needs (linked is an editable version from PEACE).
- Replacing open-ended or vague language, with explicit expectations and written, step-by-step instructions
- Clear expectations of what will happen and why
- Patience and understanding

Adjustments to service delivery

- Additional time to process information
- Adjustments to sensory environments
- Consideration of food and sensory preferences
- Support that recognises differences in emotional awareness and body signals
- Flexible approach to treatment plans e.g., slower pace such as longer mealtimes

Type and continuity of care

- One-to-one support
- Consistent and predictable routine e.g., fixed appointment times
- Consistent staff members

Environment

- Lights being dimmed or turned off for therapy sessions or mealtimes
- Quiet spaces available for people to retreat
- Grounding tools or weighted lap pads being available to support with overwhelm.
- Some people were provided with their own room during inpatient stays rather than shared spaces and were able to disengage with group related activities.
- Where in-person support felt unsuitable, some respondents explained that they were able to receive online support instead.

These adaptations were not seen as optional additions. Rather, they were essential to being able to meaningfully engage in treatment.

"My therapist emails a summary of the session. Therapy is undertaken in a preferred room in my [outpatient] OP unit. It's quiet, there's no distractions such as windows where I can see traffic etc outside."

"Autism varies so much person to person and so strategies that work for some people might not work for others. Similarly with ARFID there can be different reasons behind it and different sensory needs… it really needs to be tailored to every individual, rather than basing things on stereotypes."

"Providing lots of information about the service before starting would help make something that is already scary and new a bit less scary."

Examples of what this could look like in practice

- Discussing with the individual adaptations that may help them to engage with treatment effectively.
- Accurately and collaboratively documenting agreed adaptations in care plans, so they are consistently implemented by all staff. In England, this includes the use of reasonable adjustments digital flag.
- Providing flexibility where possible, rather than expecting everyone to engage in the same way.
- Reviewing adaptations throughout treatment to ensure that they remain effective and making further autism-affirming changes where they are not.

3.2.3 Sensory differences

Sensory differences were consistently reported by respondents as an area of difficulty in their eating disorder treatment due to reasons like finding clinical settings too loud, bright, unpredictable, and distressing.

"Being put into hospital with new loud and constant sounds, away from safe people and seeing dozens of strangers each day, with a completely different routine is a nightmare. During my time in hospital, I only got worse and actually lost more weight from stress and anxiety which stopped me from eating and sleeping."

There was a call for treatment and environments to consider the individual's needs from the start and throughout, with sensory differences being better understood and accommodated. Participants emphasised that these sensory challenges are not "excuses" or "ED behaviours," but important aspects of the Autistic experience that need recognition and adaptation.

"I feel so uncomfortable with physical contact most of the time, so constantly having to be touched to be weighed and for physical observations can be intimidating when the nurse changes constantly. Having a certain nurse do it would be great."

"I struggle with different textures of food but it's because I am autistic and this was prevalent long before my eating disorder. But it can be framed as restriction or disordered when it is actually a sensory need."

Research highlights that many Autistic people experience sensory processing differences (39,40). This can be experienced as:

- Hypersensitivity or over-responsiveness: This is where someone may respond to sensory input very strongly to the point it can cause significant distress, physical pain, and other intense involuntary responses such as being unable to talk. For example, loud noises or bright lights in a clinical setting, intolerable food smells or textures on a meal plan, the temperature in a hospital room, and overwhelm from crowded places. It can also include responding strongly to noticing even small variations or differences in sensory experiences.
- Hyposensitivity or under-responsiveness: This is where someone may seek out sensory input such as fabrics or food textures, smells or flavours, or from sensory supports like fidget toys.

In PEACE's 'Recommendations for autism and ADHD in eating disorders: Guidance for clinical teams' (41) it is advised that practical

strategies for supporting people experiencing sensory processing differences may include:

- *"considering quieter, calmer environments during meals and therapy sessions*
- *reducing sensory overload where possible, including noise, lighting, temperature, smells or crowded spaces*
- *allow and normalise the use of sensory supports such as fidgets or weighted items*
- *exploring sensory preferences around food textures, flavours, smells, colour and temperatures*
- *introducing new foods gradually alongside familiar or "safe" foods*
- *considering ways to support regulation if exercise needs to be limited, such as grounding activities, a rocking chair, music, art, sensory boxes or other agreed sensory strategies"*

The examples listed here can apply variably, and it is still important to check the individual's needs. Moreover, it is also important to note that people may need support to tolerate and manage different sensory experiences rather than accommodations alone so that the eating disorder is being treated in an appropriate way for the individual. This also applies where familiar or safe foods are insufficient.

Examples of what this could look like in practice

- Considering the individual's sensory profile and understanding how different sensory input can impact Autistic individuals.
- Adjusting the environment to suit the individual's sensory needs as much as possible.
- Considering preferences related to lighting, sounds, smells, textures, and temperatures throughout treatment, including during meal planning.
- Focusing on mental wellbeing rather than rigid clinical milestones.
- Recognising that sensory distress may affect engagement with treatment.

3.2.4 Strengths-based treatment adaptations

Autism-affirming care also means recognising that Autistic characteristics can be strengths within treatment and outcomes. Some respondents explained that the adaptations they received made use of their individual Autistic strengths, which made treatment more effective.

For example, their preference for structure, logic, or rules as part of the treatment approach, such as treatment plans being structured in a clear, step-by-step way, that made it feel like a system to support treatment outcomes. Another common example was dedicated interests being considered in therapy sessions, to improve treatment engagement.

"Knowing that I will always think in rigid ways and build rules allowed me to realise that I could also think differently and make new rules. It also allowed me to reflect on how my eating disorder had become my special interest, and that I could build other interests. It looked like challenging my world views and providing new ones, rather than focusing on feelings or actions that I had around eating and exercising. It was essentially about changing the rule book. We also focused on building supplementary behaviours that could turn into new special interests (e.g. baking, sewing, learning a new language etc) and on managing meltdowns, which frequently happened when I "over-ate" or "under-exercised"."

"The dietitian used my interest in psychology and brain chemistry to educate me on the eating disorder."

Autistic traits can be incorporated into treatment approaches in ways that are meaningful to the individual. When treatment considers the person holistically, it can lead to better treatment outcomes and long-term recovery. Outcomes that matter to Autistic people should be considered too, including quality of life, autonomy, safety, independence, relationships, and personal goals. This is particularly important given potential differences in understanding of recovery.

Examples of what this could look like in practice

- Working with the individual's Autistic strengths e.g., attention to detail, dedication to routines, special interests, direct communication.
- Recognising that autism is a difference, not something to be 'cured'.
- Involving the individual as an expert in their own experience when formulating treatment plans.
- Exploring what 'recovery' means to the individual and collaboratively working towards goals that are meaningful to them.
- Supporting shared decision-making and autonomy as much as possible.

3.2.5 Needs, not non-compliance

Another recurring theme across survey responses, was that Autistic needs and differences were sometimes interpreted as unwillingness to engage in treatment.
When respondents were experiencing distress, overwhelm, overstimulation, uncertainty, communication barriers, or other difficulties related to their experience as an Autistic person, they shared that they were labelled as "challenging", "complex", "difficult" or "non-compliant".

"I personally was in eating disorder therapy for years without any of my therapists realising I had autism. I was seen as a 'hard patient to work with' because I would be nonverbal in sessions."

"My autism was mistaken for refusing treatment and I was threatened with tube feeding and being sectioned because I was misunderstood. I wanted help but could not communicate it."

Eating disorder services need to understand that behaviours they may consider "difficult" may communicate distress, differences in ways of thinking, and needs that aren't met by typical treatment approaches.

For example, struggling to answer broad, open-ended questions, becoming unable to talk or overwhelmed during appointments, or finding particular foods intolerable does not necessarily suggest refusal or a lack of motivation to engage. Instead, they may indicate unmet needs that require a different approach to treatment, better support, or consideration of barriers.

Examples of what this could look like in practice

- Not assuming that difficulties in treatment are due to non-compliance or unwillingness to engage. Instead, exploring this with the person and consider whether it may reflect distress related to unmet Autistic needs e.g., sensory or communication differences
- Avoiding penalising or labelling people as 'treatment resistant due to difficulties in treatment
- Using collaborative problem solving and autism-affirming adaptations to overcome potential barriers and difficulties

3.2.6 The impact of previous care experiences

Some Autistic people may have experienced distress, overwhelm, or trauma as a result of interacting with healthcare services, including during previous eating disorder treatment. As highlighted by survey respondents, this can affect the individual's and their carer's trust, sense of hope, and ability to engage with future treatment.

It is therefore crucial that services take this into account when supporting Autistic people and their carers. Services should seek to understand how these experiences may influence a person's current needs and engagement in eating disorder care, and how this may appear as avoidance or unwillingness to fully engage. Recognising and addressing the possibility of iatrogenic harm can help to rebuild trust and prevent avoidable distress (42).

3.2.7 Communication preferences and needs

> *"For me the thought of having to openly exchange conversation with someone about something so personal is frightening."*

Autistic people may have different communication preferences, needs, and approaches to non-Autistic people. Research suggests that for many, there is preference for direct, concrete, and literal communication without hidden or implied meanings, assumptions, or hints.

Communication itself can be a barrier to eating disorder treatment, and this was a common theme across survey responses. Respondents described verbal information being difficult to process, uncertainty about what was expected of them, and communication that felt unclear or inaccessible. Autism-affirming approaches to communication made the difference between being able to engage with treatment or not.

It was also noted that building relationships can take time, and treatment should therefore factor for this, for example, by building a trusting and safe relationship with a small number of people rather than introducing an entire team at once, and through an understanding that the pace of treatment should consider time for processing. This is particularly important when considering the timeframe in which treatment is provided.

There were also calls for a better understanding of demand avoidance (43). This is a term used by some Autistic people and clinicians to describe an intense need to avoid or resist perceived demands and expectations, which

can be perceived by the brain as threatening. For example, following a strict meal plan or acting on the internal sensation of hunger may be difficult for Autistic people with eating disorders, and can be driven by a need for a sense of agency. However, more research is needed to better understand this and how it can present in Autistic people with eating disorders.

"...the demands of eating disorder treatment can be an additional battle for those who are Autistic."

Examples of what this could look like in practice

- Using clear, concrete language and avoiding unnecessary ambiguity.
- Providing written summaries after appointments.
- Allowing additional processing time before expecting responses.
- Using social stories before distressing events or appointments
- Offering different communication methods where appropriate, such as email or visual information.
- Using interests to reduce perceived demands and increase treatment engagement.

3.2.8 Eating experiences and preferences

A preference for certain foods, textures, or routines may be part of someone's Autistic experience, an eating disorder behaviour, or both. Understanding the individual's experience is therefore essential. As one respondent explained:

"Autism varies so much person to person and so strategies that work for some people might not work for others. Similarly with ARFID there can be different reasons behind it and different sensory needs... it really needs to be tailored to every individual, rather than basing things on stereotypes."

Examples of what this could look like in practice

- Exploring the role of routine, structure, predictability, and sensory preferences when meal planning.
- Exploring changes to food intake collaboratively and at an individually appropriate pace, considering sensory needs, eating disorder symptoms, and the person's capacity to tolerate change.
- Exploring whether food avoidance is linked to sensory needs, difficulties related to ARFID, eating disorder driven restriction, or an interaction between these.

3.2.9 Interoception, alexithymia, and emotional regulation

Some Autistic people struggle with recognising internally bodily cues, such as hunger, thirst, pain, and bathroom signals. Over time, these signals can build up and can lead to overwhelm, and physical symptoms like exhaustion, dizziness, and digestive issues. This is often referred to as interoceptive differences. Further, alexithymia refers to the difficulty anyone can experience in recognising, describing, and understanding their own emotions. These challenges can significantly contribute to and maintain eating difficulties. However, the term alexithymia is also often defined in a neurotypical way, in that Autistic people may relate to a feeling or sensation but interpret it differently to someone who is not Autistic.

Where overwhelm, or shutdowns occur, clinicians can support emotional regulation. In PEACE's 'Recommendations for autism and ADHD in eating disorders: Guidance for clinical teams' (41) it is recommended that clinicians can support regulation by:

- "validating, and exploring distress rather than immediately challenging it
- anticipating situations that may be dysregulating and reducing avoidable sources of distress where possible
- helping patients to explore, name and understand emotions, triggers and early signs of overwhelm
- teaching distress tolerance, grounding and soothing skills
- Some clinicians use the ALVS approach during distress:
  - Attend — give full attention
  - Label — name what you observe
  - Validate — acknowledge feelings
  - Soothe — support regulation"

Examples of what this could look like in practice

- Understanding that some people may struggle to identify hunger, fullness or emotions.
- Offering use of visual scales or structured prompts to support emotional awareness.
- Avoiding assumptions that someone can identify and describe internal experiences.
- Supporting with coping strategies that do not rely on being able to identify emotions.

3.2.10 Co-occurring conditions

Autism commonly exists alongside other physical health, mental health, and neurodevelopmental conditions, which was reflected in survey responses. A significant number of respondents (n=355, 83%) reported co-occurring conditions, often chronic and long-term. Common conditions included hypermobility disorders like Ehlers-Danlos Syndrome, and Post Orthostatic Tachycardia Syndrome (PoTS). Other frequently reported conditions including fibromyalgia or chronic pain, migraines, gastrointestinal issues, and asthma, highlighting a pattern of chronic and multisystem health conditions. It demonstrates that this work also applies to wider support services, including but not limited to:

- Acute hospitals and paediatric wards;
- Primary care
- Dietetic services
- Gastroenterology and other physical-health specialities;
- Service involved in physical monitoring and medical stabilisation

Over 50% reported experiencing anxiety and depression alongside their eating disorder and being Autistic, and many reported multiple overlapping mental health or neurodevelopmental diagnoses, including Obsessive Compulsive Disorder (OCD), ADHD,

and post-traumatic stress-related conditions.

Co-occurring conditions need to be considered as part of a person's treatment plan, rather than viewed separately or treated in isolation. For example, anxiety may interact with a need for predictability, trauma may influence someone's sense of safety whilst receiving treatment, ADHD may affect executive functioning and ability to concentrate in long therapy sessions, and physical health conditions may influence energy levels or eating experiences.

Without considering the person as a whole, people's individual needs may be misunderstood, not met, or attributed solely to their eating disorder or autism. This can result in eating disorder care that does not meet the needs of someone's overall experience.

"You cannot ignore either aspect when thinking about the impact on my life and the treatment I need. My eating disorder and autism are intertwined and complex."

Services should also recognise that co-occurring intellectual disabilities may affect how someone communicates, understands information, expresses themselves, and engages in treatment. Autistic people with intellectual disabilities should receive autism-affirming care that is accessible, supports their needs and autonomy, and enables meaningful involvement in decisions about their treatment.

Overall, the findings emphasise the importance of holistic, integrated approaches to autism-affirming care. This should include joint working with other teams, as discussed further on in the report.

Examples of what this could look like in practice

- Routinely exploring commonly co-occurring conditions such as ADHD, OCD, chronic pain, and gastrointestinal conditions.
- Considering how co-occurring conditions may impact treatment experience and engagement.
- Recognising that multiple conditions can exist simultaneously, to avoid diagnostic overshadowing.
- Jointly working with other professionals as appropriate, to ensure individual needs are met.

3.2.11 Consistency in autism-affirming care

Many respondents described receiving effective adaptations from individual clinicians, while other aspects of their care remained inaccessible. This shows that autism-affirming care cannot depend on individual staff members, specialist knowledge located in an individual, or the particular service a person happens to access.

Autism-affirming approaches should be embedded across eating disorder services as standard practice in the UK, ensuring that all Autistic people can access and receive care that understands and meets their needs, supports autonomy, and enables meaningful engagement.

Examples of what this could look like in practice

- Embedding autism-affirming adaptations throughout standard clinical practice, policies, and guidance, rather than relying on individual clinicians.
- Ensuring that adaptations are agreed with the person, clearly documented and communicated across transitions between professionals and services.
- Monitoring and auditing the consistency and effectiveness of autism-affirming practice across services, including through feedback from Autistic people.

Beat therefore recommends:

Providing autism-affirming care

4. Services providing care to people with eating disorders should provide person-centred, autism-affirming care as standard, that is suitable for Autistic people.

a) Appropriate, personalised adaptations to communication preferences, sensory and environmental needs, and treatment approaches should be included within care plans.

b) Adaptations should consider sensory differences (including those related to taste, smell, texture, sound, sight, and other sensory experiences), differences in recognising or responding to internal bodily signals such as hunger and fullness, food preferences, communication needs and differences, and the ways autism may influence eating behaviours and patterns and a person's experience of having an eating disorder.

c) Co-occurring mental and physical health conditions and disabilities should also be considered, including how they may affect the experience of being Autistic with an eating disorder.

5. Treatment and care plans should be developed collaboratively with the person with the eating disorder (and carers where appropriate), starting from an assumption of capacity and recognising the importance of autonomy, choice, and shared decision-making.

a) Plans should reflect individual priorities, communication preferences, support needs, and preferences around language and identity.

b) Plans should be shared in an accessible format and reviewed regularly throughout treatment to ensure they continue to meet the person's needs, including through the use of tools such as communication passports.

What these recommendations mean to me – lived experience perspectives

"This is a very important recommendation; I am particularly interested in the sensory differences surrounding autism. I felt that in early treatment, this was disregarded and noted as negative eating disorder behaviours which in turn made food and mealtimes more stressful, with negative associations. It felt forced, I think if I had been listened to, it would have created a safer space around food, and promoted recovery showing that clinicians don't want to work against you, but with you. Your voice and preferences heard."

"Ensuring good communication and teamwork will ensure fewer Autistic people fall through the gaps between services. By establishing good communication, Autistic people are less likely to be left alone with their struggles."

"In every way possible the whole system is not built for it. They want to put people in boxes and when they don't fit they don't know what to do. Services need to be joined up cohesive and collaborative. They're not."

3.3 Ensuring joined-up care

3.3.1 Why this matters

Autistic people with eating disorders may require support from multiple services, including eating disorder professionals, autism services and organisations, mental health teams, primary care, and physical health services. Yet, respondents described their care as disjointed due to a system that operates disjointly. This can have devastating consequences (44).

Although carers should not be expected to fill gaps created by poorly coordinated systems, this issue occurred consistently whereby people were routinely required to act as the link between services. Many carers described having to chase eating disorder referrals, explain the needs of their loved one repeatedly, challenge treatment decisions, and advocate for autism-affirming support that should have been considered from the start and implemented as standard.

Some carers reported that services passed responsibility between each other, leaving carers and their loved ones unclear about who was responsible for providing support. This meant that support could become inconsistent and inadequate, with needs falling through the gaps.

This responsibility carers commonly described, can place significant pressure on families, leading to carer's struggling with their own mental health. Care should be coordinated so that Autistic people and their carers are not left responsible for joining the pieces together themselves.

A comprehensive service mapping conducted as part of the National Audit of Eating Disorders in England investigated how many teams had shared care protocols, referring to how teams will collaborate with other teams when someone is receiving care from more than one healthcare provider type. It found that only 32% of teams had shared

care protocols for neurodivergence, 36% for psychiatric comorbidities, and 35% for physical comorbidities.

Services should establish clear communication pathways, shared responsibilities, and approaches that support continuity of care across teams.

> *"'It's complex' is all we ever heard but both the eating disorder and the autism are intrinsically linked. However, no one knows how to deal with it."*

3.3.2 Poorly coordinated care

Respondents described significant challenges when different services did not communicate effectively or understand their respective responsibilities. Some reported that eating disorder professionals focused primarily on eating disorder symptoms, while autism or other services focused on separate aspects of their needs. This could leave important areas of support unaddressed and create uncertainty about who was responsible for helping.

Respondents described:

- having to repeatedly explain their autism, eating disorder, and support needs to different professionals
- receiving conflicting advice from different services
- services passing responsibility between teams
- delays caused by unclear referral pathways
- difficulties accessing support when their needs did not fit neatly within one service

These experiences could increase distress, reduce trust in services, and make it harder for people to engage with treatment. They can also lead to trauma, a worsening of symptoms, increased risk, increased likelihood of more intensive treatment needs, and increased risk of the use of restrictive practices. Recognising previous treatment trauma and considering how to avoid re-traumatisation is fundamental to this work. Services should also monitor restraint, nasogastric feeding under restraint and compulsory treatment by autism status.

Examples of what this could look like in practice

- Holding regular multidisciplinary meetings between services and professionals involved in the individual's care. Autistic people (and their family/carers) should be included where possible, in which case attendance should be limited to those who need to be there, to avoid overwhelm.
- Appropriately documenting and sharing care plans (with consent as appropriate) across services.
- Advance planning and clear communication for invasive or restrictive interventions.
- Detailing Autistic needs of patients and carers within documented care plans.
- Communication and sensory adjustments during urgent or compulsory care.

3.3.3 Supporting effective transitions

Transition between services can be particularly difficult for Autistic people with eating disorders, as changes in routine, environments, relationships with professionals, uncertainty, and understanding of expectations can create significant distress.

Examples of transitions include:

- moving from children and young people's services to adult services
- moving between inpatient, day patient, and community care
- changing treatment teams

- transitioning between eating disorder and autism services

Respondents noted that transitions were often poorly planned, and they typically received limited information about what would happen next, which can be extremely anxiety-inducing or stressful. For Autistic people, uncertainty and unexpected changes can create additional barriers to engaging with care. Effectively managing transitions has also been highlighted as a key theme in Beat's report on intensive community and day treatments for eating disorders.

Examples of what effective transition planning for Autistic people could look like in practice

- Early preparation and planning prior to any changes
- Changes made slowly, rather than all at once or in a short timeframe, allowing time for processing and questions
- Clear communication about what to expect, in a way that considers the individual's communication preferences
- Opportunities to meet any new professionals
- Consideration of sensory preferences and needs
- Appropriate adjustments to reduce distress
- Continuity of care throughout the transition
- Involvement in treatment decisions related to the transition

3.3.4 Carer's needs

For many Autistic people with eating disorders, families, carers and loved ones play a key role in providing support, advocating for their needs, and helping them navigate eating disorder treatment. However, carers reported that systems were not working together effectively to support their loved one. This meant that they were often left largely responsible, having to be experts in both autism and eating disorders in order to support their loved one.

"Families need so much help and support and specific training for eating disorders and autism would be very welcome. I was left to try and get information myself from internet & charity/agencies."

Carers also highlighted that their own needs were often overlooked. Many shared receiving little to no support from eating disorder treatment teams, with their needs rarely acknowledged or discussed. They also described challenges in accessing clear information, understanding services and treatment decisions, and knowing how best to support their loved one. This can contribute to what is referred to as systems generated trauma.

Many carers who responded to the survey were also neurodivergent, making it especially important that carer support is accessible and autism-affirming. This means recognising different communication preferences and support needs, such as providing information in a range of formats, offering alternative ways to communicate, and avoiding assumptions about how carers engage with services. This should also be considered for the wider support network, such as siblings. Carers reported feeling confused, lost, frustrated, exhausted, and terrified; this highlights the significant emotional impact of supporting someone with an eating disorder, and the importance of ensuring carers receive adequate support, too.

"I've received no support… been told we should "just feed them."

Supporting carers does not mean replacing the voice, autonomy, or decision-making role of Autistic people with eating disorders. Instead, it means recognising the valuable role carers can play in treatment and recovery, while ensuring that the person receiving care remains central to decisions about their treatment and support. It also means understanding the impact that supporting someone with an eating disorder can have on those around them, and that supporting them can help them to provide more informed and sustainable support. throughout their individualised recovery.

"Been handed a meal plan and told "no one said this would be easy" is not enough support."

"It broke my daughter's spirit and confidence…The whole process distanced me from my daughter and left our relationship in tatters as well as my marriage…My life is ruined."

"It's utterly exhausting, terrifying, soul destroying and I wouldn't wish the experience on my worst enemy."

Notably, when asked how support for carers could be improved, many respondents focused first on improving services for their loved one rather than on their own needs. This suggests that carers viewed autism-affirming treatment as the most important form of support they themselves could receive.

3.3.5 What carers told us would help

Carers told us they wanted:

- Services to communicate better with each other, patients, and carers
- Clearer explanations about treatment and the reasons behind decisions
- To be involved appropriately and meaningfully in care planning, that acknowledges their role and knowledge of their loved one
- Their value as a carer to be recognised and utilised
- Accessible information on how to support autistic loved ones with eating disorders, including online and in-person support networks.
- Support that considers their own needs, including where they may also be neurodivergent

"It is exhausting, especially when the care given is disjointed and the patient is blamed for not recovering. Carers are accused of being controlling. We should spend time working with services but instead are fighting to be listened to."

When families and carers are supported as partners in care, this can improve communication, reduce distress, and help ensure that treatment reflects the needs and experiences of Autistic people with eating disorders.

Autistic people and their carers should not have to fight for coordinated, autism-affirming care. Services should work together to ensure that support is accessible, consistent, and centred around the person.

Examples of what this could look like in practice

- Involving carers in care planning (where appropriate and when consented to) whilst recognising their value and expertise.
- Offering carers support as standard practice, including regular communication, asking what they need, and recognising they may also be neurodivergent.
- Providing clear, accessible information about autism and eating disorders, treatment decisions, and care planning.

Beat therefore recommends:

Ensuring joined-up care

6. Eating disorder, autism, and other relevant services should establish clear communication pathways, agreed processes for joint working, and named points of contact to prevent avoidable gaps and delays in treatment.

a) These arrangements should be regularly reviewed to ensure they are meeting the needs of Autistic people with eating disorders.

b) Where more than one service is involved, clear responsibilities for care across providers should be set out in treatment plans, understood by all services involved, and communicated to person with the eating disorder.

7. Transitions to and between different services (such as moving from children and young people's services to adult services or from inpatient to community care) should be planned well in advance, with transition planning beginning at
least 6 months before planned transitions where possible.

a) Planning should consider the individual needs of Autistic people, including reasonable adjustments to the transition process, taking into account time needed to process information.

b) Transitions should involve shared decision-making with the patient (and carers where appropriate), be clearly communicated to everyone involved, and include ongoing support throughout the transition period.

8. Families, carers and loved ones should be recognised for the caring role they provide and routinely offered information, support and opportunities to be involved in decisions about treatment, balanced by the wishes of the Autistic individual, in line with guidance.

a) This should include recognition and support for carers who are also neurodivergent. Information and support should be accessible and autism-affirming, taking into account individual communication preferences.

What these recommendations mean to me – lived experience perspectives

"I was fortunate to experience this recommendation during treatment, when moving from CAMHS ED to adult services. My lead clinician from CAMHS introduced me to my adult service clinician months in advance. We had joint sessions for a while with both services and then I had a crossover period where I was seeing adult services but still had to contact with CAMHS. This made a difficult transition that bit easier with me feeling like I had begun to process it and settled into the 'new' version of treatment. I was able to speak freely with my CAMHS clinician who I had an amazing relationship with which made me feel safer to begin sessions with adult services as my worries had been listened to and problem solved if possible. It also meant my new clinician had seen how I interacted with someone I was comfortable with and how they could apply that to their style and future treatment with me for better outcomes."

"Having the lifesaving support my parents gave me during my eating disorder questioned and pathologised, before I knew I was autistic, was deeply harmful and wouldn't have happened had I been identified as neurodivergent earlier. The support of my family is an important part of accommodating my autism. Whilst some areas of this might be regarded as childish, by knowing I am autistic I am empowered to stand up for this requirement."

3.4 Supporting staff

3.4.1 Why this matters

Staff across healthcare services continue to face unprecedented demands for their time, and ensuring that they have the space to learn, reflect, and ask questions is an important part of continued development.

A consistent theme throughout the survey was that the quality and accessibility of care often depended on individual clinicians' understanding of autism rather than being embedded within services.

The interaction between autism and eating disorders is nuanced and multifaceted. For some people, Autistic characteristics may influence the development or maintenance of eating difficulties, while eating disorders may affect Autistic experiences.

A common misconception is that many eating disorders are primarily driven by concerns about weight or appearance. While these concerns are part of current diagnostic criteria for many eating disorders, Autistic people may experience eating difficulties for a range of reasons, including:

- Sensory differences relating to food textures, smells, tastes, or presentation
- A need for predictability and routine
- Difficulties with interoception (recognising internal body signals such as hunger or fullness)
- Emotional regulation
- Experiences of overwhelm or feeling a loss of control

It is there also worth noting that some measures may be difficult for Autistic people to complete and/or may not capture their experiences in a way they consider meaningful.

It is important that services understand the different ways autism and eating disorders can affect eating, while recognising both can exist together. For example, a preference for predictability or certain foods may be part of someone's Autistic experience, an eating disorder behaviour, or both. Understanding the individual's experience is therefore essential. Many of the practical adaptations and strategies suggested in this report can be implemented without significant additional resources.

As some respondents explained:

> *"Although he's had these disordered eating behaviours since we can remember, clinicians blamed it on his autism and being an autistic trait rather than ARFID."*
>
> *"Often, during my treatment, my autistic traits towards food were confused with my eating disorder which made recovering harder as I could not eat the foods I was being given... I was forced to eat foods that were touching and that's textures I could not eat."*
>
> *"The treatment I experienced didn't take into account my need for safe foods and safe textures and claimed everything was an eating disorder behaviour when it was not."*

Many respondents reported that some staff members adapted treatment to meet their needs as an Autistic person, but other staff and teams didn't. Similarly, other clinicians were trialling approaches with no evidence-base, admitting that they were unsure how best to help, emphasising the need for further evidence as recommended in this report. It also highlights the inconsistent approach to treating Autistic people with eating disorders in the UK. It is therefore fundamental that autism-affirming care is a standard part of eating disorder treatment, rather than something dependent on individual knowledge or awareness.

Autistic people are experts in their own experiences. Training should be co-produced with people with lived experience, and clinical and research teams, and delivered alongside statutory training. This has also been recommended by PEACE colleagues (45), and should include:

- Adapting communication styles
- Supporting emotional regulation and expression
- Providing information in accessible formats
- Understanding and adapting for sensory needs
- Understanding different ways of expressing needs
- Making environments autism-affirming
- Co-occurring conditions
- Considering food preferences and sensory experiences
- The role and importance of considering intersecting characteristics
- Consent, confidentiality, capacity and safeguarding
- Supporting and addressing potential past negative experiences
- Involving Autistic people in decisions about what support would help

Moreover, simply measuring whether training has been completed is not sufficient alone. It should also be measured whether care is being adapted and the effect this is having. For example, percentages of people with a recorded communication profile, sensory assessment or documented sensory needs, whether adjustments were or are being delivered, continuity of clinicians, and whether advance information has been provided. It

should also include whether the person felt listened to and involved, whether treatment pace and format were adapted, and carer involvement where this has been agreed by the patient.

This should be delivered in a way that meets the needs of professionals and is considerate of the significant pressures services currently face.

3.4.2 The role of autism-affirming care leads

As mentioned above, people described navigating siloed services, unclear pathways, and poor communication between services, which impacted treatment outcomes. They suggested a more coordinated approach, including professionals who understand both autism and eating disorders, and who have part of their role dedicated to ensuring Autistic people and their carers are appropriately supported during contact with a service.

Carers also highlighted that professionals often lack knowledge about how autism and eating disorders interact. They reported that eating disorder treatments have been ineffective because they did not consider their loved one's autistic traits, such as sensory sensitivities, language differences, or demand avoidance. They emphasised the need for staff to receive training on both autism and EDs, including ARFID, and to understand the variety of ways eating disorders can present in Autistic individuals.

Having a staff member strategically responsible for addressing issues such as gaps in patient care, staff training, or the treatment environment, who delegates responsibilities where relevant could help to ensure that each service is taking a proactive approach. It also opens up a network of leads to share best practice and develop a community of practice across services. Leads should have defined competencies, protected time, access to supervision and organisational authority to influence training, pathways, environments, data and quality improvement. Their remit, governance and succession arrangements should be documented.

This role should complement, rather than replace, responsibility across the whole service for providing autism-affirming care by building team capability and accountability.

Examples of what this could look like in practice

- Supporting colleagues with advice and implementation of autism-affirming adaptations.
- Working with Autistic people and carers to review and improve local services.
- Using service data and patient feedback to identify and address inequalities in access, experience, and outcomes, and support service improvements.

Beat therefore recommends:

Supporting staff

9. Staff providing treatment and care to patients with eating disorders should receive regular and up-to-date training in autism-affirming care that builds on statutory training. This may be internally delivered or through a national provider.

a) Training should be co-produced with people with lived experience of autism and eating disorders, and clinicians and researchers.

b) It should include Autistic presentations, communication and sensory needs, treatment adaptation, masking and diagnostic overshadowing, how autism and eating disorders can interact, reasonable adjustments, awareness of co-occurring conditions, and practical approaches to adapting assessment and treatment to meet individual needs.

10. Services should appoint 'Autism-affirming care leads' within their teams who can bring together different perspectives, evidence, and lived experiences, and lead on ensuring the right support is available.

a) These leads should have appropriate knowledge, protected time, and organisational support to influence practice and service development.

b) Insights and improved data collection should be used by commissioners and providers to meet the needs of local populations and reduce inequalities in access to care.

c) This role should complement, rather than replace, responsibility across the whole service for providing autism-affirming care.

What these recommendations mean to me – lived experience perspectives

"Dedicating time and effort to improving the lives of autistic patients is essential. It shouldn't be understated how much education is needed to defeat stereotypes and outdated information. People can only begin to make changes in their practise once they have been given the education and tools to do so."

"Learning from autistic people about autism is so key to making sure education will benefit autistic patients. We should always endeavour to see real experiences and stories shared in training."

3.5 Improving data collection and the evidence base

3.5.1 Why this matters

It has long been difficult to compare outcomes or understand which approaches work best across different eating disorder services in the UK because of different types of information collected. As noted earlier in the report, the Eating Disorders Clinical Research Network (EDCRN) aims to establish a UK-wide network of eating disorder services (across all age groups) who will collect the same standardised information, including on eating disorder symptoms, outcomes, demographics, and risk factors. This will also allow for further research and understanding where improvements are needed. As part of the consensus building work to agree a standardised dataset for use within the network, autistic traits were strongly endorsed as an area for consideration (46). As a result, the AQ-10 has been included as a core questionnaire for use at different timepoints for adults and children. Lived experiences shared during one of the workshops align with findings from Beat's survey, with an adult with lived experience involved in the consensus work stating, *"I had other factors of trauma, physical disability, autism, and…if they weren't dealt with in the correct way, it made the motivation for change for eating disorder recovery much more difficult until they were addressed in a holistic way and bringing all those strands together and piecing them all up."*

Although awareness of the relationship between autism and eating disorders has increased in recent years, significant gaps remain in the evidence base. More research is needed to understand how autism, eating disorders, and other conditions interact, which interventions best support Autistic people with different eating disorders, and how effective models of care can be implemented consistently across services. There is also an urgent need for research examining the role of race, ethnicity, culture, class, or sexuality in supporting Autistic people with eating disorders, a lack of which limits generalisability.

When improving data collection and the evidence base, different types of outcomes should be explored. This includes:

- Clinical and physical outcomes
- Treatment-process related outcomes
- Service outcomes
- Patient-reported outcomes
- Quality of life and participation outcomes
- Care outcomes
- Safety and harm outcomes

When asked about what needs to change, both Autistic people and carers consistently called for more research to allow for tailored support. There was also a clear message that Autistic people and carers must be meaningfully involved in shaping research, services, and improvements. Their experiences provide essential insight into what helps, what causes harm, and what needs to change. This should include reimbursement where relevant.

> *"So much more research and understanding is needed, so that support can be given to both the person and their carers."*

Importantly, an absence of evidence should not be interpreted as evidence that adaptations are unnecessary.

As noted in the literature review (Appendix A) that has informed this report, projects that have examined the research priorities of Autistic and neurodivergent people with disordered eating or eating disorders include the impact

of early experiences, barriers and facilitators to eating disorder recovery, understanding and considering for co-occurring conditions and intersecting characteristics, and changing research culture.

A vicious cycle of funding in eating disorders research has previously been highlighted in a report compiled by Beat (47), which found that targeted actions and a coordinated, strategic approach towards building the capacity of the field is needed. This makes the case for targeted funding calls on this topic, and to develop centres of excellence building on existing networks. The networks described in this section rely on precarious funding, and to take this work further, long-term and stable investment is crucial.

3.5.2 Building on existing work

Two key projects leading the way in the field are the PEACE Network and the Eating Disorders and the Autism Collaborative (EDAC). PEACE provides pioneering work in the research and clinical innovations as well as crucial insight into how care can be tailored to a person's needs, strengths and lived experiences, and EDAC is an interdisciplinary network that brings together the field of autism and eating disorder research. Sustaining and growing these networks to better develop our understanding will be a key part of addressing some of the challenges addressed in this report. Details on both are presented on the next few pages.

Pathway for Eating Disorders and Autism (PEACE)

PEACE is led by Professor Kate Tchanturia MBE, who was consulted through the process of developing this case study. Prof Tchanturia was supported to generate research evidence and translate this into an innovative neurodivergent inclusive eating disorder pathway from The Health Foundation, Medical Foundation Research, Maudsley Charity, BRC, MRC.

What is PEACE?

The Pathway for Eating Disorders and Autism (PEACE) was developed by the Maudsley team at South London and Maudsley NHS Foundation Trust and King's College London in 2019 (48). Using an iterative approach through the Institute for Healthcare's Model of Improvement quality improvement methodology, it identified the barriers experienced by Autistic people with eating disorders when accessing and receiving treatment, and sought to improve care. Developed with Autistic people with eating disorders, clinicians, carers, and researchers, its evidence base and use has continued to grow since then, calibrating care around personalised formulation, resources and interventions informed from research evidence and lived experience.

The PEACE pathway website (www.peacepathway.org) is regularly updated by Professor Kate Tchanturia's research and clinical multidisciplinary team as well as a collaborative network of people with lived experience. PEACE has had international interest and implementation, with website analytics demonstrating that resources and materials have been downloaded widely in 160 countries across the world, as seen on the next page.

87,300 downloads from 160 countries for 2025/2026

The original pathway was implemented using several different approaches which included:

- Training for clinicians through regular training events and translating information into applicable adaptations.
- Support for clinicians through weekly team huddles (49) to provide psychoeducation, supervision, knowledge exchange, ensure continuity, and identify any additional training needs
- Introducing screening for better patient identification
- Addressing sensory sensitivities through a brief sensory screener (50), the development of

a specialised PEACE menu, and environmental adaptations
- Flexibility with the length, pace and focus of treatment sessions
- Psychoeducation materials for patients and supporting adapted materials
- Autism-friendly welcome packs for patients sent prior to an inpatient admission
- Communication passports for each patient (51).
- Ensuring carers were considered key 'stakeholders', and adapted carers' workshops to consider Autism
- Resources for patients, carers, and professionals

Since the start PEACE has become widely recognised as an example of good practice. It has also improved patient and clinician experiences, alongside reducing inpatient admissions. An evaluation of its implementation at an adult inpatient eating disorder unit saw a reduction in the average inpatient stay for Autistic patients from 19 to 13 weeks. Estimated cost-savings were approximately £22,837 per patient, and approximately £275,000 per year for the service as a whole (52).

Clinicians' perspectives of the Pathway highlight clinical benefits such as improved treatment engagement and flexibility, as well as service benefits such as increased confidence, team collaboration, and awareness.

How can PEACE be implemented in different services?

A recent paper from (53) examined key lessons from the development and implementation of the PEACE Pathway, offering practical insight, and a checklist for self-assessment for teams to adopt or expand beyond these adaptations. This is particularly important given research indicating the potential for harm when neurodivergence is not understood or accommodated (54).

The above study used data on implementation and adaptation of the Pathway from three different UK sites to explore how it was integrated, challenges faced, and what helped with implementation. This was then used to support key components essential for embedding autism-informed adaptations in eating disorder services.

These three sites were:
- PEACE-Maudsley—The original PEACE at SLaM, focusing on clinical adaptation in a specialist eating disorder service.
- BOB-PEACE—Buckinghamshire, Oxfordshire and Berkshire West— First adaptation of PEACE for community child and adolescent mental health services (CAMHS) across a broader NHS network (Integrated Care System).
- EDAC — Eating Disorders and Autism Collaborative in Scotland—A research and collaboration initiative integrating Autistic individuals' lived experience to guide best practices.

These core domains were approached differently in each site, tailored to different settings, as can be seen on the next page.

Domain	PEACE-Maudsley (Specialist Adult ED Service)	BOB-PEACE (Community Child and Adolescent ED Service)	EDAC-PEACE (Research Initiative Focusing on Lived Experience Collaboration)
1. Knowledge on PEACE Pathway	In-person and online training sessions; annual conferences.	Monthly webinars for all staff; outreach to schools and voluntary organisations.	Webinars and podcasts for training.
2. Assessment and Treatment Planning	Initial assessment by autism screening tool, communication passport, and sensory screening.	Similar tools adapted for CAMHS populations and multi-agency settings.	Co-developing assessment tools with Autistic individuals.
3. Psychological Treatments and Individualised Support Plans	Tailored session structure and communication strategies based on needs screening.	Additional psychoeducational content to support treatment delivery and emphasis on family involvement.	Systematic adaptations of evidence-based ED interventions.
4. Sensory Wellbeing Management	Structured environmental sensory support; sensory wellbeing workshops.	Similar sensory support in sessions with young people; supplementary clinician-supported modules.	Patient-led adaptations based on sensory audit of the clinical environment.
5. Nutritional Management	Adjustments to textures, flavours, and food temperatures guided by sensory needs.	Adjustments to textures, flavours, and food temperatures guided by sensory needs.	In progress.
6. Lived Experience Network and Feedback	Patient input informs clinical team decisions.	Co-production activities in collaboration with Autistic people.	Co-production activities in collaboration with Autistic people.
7. Family and Community Engagement	Structured guidance for family involvement in treatment; family workshops; partnerships with autism community and organisations.	Family therapy as the central treatment model; partnership with autism community and organisations.	Priorities for support shaped by community voices.
8. Staff Training and Development	Regular training through workshops, supervision, clinician huddles and structured learning materials.	Regular training webinars, clinician huddles, training led by Autistic individuals with lived experience of eating disorders.	Training led by Autistic individuals with lived experience of eating disorders.

In recognition that it is important to consider the risk of compromising intervention effectiveness due to adaptations that may compromise fidelity, the PEACE Self-Assessment Checklist offers a structured framework for services to align with the principles of PEACE, and to identify any gaps in autism-informed care.

The checklist was refined using a co-design approach and was piloted in six outpatient teams and two inpatient services, with clinician feedback gathered at each site.

Category	Definition	Assessment Criteria	Indicators of Implementation
1. Knowledge on PEACE Pathway	Familiarity with the PEACE Pathway, including access to resources and understanding of its principles PEACE-Maudsley peacepathway.org (accessed on 14 April 2025) PEACE—BOB peacepathwaybob.org. (accessed on 14 April 2025) EDAC edacresearch co.uk (accessed on 14 April 2025)	□ Staff have access to PEACE Pathway resources (e.g. conference recordings, book, guides, PEACEBOB showcase). Staff demonstrate understanding of PEACE Pathway principles.	Staff can articulate key principles of the PEACE Pathway. Evidence of resource utilisation in treatment plans or staff discussions. Evidence of collaboration or engagement with wider teams, including neurodevelopmental services.
2. Assessment and Treatment Planning	Focuses on the use of autism-specific tools for assessment and individualised treatment planning.	□ Short assessment screens (e.g. AQ-10, SRS-based formulation) are used. Autism diagnostic pathways are also in place (if further evaluation is required). □ Reasonable adjustment checklists are used/considered. □ Sensory sensitivity screens are consistently documented. □ Patients are routinely offered the opportunity to complete a communication passport. Individual treatment plans include sensory and communication needs.	Regular use of tools for screening and planning. Comprehensive, individualised treatment plans addressing autism-specific needs. Evidence of reasonable adjustments being made in care plans/treatment delivery.

Category	Definition	Assessment Criteria	Indicators of Implementation
3. Psychological Interventions and Individualised Support Plans	Evaluates adaptations in psychological therapy to align with Autistic needs.	□ Therapy formulations are adapted to Autistic needs. □ Communication strategies in therapy are individualised. □ Therapy sessions follow a clear, structured approach and are adapted to Autistic needs where possible (e.g. shorter or more frequent sessions, visual guides, etc.). □ Consider supplementary sessions focusing on increased understanding of the overlap between autism and EDs and related needs.	Documented evidence of therapy adaptations. Positive feedback from Autistic individuals on therapy structure and communication.
4. Sensory Wellbeing Management	Addresses sensory-friendly environments and access to sensory tools.	□ Quiet rooms or sensory-friendly spaces are available (Consideration should be given to the overall clinical environment, with an emphasis on reducing sensory stressors such as bright noise, smell, cluttered wall space, arrangement of furniture). Environmental modifications might also include tools to enhance communication about the environment (e.g. videos of services, pictures of waiting rooms, or other visual aids to familiarise patients with the space before their visit). □ Sensory tools (e.g. sensory boxes, weighted pads; the use of weighted pads should be considered carefully for patients with anorexia nervosa), noise-cancelling headphones are accessible. □ Sensory well-being workshops and/ or psychoeducation leaflets are offered to patients. □ Using sensory needs assessments (i.e. communication passport).	Presence of sensory-friendly spaces and tools. Scheduled sensory well-being workshops as part of treatment plans. Patients' awareness of their sensory needs and the resources/handouts. Sensory needs are assessed and documented within communication passports and care plans. Staff are making conscious effort to reduce sensory stressors like the use of key covers, dimming lights, etc.

Category	Definition	Assessment Criteria	Indicators of Implementation
5. Nutritional Management	Focuses on accommodating dietary sensitivities and nutritional needs.	□ Meal plans consider dietary sensitivities and sensory preferences. □ PEACE menu guidelines are followed. □ Patients report satisfaction with nutritional planning.	Documented dietary adjustments for sensory sensitivities. Positive patient feedback on meal plans.
6. Lived Experience Network and Feedback	Ensures incorporation of insights from Autistic individuals.	□ Patient feedback forms or interviews are regularly conducted. □ Feedback from Autistic individuals informs pathway improvements.	Clear process for collecting and using patient feedback, ensuring people have meaningful opportunities to participate in the design and evaluation of the service. Organisations should also demonstrate how this feedback has influenced and resulted in tangible changes to improve service delivery. Examples of pathway adaptations based on lived experience insights.
7. Family and Community Engagement	Measures involvement of families and community groups in support processes that are autism informed.	□ Support network involved in treatment planning and reviews. □ Autism community groups collaborate with the organisation and/or are clearly signposted. □ Autism-specific family support programmes or resources are available.	Regular family involvement in treatment reviews where appropriate. Partnerships with local autism-support organisations.

Category	Definition	Assessment Criteria	Indicators of Implementation
8. Staff Training and Development	Assesses staff training on autism-specific needs and the PEACE framework.	□ PEACE resources or materials included routinely in induction of new staff across relevant pathways in ED and neurodevelopmental teams. □ Staff participate in PEACE huddles or autism-specific training sessions. □ Training materials are readily available. □ Staff receive ongoing professional development on autism-friendly practices. □ The service adopts an autism-affirming stance, focusing on promoting Autistic strengths in treatment planning and avoiding deficit-based models of autism.	Majority of staff trained in autism-friendly practice. Evidence of ongoing professional development (e.g. workshops, seminars). PEACE website resources are accessed. Training materials available for autism-friendly and autism-affirming approaches. Evidence of autism-affirming practices, including resources celebrating neurodiversity (e.g. pamphlets, online materials), policies reflecting an autism-affirming stance, and feedback demonstrating awareness of neurodiversity-affirming approaches.

For more detailed information and relevant references please visit peacepathway.org

The Eating Disorders and Autism Collaborative (EDAC)

This case study was compiled by Dr Fiona Duffy and Dr Karri Gillespie-Smith.

What is EDAC, and what is it aiming to do?

There is a pressing need for new research focusing on eating disorders in Autistic people, involving wider and more diverse collaborations. The Eating Disorder and Autism Collaborative (EDAC: edacresearch.co.uk) is an interdisciplinary network that brings together the field of autism and eating disorder research. EDAC is led by Dr Karri Gillespie-Smith and Dr Fiona Duffy from the University of Edinburgh alongside other academics and third sector partners across the UK. The aim is for all research activity to be led and co-produced by Autistic individuals with living and lived experience of eating disorders. It is jointly funded by the Medical Research Foundation, UKRI and the National Institute for Health and Care Research.

EDAC aims to improve our understanding of eating disorders in Autistic people and develop better treatments for them by

- Bringing together an open and diverse research network led by Autistic people and lived experience.
- Bridging the gap between autism and eating disorder research.
- Creating better opportunities for early career researchers and peer researchers

At EDAC we feel passionate about making sure the research we do is meaningful and can have a direct impact on the treatment and care of Autistic individuals with eating disorders. As a result we focus on actively integrating our research into clinical services and translating research findings into eating disorder treatment and care. Over the past two years we have been working with clinical services in NHS Lothian to integrate research findings into care and some of this work is included in this case report.

What kind of projects has EDAC worked on?

EDAC has been able to work on a range of different research studies over the past three years that have translated into clinical tools or interventions. The following is a snapshot of some of this activity.

- **Adapting FT-ED for Autistic young people and their families.**

Eating disorder focused family therapy (FT-ED) is the first line intervention for young people presenting with Anorexia Nervosa. However, eating disorder services delivering FT-ED report that Autistic young people and those with higher autistic traits have an increased likelihood of needing more intensive care and longer treatment duration (55-57). EDAC's work exploring clinician (58, 59), young people (60) and parents/carers (58) experience of delivering or receiving this intervention identified specific themes that would lend themselves to making adaptions to the model. Thanks to funding from the Medical Research Foundation we were able to translate this research into co-produced guidelines on how to adapt FT-ED for Autistic young people and their families. The guidelines are now published (62) and training for clinicians is freely available via EDAC's website.

- **Social Stories to support use of nasogastric feeding in inpatient units.**

Nasogastric tube (NGT) feeding can be used in inpatient care for people with eating disorders, and in certain incidences is necessary under

physical restraint. While at times necessary, it is highly distressing. A high proportion of young people who receive NGT feeding under restraint may be Autistic. The Melville adolescent inpatient unit in NHS Lothian CAMHS introduced autism-affirming resources (social stories, individual preference sheet) embedded in a service improvement project to reduce NGT feeding under restraint. A service evaluation found that most young people reported the social stories were helpful, or would have been when they first received NGT feeding and most clinicians who had used them stated they had reduced distress. All staff and young people who had used the preference sheet to support collaborative care planning found it helpful. These findings were embedded in a larger QI project which saw a reduction in NGT feeding under restraint from a median of 20 to 1.5 a week over one year. The evaluation has been written up, alongside all of the NG stories for other services to use, and available here (64).

- **Use of a sensory checklist to audit our clinical environments.**

At EDAC we co-produced a sensory checklist which can be used as part of a walk around audit of the clinical environment (clinic rooms, waiting rooms, physical health treatment rooms, inpatient units etc) with Autistic people with eating disorders. The aim is to identify sensory experience of these spaces (e.g. bright overhead lighting, food smells) that might be overwhelming for some Autistic patients. This information can then be used to develop an action plan to amend the environment, or where this is not possible to be able to prepare people for this (e.g. providing photos of the environment in advance), to make our clinics as accessible as possible. The audit tool is free to download here: EDAC's Sensory Environment Audit Tool | EDAC (64)

- **Autism affirming eating environments.**

Hospitality plays such an important part of socialising and family life and we know that eating environments and services can play a role in the isolation and loneliness of Autistic people and those with intellectual disabilities. Previous research has revealed that there are three key factors that contribute to this: the food and menu, the utensils and crockery, and the wider eating environment. EDAC has been able to team up with hospitality services at Edinburgh University to trial neuro-inclusive eating services. This has involved special staff training, adapting the environment, being thoughtful around how orders are taken and food is presented. We are currently writing up this trial and look forward to sharing the results so other restaurants can begin to incorporate these findings.

What's next for EDAC and how can people get involved?

We have been privileged to do this work over the past three years. The project has been able to support meaningful research, driven by Autistic people with lived experience. We have been able to set the platform for future research by co-producing research priorities for Autistic people with eating disorders (65) and best practice guidelines of how to co-produce research in this field (66). We fully support the campaign to increase research funding in eating disorders so more meaningful research can create an impact on eating disorder treatment outcomes (67). If you want more information, please see our website: edacresearch.co.uk or follow us on LinkedIn or Instagram for more information.

Beat therefore recommends:

Improving data collection and the evidence base

11. Researchers and services should be supported and funded to strengthen the evidence base for autism-affirming eating disorder recognition, treatment, and service models.

a) Research should be co-produced with Autistic people with lived experience of eating disorders, and families, carers and loved ones.

b) Approaches should be evaluated and published, so that models which deliver the best outcomes can be identified and promoted for adoption.

c) This should include longer-term follow-up data, economic evaluation, outcomes that are meaningful to Autistic people, and carer outcomes, and be used to inform service development, improvements, and future research priorities.

12. Research funders should continue to support networks for autism and eating disorders that bring together lived experience, clinical expertise, and up-to-date research evidence, such as the Pathway for Eating Disorders and Autism (PEACE) and the Eating Disorders and Autism Collaborative (EDAC). These networks offer opportunities to inform and share evidence, develop good practice, facilitate collaboration, reduce variation in care, and support the implementation of vital autism-affirming approaches across the UK.

What these recommendations mean to me – lived experience perspectives

Research into new treatments and different ways of supporting neurodivergent people will give a lot of people hope.

4. CONCLUSION

"I believe I have an eating disorder mostly due to the fact that I am an Autistic person, which is to live in a world in which you aren't listened to, you are expected to jump through impossible hoops, you are consistently told your perception is untrustworthy, and at the same time, you should just be able to get on with these things like anyone else."

This report highlights the tangible impact late recognition of autism can have on outcomes during eating disorder treatment. Similarly, individuals who receive an autism diagnosis may also experience the negative impacts of late recognition of an eating disorder. Diagnosis must not become another barrier to ensure communication, sensory, and other needs are met, nor should one diagnosis overshadow another. The report also indicates the need for earlier intervention.

We know inconsistent access to eating disorder care affects many people with an eating disorder as a systemic issue. For Autistic people there are further inconsistencies in relation to autism-affirming care. This also impacts carers, who find themselves in positions of needing to advocate and coordinate care for their loved one.

The so-called 'complexity' of Autistic people that we have repeatedly heard of sits partly within fragmented and inflexible systems, not within the person as a defect. There is a clear need for further research, particularly in exploring the experiences of underserved groups, but we know enough to start changing services and to make a meaningful difference. What is also evident is that autism-affirming care changes lives, and these adaptations are not optional extras. They have their foundations in legal requirements, guidelines, and specifications, and are needed to improve experiences, safety and engagement. Work from PEACE, EDAC, and local services (see Appendix 4) demonstrate this, as do the experiences of clinicians we spoke to as part of this report.

Scaling these efforts through co-production can drive meaningful culture change across the UK, ensuring that people receive consistent, personalised support and that recovery is shaped around treatment outcomes that are meaningful to them. This in turn has the additional benefit of cost-savings that can then be re-invested back into services, relieving some of the pressure on strained services, creating a cycle of better, more effective and sustainable care.

Survey respondents spoke highly of the professionals who worked with them and their families to understand their needs, reflective of the important work services do every day. Implementing the changes described in this report at a service level are crucial, and it is therefore only right that the appropriate resources and research funding should be made available to build on these much-needed changes.

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APPENDIX 1: POLICY CONTEXT

This section outlines relevant policy documents across the UK, emphasising that the direction of travel across nations is towards integrated, person-centred care delivered locally. Moreover, while some of the documents are nation-specific, many have learnings and information that are more broadly relevant.
Under the Equality Act 2010 (which is applicable in England, Scotland, and Wales) (33) and the Disability Discrimination Act 1995 (applicable in Northern Ireland) (34), it is a legal requirement for health and social care organisations to make it as easy as possible for Autistic people to use health services as it is for people who are not Autistic. This is an anticipatory duty, which means services and organisations must proactively take steps to remove barriers Autistic people face.

The National Institute of Health and Care Excellence (NICE) provides guidance and information on different health-related topics, and is used in England, Northern Ireland, and Wales. This includes a guideline on eating disorders (NG69) (68). There are also two separate pieces of guidance, on autism in under 19s (69), and in adults (70). While the eating disorders guideline does not reference Autism, and vice versa, all three refer to the importance of collaborative working.

Scottish Intercollegiate Guidelines Network (SIGN) Guidelines for eating disorders (71) reference Autism as a condition to consider when managing patients with eating disorders, and it is noted as having been considered in all key questions that formed the basis of the evidence used to develop the guideline. Similarly, SIGN Guidelines on the 'Assessment, diagnosis and interventions for autism spectrum disorders' (72) identify the disproportionate risk of eating disorders.

1.1 England

The Autism Act 2009 (73) requires the UK government to publish and continue to review an autism strategy. The Autism Strategy 2021-2026 (74) covered children and young people alongside adults for the first time and has priority areas including preventing inpatient admissions where possible, improving inpatient mental health settings for those who need them, and improving community mental health and crisis support. The House of Lords made recommendations (75) for the next autism strategy in 2025.

An independent review of mental health conditions, ADHD, and Autism has sought to "make recommendations to create a fairer and better system of treatment and support". It is due to have reported at the time of publication. The interim report found that the rate of eating disorders has increased. This review is expected to inform the development of a new autism strategy (76), for which timescales have not yet been published.

Under the Health and Care Act 2022 (77), it is a legal requirement for health and social care providers registered with the Care Quality Commission to have all staff trained in autism and learning disabilities relevant to their role. The training (78) was named after Oliver McGowan, whose death emphasised the need for better training. The Act also placed a duty for the government to issue a code of practice covering further details on the training such as content and accreditation, which was published in 2025 (79). It sets out standards for the training and takes a tiered approach to the content, based on the Core Capabilities Framework for Supporting Autistic People (80). The first tier includes reasonable adjustments,

self-reflection on own attitudes and behaviour, with further tiers including avoiding diagnostic overshadowing, accessible communication, and frequently co-occurring conditions including eating disordersThe underlying approach to NHS England's guidance for children and young people's (CYP) eating disorder services (81), published in 2026 is to take a personalised care approach. It states that where assessment for autism is required from another service, the eating disorder service (EDS) should continue to provide treatment without delay. Reasonable adjustments or adaptations should be made across settings, throughout treatment, and throughout transitions. A diagnosis is not required for the consideration and provision of reasonable adjustments. The guidance notes that staff working in CYP mental health services, and in eating disorder services should develop the skills to support people with neurodevelopmental conditions and/or who have a learning disability. It also states that it is 'imperative' for all clinicians to be familiar with Dynamic Support Registers and Care, (Education) and Treatment Review (C(E) TR) processes.

The equivalent guidance for commissioners and providers of adult eating disorder services (82) notes that community eating disorder services should take an integrated approach where multiple services are required. It also notes the need to consider Autism as a co-occurring condition, as there may be a need to adapt treatment.

The Dynamic Support Register (DSR) and Care (Education) and Treatment Review (C(E) TR) Policy (83) was published in 2023 by NHS England and set the expectation for Integrated Care Boards to maintain a register of Autistic people and people with learning disabilities who are at risk of being admitted to a mental health or a specialist hospital to allow for early recognition of crisis and implement support in the community. Where there is a risk of admission a C(E)TR should take place to explore options in the community to avoid this, or to explore discharge if someone is already in hospital.

In 2023, NHS England published guidance for ICBs, health organisations and wider system partners on meeting the needs of Autistic adults in mental health services (84). It includes within its scope all services within an ICB area that are involved in assessing, supporting, or treating the mental health of Autistic adults, including those who do not yet have a formal diagnosis. It sets the expectation for ICBs to develop a local commissioning strategy to ensure appropriate support. It also has a number of different aims, including reducing restrictive practices (which include a lack of control or choice), reducing inpatient admissions, and improving experiences of accessing services. The guidance also sets out how its different principles can be applied at different levels of the stepped care system.

In relation to inpatient care specifically, NHS England's draft adult eating disorder inpatient service specification (85) states that services must not exclude patients purely on the presence of a learning disability or autism. The CAMHS Tier 4 inpatient specification, which includes eating disorders, also covers neurodevelopmental conditions within its acceptance criteria. In 2024, NHS England published culture of care standards for mental health inpatient services (86), which cover autism-informed, culturally competent, and trauma-informed inpatient care.

While many of the policy and guidance documents mentioned above do not always overlap in their mention of autism and eating disorders, in 2026, NHS England developed a draft guidance on eating disorders and

autism for all age groups with eating disorders or disordered eating (30). Aimed at all services and teams that interact with or offer treatment and support for eating disorders and/or disordered eating, it highlights multiple key areas. This includes the importance of early identification of eating disorders and disordered eating, screening for autism as part of an initial eating disorders assessment, how to conduct a collaborative formulation, and accessible service design and reasonable adjustments. It also considers the treatment process, reducing the risk of an avoidable admission, managing an inpatient stay where needed, managing transitions, and the importance of training and supervision. It covers the whole treatment pathway. It also makes reference to current data collection requirements.

1.2 Northern Ireland

The Autism Act (Northern Ireland) 2011 (87) requires the Department of Health to publish an Autism Strategy for all ages, and to report on it. This legislation was further strengthened by the Autism (Amendment) Act (Northern Ireland) 2022 (88), introducing provision for improvements such as reducing diagnostic waiting times, and requirement for the strategy to take a cross-departmental approach. The Autism Strategy 2023-2028 (89) sets out multiple commitments, including access to early intervention in support, and creating inclusive environments. In addition, an independent Autism Reviewer has been appointed to monitor and report annually to the NI Assembly on progress related to implementation of the Autism Strategy and 2022 Amendment.

The Regional Care Pathway for the Treatment of Eating Disorders (90) published by the Health and Social Care Board (HSCB) states that treatment should focus on personal strengths, and support people in making decisions about their own care. It also refers to clear agreements that should be in place when care is shared between more than one service, and a duty for mental health services to address needs of groups who may be experiencing inequalities.

The Mental Health Strategy 2021-2031 (91) includes an action to "Provide enhanced and accessible mental health services for those who need specialist mental health services… The services must be able to care for those with disabilities, including physical and sensory disabilities, [Autism], and intellectual disabilities". Action 29 said it should be ensured that "there are specialist interventions available to those who need it. In particular…[to] enhance the regional eating disorder service". A Review of the deliverability of the Strategy's Actions 2026-2029 (91) identified progress on Action 29d although the full funding has not yet been allocated for its implementation. However, in 2026 the Eating Disorder Managed Care Network was established as a strategic partnership to bring together key stakeholders to standardise and improve care pathways, build a resilient and appropriately-trained workforce, strengthen outcome monitoring and advance research and innovation via a low-cost/no cost approach.

1.3 Scotland

The Population Health Framework (93) provides an overarching cross-government and cross-sector approach to improving population health, preventing ill health and reducing health inequalities in Scotland.

Getting it Right for Every Child (GIRFEC) (94) is a long-standing approach, based on clear principles and values, committed to providing all children, young people and their families with the right support at the right time. Getting

it Right for Everyone (GIRFE) (95) builds on these principles and extends this co-ordinated, person-centred approach into adulthood.

Within this context, multiple policies affect Autistic people with an eating disorder, but all share common themes including upholding individual rights, collaboration with accountability between services, and fully involving people in decisions about their care. These documents include:

- The Mental Health and Wellbeing Strategy (96)
- The Child and Adolescent Mental Health Services (CAMHS) national service specification (97)
- The National Neurodevelopmental Specification for Children and Young People: Principles and Standards of Care (98)
- The National Specification for the Delivery of Psychological Therapies and Interventions in Scotland(99)

The National Specification for the Care and Treatment of Eating Disorders in Scotland (100) is particularly important. It applies to all ages and eating disorder diagnoses and sets out a baseline of provision for services to work towards over a 10-year period. It aligns closely with the recommendations made in this report, and much of the work of implementation is already in progress. In particular, it calls for eating disorder services to have specialist pathways for Autistic people, whether there is a formal diagnosis or not, developed in partnership with people with living or lived experience.

The National Review of Eating Disorder Services (101) that led to the development of the eating disorders specification made other relevant recommendations including a call for specific funding for eating disorder research.

In 2011 the Scottish Government and the Convention of Scottish Local Authorities (COSLA) published The Scottish Strategy for Autism (102). This ten-year plan was refreshed and reframed in 2015 and 2018 so that it was outcome focused. These outcomes included timely access to diagnostic assessments, post-diagnostic support, and mental health support.

In the 2021-22 Programme for Government (103) the Scottish Government made a commitment to bring forward a Learning Disabilities, Autism and Neurodivergence Bill, which would include promoting the rights of Autistic people. Work on this has been ongoing, including significant scoping work, and a consultation that asked for views on themes including mandatory training in the public sector, inclusive communications, better data collection and reporting, and independent advocacy. Shortly before the 2026 Scottish Parliament election a policy paper (104) set out the Scottish Government's thinking with illustrative draft provisions.

1.4 Wales

Wales was the first country in the UK to develop an Autism Strategy in 2008, which was further updated in 2016 (105). In 2021, the Welsh Government published a statutory Autism Code of Practice (106), which highlighted and reinforced existing duties instead of a separate Autism Bill. It covers multiple areas including identification, assessment, diagnosis, support for carers, and services for Autistic people with co-occurring conditions. This focus has since expanded to look at neurodivergence more broadly, with a Review of Neurodevelopmental Services (107) published in 2022 to support this work.

The Welsh Government Eating Disorder Service Review 2018 (108) made a specific recommendation that eating disorder and

neurodevelopmental teams for both children and young people should develop national protocols to work together. It recognised overlaps between eating disorders and autism and recommended a "national multidisciplinary subspecialist team within the national eating disorder service which has dual expertise in autism and eating disorders". Its recommendations also included that there should be a single point of access for all referrals to reduce barriers to help seeking, with eating disorder services accepting referrals from all sources. It was also noted that eating disorder staff should receive training on other mental health conditions, and that eating disorder services should develop and maintain relationships with other services to meet the needs of people with co-occurring conditions.

The Mental Health and Wellbeing Strategy 2025-35 (109) sets out four vision statements, with the third referring to a connected system that means people receive the right help wherever they reach out for help, and the fourth referring to seamless mental health services. Particularly pertinent are its references to a rights-based and intersectional approach, equity of access, experience and outcomes without discrimination, and a 'no wrong-door' approach.

This links into work by NHS Wales on open access mental health support (110), moving away from traditional tiered approaches of care to adopt the Stepped Care 2.0 model, which is part of the ambition to achieve same-day mental health care. It emphasises the need for collaborative working between services, and that people will require different approaches.

APPENDIX 2: ACADEMIC LITERATURE REVIEW - AUTISM AND EATING DISORDERS

This review was compiled by Dr Amelia Austin, Dr Fiona Duffy and Dr Karri Gillespie-Smith who are part of the Eating Disorders and Autism Collaborative. It was also used to inform the rest of the report.

Note: Research related to feeding and eating disorders was prioritised, however, when this evidence was not readily available, research related to disordered eating or harmful eating behaviours that do not necessarily meet criteria for a clinical diagnosis was considered.

What is the prevalence of autism across different eating disorder diagnoses and age groups?

A systematic review and meta-analysis by Inal-Kaleli and colleagues (8) suggests that 29% of individuals with Anorexia Nervosa (AN) met the diagnostic criteria for autism on semi structured observation tools (n=7 studies). Sader and team (9) found that 16% of individuals with Avoidant Restrictive Food Intake Disorder (ARFID) were diagnosed as Autistic (n=18 studies). Less data are available for Bulimia Nervosa (BN) and Binge Eating Disorder (BED): a systematic review covering a small number of studies (n=3) suggests that autistic traits are elevated in adults with BN or BED (10108) It is difficult to produce a prevalence figure for OSFED given the heterogenous nature of this diagnosis. While very limited data on the prevalence of autism in Pica is available (112), there is literature on the prevalence of Pica in Autistic children: epidemiological evidence has estimated that 20-23% of young Autistic children engage in eating non-food items (112,113). No data was found in relation to Rumination Disorder.

How common are co-occurring conditions in Autistic people with eating disorders?

Data on the rate of Attention Deficit Hyperactivity Disorder (ADHD) in Autistic people with EDs is limited. Findings from a specialist eating disorder clinic in London showed that, of 1,252 adult patients with anorexia nervosa, bulimia nervosa, and OSFED, 6.15% (n=77) were Autistic or potentially Autistic. Of these individuals, 41.6% (n=32) also had ADHD or suspected ADHD (114).

While no data on the rate of intellectual disabilities in Autistic people with FEDs is readily available, one study from Italy found that rates of FEDs were higher in adults who were Autistic and had an intellectual disability in comparison to non-Autistic adults with an intellectual disability (115). In their sample of Autistic adults with intellectual disability (n=122), 7.4% (n=9) experienced rumination disorder and 19.7% (n=24) experienced Pica. Relatedly, Fields et al. (113) found that the rate of Pica in young Autistic children with an intellectual disability was 28.1%.

Epidemiology research in eating disorders broadly is underfunded, and data on the rate of other mental health conditions in Autistic people with FEDs is not readily available. Given the high rate of mental health comorbidities in EDs generally (116), it feels reasonable to assume that Autistic people with EDs also experience high co-occurrence of mental health conditions.

More broadly, in autism generally, a systematic review and meta-analysis (117) on the prevalence of co-occurring conditions in Autistic children and adults

found that prevalence varied depending on the age group, but among mental health and neurodevelopmental co-occurring conditions, the most frequently recorded included dyspraxia, sleep problems, ADHD, anxiety disorders, and feeding and eating disorders. For neurological and medical co-occurring conditions, this included motor problems and gastrointestinal issues and disorders. For differences in ages groups, ADHD, sleep problems and celiac disease were higher in children and adolescents, while motor problems, gastrointestinal disorders, and depressive disorders were some of the conditions that were higher in adults.

How might the drivers and development of an eating disorder look differently for Autistic people?

Several drivers in the development and maintenance of eating disorders in Autistic people have been hypothesized. Much of the existing evidence is qualitative in nature.

Multiple qualitative studies support the idea that sensory processing differences may underlie or contribute to the connection between autism and anorexia (118-120). Most of this literature refers to hypersensitivity to textures, smells, tastes leading to food avoidance, but one qualitative study suggests that some neurodivergent individuals, including those with ADHD, may binge eat as a form of sensory seeking (114). More broadly, a systematic review by Nimbley et al. (120) found consistent evidence of a relationship between sensory processing and eating behaviours in Autistic individuals, although these were not ED samples (n=25 studies).

Qualitative evidence also suggests that interoceptive awareness, including difficulties in perceiving internal physical sensations, may drive limited eating in Autistic individuals (14, 119). For some, this is linked to the difficulties or differences identifying (alexithymia), regulating, and communicating emotions, which can then lead to a displacement of a drive to eat (118).

Another potential factor is cognitive differences, such as literal thinking styles and detailed oriented thinking. This is supported by the qualitative literature, which found that it was difficult for Autistic individuals to move away from internalized food rules or habitual behaviours (14, 121). A recent scoping review found that repetitive and restrictive behaviours were consistently associated with autism and FEDs, although the cross-sectional nature of most studies meant that directionality could not be presumed (121).

It is also important to acknowledge the impact of late autism diagnosis and minority stress. Brede et al. (14) found that some Autistic women report using restrictive behaviours as a way to fit in with peers, while Nimbley et al. (123) found that some Autistic individuals struggled with social connection and not feeling worthy, which translated into not feeling deserving of food, or that the low mood or emotional arousal dampened or removed the drive to eat. Finally, a quantitative study by Bradley et al. (124) found that camouflaging predicted ED symptoms in Autistic adults. A cluster analysis by Nimbley et al., (125) suggests that Autistic individuals grouped as both high in social camouflaging and high in sensory differences had significantly worse eating disorder symptom severity in comparison to Autistic individuals with low camouflaging and average sensory differences.

There have also been suggestions that the gut microbiome may play a role in the link between Autism and ARFID (126).

What barriers do Autistic people with eating disorders and their carers face in accessing and benefitting from services?

Autistic people with EDs have reported a "one size fits all" approach to ED treatment (32, 16, 128). Similarly, parents and carers of Autistic adults and young people with anorexia nervosa reported a lack of adapted ED services and therapies, creating a mismatch between need and offerings (128, 129, 56, 130). Parents and carers of adults also highlighted limited access to autism-specific supports and resources for themselves (128, 129).

What are the outcomes for Autistic people with eating disorders using current evidence-based models for eating disorder treatment?

Systematic review evidence indicates that, broadly, Autistic patients are as likely to achieve ED recovery as their non-Autistic peers, although treatment experiences are poorer, longer, and more intensive settings are needed (21).

For children and young people, the main outpatient treatment for anorexia nervosa is family therapy for eating disorders (FT-ED). Stewart and colleagues (57) in London found that young women who reached a cut-off score on an autism questionnaire at assessment were equally likely as their lower scoring counterparts to reach physical recovery but were significantly more likely to need intensive treatment beyond FT-ED, such as day- or in-patient care. This need for more intensified care, i.e., transfer to in-patient settings, for Autistic children and young people in FT-ED was replicated by Bentz and colleagues (55, 56) in Denmark.

For adults, there is no readily available data on the clinical outcomes in community/outpatient settings or the specific therapeutic modalities used, i.e., Cognitive Behavioural Therapy for Eating Disorders (CBT-ED) or Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA).

Autistic individuals are disproportionately impacted by rates of nasogastric tube feeding under restraint. In a case series of 143 patients receiving Nasogastric Tube (NGT) feeding under restraint in England's psychiatric inpatient units, 33% were identified as Autistic (131). A survey specific to paediatric wards in England found that 43% of the children and young people receiving NGT under restraint had an autism diagnosis (132). A similar study conducted in Australia (133) found that 65% of young people who required feeding under restraint were Autistic or suspected to be Autistic.

What does research show about adapting treatments and service pathways for Autistic people?

The PEACE pathway is an autism-affirming care pathway for adults with EDs. Implementation of the PEACE pathway saw reduced admission duration—from an average of 19 weeks before implementation vs 13 weeks after—in a London ED ward (45). Aspects of the PEACE pathway were also implemented in a community-based child and adolescent ED service in Buckinghamshire, Oxfordshire and Berkshire, with descriptive data suggesting that it was well received by clinicians, patients, and families (133). Clinical teams have described experiencing implementation of the PEACE pathway as beneficial (134-137).

Qualitative data suggests that Autistic people report better treatment experiences when therapy is adapted to be more Autism-affirming (32, 16, 60).

Data from one quality improvement project in Scotland suggests that the use of social stories and preference planning could be a reasonable way to reduce distress before,

during, and after nasogastric tube feeding (63).

There is emerging evidence from small scale research studies that adjunct digital tools and AI can support PEACE pathway recommended adaptations to assist patients in their treatment journey (138-140).

What does the research tell us about the role of intersectionality in supporting Autistic people with eating disorders across different aspects of their identity?

A lived experience led scoping review (141) found that Autistic trans and gender diverse individuals had a higher lifetime prevalence of EDs than neurotypical trans and gender diverse individuals (n=3 studies). Recent UK-based survey data suggests that higher levels of autistic traits, ADHD traits, and gender diversity were associated with elevated disordered eating (142). There is little data on the role of gender affirming care on ED treatment outcomes in these individuals.

Girls and women with anorexia nervosa are still likely to experience diagnostic overshadowing of autism (139).

A lack of understanding has also been shown to have negative impacts on wellbeing, identity, family, and treatment, and that facilitating a safe environment can help to promote connection and create the foundations for effective treatment (32).

There is little research examining the role of race, ethnicity, culture, class, or sexuality in supporting Autistic people with eating disorders.

What does the literature suggest about the support needs of carers of Autistic people with eating disorders, particularly when carers are also neurodivergent?

For children and young people, parents and carers are often directly involved in treatment itself, such as ED focused family therapy (FT-ED). A new coproduced guideline on the adaptation of FT-ED for Autistic young people with anorexia nervosa (62) suggests prioritizing parent/carer insight into what historically helps, or doesn't help, their child. It also recommends considering parental neurodivergence and adapting communication as needed, such as using more direct and pragmatic speech.

Alford et al. (32) highlight challenges when family neurodivergence is not accommodated, including when this information was offered, in that communication with family members did not change as a result, impacting the treatment journey.

Various models of adjunct group intervention or peer support for parents and carers have begun to emerge (144-146) although none have been evaluated for effectiveness.

What are the priorities for research on this topic?

Two projects have examined the research priorities of Autistic and neurodivergent people with disordered eating or eating disorders. Nimbley and colleagues (65) found that priority areas for future research as identified by Autistic individuals included the impact of early experiences, the function of EDs, barriers and facilitators to ED recovery, understanding and accommodating for complexity (e.g., co-occurring conditions, intersectionality), and changing research culture. Keller and team (54) found that Autistic and ADHD adults prioritised research that improves outcomes or identifies causal mechanisms.

APPENDIX 3: EXAMPLES OF INNOVATIONS IN RESEARCH

3.1 Improving awareness, understanding, and support for eating disorders in Autistic, ADHD, and trans and gender diverse populations

This project is being led by Dr Kai Thomas at Cardiff University (who compiled this case study) and funded by a Health and Care Research Wales Advanced Fellowship [AF-24-04].

About the research

People with eating disorders often hold multiple identities and life experiences that shape how their eating disorder develops and how recovery is experienced. Yet services have traditionally tended to focus on individual diagnoses or characteristics in isolation. Our research focuses on Autistic, ADHD, transgender, and gender diverse people, who are all disproportionately affected by eating disorders but remain underserved by current research and clinical guidance.

Our ongoing programme of research involves nearly 500 adults in the UK with lived experience of eating disorders and combines large-scale surveys with accounts of people's experiences. We aim to understand how autism, ADHD, and gender diversity intersect to shape experiences of eating disorders, treatment, and recovery.

Findings so far

Our early findings suggest that eating disorders cannot be fully understood through any single aspect of a person's identity. Neurodivergent trans and gender diverse people described their eating disorders as ways of coping with a range of challenges, including social exclusion, sensory overwhelm, gender dysphoria, experiences of stigma and discrimination, and concerns about safety and belonging. These experiences often interacted with one another in complex ways. For example, our findings suggest that gender dysphoria may intensify eating disorder symptoms among Autistic people, potentially by increasing body-related distress.

We also found that many participants felt misunderstood or unsupported within services that are largely designed around neurotypical and cisgender experiences. A lack of awareness of neurodivergence and gender diversity could make accessing treatment more difficult, with some people carefully weighing the risks of seeking help against the potential benefits.

Next steps

Together, these findings reinforce the importance of an intersectional approach to care. Assessment and treatment should create space for people to explore how different aspects of their identity and experiences interact, rather than assuming that eating disorders have a single cause or presentation. The next stage of this work will explore these lived experiences in more depth through interviews and identify ways services can provide more inclusive, neuro-affirming, and gender-affirming care. Our findings will be shared later this year through peer-reviewed publications and accessible summaries (which will be available here: linktr.ee/leading_study). We will use insights from the project to co-design resources for eating disorder clinicians supporting Autistic, ADHD and trans and gender diverse communities.

3.2 Shared Genetics in Autism and Eating Disorders

This case study was developed by Dr Samuel Chawner who has received funding from the Medical Research Council (MR/T033045/1), the Medical Research Foundation (MRF-058-0015-F-CHAW), Rosetrees (PGL25-Full/100001, cofunded by The Stoneygate Trust and Robert Luff Foundation) and the Wellcome Trust (304028/Z/23/Z).

This report highlights the growing evidence for an overlap between autism and eating disorders. Research suggests that genetics may partly explain why these conditions co-occur in some individuals[1].

Some of the genetic liability for both autism and eating disorders comes from the combined effects of many genes, each with a very small effect. Research has shown overlap between the common genetic factors associated with neurodevelopmental conditions, including autism, and eating disorders such as Anorexia Nervosa[2,3], Bulima Nervosa[2], and Avoidant Restrictive Food Intake Disorder[4]. This suggests that some biological pathways may contribute to both conditions.

Rare genetic variants may also play an important role. These include copy number variants (CNVs), which are small deletions or duplications of sections of DNA. Certain rare neurodevelopmental CNVs are known to increase the likelihood of autism and other neurodevelopmental conditions.[5] Some of these same CNVs are associated with changes in eating behaviour and weight. For example, Prader-Willi syndrome is linked to overeating[6], 16p11.2 deletion syndrome can lead to increased appetite and weight, whereas 16p11.2 duplication syndrome can lead to restrictive eating and low weight[7]. There is ongoing work at Cardiff University investigating if CNVs contribute to eating disorders.

Although research in this area is still at an early stage, current findings suggest that autism and eating disorders share genetic influences. Importantly, this evidence can help reduce stigma and feelings of caregiver blame by demonstrating that eating disorders can arise, in part, from underlying biological and genetic factors. The biology of neurodiversity may also shape eating disorder risk. A better understanding of the genetic links between autism and eating disorders could improve early identification of those at risk, support more personalised approaches to care, and provide much-needed new insights into the biology underlying eating disorders.

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3.3 An Anthropological Approach to Eating Disorders: Developing an Innovative Socio-cultural Strategy for Research, Treatment and Prevention

This research case study was compiled by Karin Eli (University of Warwick) and Anna Lavis (University of Birmingham), based on work undertaken by the study team.

Led by the University of Birmingham (UoB), and partnering with the University of Warwick, Forward Thinking Birmingham, and Coventry & Warwickshire Partnership NHS Trust, the UKRI-funded project, "An Anthropological Approach to Eating Disorders: Developing an Innovative Socio-cultural Strategy for Research, Treatment and Prevention", explores experiences of disordered eating and eating disorders among underrepresented communities (2023 – present; Principal Investigator: Professor Anna Lavis, UoB; Team: Karin Eli, Jwana Aziz, Kat Edwards, Melissa Kirby, Maria Kolitsida, Sheryllin McNeil, Lizzie Mitchell, Kristina Newman, Rosina Pendrous, Shanta Raj, Amanda Rodney, Anthony Winston).

In our interviews and research co-production activities with people with lived experience (PWLE) from multiple groups, intersectional experiences of autism in the context of disordered eating have emerged as critically important for prevention and treatment. In the following summary, we highlight findings identified through interviews and co-production activities conducted with people from a range of underrepresented groups. These include PWLE with binge eating, longstanding eating disorders, physical disabilities, trans/nonbinary gender identities, and care experiences. Our data feature participant-led discussions of their autism in relation to diverse disordered eating histories, practices, and treatment experiences.

- Participants described experiences across the spectrum of disordered eating, including restriction and binge eating.
- They explained their eating disorders emerged at the intersection between the challenges of living with autism in a non-accepting society; a range of adverse experiences, such as bereavement, bullying, family breakdown or abuse; multiple mental health and chronic physical conditions; reflections on and challenges with gender identity; and life transitions, such as leaving home and enrolling at university.
- Once disordered eating had become established, multifaceted aspects of living with autism, from embodied experiences of sensory overwhelm, obsessive worry, or rumination to social experiences of misunderstanding, lack of belonging, or exclusion, could trigger episodes of disordered eating. Participants explained their disordered eating served as a "distraction" from these distressing

experiences, providing a comforting sense of "numbing" or "control".

- Additionally, experiences of autism intersected with self-harm, which some participants described as a form of coping alongside disordered eating.
- The tendency to adopt and maintain routines meant that some participants found it difficult to stop disordered eating practices that had become integrated into their daily lives. Some participants expressed that, as Autistic people, first-line treatments for eating disorders, specifically CBT and MANTRA, did not match their needs and processing styles, and they experienced these treatments as harmful instead of helpful. However, a few noted that personalised meal plans were helpful.
- When speaking about their eating before the development of eating disorders, some participants described seemingly unusual eating habits and patterns that felt 'normal' to them, and through which they navigated the social and sensory aspects of food as Autistic people. These experiences made it difficult for participants to demarcate their 'normal' eating from disordered eating, and to engage in treatment that prescribed normative eating patterns which did not correspond to their experiences of food.
- A participant who experienced binge eating noted they felt marginalised in discourses surrounding autism and eating disorders, as these tend to focus on restrictive practices.
- While lived experiences of autism should be recognised in eating disorders management, one participant cautioned that healthcare professionals should avoid essentialising Autistic people, as this could be detrimental to their self-concept and emotional wellbeing: *"don't assume that that everybody who's Autistic has exactly the same features as everyone else, because, see, we know everybody's different"*. The same participant added, *"when a medic makes suddenly makes lots of assumptions, [you think that] oh, well, that's another reason, another reason why you are messed up".*

Taken together, our findings highlight that autism intersects with all eating disorder diagnoses, and that Autistic people face a range of challenging life experiences exacerbated by embodied and social experiences related to their neurodiversity, with eating disorders and disordered eating emerging as forms of coping and surviving. Of note, Autistic people may experience eating disorder treatments as poorly matched to their needs, and even harmful, conveying the importance of paying urgent attention to the intersectionality of autism and eating disorders/disordered eating.

APPENDIX 4: EXAMPLES OF SERVICE DEVELOPMENT

4.1 Lancashire and South Cumbria All Age Eating Disorder Service

The Lancashire and South Cumbria All Age Eating Disorder Service comprises five community eating disorder teams across the Trust. To support the delivery of neuro-affirmative care, the service has established SNAP (Supporting Neuro-Affirmative Practice), a multidisciplinary working group that meets monthly and includes clinicians from across the service alongside lived experience representatives. SNAP provides strategic oversight of service developments, ensuring improvements are informed by co-production, current evidence and continuous quality improvement. The programme of work remains ongoing, with implementation continuing across the service.

Environmental adaptations

Following a neurodiversity environmental audit, a programme of improvements has been implemented to create more accessible and sensory-informed clinical environments.

Changes implemented

- Replaced audible clocks with silent clocks.
- Installed dimmable lighting in most clinical areas.
- Improved seating options to better meet a range of sensory and physical needs.
- Reduced clutter and improved organisation of clinical spaces.
- Redecorated selected areas using calm, muted colour schemes.
- Introduced staff photo boards in private waiting areas to reduce uncertainty about who patients will meet.
- Made sensory and fidget items available in some clinical locations.

Work is continuing to improve communication before and during appointments, including the development of one-page clinician profiles and clearer information about available reasonable adjustments. Planned developments also include improving signage and navigation, expanding sensory resources across sites, developing virtual walk-throughs of clinical environments, updating environmental accessibility information on AccessAble, and making further improvements to storage and soundproofing where feasible.

Workforce development

The service has established an ongoing programme of autism-enhanced workforce development to increase staff confidence in delivering neuro-affirmative care.

Changes implemented

- Annual access for all staff to the PEACE Pathway Conference on Neurodiversity and Eating Disorders.
- Regular multidisciplinary teaching sessions covering autism recognition, autism-informed communication, key-working and other neurodiversity-related topics.
- Staff are supported to undertake specialist external training, including the National Autism Trainer Programme, Maudsley Autism and Eating Disorders training, neurodiversity-affirming schema therapy training and PEACE Pathway educational events.

The programme of education continues to evolve in response to staff feedback and emerging evidence. Planned teaching sessions include neurodiversity-informed dietetic

practice, sensory integration, monotropism and early identification of autism.

Clinical pathway developments

The service has begun embedding neuro-affirmative principles within clinical pathways through both assessment processes and treatment delivery.

Changes implemented

- Improved information about the service available on the Trust website.
- Links to AccessAble to provide information about clinical environments.
- Sensory summaries completed during initial assessments.
- Routine enquiry regarding diagnosed or suspected neurodivergence for individuals and family members.
- Greater flexibility within dietetic and psychological pathways, including increased session availability where clinically indicated.

Work is ongoing to strengthen multidisciplinary collaboration for complex cases, develop guidance to support adaptations to psychological interventions, improve the recording of communication preferences and reasonable adjustments, and continue embedding sensory-informed practice across all five community eating disorder teams. The service also plans to review the changing needs of the local eating disorder population to inform future service development.

4.2 Community Eating Disorders Service for Children and Young People in Manchester Foundation Trust

Improving identification and access to autism-affirming care

The Community Eating Disorders Service (CEDS) for Children and Young People in Manchester Foundation Trust (MFT) began autism assessments in 2022, with additional staffing introduced in March 2024. This was followed by the development of a dedicated Neurodevelopmental Pathway in January 2025, consisting of approximately six practitioners.

A key focus of service development has been the implementation of a neuroaffirmative approach to practice. This has included a conscious shift in language from "ASD" to "autism" and the integration of communication and engagement strategies (such as developing one-page profiles for initial assessments) that are more accessible and inclusive for neurodivergent young people.

If it is suspected (by a patient, their family or carers, or a professional) that a patient is neurodivergent, the following process is followed:

- A discussion is held at a CEDS multidisciplinary team (MDT) case discussion meeting, with a summary of the discussion recorded on the electronic patient record.
- If after a minimum of six appointments it is apparent that neurodivergence is impacting on the eating disorder or eating difficulties, the case is brought back to the MDT case discussion.
- The assessment process is then discussed with the child or young person and their parent or carer. Consent is then sought for the assessment from the child or young person if they are over the age of 13, and the parent or carer.
- The caseworker then sends forms to young person's school and arranges a discussion with a staff member. The relevant information is gathered for a developmental history, and a QbTest is also agreed if necessary, though it is helpful in most cases.

- This is then brought back to the MDT case discussion meeting, and an assessment (typically the Autism Diagnostic Observation Schedule, or equivalent) is arranged if indicated. An 'ND case expert panel' is also available if needed.
- Following this, it is brought back to the MDT case discussion for a final time, with diagnoses or otherwise agreed. The child or young person and their family or carer is updated, and the caseworker concludes by writes a report.

Since September 2024, the pathway has completed 40 autism assessments and 21 ADHD assessments, with the aid of QbTesting for ADHD. The majority of ADHD assessments have formed part of dual autism and ADHD assessment processes, reflecting the high prevalence of co-occurring neurodevelopmental presentations within the service population.

Supporting staff

Several team members have completed Talking Mats provider training and now routinely utilise visual supports during clinical work. Staff have also undertaken social stories training, while sensory integration expertise within the team has continued to develop, with one clinician achieving Level 5 training and another progressing from Level 2 to Level 3. Plans are underway to introduce both individual sensory assessments and sensory-focused group interventions.

Continued development

Continued professional development remains a priority within the pathway. Future priorities include the development of a parent support group for families of young people with autism and/or ADHD who also experience eating disorders. The service is additionally working towards strengthening post-diagnostic support to help young people and their families understand the relationship between neurodevelopmental differences and eating difficulties, and to ensure that a diagnosis can be meaningfully integrated into ongoing care and treatment. There are also plans to increase young person involvement in service development and pathway design.

Patient and carer experiences

"The support we received from CEDS throughout my daughter's autism assessment was outstanding. Because the team had worked with her for such a long time, they had built a strong understanding of her and were able to recognise features of autism that we had not previously considered. Initially, I was unsure about an assessment because I hadn't recognised any developmental differences when she was younger, but the team listened to my concerns, explained their reasoning with sensitivity, and kept me informed throughout. The fact that the assessment was expedited because of her eating disorder was invaluable, enabling us to gain answers sooner and better understand her needs at an earlier stage. CEDS have also worked closely with her school and contributed to her EHCP planning, helping to ensure that both her eating disorder treatment and educational support fully take account of her autism. I am extremely grateful for their professionalism, compassion and expertise, which have given both my daughter and me a much better understanding of her needs and how best to support her."

- Allison

"After more than 10 years of trying to get help for our daughter, CEDS were the first team who really listened to us. They took the time to understand her as a whole person, rather than just looking at her disordered eating. They listened to our concerns, and recognised things that had been missed by other services for years. Being told that she was neurodivergent suddenly made so much of her life make sense to us.

The whole assessment process was quick, felt supportive, understanding, and we felt involved at every step. The diagnosis has helped us understand our daughter so much better and has changed the way we can support her. We are incredibly grateful to the team at CEDS for seeing what others hadn't and for giving us answers after such a long time.

My daughter and I felt listened to, involved in every decision and treated with kindness and respect throughout. Her voice and needs were always the most important in every appointment. The team made every effort to try to hear directly from her and ensure she felt included, while recognising that most of the time she found expressing herself difficult. They were strong advocates for her throughout the process.

Communication was clear and consistent, appointments and assessments happened quickly, and we always knew what to expect next. The team worked to make sure both my views and my daughter's needs were at the centre of every decision. Even after the diagnosis, the ongoing support has been invaluable, and I have never felt like I was left to cope on my own. My experience has been of a service that is caring, and committed to improving outcomes for young people and their families"

- Emma

Further details

For more information on the current service, please contact the team on mftceds@mft.nhs.uk

4.3 Evolve's Autism and Eating Disorders Pathway: A Stepped-Care Approach

Evolve has developed an autism and eating disorder pathway to improve identification, access, engagement and outcomes for Autistic people and those with suspected neurodivergent needs. It combines screening, reasonable adjustments, autism-informed adaptations, PEACE resources, staff training and collaboration with local autism and third-sector partners.

This case study describes how Evolve identifies and responds to autism and suspected neurodivergence within eating disorder care, including referral routes, screening, reasonable adjustments, treatment adaptations, staff training and intended outcomes.

Service model

Evolve provides community-based eating disorder treatment for adults in Hull, with early intervention support for some people in the East Riding. The service offers outpatient, day service and intensive treatment, bridging the gap between outpatient and inpatient care,

reducing avoidable out-of-area admissions and supporting earlier step-down. Patients can move flexibly between levels of care according to clinical need.

Access and referral routes

- **Referral routes:** Evolve accepts digital self-referrals and digital referrals from healthcare professionals, helping reduce barriers to accessing treatment.
- **Timely access:** The service aims to ensure there is no waiting list, with a maximum wait of six weeks from assessment to treatment.
- **Reasonable adjustments:** Reasonable adjustments and accessible information needs are identified at referral for all patients entering the service and reviewed as required.
- **Assessment criteria:** Assessments are offered where an eating disorder is suspected.

Autism and neurodivergence pathway

Evolve implemented its autism pathway in 2021 with Matthew's Hub (a charity providing support for ADHD and autism) to improve access, engagement and outcomes for Autistic people and those with suspected neurodivergent needs. The pathway supports earlier identification, adapted care and ongoing review in line with emerging guidance, specialist training and local autism provision.

Screening and identification

Routine screening uses the AQ-10 alongside clinical judgement and patient and carer information, recognising that tools may miss some Autistic presentations. Where suspected neurodivergence is identified without diagnosis, Evolve offers need-based reasonable adjustments.

Referral and signposting

Where appropriate and with consent, Evolve makes autism assessment referrals. External support may include Humber Autism Mental Health Service, Matthew's Hub, or the Humber and North Yorkshire Provider Collaborative Dynamic Support Register, supporting Autistic service users to reduce avoidable admissions and help ensure any inpatient care meets their needs.

Autism-Informed Treatment Adaptations

PEACE resources and autism-informed strategies are used to support reasonable adjustments, improve accessibility and adapt treatment to individual needs.

Early Intervention and Assessment

- Reasonable adjustments and accessible information needs are identified at referral and reviewed during assessment.
- Adjustments may include a quiet space, dimmed lighting, support person, fidget tools, shorter appointments, written information, consistent appointment arrangements and a quieter waiting area.
- Patients are offered the appointment format that best supports engagement, where clinically appropriate.
- Communication needs are explored early to support trust, engagement and access to treatment.

Community Treatment

- **Communication:** Staff use empathetic, clear and predictable communication, supported by written information and agreed plans. PEACE resources can support formulation, communication passports, sensory assessment and positive behaviour support planning.
- **Therapeutic adaptations:** Treatment is adapted to the person's communication style, sensory profile, cognitive flexibility and need for predictability.
- **Dietetic adaptations:** Assessment explores sensory triggers, routines, food preferences, eating environment, meal pacing,

presentation and family or carer support. Meal plans, supplements and re-feeding approaches are sensory informed and individualised.

- **Occupational therapy support:** OT input focuses on sensory profiles and safe self-regulation strategies, such as fidget tools, stimming space, grounding strategies or meaningful activities.
- **Predictability and consistency:** Visual supports, consistent clinician, routines, appointments and clear staged discharge plans and patient-needs summaries help staff provide consistent care.

Day Service and Intensive Community Support

- Patients requiring day service or intensive support may need additional adjustments to reduce distress and support engagement.
- Adjustments may include separate eating areas, longer mealtimes, slower pacing, environmental adaptations, flexible approaches and meal plan adaptations where clinically appropriate.
- Carers support and guidance when anxiety or distress affects food or safety plans.

Workforce Development and Training

Internal Training

- All team members are required to complete Tier 1 Oliver McGowan mandatory training.
- Named staff have completed Tier 2 Oliver McGowan training and act as autism champions, supporting autism-informed practice across the team.
- Additional learning has strengthened knowledge in autism and eating disorders, ARFID, interoceptive awareness, PDA-informed practice and neurodivergent approaches to eating disorder treatment.
- Autism champions, local autism services and local third sector organisations provide opportunities for consultation, peer support and continued learning.
- The service has a designated FREDIE (Fairness, Respect, Equality, Diversity, Inclusion, and Engagement) Champion to support inclusive practice.

Specialist Training and Professional Resources

Eating disorder practitioners and a specialist dietitian have completed external specialist training to strengthen autism-informed practice within eating disorder care.

- **Neurodivergent eating disorder treatment:** Navigating Complexity: Optimising Treatment of Eating Disorders in Neurodivergent Treatment, Maudsley.
- **PDA-informed practice:** Working with and supporting PDA young people and adults, CPD-accredited training through the PDA Society.
- **Dietetic approaches:** Autism and Eating Disorders: Comprehensive Nutrition Approaches Workshop, Sarah Elder Nutrition.
- **Professional learning and resources:** BDA Mental Health and ARFID group membership, including access to dietetic resources and online webinars.

Impact and outcomes

Patient and carer experience

- The pathway improves patient and carer experience by identifying access needs earlier and making communication, assessment and treatment more responsive.
- Reasonable adjustments, predictable structures and sensory-informed planning reduce uncertainty and support treatment engagement.
- Patient and carer feedback through the Friends and Family Test and service user questionnaires informs ongoing pathway review and refinement.

Autism Pathway Impact

- The pathway supports more consistent identification of Autistic presentations and

suspected neurodivergence.
- Staff feel more confident discussing autism and using reasonable adjustments and autism-informed adaptations.
- The pathway provides a clearer framework for individualised care across assessment, treatment and support.
- PEACE resources and sensory-informed approaches strengthen collaboration with patients, carers and the MDT.

4.4 West Midlands Adult Eating Disorders Provider Collaborative

The West Midlands Adult Eating Disorders Provider Collaborative (WM AED PC) has recognised the significant overlap between Autism and eating disorders (ED) and has implemented a number of initiatives to improve identification, engagement, treatment delivery and care transitions for Autistic people accessing specialist eating disorder services.

Dedicated Autism Clinical Liaison Practitioner role

A key development has been the introduction of a dedicated Autism Clinical Liaison Practitioner (CLP) role. The practitioner is an Occupational Therapist with specialist autism expertise and advanced sensory integration training. They operate as part of the ED Provider Collaborative framework, working closely with the other Clinical Liaison Practitioners and the Case Manager.

The Autism CLP can become involved at the point of referral for specialist inpatient services and supports admission avoidance wherever possible. This includes advising community teams on reasonable adjustments, the Dynamic Support Register (DSR) processes, supporting Care, Education (where relevant) and Treatment Reviews (C(E)TR's) or LEAP's, and Transforming Care Programme (TCP) requirements. By helping teams understand and implement recommendations arising from these processes, the role has contributed to more proactive support planning and, in some cases, reduced the need for admission through enhanced community intervention and collaboration with specialist services such as Intensive Support Teams (ISTs).

Where admission is required, the Autism CLP supports ward integration, assessment of sensory and communication needs if required, and collaborative discharge planning to facilitate successful transitions back into community services.

A significant aspect of the role is specialist sensory assessment. The practitioner recently completed postgraduate sensory integration training, which focuses on understanding how individuals process, interpret and respond to sensory information and how sensory differences can impact daily functioning, emotional regulation, participation in treatment and recovery. Individual sensory assessments, including use of the SPM-2 (Sensory Processing Measure), helps identify a person's sensory profile and generate practical recommendations that can be embedded within treatment plans. This has enabled services to tailor environments, interventions and communication approaches to better meet individual needs.

Examples of the Autism CLP's work include:
- Supporting community and inpatient teams to adapt care approaches for Autistic patients who have experienced disengagement or distress during treatment.
- Providing specialist consultation and training to supported living providers, social care staff and support workers to improve understanding of the interaction between autism, eating disorders and individual support needs with aim of this reducing risk of relapse

- Completing sensory assessments where local expertise is unavailable and translating findings into practical recommendations.
- Supporting Autistic individuals receiving treatment within acute medical settings by advising on environmental adaptations, communication approaches and sensory needs.
- Facilitating transition planning and collaboration between inpatient, community, social care and third-sector providers to promote successful discharge and reduce readmission risk.
- Supporting referrals for autism assessment where neurodivergence is suspected but not formally identified.
- Preparing individuals and teams for complex meetings, treatment milestones or care planning discussions that have previously led to heightened anxiety, distress or disengagement.

Wider service development

The Provider Collaborative has also undertaken a wider programme of service development. Since 2024, alternate year sensory environment reviews have been completed across all specialist eating disorder units (SEDUs) within the collaborative. These reviews consider sensory factors such as noise, lighting, privacy, predictability and environmental demands that may affect Autistic patients. Importantly, this work has been co-produced with people with lived experience of autism and eating disorders. Each ward receives a detailed report with recommendations for improvement and dedicated funding has been allocated to support implementation of sensory resources and environmental adaptations.

Recognising the need for consistency across services, the Collaborative established a multidisciplinary working group to develop a set of Autism Standards. These standards outline best practice expectations across the patient journey, including pre-admission planning, admission processes, inpatient care and discharge. The standards incorporate principles relating to C(E)TRs, LEAP processes, reasonable adjustments, sensory needs, communication adaptations, structured and predictable approaches to care, and transition planning. Recommendations are categorised according to priority to support implementation by multidisciplinary teams.

Training

Alongside service developments, the Collaborative has delivered training to both community and inpatient eating disorder services on autism-informed care. Topics have included autism and communication, adapting care plans and interventions, avoidant/restrictive food intake disorder (ARFID) training, autism and eating disorders, sensory processing, and reasonable adjustments in practice.

Feedback

Feedback from services suggests that the introduction of a dedicated autism specialist role has improved confidence amongst clinicians, strengthened multidisciplinary working, increased awareness of autism-specific care requirements and enhanced the ability of services to provide personalised and accessible treatment for Autistic people with eating disorders.

There have been individual cases were patients who have re-currently needed readmission to a SEDU have been successful with an enhanced community treatment plan and remained out of hospital, and at times returned to education or work, achieved a healthy weight and been successfully discharged from an eating disorder service.

4.5 Wisteria Ward in South West London and St George's Mental Health NHS Trust

Wisteria Ward is a 12-bed mixed gender specialist eating disorder unit for young people aged 12-17. It mainly supports young people with restrictive eating disorders and provides multi-disciplinary care, including nursing, medical input, psychology, art psychotherapy, family therapy, occupational therapy, and dietetics.

Developing a neuro-affirming treatment pathway

In 2025, an increasing prevalence of autistic young people on the ward highlighted the need for a more adapted and neuro-affirming clinical pathway. A multidisciplinary working group was set up to develop a protocol outlining neuro-affirming adjustments to treatment at each stage of admission. These adjustments were informed by the team's learning from weekly PEACE pathway huddles, as well as the SPACE framework for supporting autistic people in healthcare settings (Doherty et al., 2023).

The protocol was reviewed by a carer of a former autistic patient on the ward, individuals with lived experience of autism and an eating disorder, and colleagues from the PEACE pathway. This helped ensure that the protocol was shaped by both professional knowledge and lived experience.

Pre-admission / start of admission

Holding in mind autistic needs from the start:

- Local Area Emergency Protocol (LAEP) or Care Education Treatment Review (CETR) meeting to ensure all community treatment options have been exhausted
- A dietetic assessment to assess any sensory needs related to food/eating
- Provide the young person and family with information about the ward before arrival to know what to expect: Welcome Pack, document of photos of the ward, guidance around the day of admission
- Gather information from the family about the young person's routines and sensory needs

During admission

Support during an admission includes:

- Creating a communication passport with the young person (PEACE pathway resource)
- Creating a door sign with the young person covering important information such as pronouns, interests, what helps when distressed, and coping strategies
- A sensory room
- A sensory assessment with an occupational therapist
- Fidget toy boxes
- Easy read treatment plans if indicated
- Written feedback after weekly treatment review meetings
- Offering space to understand autism diagnosis if indicated
- Adjusting therapy sessions to accommodate any sensory needs, communication differences, processing needs
- Exploring the interplay between autism and their eating disorder in family therapy and individual therapy spaces

The end of an admission

Ensuring a smooth transition back to community care:

- Consider joint work with the community team in the final weeks to smooth the transition back to outpatient care
- Share a visual plan of the young person's care post-discharge if indicated
- Share recommendations for support with the community team and parents/carers (e.g. communication passport, sensory assessment, any adaptations to therapy)

Work in development

The Wisteria team is continuing to develop this work and identify ways to better meet the needs of autistic young people. This includes exploring changes to the sensory environment, which continues to present challenges, as well as further autism-informed training to increase staff understanding and confidence.

The current protocol will be reviewed in October 2026 using feedback from the team, autistic patients, and their families to help shape future iterations.

4.6 Tees, Esk and Wear Valleys NHS Foundation Trust's Community Eating Disorder Service

Embedding Autism Identification and Assessment

Background

Referrals to Tees, Esk and Wear Valleys NHS Foundation Trust's Community Eating Disorder Service (CEDS) for children and young people increased post pandemic, with more co-occurring needs. Clinicians noted many young people showed signs of undiagnosed autism but faced waits of several years for assessment, limiting timely adaptation of treatment and contributing to poorer experiences and outcomes. Those aged 16+ were frequently falling off paediatric assessment lists and missing diagnosis opportunity entirely despite years of waiting and during high-risk transition ages.

Service Development

From 2021, the service developed an autism centred pathway, formalised in 2024. Staff completed additional autism assessment training (including ADOS and ADI R) and strengthened links with neurodevelopmental services. The pathway begins with enhanced developmental history taking, and where autism is strongly indicated and would meaningfully influence care, the team can complete a multidisciplinary autism assessment. Autism informed approaches are applied from first contact.

"This service helped me get to know my child."

Improving Identification and Access

The new approach enables autism to be explored while young people are already engaged with clinicians they know and trust.

"…the process was easy to follow and we were informed with every step."

Benefits for Young People and Families

- Assessment occurs within a familiar service with existing therapeutic relationships. This reduces the need to meet new clinicians, visit new locations or repeat their story.
- Findings can be applied immediately to care plans. There is no delay between assessment and meaningful clinical impact - improving continuity and reducing delays.
- Timely diagnosis enhances formulation, supports self understanding and identity, and improves family communication and strategies.
- Identified needs support better educational, social and future planning.

"…it's all making sense now… why I could not see that in my daughter."

Clinicians report that receiving an autism diagnosis often provides significant relief for both young people and families by helping them understand lifelong experiences and challenges through a neurodevelopmental lens.

Benefits for Staff and Services

- Increased autism knowledge and confidence across the multi-disciplinary team (MDT)
- Stronger collaboration with neurodevelopmental services
- Improved ability to formulate presentations with co-occurring needs and tailor interventions
- Enhanced development opportunities and clinical satisfaction

Outcomes

Early outcomes are positive. Earlier autism identification has shaped treatment planning and helped avoid escalation to restrictive interventions. **Teesside has recorded no Tier 4 eating disorder admissions in five years** and no routine transitions to adult services, with one crisis related exception.

Key Learning

Early autism identification within eating disorder services can fundamentally change treatment pathways. Integrating autism informed assessment within CEDS enables truly personalised care, reduces delays and transitions, improves service user experience and staff satisfaction and helps prevent avoidable escalation.

Wider Provider Collaborative Regional Pathway Developments include:

- An Eating Disorder Co-occurring Needs Forum facilitating access to specialist autism expertise
- A regional Statement of Commitment towards Neurodivergent Affirming Care
- Co produced acute admission guidance and hospital passports for autistic individuals with an eating disorder
- Planned social stories training and the development of visual communication tool templates to improve accessibility and consistency across the pathway.

4.7 Positive practice case: autism and an eating disorder

A parent's lived-experience account

This case study was provided by InsightEating, which provides NHS and private services. Its learnings and the examples provided are applicable in NHS services.

It refers to Section 117 funding, which provides free community aftercare for people who are discharged from hospital after being compulsorily detained, and is relevant in England and Wales. An EHCP is an Education, Health, and Care Plan that is a legal document for children and young people up to the age of 25. It outlines the support an individual needs in these areas and how these needs should be met.

Before Section 117 funding

My child developed anorexia nervosa in early adolescence. Their weight fell rapidly and, within weeks of telling me they were struggling to eat, they were admitted to hospital with low blood glucose and low blood pressure. They also disclosed suicidal thoughts. They later experienced repeated admissions, nasogastric feeding and a period of compulsory treatment .

Autism was eventually identified, with ADHD recognised later, but the diagnosis did not initially change how care was delivered. My child was often treated as difficult or non-compliant rather than overwhelmed, frightened or unable to communicate what they needed. A distressing restraint on a children's ward added significant trauma and damaged their trust in professionals. Even when their weight

had improved in a specialist eating-disorder unit, there was still little practical understanding of how autism, sensory processing, executive functioning and anorexia interacted.

After discharge, their weight fell again and their world became very small. They could not tolerate anyone else preparing food or drinks, attended education only minimally and became socially isolated. Engagement with services deteriorated and I felt I was repeatedly trying to hold together fragmented care while their health worsened. Standard treatment often brought more rules, targets, weighing and numbers to an illness already dominated by rigidity. My child later described this as professionals meeting "a rule-based, rigid illness with more rules and rigidity".

What changed after Section 117 funding and EHCP

The turning point came when Section 117 funding enabled a coordinated package of specialist support via EHCP. This included an autism-informed dietitian, a psychologist with expertise in neurodivergence and eating disorders, occupational therapy, speech and language therapy, specialist educational support and community outreach. For the first time, the team shared information and worked from a common understanding, rather than expecting my child and me to keep explaining the same difficulties to separate professionals
.

The dietetic approach was particularly important. It was slower, gentler and more collaborative while still taking physical risk seriously. Previous treatment trauma was acknowledged, work was adapted to sensory and executive-functioning needs, and unnecessary emphasis on weight and numbers was reduced. The dietitian helped us distinguish restriction driven by anorexia from genuine sensory barriers. My child's extensive nutrition knowledge could be "sense-checked", so that it gradually became education rather than obsession. Most importantly, they felt understood: "For the first time, they were able to trust a dietitian."

Sensory integration therapy improved body awareness and emotional regulation and was experienced as supportive rather than punitive. Speech and language therapy helped my child understand why particular situations were so difficult and develop ways to advocate for themselves. The psychologist picked up undiagnosed ADHD and significant executive dysfunction and helped them make sense of the links between bodily reactions, anxiety, behaviours and overwhelm. Outreach offered carefully paced practice in food environments, including ordering drinks and coping with noise, smells and uncertainty without relying entirely on me.

Impact

Progress has not been quick or linear, and ongoing support is still needed. However, my child has become more nutritionally and medically stable, more curious about their own experience and more able to question eating-disorder thoughts. They returned to education, completed work experience, volunteered, achieved good qualifications and began to imagine a future. They can now engage with hospital and community mental health care despite understandable anxiety.

The greatest difference was not one isolated intervention, but a coordinated, autism-informed and trauma-aware approach that adapted treatment to the person rather than expecting the person to fit the treatment. As a parent, I no longer felt that I was fighting alone. We do not describe this as a simple recovery story. We talk about "stability, progress, hope and the future".

APPENDIX 5: SURVEY LIMITATIONS

The survey offers valuable insight into the experiences of Autistic people with eating disorders and those who support them. However, several limitations should be considered.

Firstly, because participation was voluntary and self-selecting, people were more likely to take part if they had particularly strong views about the subject. As such, findings may not be truly representative across all Autistic people with eating disorders or their carers.

Secondly, the survey was not designed to estimate prevalence or to compare outcomes between different groups, such as people with different eating disorder experiences or treatment settings. The findings should therefore be interpreted as highlighting key experiences, challenges, and priorities for service change, rather than as evidence of how common specific experiences are across the wider population.

Lastly, though the survey captures important perspectives from Autistic people and their carers, more research is needed to identify which approaches and adaptations most effectively improve outcomes. Future research should continue to be co-produced with Autistic people with lived experience of eating disorders and carers, families, and loved ones, so that evidence reflects the needs and priorities of those directly affected.

Despite these limitations, the survey findings undoubtedly provide important insight into shared experiences reported by Autistic people with eating disorders and those who support them. They highlight areas where services can improve to better meet the needs of those accessing care and support.

APPENDIX 6: GLOSSARY

ADHD	Attention Deficit Hyperactivity Disorder refers to the persistent pattern of inattention and/or hyperactivity-impulsivity that someone can experience, that interferes with daily functioning and/or development.
Anorexia Nervosa (AN)	A type of eating disorder that causes individuals to limit how much they eat or drink. Some people develop strict "rules" about what, when, or where they can eat.
Autism	Sometimes referred to as autism spectrum condition (ASC), autism is lifelong neurodevelopmental difference that affects how a person communicates, interacts, and experiences and makes sense of the world.
Autistic	The identity-first term used throughout this report to describe people who are autistic. The report uses this term in line with the language preferences of many Autistic people.
Autism-affirming care	Care that seeks to understand and respects Autistic ways of experiencing and communicating, individual needs and preferences, and makes appropriate adaptations to communication, environments, and treatment.
Avoidant and/or Restrictive Food Intake Disorder (ARFID)	A type of eating disorder characterised by the person avoiding certain foods or types of food, having restricted intake in terms of overall amount eaten, or both. ARFID is not driven by concerns about body weight or shape. Food avoidance or restriction may be related to things such as sensory sensitivities, a lack of interest in eating, or fear of negative consequences from eating, such as choking or becoming unwell.
Binge Eating Disorder (BED)	A type of eating disorder where a person regularly has episodes of binge eating. During these episodes, they may eat more than they usually would and feel unable to control their eating, such as being unable to stop eating or control how much or what they eat.
Bulimia Nervosa (BN)	A type of eating disorder where a person regularly has episodes of binge eating, followed by behaviours intended to prevent weight gain. These may include making themselves sick, misusing laxatives or enemas, or exercising excessively.
Carer/s	In this report, anyone who supports a person with an eating disorder in a personal capacity, including parents, partners, siblings, grandparents, other family members and friends.
Cognitive Behavioural Therapy for Eating Disorders (CBT-ED)	A type of talking therapy specifically adapted to treat eating disorders. It focuses on supporting the individual to develop healthier eating patterns through understanding and changing thoughts, feelings, and behaviours that may contribute to the maintenance of an eating disorder.
Diagnostic overshadowing	When clinicians or caregivers mistakenly attribute behaviours or symptoms associated with one condition, such as autism or an eating disorder, entirely to another existing condition, resulting in the underlying condition being overlooked or inadequately addressed.
Ehlers-Danlos Syndrome	A group of 13 rare inherited conditions that affect connective tissue. Common symptoms include joint hypermobility, chronic joint and muscle pain, severe fatigue, and stretchy and fragile skin that bruises easily and scars poorly.

Feeding and Eating Disorders (FEDs)	A group of mental health conditions characterised by disturbances related to eating behaviours, food intake, or appetite, which negatively affects a person's health or everyday life.
Family-Based Therapy or Family Therapy for Eating Disorders (FBT/FT-ED)	Also known as the Maudsley approach, is an intensive outpatient treatment for children and adolescents with eating disorders. It follows three phases: weight restoration, returning control, and adolescent development.
MANTRA	Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA) is an evidence-based, structured psychological therapy specifically designed for eating disorders, primarily anorexia nervosa
Masking or camouflaging	Masking is a strategy that some autistic people may use to appear non-autistic, such as mirroring the behaviour of others in specific situations.
Neurotypical	"Neurotypical" is a term used to describe people whose brains develop and work in ways that are considered 'typical' or standard in society.
Nasogastric tube feeding (NGT)	This is a medical way to provide someone with nutrition, fluids, or medicines directly into the stomach via a thin tube through the nose.
Obsessive Compulsive Disorder (OCD)	A mental health condition characterised by obsessions and/or compulsions. Obsessions are cycles of unwanted, recurring, and intrusive thoughts, images, or urges. Compulsions are behaviours that someone feels compelled to engage in, to try and stop the obsessions and/or decrease distress. They can be repetitive behaviours or mental acts.
Orthostatic intolerance	A condition where a person develops symptoms when standing or sitting upright that improve when they lie down. Symptoms can include dizziness, light-headedness, fainting, fatigue, weakness, headaches and difficulty concentrating.
Other specified feeding or eating disorder (OSFED)	A type of eating disorder diagnosed when a person has symptoms of an eating disorder that cause distress or affect their everyday life, but do not meet all the criteria for another specific eating disorder diagnosis. This does not mean the eating disorder is less serious or that the person needs less support.
Pica	A type of eating disorder where a person regularly eats things that are not food and do not provide nutritional value, such as soil, chalk, paper, plastic or metal. The behaviour is persistent or severe enough to affect a person's health or everyday life, or to put them at significant risk.
Post Orthostatic Tachycardia Syndrome (PoTS)	A condition that affects the autonomic nervous system, which controls functions such as heart rate and blood pressure. It causes an unusually large increase in heart rate when moving from lying down or sitting to standing. Symptoms can include dizziness, light-headedness, fainting, fatigue, weakness, headaches and difficulty concentrating.
Rumination-regurgitation Disorder (RD)	A feeding or eating disorder involving repeated regurgitation of food after eating, which may then be re-chewed, re-swallowed or spat out.

APPENDIX 7: ADVOCATING FOR YOURSELF

The topics and recommendations covered in this report may be relevant to you or a family member or friend. If you are looking for or are struggling to access eating disorder support that is autism-affirming, whether that is in the early stages of seeking support or further on in the eating disorder treatment journey, this section is for you.

It covers how you can advocate for yourself or a loved one. Advocacy is about making sure your voice is heard when you are seeking support and can help you with navigating services and ensuring your needs are properly considered.

In an ideal scenario, this would be a straightforward process. However, the experiences described in this report demonstrate that this is not always the case, for lots of different reasons. It is also not always clear what would be helpful, or what is next, and the steps described below may help you to bring this all together.

The aim is to clarify what is currently happening, what would be helpful, and to then discuss this with your treatment team. This can feel overwhelming, and it is important to remember that you deserve (and are entitled to) care that meets your needs. You can ask a family member or friend for support you with these steps if it would be helpful for you.

What steps can I take to receive autism-affirming care for my eating disorder?

1. Coordinate the relevant information about what your treatment currently looks like

If you are already receiving support from a service or different services, a helpful first step can be to review what this currently looks like and to write down what your understanding of this is. For example:

- Which services are involved?
- Who is your lead clinician?
- What type of support are you receiving?
- Where do you receive this support?
- How long will this support last?
- What will happen when this support ends?

Your care plan can help you answer some of these questions. A care plan is a plan that is personalised to you. It is usually presented in a document and developed at the beginning of treatment, and then regularly reviewed. It includes (but is not limited to) the challenges you're currently facing as well as the support you will receive and goals that have been identified. You should be involved in discussions about your care so if you haven't seen a copy of your care plan you can ask for one.

2. Think about and write down what's not working, and what would be helpful

Next, consider what you would like to happen in your treatment to make it autism-affirming. The

information you collected in step one can help to figure out where you feel there are gaps, or where things could be improved.

A good starting point can be a communication passport, even if you haven't explored the possibility of autism with your team yet. A communication passport is designed to help clinicians to understand how you would like to be communicated with, and to prevent you having to repeat what you need, which we know can be tiring. PEACE have a short and long template for a communication passport here. PEACE BOB (which was designed for children and young people) have similar resources here, which includes templates with prompts and ideas.
There might be additional things you would find useful in your treatment, which you can include too. You might not know what would be helpful for you, and that's okay too. In this situation, it will be helpful to write down the parts of your treatment you're finding challenging instead.

3. Read the policy context section in this report

Understanding your rights and reasonable entitlements is an important part of advocacy. The 'policy context' section in this report outlines the guidelines and frameworks that support the provision of autism-affirming care.
It can be helpful to reference these guidelines and frameworks when asking for your treatment to be reviewed. Have a look at these to help support the requests you're making.

4. Speak to a member of your care team

If you have a 'key worker' (the title of this role varies, but it refers to the person who coordinates your care and is your point of contact), ask them if you can discuss your care and the information you have coordinated. If you don't feel comfortable doing this with your key worker, or don't have one, speak to the clinician you're most comfortable with. If you'd prefer to send over the information via email that is also an option.

You can say that you want to talk about your care, and how it could be more useful for you. You might want to give them the notes you've made, or you can use them to help guide the conversation instead.

If you have ideas about what might be helpful, ask if they can be trialled or implemented. If you don't, discuss the elements you're finding challenging to see if they have any ideas about what could be trialled.

The person you speak to might need to discuss any adjustments with their team, but you can also request that these are incorporated into your care plan.

What if I'm told what I'm asking for is not possible?

You might be told that the adjustments you're requesting aren't possible. We know this can be disheartening, and it can be difficult to know what to do next. You should be given a clear explanation of why it's not possible and what is possible.

The Beat website has a section called 'I'm struggling to access eating disorder support' which has some steps on taking these decisions further depending on the country you live in, as well as information on how we can support you with advocacy. We would recommend reading this for further information and advice. We also have a helpline that you can contact via email, webchat, and telephone where a trained advisor can help you explore next steps.

APPENDIX 8: RESOURCES

Further resources to support this report can be found on the Beat website.

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ABOUT BEAT EATING DISORDERS

We're Beat Eating Disorders, we're here to ensure no one faces an eating disorder alone.

Right now, around 1 in 20 people in the UK have an eating disorder – and the emotional and physical toll also affects millions of loved ones. But there is hope. With better understanding, faster diagnosis and proper treatment, recovery is possible.

That's why we're here. We're here when people need us most, empowering them to take the steps they need towards recovery. We support those around them, so they know what to do to help. And we work to stop others being affected in the future. Together we are changing lives.

Beat
Eating disorders

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Use **helpfinder.beateatingdisorders.org.uk** to find support in your area.

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