Evidence-informed, coproduced clinical guideline for adapting eating disorder focused family therapy for Autistic children and young people

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The Eating Disorders and Autism Collaborative (EDAC), alongside key collaborators, are delighted to introduce this ***evidence-informed and coproduced clinical guideline for adapting eating disorder focused family therapy for Autistic children and young people***. This guideline was developed across a series of workshops with clinicians, researchers, third sector representatives, Autistic individuals with lived/living experience, and parents/family members. The belief underpinning this guideline is a commitment to coproduction. More specifically, we believe that meaningful and impactful research and clinical practice can only be developed in partnership with the community that is most affected by it. We hope to support clinicians in more confidently adapting eating disorder focused family therapy (FT-ED) as well as families advocating for more inclusive care.

This guideline and all associated resources are freely available.

The EDAC Team

www.edacresearch.co.uk

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What is Coproduction?

Coproduction is the development of new research knowledge by all participants working together on a research topic without privileging one form of knowledge over another. It tries to break down the “us and them” distinctions of traditional research and instead supports the joint production of research and co-ownership of it. This provides a platform to support the development of meaningful research, aligned with the needs of individuals and communities.

Eating Disorder Focused Family Therapy (FT-ED)

Eating disorder focused family therapy (FT-ED) is a form of family therapy that is specific to eating disorders, unlike other forms of family therapy, which may focus more heavily on family dynamics. FT-ED has a few variations, including family-based treatment (FBT) and Family Therapy for Anorexia Nervosa (FT-AN). This guidance focuses specifically on FT-ED for Anorexia Nervosa, although some key principles may be helpful in other feeding and eating disorder presentations. A key practice in FT-ED for Anorexia Nervosa, especially at the beginning, is for parents or carers to be responsible for renourishing their child. Gradually, the responsibility of eating is handed back over to the young person. FT-ED is usually offered in an outpatient setting, meaning that the young person does not stay at a hospital, but is treated in community clinics.

The Eating Disorders and Autism Collaborative (EDAC)

The Eating Disorders and Autism Collaborative (EDAC) is an innovative project aiming to increase research capacity by supporting research collaborations on the interface between eating disorders (EDs) and autism. (for more information on EDAC see edacresearch.co.uk or Duffy and Gillespie-Smith, et al., 2023).

Project Goals

The goals of the project were to support clinicians to deliver more acceptable and effective interventions for Autistic young people with EDs by:

- Developing a shared understanding of the experiences and outcomes of Autistic young people and families in FT-ED, as well as proposed adaptations
- Agreeing to a set of recommendations to support autism-affirming FT-ED
- Coproducing a guideline based around these recommendations and including examples and implementation considerations
- Making this guideline accessible and useful to support adoption by FT-ED clinicians.

Key terms

The following section will outline terms and concepts used within this guideline and provide a definition of each.

Autism-affirming is a strengths- and rights-based practice that promotes and affirms the person's Autistic identity

Circular questioning is a systemic therapy technique that asks members of a system (like a family) to comment on the relationships and interactions between other members, shifting focus to relational patterns and revealing different perspectives

Externalisation is a technique used in FT-ED where language is used to talk about the eating disorder like it is a separate thing from the individual.

Neurodivergent describes an individual who thinks, processes information and interacts in ways that differ from the perceived norm of social groups, peers and particular cultures.

Contents

The following document presents an *evidence-informed, coproduced clinical guideline for adapting eating disorder focused family therapy for Autistic children and young people*. The guideline emerged from a series of workshops with Autistic people with lived/living experience of an ED, parents and carers, clinicians, researchers, and third sector representatives (please see **Appendix 1** for more details). Everyone who contributed to the workshops has been invited to co-author this guideline.

Within this guideline, we first present a **Summary of recommendations for adapting FT-ED** to serve as quick reference for all 12 recommendations. We then outline **Detailed recommendations for adapting FT-ED** to be more autism-affirming, which includes examples, links to potential resources, and implementation considerations.

Summary of recommendations for adapting FT-ED

1. **Take a strengths-based approach to neurodivergence** recognising talents and resources, not just difficulties.
2. **Take a collaborative approach**, working alongside the young person and their family, recognising the expertise that they bring
3. **Offer early screening for autistic traits** such as the AQ-10
4. **Develop a shared understanding of autism and the ED**, for example, through formulation
5. **Offer education on how autistic profiles interact, influence, or protect against the ED**, including topics like interoceptive differences, recognition of emotions, and communication styles.
6. **Adapt the physical environment based on the young person's—and the family's—sensory needs**.
7. **Adapt food choice, meal plans, and eating tools based on the young person's unique sensory needs**
8. **Adapt communication based on the young person's—and the family's—unique needs and preferences.**
9. **Use externalisation sensitively** and consider that this approach may not suit all members of the family
10. **Offer more flexibility in FT-ED session length, overall treatment pace, and format.**
11. **Give advance notice of changes or endings**
12. **Use reflective practice when adapting FT-ED** including supervision

Detailed recommendations for adapting FT-ED

1. Take a strengths-based approach

A strengths-based approach means recognising someone's abilities, talents, and resources in addition to their difficulties. It avoids viewing or speaking about autism as something that should be fixed. In the context of FT-ED for Autistic children and young people, it means actively harnessing the strengths and autistic traits of the individual as part of the recovery process. Taking a strengths-based approach provides the essential foundations of autism-affirming FT-ED.

Examples:

- Avoiding deficit-based language, such as 'disorder' or 'ASD' (There is a helpful guide from NHS England here)
- Using the language preferences of young people and their families
- In the absence of stated preferences, use identity-first language (i.e., Autistic person instead of person with autism)
- Harnessing a strong preference for routine and predictability in establishing eating routines to support recovery
- Integrating an Autistic young person's interests into FT-ED

Considerations:

- A strengths-based approach does not mean ignoring the challenges and realities of Autistic young people and their families but rather acknowledges when the source of the difficulties lies outside the individual.

2. Take a collaborative approach

Work alongside young people and their families to make joint decisions when possible, knowing that Autistic people and their families bring significant experience and insight into what will and won't work for them.

Examples:

- Valuing parental insight on what has worked in the past, and integrating this into treatment

"They've found ways to parent their child with who's Autistic and actually we will be really wanting to draw on those strengths and that knowledge from that family, and even more so to be helpful in thinking about how we get eating disorder recovery in the context of having Autistic child." -Clinician, Duffy et al., 2025

- Asking the young person directly about their Autistic experience

"Even though still trying to be guided by the family and their knowledge of the child, might use the young person to upskill the parents on their Autistic identity and what they need of the parents from that point of view, especially if the diagnosis is new." -Clinician, Duffy et al., 2025

- Providing the young person choice wherever possible, such as selection from a number of options

Considerations:

- We acknowledge that within ED treatment, sometimes assertive action is needed quickly to support a young person's health and wellbeing. However, even in these situations, aspects of choice around care and treatment should be encouraged and supported.

"We need to find ways to still hold the non-negotiables but be presenting in choice, and kind of collaborative tone… I feel like people can get really stuck in saying that this is how it has to be and not feeling like they have permission to slightly change the semantics of how things are set up or even the way that it's set up." -Clinician, Duffy et al., 2025

3. Offer early screening for autistic traits

Screening for autism should ideally take place at the point of ED assessment to support appropriate adaptations to FT-ED.

Examples:

- Incorporating the Autism Quotient-10 into routine assessments
- Using EDAC's assessment toolkit for young people scoring 6+ on the Autism Quotient-10

Considerations:

- Young people and families may come with a range of beliefs around autism, including deficit-based beliefs, and so screening should be introduced sensitively
- Autism screening or diagnosis should never be used as a reason to deny someone access to FT-ED

"I think everybody who presents to eating disorder services should be screened for autism. Absolutely, first of all." -Parent, Nimbley et al., 2026

"There are some things we're trying to do a little bit more systematically, like the screening, like the reasonable accommodations from the outset, rather than waiting until a patient brings it up." -Clinician, Duffy et al., 2025

4. Develop a shared understanding of autism and the ED

At the beginning of treatment, work together with the young person and their family to collaboratively make sense of how autistic traits interact with, influence, or protect against the ED. We think about this as the ability to view the eating disorder through an autism lens.

"I do think just yeah, providing the space even early on in treatment when there is, you know, the priority of life and death issues to still create space, of understanding what's autism and what's the eating disorder." -Clinician, Duffy et al., 2026

Examples:

- Having a discussion during assessment about how sensory processing, expression of emotions, social camouflaging, or executive functioning differences may impact eating
- Using Baudinet and team's FT-ED formulation model, while thinking about how autism and the ED may interact in ways that perpetuate the ED

Considerations:

- The process of formulation may already be routine in some ED services, such as those implementing FT-AN (Eisler et al., 2016; Baudinet et al., 2021) and therefore would only involve extending the process to the consideration of autistic traits

"They were basically just, you know, your child has an eating disorder, she's diagnosed with anorexia, that's the only thing we are thinking about. 'Even if she is autistic, that hasn't got anything to do with this." -Parent, Nimbley et al., 2026

"We could spend more time in the beginning understanding the young person as a person, their likes, dislikes, preferences, natural kind of ways of being…. rather than imposing quite a rigid kind of schedule of things on to them. So I guess having a bit more time to formulate in the beginning, with the hope that I suppose that will lead to more meaningful, sustained behaviour change." -Clinician, Duffy et al., 2026

5. Offer education on how autistic profiles interact, influence, or protect against the ED

Autistic young people and their families may find information on autism and autistic traits to be helpful, especially in relation to how these may interact with disordered eating. Topics of interest may include social camouflaging, emotion recognition and regulation, interoceptive differences, communication styles, the theory of monotropism (a tendency to deeply focus on a small number of interests at a time), and the double empathy problem (bidirectional mismatch between autistic and neurotypical ways of interacting).

Considerations:

- Given that some families will already feel burdened by the demands of FT-ED, clinicians may wish to consider if additional education will feel helpful or overwhelming to the specific young person and their family
- Simply signposting to available literature may not be appropriate for all families
- Education may be delivered in a variety of formats (e.g., individual, group) and with diverse materials (written, audio, visuals, etc.) to support the communication needs of a young people and families

6. Adapt the physical environment based on the young person's—and the family's—sensory needs

The physical environments, including the clinic room, physical monitoring spaces, home, or a virtual platform may need adjustments to reduce unnecessary distress.

Examples:

- Identify sensory needs by openly communicating and collaborating with the young person and their family
- Using the PEACE sensory measure
- Conducting an environmental audit to improve common sensory sensitivities using EDAC's Sensory Environment Audit Tool
- Providing sensory tools or fidgets
- Consulting an occupational therapist with expertise in sensory assessment and environmental adaptation

Considerations:

- Be upfront about what can and cannot be modified (e.g., core infrastructure)

7. Adapt food choice, meal plans, and eating tools based on the young person's unique sensory needs

Consider adaptations that remove unnecessary distress from the renourishment process. Adaptations should be based on a thorough assessment of historical eating prior to the onset of the ED to identify food and eating preferences.

Examples:

- Being aware that rapid change may be distressing—you may have to take an approach where you collaboratively agree which elements of refeeding to prioritise (e.g., weight restoration using current foods)
- Collaboratively developing short- and long-term goals around food variety using a "return to before" approach
- Allowing the use of preferred cutlery and crockery
- Consulting a dietitian with expertise in sensory assessment

8. Adapt communication based on the young person's—and the family's—unique needs and preferences

The therapeutic communication style may need to be tailored to the young person. Moreover, given that neurodivergence tends to run in families, it may also be worth considering if communication with parents, carers, or other family members needs to be adapted.

Examples:

- Using direct language rather than guided exploration or circular questioning
- Avoiding metaphor or imagery-based language if not resonating
- Using the PEACE communication passport
- Providing written materials in advance when preferred
- Not requiring eye contact during FT-ED sessions

Considerations:

- Any tools or resources used to enhance communication (e.g., communication passport) should be revisited to ensure that they are being implemented

9. Use externalisation sensitively

Aligned with FT-ED, offer externalisation as a way to conceptualise the ED. In FT-ED this can be where the illness is talked about as separate from the young person, often using metaphor. This technique was designed to reduce guilt and blame and align the young person and their family as united against the problem. However, the abstract use of metaphor may not be aligned with autistic thinking styles and some young people have described externalisation being delivered in ways that are invalidating. If this does not resonate with some family members, consider trying other approaches that preserve the intention of this technique—to remove blame and criticism.

Examples:

- Not requiring young people who have difficulty with the visual/imaginative nature of this approach or feel invalidated by this technique to just 'stick with it'

"It just doesn't work for her. She's never given it a name or separated it from herself. Cannot do that. I think she has a real problem with visualising things and all the rest of it. It's just not for her." -Parent, Nimbley et al., 2025

- Alternatively offering education on the role of starvation on the brain or the neurobiology of anorexia nervosa

Considerations:

- The sensitive use of externalisation may already be in practice in some ED services, such as those implementing Maudsley family therapy for anorexia nervosa (Eisler et al., 2016; Baudinet et al., 2021). You will also have to consider that sometimes parents do find this approach helpful, even if their child does not, and how to navigate this tension.

"So generally I would ditch the kind of language externalisation and then just focus on so was such and such like this before eating was a problem and just use kind of time comparisons. To bring into the picture that this particular situation is a result of the eating disorder, not because the young person's chosen there. So I will try to find, yeah, other ways to reduce parental criticism and just totally kind of abandoned the language but hold the philosophy. Yeah. Obviously that the young person's not to blame and to find ways to help the family see that as well. It doesn't just rely on the language aspect." -Clinician, Duffy et al., 2025

"I'm sitting there going, absolutely all of this externalisation, definitely the way forward. So, we thought this is really helpful as parents. She just could not get her head around this. She talked about [externalised name for ED], but she just said, 'but my thoughts are my thoughts?'" -Parent, Nimbley et al., 2025

10. Offer more flexibility in FT-ED session length, overall treatment pace, and format

Autistic young people and family members may benefit from adjustments to treatment formats that support information processing, reduce distress, and provide predictability. This will vary for every family.

Examples:

- Offering longer FT-ED sessions to allow the young person more time to process information
- Offering shorter FT-ED sessions for a young person who struggles to manage the typical length
- Taking a more gradual pace to allow for adjustments to changing FT-ED phases
- Seeing parents/carers separately from the young person when emotions get too high

Considerations:

- Flexibility in pace does not necessarily mean a longer treatment timeline—some families may also need shorter treatment
- FT-ED already recommends using separated sessions when expressed emotion is high (Allan et al., 2018; Eisler et al., 2000, 2007)

11. Give advance notice of changes or endings

Notify the family in advance if there are any upcoming changes or endings in treatment.

Examples:

- Notifying the family when there are changes to staff or therapy rooms
- Communicating if there will be disruptions, like building construction or fire alarm testing
- Sending visuals of the clinic and therapy team prior to first appointment
- Preparing for a transition to adult services by consulting a relevant guideline (RCPsych guidance for good practice; Canadian eating disorder transition guidelines; ESCAP practical guidance)

12. Use reflective practice

In the absence of robust evidence on the impact of a specific adaptation to FT-ED, reflective practice may support the balance of evidence-based practice, which combines research evidence, clinician expertise, and patient needs and preferences (Sackett, 1996).

Examples:

- Using supervision time to talk through the balance between fidelity and person-centred treatment
- Reflecting on and challenging neurotypical expectations you have around food, eating and communication
- Reflecting on and challenging any deficit-based stereotypes you have around autism
- Speaking with your team's or service's 'champion' on autism-affirming care
- Scheduling huddles with your team—huddles are time-limited and focused meetings to discuss autism-affirming care (Smith & Tchanturia, 2020)

Considerations:

- Rural and remote areas may not have the requisite expertise on-site, necessitating the creation of virtual networks

"I don't think it's a case of throwing the baby out with the bathwater, but it would have been more helpful if we could have discussed adaptations and reviewed them. Now that's working for her, let's do more of it. That isn't working for you as a family, let's check out another idea." -Parent, Nimbley et al., 2026

"I certainly have found that the model in general can be applied well, as long as you are willing to kind of, adapt it, I suppose, as you go…and be considerate, be considerate to whatever the young person in the family, where they're at, what they need." -Clinician, Duffy et al., 2026

Appendix 1

Process of the workshops:

Coproduction group members were invited based on previously existing relationships and professional networks (e.g., the UK ED charity Beat). All collaborators with lived/living experience and parents and carers were reimbursed, adhering to the National Institute for Health and Care Research policy. The group included thirteen people, including Autistic individuals with lived or living experience of an ED, parents and carers, researchers, clinicians and third sector representatives. Five group members were Autistic individuals with an ED or family members who had participated in FT-ED.

An overview of the coproduction process can be seen in Figure 1 below:

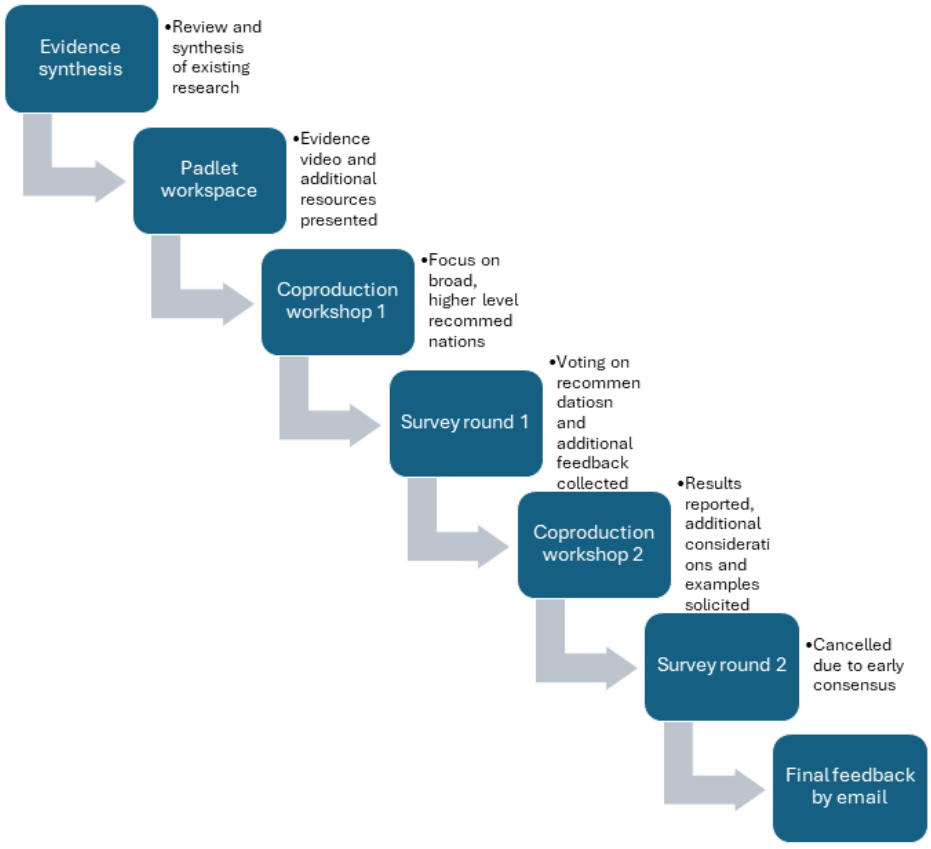

Figure 1. Overview of the coproduction process for the guideline

Prior to any data collection, all coproduction group members completed an online consent form. Following this, coproduction group members were invited to complete a brief, online demographics questionnaire, and given access to a Padlet resource page. This resource page included A) a schedule for the workshop sessions, B) a list of key terms that would be used within the coproduction process, providing definitions and explanations of each, C) a short list of group 'rules' for the workshop to ensure fair and respectful engagement, and D) a 14-minute video outlining the current evidence on adapting FT-ED for Autistic young people and their families.

All group members were invited to two 2-hour workshop sessions in February 2026. The first workshop focused on creating the recommendations statements for the guideline. The second workshop focused on producing the examples and considerations for each. Between these two workshops, an online survey was completed by all coproduction group members to vote on the main recommendation statements. Agreement on each statement was defined as at least 70%. The online survey was completed by all workshop participants. All of the recommendation statements achieved more than 70% with one round of voting.