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ADULT EATING DISORDERS
LEAD PROVIDER COLLABORATIVE
NORTH WEST
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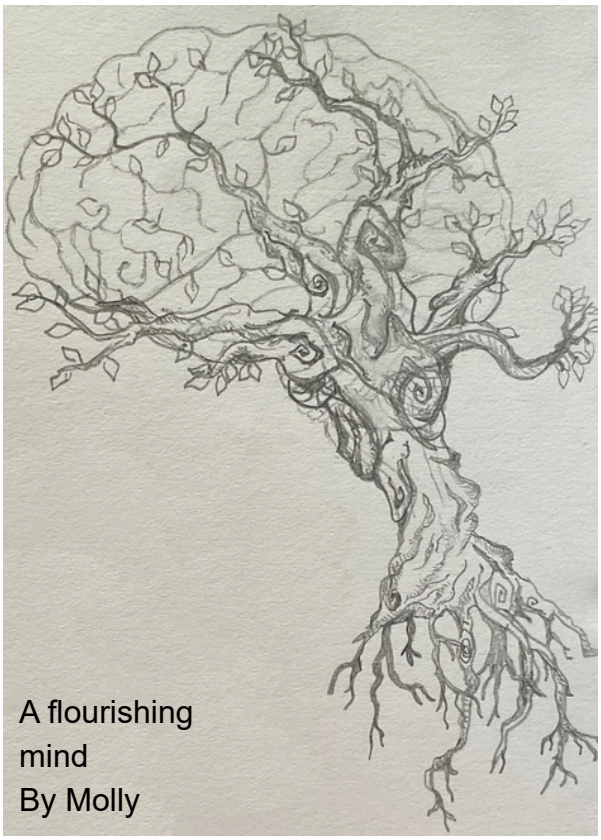
The Recovery EDit

ISSUE #3 April 2026

Experts by Experience



A flourishing mind
By Molly

In this bulletin you can expect:

Focus on: Neurodiversity in eating disorders

Hello. Welcome to the April issue of the Recovery EDit. Last month saw neurodiversity awareness week. As such this issue of the bulletin will focus on neurodiversity in eating disorders. It's something we here at EmpowerED have reflected on, discussed and debated on numerous occasions. It's fair to say it's something we all feel passionately about. Rates of neurodivergence in eating disorder populations are far higher than in society as a whole and yet therapy approaches and staff training often don't reflect this. In this issue we'll look at some of the latest research, share individual experiences, and suggest tips for both individuals and clinicians to help all of us thrive with neurodivergences.

The Experts by Experience

Research Focus

What we know from literature

Prevalence

- Autistic individuals are twice as likely as non-autistics to experience an eating disorder [1]
- It is estimated that between 20-40% of people with anorexia have autistic traits [2]
- Autistic individuals have a higher likelihood of receiving inpatient care (46% vs 23% of non-autistics) [3]

Behaviours

- Close overlap between autistic traits and symptoms of anorexia nervosa often led to staff misinterpreting autistic traits as eating disorder related behaviours [4]

Treatment

- The ability to recognise autistic traits and understand autism in eating disorder services is vital in enabling autistics to effectively engage, irrespective of if they have a diagnosis at the time or not [4]
- The ability for abstract thinking that is required within CBT is often a barrier [4]
- Services are based around neurotypical norms and the perceived difficulties of autistics to engage led to early discharge, with some describing experiences of being blamed for lack of treatment success [5]
- Clinicians expressed that less experienced colleagues may misunderstand autistic people's communication style as being disinterested [5]
- Clinicians noted that differences in thinking styles can hinder engagement in traditional therapy if not adapted [5]

Overlap

- Eating difficulties may arise as an attempt to cope with the challenges of being autistic [6]
- Restricting and the subsequent effect of starvation numbs emotional and sensory overload [6]
- Controlling food intake can counter anxiety caused by unpredictable environments [6]

Autism diagnosis

- Being female and having other co-occurring mental health conditions are implicated in missed or delayed autism diagnoses, compounded by living with undiagnosed autism being associated with development of further mental health difficulties [6]
- Receiving an autism diagnosis was often seen as beneficial – it enabled greater self-knowledge and compassion and advocacy for own needs. It allowed for better understanding of themselves [7]

What this means in practice

You will meet individuals with diagnosed and undiagnosed neurodevelopmental conditions during your time in eating disorder services. While estimates vary, this is likely to be at least one in five patients. This will impact on their eating disorder, their recovery and their general cognitions. You can provide simple adaptations to enable individuals to better engage with their treatment and gain more from treatment than they may without these (see examples in neurodivergence toolkit, pg 6) These changes have been shown to benefit all patients, with or without autism [8]

We fully appreciate it can be difficult to unpick the eating disorder from autistic/neurodivergent traits, but seeing each person as the individual they are and spending the time to discover the roots of these behaviours can help to develop a more trusting, open therapeutic relationship and better engagement in treatment.

By Danielle, EmpowerED expert by experience

*For references see Appendix

The difference a diagnosis makes:

A comparison of two inpatient experiences

I've had two admissions to inpatient services. Both were to the same 14 bed unit. Though my admissions were ten years apart the unit itself had changed very little. I knew a lot of the staff; physical spaces, rules and regulations were unchanged; even the three-week rolling food menus were the same (who knew there are so many variations on the humble spud!) And yet, my experience of inpatient care felt very different the second time compared to the first and the trajectory upon discharge has been very different. So what did change?

For this second admission, my understanding of 'me' was very different. I'm still the same person – a bookworm, rather nerdy, craft enthusiast and more than slightly daft – but this time I came to inpatient care understanding myself also to be a person with autism. It's a short label. But it has real impact. I believe it markedly changed my experience of inpatient care and its outcomes.

Of course, everybody should be treated as an individual regardless of labels. Even when almost entirely consumed by an eating disorder there is still an individual at the core of the disorder. And, though it is difficult in such a regulated environment, my experience is that staff do create the space for us to be individuals where they can.

Essentially, an inpatient stay is designed to squash eating disorder symptoms. But, what if your eating disorder is not the root of the problem? What if the eating disorder symptoms are secondary to another neurodivergence?

Squashing the eating disorder in many ways makes me sicker. Deprived of coping mechanisms (i.e. reducing food intake) the stress only feels worse and my desire to restrict strengthens.

During my first admission I felt constantly overwhelmed and thus unable to make the most of therapy offered. Hospitals are noisy and overstimulating and emotions run high. I hated the way eating woke up my over-active brain. This all led me to cheating the system as much as possible – I'd sneak in snacks just under the 100 calorie minimum; always choose the safest options on the menu, refused sauces, drank only black drinks when I prefer white… Instead of working with the system, to recover, I worked to get out. It's horrible to feel untethered and this is just how admission one made me feel. Hospital reinforced my need for the eating disorder in order to cope.

At the time of my first admission I didn't know that I might be neurodivergent and that there are ways, other than food, of managing neurodivergence symptoms. All I knew was that I felt constantly stressed and anxious and restricting what I ate helped with this.

The second admission I was treated by others, and treated myself, as a person with autism. What did this mean? There were practical adaptations such as wearing headphones most of the time as I now know noise causes me stress and agitation. The central ward tends to be noisier and busier, claustrophobic and crowded but I was able to have a room further from the central hub. I was able to take my weighted blanket. I still had outbursts of emotion that I didn't understand but I no longer judged myself for them. With this new understanding of myself, with the additional label, I was able to develop and try out alternative coping mechanisms to food. I was able to engage in therapy because my stress and autism were managed. And so, I was discharged this second time not 'recovered' but heading in the right direction. Hospital wasn't the highly traumatic experience it had been first time.

So, is a label helpful? I would argue yes. To complicate the picture and look at what lies behind the eating disorder is essential in giving individuals the best chance of recovery. We know comorbidities are high and it is important for the individual, for their supporters and for therapists to understand the individual's window on the world. Neurodivergence shapes our window.

By Molly, EmpowerED expert by experience

> "What if your eating disorder is not the root of the problem?"

Focus: 5 minute barrier buster

The following questions are designed as a quick "5-minute barrier buster" to help enhance the care and experience of neurodivergent patients. We recognise that making reasonable adjustments for every patient can be challenging in busy clinical settings, but taking a few moments to approach care with curiosity can have a significant impact on patient experience and outcomes.

You might consider asking yourself and your patients:
"Am I treating fear as defiance?"
"Are there environmental changes I could make such as dimming the lights, reducing external noises, that would make it easier for you to attend/engage in treatment?"
"Do you prefer direct questions, or some time to think before answering?"
"Do you ever feel you have to mask or hide your feelings in appointments?"
"Am I bringing any assumptions about eating disorder behaviours that might overlook the role of neurodivergence?"

Behaviours that might be mistaken for being eating disorder related but could reflect neurodivergence-

Behaviour	ED	Neurodivergence
Anxiety to changes to meal plan	Fear of weight gain, or introduction of fear foods	Difficulty coping with changes and unpredictability
Pacing	Urge to burn off calories	Repetitive, self-stimulating behaviour to self-regulate, process thoughts or manage sensory input
Avoiding certain foods	Fear of things that feel unsafe due to calorie content, ideas around good and bad food	Struggle with different textures, tastes and smells (sensory challenges)
Slow eating	Prolong periods of eating to feel more in control	Sensory overwhelm or challenges with interoceptive awareness (recognising hunger and fullness)
Finding group meals or busy dining room environments overwhelming	Fear of other people seeing them eat, comparing food to those around them	Sensory challenges or social demands

> "Looking back on my eating disorder through this [ADHD] new lens, I can now understand why certain things felt so overwhelming and why the disorder clung to me so tightly."

By Emily, EmpowerED expert by experience

Our latest content

> "Receiving an autism diagnosis provided clarity, self-understanding, and permission to seek support in different ways."

What I Wish I Had Known: Neurodiversity and Eating Disorders

For some people with eating disorders, neurodivergence is only recognised later in their recovery journey. In this new resource, members of the EmpowerED Experts by Experience forum share honest reflections on what they wish had been understood earlier in their treatment. Their insights highlight how neurodivergence can shape experiences of eating disorders, the challenges of navigating services when neurodivergent needs are not recognised, and why adapting support can make a meaningful difference to recovery.

Scan or click here to read more

A recovery story:

Avoidant Restrictive Food Intake Disorder, Autism and Me

> Getting an autism diagnosis helped me immensely

Avoidant Restrictive Food Intake Disorder (ARFID) is an eating disorder categorised by a person avoiding certain foods and perhaps limiting how much food they eat. It is very common for ARFID and autism to co-occur because of sensory difficulties.

From an early age I struggled with my eating, I was classed as the 'fussy eater'. At the time, myself and family were unaware of my autism. It wasn't until a year into my treatment for anorexia (at the age of 26) that autism was suggested to me.

As a child I really struggled especially around textures of certain foods, I had a very limited food profile. A lot of foods/drinks felt unsafe, and would cause me distress, but being an undiagnosed autistic female growing up in the 90s I was labelled as being 'awkward'.

My father could see I was different to my two older sisters. If I was not able to have my 'safe foods' I simply would not eat. Food had to be separated to avoid flavours touching each other. And it also had to be cut into small pieces.

Hear more from Amanda and other experts by listening to our podcast

At the age of 6 I developed childhood epilepsy. Terrifying for any family but made a lot worse by my sensory issues - I was terrified by the noises and bright lights of a brain scanner. ARFID became a problem again - it impacted my ability to take oral medications. One nurse found this out after I spat medication out all over her. At the time this wasn't understood as ARFID. Instead I was restrained - a highly traumatic experience.

Before my diagnosis of autism I found it really difficult to discuss my sensory issues with the ED service. When I said that I couldn't eat certain foods it was said to be my anorexia trying to restrict. Getting an autism diagnosis helped me immensely. I felt more validated, which made me feel more confident to discuss my issues around food. This made choosing active recovery more attainable.

Over the years my ARFID has become considerably better. Even though it took a long time, I now have a more varied diet. What helped me was trying more foods with similar textures and tastes to the foods that I already liked and building from there.

By Amanda, EmpowerED expert by experience

The power of a smell

All of my senses are oversensitive and at some points have impacted on my eating disorder symptoms in the past. Smell is one that has had the most direct overlap between autism and eating disorder.

I struggle with very strong smells. Even ones I do like can be overpowering. While I was unwell this translated to strong food smells feeling like they seeped into my skin and contaminated me, to the belief that they would cause me to gain weight, to start to panic that the smell and the food was inside me. Logically, I knew this had no grounding in reality. In my anorexic, over-stimulated brain, logic did not matter. While this cognition is not something that affects me now, strong smells still do. They can still feel like they contaminate me, making me feel very uncomfortable in my skin. To others this may seem like an over-reaction, but to me it is real physical discomfort in my own skin that I cannot escape. I can leave the area of the smell but the feeling still follows for a while. The disgust, and yes, the illogical contamination.

By Danielle, EmpowerED expert by experience

A Neurodivergence Toolkit: small ways to support

For Individuals:

- Complete a healthcare passport which can be shown in appointments
- Write things down or ask for written summaries of appointments or meetings
- Have a routine - write it out. (Remember to build in nice things and self-care not just 'tasks')
- Choose hobbies that match your sensory profile - do you need calm or stimulation?
- Be aware of and manage sensations. Think about:
  - light - wear sunglasses or adjust lights
  - sound - wear headphones or loops
  - touch - use a weighted blanket; avoid certain fabrics
  - smells - identify smells you find soothing
  - taste - try new foods in safe places; reduce distractions while eating
  - internal signals - set alarms for food and drink breaks; set mealtimes into a routine
  - temperature - layer clothing

Scan here or click for a short video produced by the BBC: 'There's no one way to be autistic'.

For clinicians:

Communication:

- Check whether the individual has a healthcare passport or similar
- Offer a written summary and reassure patient that it's okay to take notes
- Use communication aids such as objects of reference or emotion wheels

Routine and change:

- Be aware of times of appointments and try to avoid last minute changes to time or place

Environment:

- Reduce clutter in the appointment space
- Be aware of strong smells and perhaps open a window
- Adapt lighting levels e.g. offer to switch to a softer lamp rather than main room lights

A detailed toolkit compiled by expert by experience Emily can be found here

> Whilst autism knowledge does not erase the reality of my eating disorder, it reshapes the story.
>
> Emma, EmpowerED expert by experience

Event News

28th April:

EmpowerED expert by experience content creation day

3rd June:

Transformation day

Get in touch: cwp.empoweredforum@nhs.net
Visit our website: www.empowerednw.nhs.uk

Appendix:

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