Eating Disorder and Autism Collaborative

Karri Gillespie Smith and Fiona Duffy

EDAC

Eating Disorders and Autism Collaborative

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Helen Sharpe, Sarah Kettley, Gordon Waiter, Kate Tchanturia, Jess Kerr-Gaffney, Emy Nimbley, Ellen Maloney, Michelle Sader, Kyle Buchan and our EDAC collaborators (including SWAN and Scottish Autism)

A UK wide collaborative network bridging the gap between autism and eating disorders research

@EDACautism_ED www.edacresearch.co.uk @edac.uk

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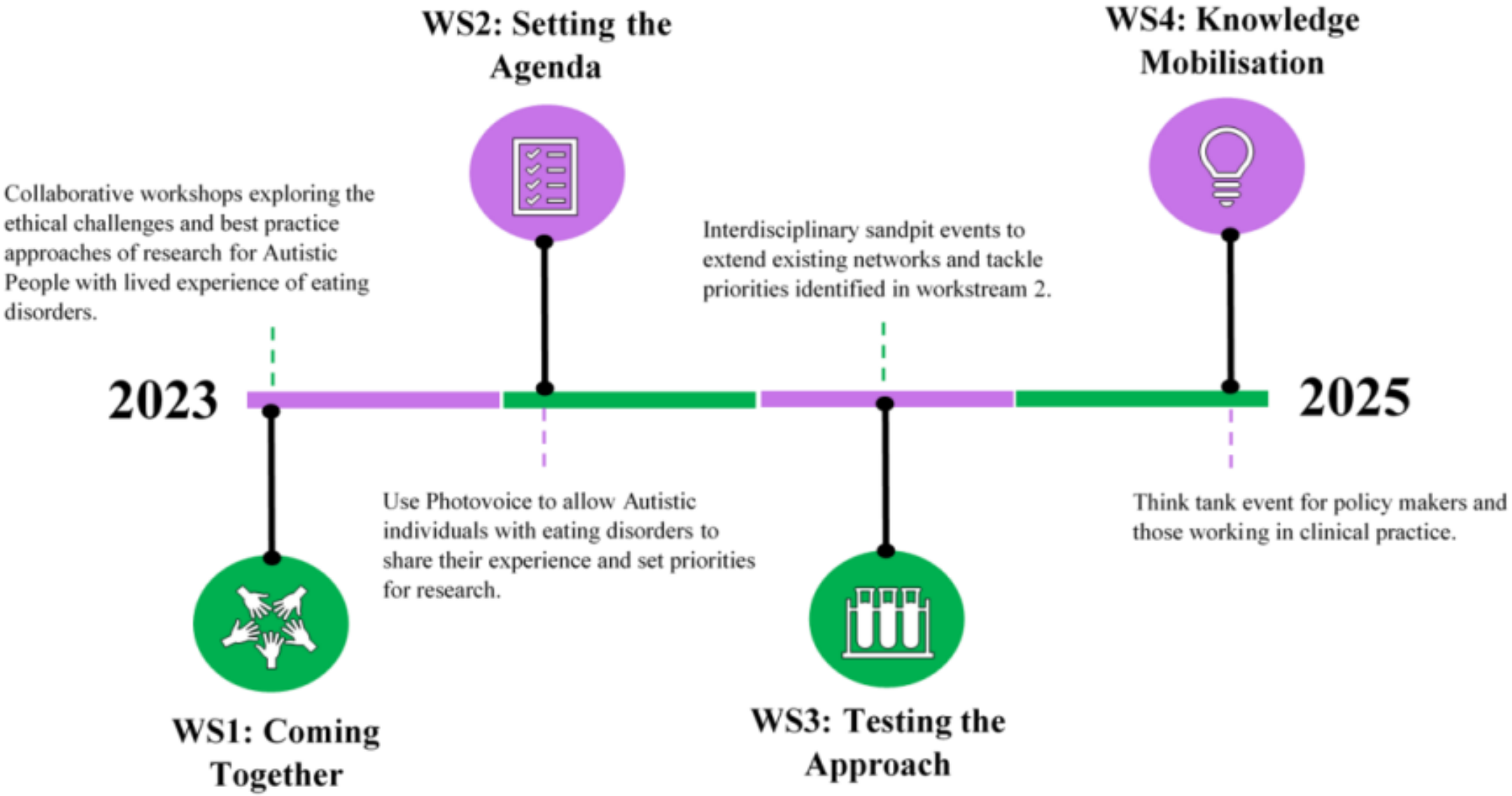
WS2: Setting the Agenda
WS4: Knowledge Mobilisation
Collaborative workshops exploring the ethical challenges and best practice approaches of research for Autistic People with lived experience of eating disorders.
Interdisciplinary sandpit events to extend existing networks and tackle priorities identified in workstream 2.
2023
2025
Use Photovoice to allow Autistic individuals with eating disorders to share their experience and set priorities for research.
Think tank event for policy makers and those working in clinical practice.
WS1: Coming Together
WS3: Testing the Approach

Why is it important?

International Journal of
EATING DISORDERS

REVIEW | Open Access

A Mixed Method Systematic Review Into the Impact of ED Treatment in Autistic People and Those With High Autistic Traits

This article relates to:

Emy Nimbley, Helen Sharpe, Ellen Maloney, Karri Gillespie-Smith, Kate Tchanturia, Fiona Duffy

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- Autistic people and those with higher Autistic traits report poorer experiences of ED treatment
- Both Autistic and neurotypical groups report similar improvements in ED symptoms and BMI
- BUT increased likelihood of inpatient admission and prolonged inpatient treatment
- Higher rates of psychosocial difficulties pre and post treatment

EDAC implementation of PEACE in Lothian

1. Knowledge on PEACE pathway
2. Assessment and Treatment Planning
3. Psychological Treatments and individualised Support Plans
4. Sensory Wellbeing Managemen
5. Nutritional Management
6. Lived Experience Network and Feedback
7. Family and Community Engagement
8. Staff Training and Development

Open Access Article

Implementation Insights from the PEACE Pathway Across UK Eating Disorder Services

by **Kate Tchanturia** [1,2,3,*], **Dimitri Chubinidze** [1,*], **Fiona Duffy** [4,5], **Emy Nimbley** [4,5], **Zhuo Li** [1] and **Joanna Holliday** [6]

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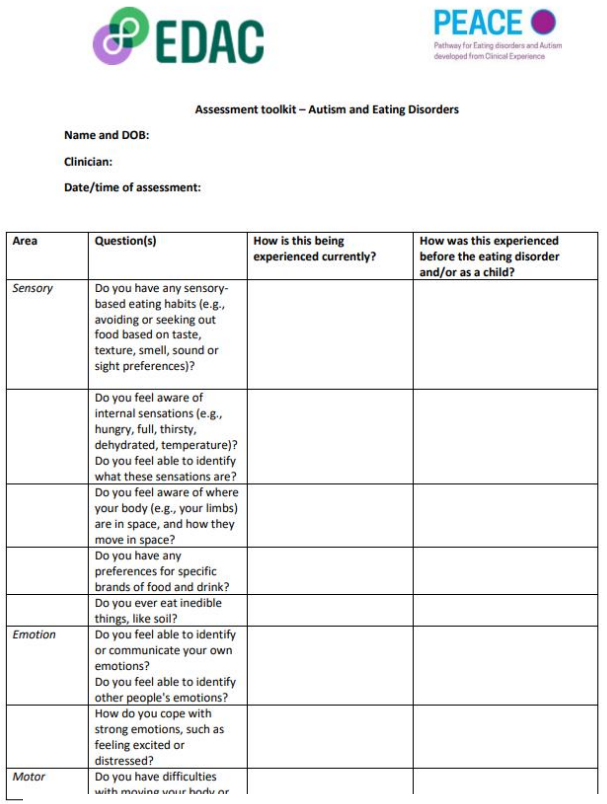
Assessment Toolkit

- Aim: to extend a traditional eating disorder assessment by exploring specific factors related to the development and maintenance of ED presentations in autistic individuals
- Not an autism assessment
- Supports differentiating between current experiences (which may be ED transitory) and long term traits
- Identification of autistic strengths that can be used in treatment



EDAC PEACE
Pathway for Eating disorders and Autism developed from Clinical Experience

Assessment toolkit – Autism and Eating Disorders

Name and DOB:

Clinician:

Date/time of assessment:

Area	Question(s)	How is this being experienced currently?	How was this experienced before the eating disorder and/or as a child?
Sensory	Do you have any sensory-based eating habits (e.g., avoiding or seeking out food based on taste, texture, smell, sound or sight preferences)?		
	Do you feel aware of internal sensations (e.g., hungry, full, thirsty, dehydrated, temperature)? Do you feel able to identify what these sensations are?		
	Do you feel aware of where your body (e.g., your limbs) are in space, and how they move in space?		
	Do you have any preferences for specific brands of food and drink?		
	Do you ever eat inedible things, like soil?		
Emotion	Do you feel able to identify or communicate your own emotions? Do you feel able to identify other people's emotions?		
	How do you cope with strong emotions, such as feeling excited or distressed?		
Motor	Do you have difficulties with moving your body or		

With thanks to:

Emy Nimbley, Fiona Duffy, Ellen Maloney, Karri Gillespie-Smith, Sarah Wilcock, Rachel Loomes, Phaedra Longhurst, Jess Kerr-Gaffney, Kate Tchanturia, Lisa Thomson and Bryanna Lazich.

Sensory Processing

Exteroception refers to external stimuli such as taste or sound (covered by sensory screener). This can lead to dietary avoidance due to sensory aversions and/or sensory seeking leading individuals to seek out specific tastes or textures. Exteroception may also lead to preferences to eating alone to avoid sensory overwhelm e.g. sounds, smells etc.

Interoception refers to the body's ability to identify and process internal sensations such as hunger, thirst, pain etc. This can lead to hypersensitivity (for example acute awareness of fullness sensations or bloating, leading to avoidance of food) or hyposensitivity where it is more difficult to identify and process this information (for example a lack of hunger cues leading to missing meals, or lack of cues of fullness leading to increased risk of bingeing).

Identification and expression of emotion

Alexithymia refers to the ability to identify and communicate your own emotions. Alexithymia has been linked to different eating behaviours, including restrictive eating, binge eating and emotional eating. Alexithymia is also closely linked to ***interoception***, as people with poor alexithymia struggle to distinguish between emotional states and physical sensations.

- Do you feel able to identify or communicate your own emotions?

Emotion recognition refers to the ability to identify and understand emotions in others. It is an important part of emotion regulation, as well as interpersonal interactions.

- Do you feel able to identify other people's emotions?

Emotion regulation refers to how an individual understands and manages emotions. Disordered eating behaviours, such as binge eating or restricting/avoiding eating, can be used as a way of coping with negative emotions.

- How do you cope with strong emotions, such as feeling excited or distressed?

Assessment Toolkit

Motor skills. This includes **fine motor skills** necessary to pick up cutlery and bring food to your mouth. This can present as a preference for specific cutlery, or eating with fingers, behaviours that can be misattributed to disordered eating. This can also include **oral motor skills** that may impact eating behaviours, such as difficulty chewing or swallowing, co-ordination or strength of lips, tongue or jaw, or gag reflex issues.

- Do you have difficulties with moving your body or limbs to perform certain tasks, such as lifting?
- Do you have any difficulties with chewing or swallowing?

Gastrointestinal issues (GI). GI issues are highly prevalent in Autistic people and may impact eating in several ways. Examples of common issues are constipation, diarrhoea, reflux, bloating, food intolerances and sensitivities. These behaviours can be mistakenly attributed to being driven by weight and shape concerns, such as purging (following discomfort) or restrictive eating (to avoid certain textures or abdominal pain).

- Do you have any stomach or digestion issues (e.g., abdominal pain, constipation or diarrhoea))
- Do you have any allergies or food intolerances).

Social Domains

This includes differences in social communication, interactions and relationships.

- ***Camouflaging (sometimes also referred to as masking)*** refers to when an individual consciously or unconsciously changes or inhibits their behaviour to fit in with societal expectations. Within individuals with eating disorders, we can see some individuals adopting diet culture or take part in weight and shape talk amongst peers. It can also involve repressing stimming behaviours or forcing eye contact, leading to high levels of distress. Camouflaging behaviours can be hard to see but they often put a significant burden on the individual and only become apparent when they are completely overwhelmed.

How do you experience eating around other people? For example, do you prefer to eating around other people or struggle with this?

Do you ever copy or mimic other people's behaviours to fit in (e.g., copying eating habits, learning food or body ideals from other people or from the TV, etc.)?

Do you ever feel like you have to hide parts of who you are during social interactions?

- ***Rejection Sensitivity*** refers to an intense emotional response to perceived or real rejection, criticism from others or exclusion. This may make the individual more susceptible societal pressures and fear of judgement from others. This is within the context of high levels of stigma associated with autistic behviours.

How do you react to rejection from other people? (can be real or perceived)

Executive Functioning

- This refers to a set of cognitive processes that help with problem solving, goal-orientated behaviours and self-regulation.
- ***Attention*** refers to the ability to focus on certain information whilst filtering out non-relevant information. This may look like focused attention or hyperfocus on preferred interests, making shifting between tasks more difficult. A closely related concept is ***monotropism,*** which is an autism-led theory for the Autistic ability to deeply immerse themselves and their attention in specific tasks.
- ***Routines*** refer to structured habits or tasks that serve to increase predictability and reduce cognitive load. Routines can serve to manage daily life and minimize uncertainty. This can help reduce anxiety and serve as structured reminders to complete certain tasks. This is linked to **p*reference for sameness,*** doing certain things the same way, which can help reduce uncertainty.
- ***Demand Avoidance*** refers to a strong need to avoid doing something that is expected or requested of you. The individual may want to do what is asked of them but avoid doing so due to anxiety or overwhelm.

Additional considerations and intersectionality

Co-occurring considerations **Any co-occurring neurodivergent (e.g., ADHD), mental health (e.g., OCD) or physical (e.g., autoimmune) conditions? The impact of these will need to be considered within the formulation**
Demographics and intersectionality **(consider gender, ethnicity and sexuality)**
Environmental considerations **Ask about any immediate changes to the clinical environment that can be made t (e.g., removing ticking clocks, alternative seating, light control)?**
Language Preference: **Autistic/ person with autism/ other?**

Co-production and environmental changes

- Making therapeutic environments accessible – **autistic people tend to function well when enabled to anticipate, avoid, or regulate sensory and social input**
- Development of clinic audit tool with Autistic individuals
- Pay Autistic ED patients to support audit of environment
- Action plan for change

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PEACE
Pathway for Eating disorders and Autism developed from Clinical Experience

Clinical Environment Audit Tool

The following tool is designed to be used in partnership with Autistic individuals currently accessing the eating disorder service via a formal walk around the building or via informal feedback. It is intended to be used in waiting rooms, clinical meeting rooms, physical monitoring spaces and inpatient unit environments.

Action points can include modifications to the environment, or in some situations where modifications are not possible, considerations of how to prepare individuals for the environment (e.g., photographs of the clinical space available in advance) and/or sensory tools available to support coping e.g., fidgets, aligned with the specific sensory presentation of that environment

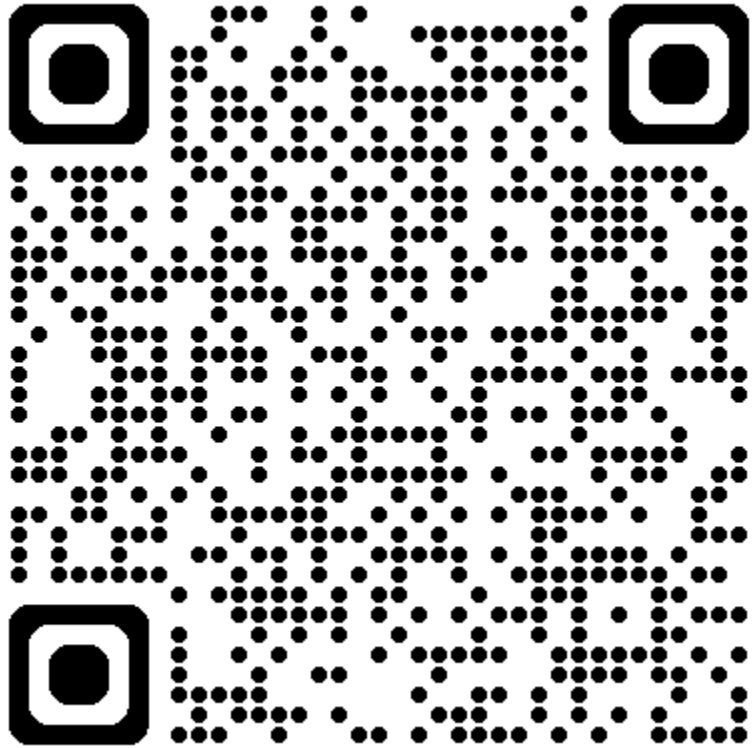
	Sight			
		Yes	**No**	**Action**
1	Are the walls a neutral/low arousal colour?			
2	Is the furniture a neutral/low arousal colour?			
3	Is the carpet/rug a neutral/low arousal colour and pattern?			
4	Is the furniture arranged considering the light from the window?			
5	Are there curtain or blinds to adjust the natural light?			
6	Is the lighting of the room harsh, overly bright or fluorescent?			
7	Are you able to adjust the lighting in the room, through dimmer switches or diffused lights (e.g., lamps)?			
8	If there is a noticeboard/ posters/info , have you made sure that it is not cluttered?			
9	If there are screens, can you adjust the brightness of them?			
10	Any other comments?			

Co-Production of service design

- Consideration of communication to patients and their families e.g. assessment letters, information on service, description of process etc.
- Photographs and videos of environment and a sensory report on the building to predict sensory load
- Sensory tools available in outpatient and inpatient – weighted blankets, fidgets, etc.

Barriers and Enablers to neuro-affirming care in eating disorder services

- Eating Disorder clinicians (not part of official “PEACE” sites)
- Interviews on TEAMS (approx. 1 hour) on barriers and enablers to adapting or modifying treatment for Autistic people with an eating disorder e.g. PEACE pathway.



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Clinicians' experiences of eating disorder focused family therapy with Autistic young people

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[1]University of Edinburgh, [2]NHS Lothian Child and Adolescent Mental Health Services, [3]Eating Disorders and Autism Collaborative (EDAC), [4]South West London and St George's Mental Health Trust, [5]University College London

Aim: to explore the experiences of clinicians in the delivery of FBT or FT-AN for Autistic young people with AN

Inclusion criteria: healthcare professionals formally trained in FBT or FT-AN who had delivered the model to at least one Autistic young person and their family in the past three years.

Theme 1 Systemic Context

Subtheme 1: Neurodivergent parents and carers: Some principles of FBT were well aligned with Autistic families e.g. pragmatic approach, but other techniques more problematic e.g. externalizing and circular questions

Subtheme 2: Multiple Layers: Different neurotypes within the family and therapeutic relationship

"Where the autism isn't recognised or there's multiple layers of kind of the double empathy problem in action. That can make FBT hard because I think there has to be a good relational base and a shared understanding and a way that it's done so that everyone feels like this is coming from a caring position, not a misattuned kind of punitive position. Yeah and I've just found it can just more easily fall into that latter category with autistic young people and their families." (HCP 2)

Missatunement across the therapeutic relationship can lead to perception, or even inadvertent adoption, of a more negative or punitive position for the FBT therapist.

Subtheme 3: Parenting an Autistic Child: Historical experience of parenting an Autistic young person that families bring to appointments, particularly those with experience of a young person with a demand avoidance profile, and the FBT requirement of a different style of parenting including rapidly engaging in the distressing process of eating

Theme 2: Raising potential autism

Clinicians noted most young people present to ED services without autism having been explored before. Contemplating an autism assessment at a point of heighted distress owing to the recent onset of the ED can be overwhelming.

"We're making the diagnosis or we're suggesting they pursue a diagnosis. And so these families and young people are getting their heads around what it means to be autistic as well as getting their heads around what it means to have an eating disorder." (HCP2)

Clinicians describe the tension between exploring whether an individual is Autistic (and the potential negative implications if you do not) when you are still trying to engage a young person and the family alongside supporting the urgency of the refeeding process.

Theme 3:Autism and ED crossover (3 sub)

Subtheme 1: Differentiating between autism and ED's: Dilemma of considering autism when YP is acutely starved and the associated secondary impacts of this. Struggle to confidently differentiate anorexia from Autistic traits which appeared more challenging due to the need to respond differently to autistic traits and disordered eating,

"I think working out what's being driven by the eating disorder and what's being driven by their autistic identity and then of course, there's going to be a crossover. In my experience, that crossover is where the conflict and stuckness kind of happens because it's hard to know whether to embrace that aspect of the young person's kind of character and interactions, or whether it's something that needs to be challenged because it's just so entwined."

However the process of questioning and uncertainly comes at a time when a therapist needs to be clear and containing for a family:

"I think sometimes always that question of is this autism or is this anorexia can knock a parents kind of confidence and clinicians confidence"

Subtheme 2: Agnostic stance in context: Clinicians valued the agnostic stance of FT-ED, however, they felt there was a risk of being blinkered to the impact of Autistic traits on ED presentations. Need to understand Autistic preferences and traits, how they interact with the ED, to support adaptations of treatment and recovery

"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"

Theme 3 Autism and ED crossover

Subtheme 3: Autistic empowerment

The opportunity for young people to bring their experience of being Autistic to share with the family and clinician.

"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"

"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."

Theme 4: Manual vs adaptations (2 subs)

Subtheme 1: Tensions between evidence-based practice and harm: Several clinicians perceived FT-ED as an adaptable treatment, others felt pressure to follow the manual to align with an evidence-based approach. Tension related to the potential to cause harm.

"We also don't want to cause harm and like I want to help this family recover and, you know, be rid of the illness but actually I also don't want to add even more harm at this stage."

There were concerns that dogmatically adhering to specific techniques can lead to harm. However, also fears about adapting therapy to the point that they loose the basic principles of ED treatment

"it's a kind of slightly paranoid voice in the back of my shoulder of, if I am going to make any adaptations, am I actually appeasing or accommodating this eating disorder versus am I actually accommodating a young person in a helpful way because of their other needs."

Subtheme 2: Autistic specific considerations - In additions to autism specific adaptions clinicians identified that a solution was to make adaptions but to adhere to underlying principles of FT-ED (mainly Autistic YP needing more time, both to support communication and information processing within appointments) but also to expect a slower pace of change to reduce overwhelm

"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"

Conclusions

- Double empathy problem (Milton, 2022) a breakdown in reciprocity and mutual understanding between people with different ways of experiencing the world (i.e. neurotypes). Concerns misatunement may result in clinicians adopting an authoritarian style and potentially even punitive cycle of communication with families
- Some FT-ED manualised techniques e.g. externalisation and circular questions may be at odds with Autistic characteristics including considerations of cognitive flexibility, ability to manage abstract concepts and perspective taking.
- More time understand Autistic preferences and traits and formulation how they might interact with the eating disorder
- Making adaptions while adhering to underpinning principles.

CBT-E Next!

Survey and optional interviews with ED clinicians formally trained in CBT-E who have had experience of delivering this with at least one Autistic adult for AN, BN or BED in the last 3 years

AND

Autistic adults (over 16) experience of CBT-E for eating disorders in past 3 years

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Bridging the gap between autism & eating disorder research.

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