North East and North Cumbria
Mental Health, Learning Disability and Autism Partnership

Neurodivergent Affirming Care across the Eating Disorders Pathway
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5 Clinical Practice Reflections and Suggestions from those with Lived Experience

In all autistic individuals with an eating disorder it is essential to remember that they are autistic but also have an eating disorder. This re-frame can help you to differentiate and always remember that the clinical aim is to treat the eating disorder, not autism.

These 5 clinical practice reflections and suggestions for across the whole pathway have all be drawn from those with lived experience of both autism and an eating disorder:

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1. **Reflection:** my autism doesn't need changing - perhaps it can be used more helpfully?
2. **Suggestion:** instead, of blanket assumptions - use a 'strength based approach'

Moving away from rigidity is generally seen as a positive step in eating disorder treatment. Things like counting calories, having rigid meal times, eating a narrow range of safe foods and having limited food flexibility are all typically seen as negative consequences of an eating disorder. This may be very true for most individuals, some of whom may also be autistic, but lived experience tells us that these assumptions are unhelpful and don't take reasonable treatment adjustments for autism into account. Imposing assumptive and arbitrary rules about when, what and how to eat and how to live a normal daily life, left one individual feeling like *"if I follow all these rules exactly then I can fix all of the broken things about myself"*. This is a deeply damaging, unhelpful and untrue internal dialogue that could be avoided through better, neurodivergent affirming care.

A *strength based approach* advocates for using the strengths of autism more helpfully. It recognises that these traits or behaviours may be part of an individuals authentic autistic self, and an important part of how they can live most comfortably and congruently. Structure, predictability and inflexibility should not be seen as inherently negative things and can be used helpfully, particularly to support the challenges of executive function. In this way, instead of seeking to change, remove or minimise these traits, a strength based approach seeks to recruit them for recovery. For example:

- Instead of banning calorie counting → how do we use calorie counting as a way of reaching a minimum number to support recovery, rather than unhelpfully using it as a maximum target and aiming to eat below it.

- Instead of pushing social eating and flexibility → how do we develop a minimally safe tolerance of food flexibility and uncertainty. For example supporting eating the same limited foods but developing a tolerance for one or two alternative meals if (for example) the food you wanted was unavailable to buy. Accepting that social eating may not be a sensory or social preference for everyone and supporting this.
- Instead of pushing the requirement for food variety → how do we support a minimally safe intake of preferred foods that work for, rather than against, recovery. Using foods that reflect preference and individual sensory profiles, and which may be eaten in combinations or at times that are different from social norms.
- Instead of removing planning and rigidity → how do we use this helpfully. How can we use planning, food predictability, advanced decision making and visual aids (for example) to support a consistent and helpful intake that works for the individual.

For all the above the key is *individuality*. Avoiding assumptions about unhelpful behaviours is just as important as avoiding assumptions about a persons strengths. For example, we should absolutely not assume that all autistic people would find continued calorie counting helpful, but leave space to consider that some *may*. Clinicians should work to foster a trusting dialogue and team culture that leaves space for individuality and adjustments where these enable the person to find a recovery which feels most helpful to them. As one person with lived experience reflected: *"refusing to accommodate my own needs was ultimately holding me back".*

1. **Reflection:** talking about 'returning to normal' as a recovery aim is unhelpful to me
2. **Suggestion:** instead, think about my new identity and strategies I can use to move forwards

In eating disorder recovery, we often talk about 'returning to normal' meaning to recover and return back to the person you were before the eating disorder took hold. Whilst this may be helpful for some, those with lived experience tell us that this can be deeply difficult for an autistic person on many levels:

- 'Normal' is a social construct and the word itself conjures neuro-normative assumptions or expectations which feel inherently unhelpful and pressurising.
- The lived experience of the individual prior to the onset of the eating disorder is often remembered as unhappy, highly anxious, or unauthentic. In many ways, the development of the eating disorder is a coping mechanism challenges faced in their life and it likely served to make the individual feel happier, more focused, less emotional (numb) or more in control, amongst others. In this way, 'returning to normal' brings about feelings of anxiety and fear, and a perception of returning to a different 'unwell' version. It can serve to unintentionally minimise predisposing factors for any individual, but especially for an autistic person.

Instead, lived experience tells us that it is more helpful to spend time creating something different, and thinking about moving forwards rather than backwards. Spending time developing the individuals true authentic self and using a strength-based approach that allows an individual to keep all the helpful aspects of an eating disorder (control, focus, routine, predictability) without the negative consequences (weight loss and physical health compromise). As this individual with lived experience described: *"my eating disorder fit so well into my sense of finding authenticity and calm, it felt very protective and numbing. Understanding what 'better to me' meant was essential for my recovery".*

Also allow space and time to work through this process. For any individual, giving up on the version of 'normal' or on the future version they thought they would become is really difficult. It requires careful and skilful therapy and time.

1. **Reflection:** finding gaining weight difficult isn't just about my eating disorder - stop minimising it
2. **Suggestion:** instead, think about the holistic impact on me as an individual and the language you use

Weight gain anxiety is understandably considered to be the resultant distress of an eating disorder. However, weight gain can be more complex than that, especially for an autistic person and attributing all expressed distress about this as 'part of your eating disorder' can feel highly dismissive. Weight gain can represent a sensory change (how clothes feel) or an emotional/internal feeling change (return of menses). The weight number could have meaning, represent a social rule that feels hard to change, or have an associated fixed belief. An autistic person may also be focused on certain types of numbers (such as round numbers, or even numbers, or number patterns) in many areas of their life. There are many examples and experiences will be individual. The main stop-and-think point here is that there may be many causes of the distress that is experienced from weight recovery and it is *possible* that the eating disorder does not account for them all. Blanketly attributing all distress to an eating disorder is likely to feel dismissive and unhelpful.

Ultimately, weight gain also represents a change and changes are generally more challenging for autistic people. Exploring an individuals relationship with numbers in all aspects of their life and development will be a helpful part of developing an understanding about this. A detailed sensory profile may also help to unpick and understand the individuals experiences, challenges and resistance to weight gain. Lastly, eating disorder distress can absolutely still be a feature - exclusively, or as part of the distress experience. The key is to avoid assumptions and inferences.

Ultimately, we can't avoid weight recovery in an autistic population but understanding how best to support this process is likely to be much more helpful and meaningful. It may also be appropriate, depending on the sensory profile and level of risk, to consider reasonable adjustments to expected weight recovery rates.

1. **Reflection: '**take away your safety blanket and face your fears' really isn't helpful with my autism
2. **Suggestion:** instead, think about what safety strategies could replace unhelpful ones

'Facing your fears' can be a common therapeutic strategy in eating disorders care and treatment, but doing so relies on well established alternative coping strategies. It is also broadly neuro-normative in the assumption of how facing ones fears will be experienced. Autistic individuals often have many safety seeking behaviours and some of these may be maladaptive or unhelpful. Suggesting that an autistic person should remove the safety blanket and face their fears is likely very unhelpful. Instead, build healthy safety blankets / coping strategies to use as you move away from unhelpful eating disorder behaviours.

1. **Reflection:** what I eat isn't weird, why are you making me change it
2. **Suggestion:** instead, always consider what is disorder vs difference

As clinicians, we often make blanket assumptions about 'normal eating' behaviour as we strive towards normalised eating from disordered eating. But it is very important to tease out what is

disordered from what is *different*. Suspending neuro-normative assumptions about food and food behaviour is very important. There are many examples of difference but include avoiding assumptions and rules about what foods should be paired together, how foods should be presented, what crockery/cutlery is used, what defines a normal eating pace or normal meal-time distractions, and assumptions about what time of day foods are served. If the food choice or eating pattern is different, but still promotes and supports recovery, this could be an example of difference rather than disorder. Working with difference helps to support recovery in a much more authentic way than the imposition of unhelpful social rules and assumptions. As one individual with lived experience described; "*don't make fun of my food choices, I'm not an object of amusement, I'm a human being'.*

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