Issues that impact on autistic women for council and NHS staff supporting them in the community

Tuesday 18 June 2024

Local Government Association | directors of adass adult social services | Partners in Care and Health

The **Local Government Association** and **Association of Directors of Adult Social Services** are **Partners in Care and Health** (PCH) working with well-respected organisations.

PCH helps councils to improve the way they deliver adult social care and public health services and helps Government understand the challenges faced by the sector.

The programme is a trusted network for developing and sharing best practice, developing tools and techniques, providing support and building connections.

It is funded by Government and offered to councils without charge.

www.local.gov.uk/PCH

Virtual event housekeeping

- **We will take questions at the end in a panel session, so please post your questions in the Q and A**
- **The slides will be circulated after the event**
- **This webinar is being recorded**

Programme

2pm	Welcome and Introduction	Kirstie Haines, Principal Improvement Adviser, Learning Disability and Autistic People, Partners in Care and Health
2.05pm	Presentation 1 Issues that impact on autistic women and girls	Molly Anderton & Kay Louise Aldred, Consultants at Neurodiverse Connection
3.05pm	**BREAK**	
3.10pm	Presentation 2 New approaches to supporting autistic women and girls with issues relating to food – hospital at home	Emily Morgan Clinical Nurse Lead & Lorna McGuigan Modern Matron, Child and Adolescent Mental Health Services, Hospital at Home Eating Disorder Service, Oxford Health NHS Foundation Trust
3.40 pm	Panel Question and Answer session	ALL
4.00pm	Close	Kirstie Haines, Principal Improvement Adviser, Learning Disability and Autistic People, Partners in Care and Health

Chair's introduction

Kirstie Haines Partners in Care and Health Principal Advisor Learning Disability and Autistic People

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Working with Autistic Women and Girls in the community

Molly Anderton & Kay Louise Aldred

Consultants at Neurodiverse Connection

Neurodiverse Connection

Working with Autistic Women and Girls in the Community

Kay Louise Aldred and Molly Anderton
Lived Experience Development Leads
Neurodiverse Connection

Neurodiverse Connection

The aims of the session are to explore:

1. Inclusion and Language
2. Gender bias in diagnosis
3. Statistics and myth-busting
4. Masking
5. Sensory and social processing differences
6. Understanding regulation and dysregulation
7. Presentations of dysregulation
8. Ways of regulating
9. Self-harm
10. Eating Disorders
11. Autism and mental health: my story

Inclusion and Language

We acknowledge that the marginalisation and challenges experienced by Autistic women and girls may also affect Trans and Non-Binary individuals.

In addition, Trans and Non-Binary people may also experience pregnancy, menstruation, and menopause.

We use ‘Autistic people’ instead of ‘people with autism’. Identity-first language is preferred in the Autistic community.

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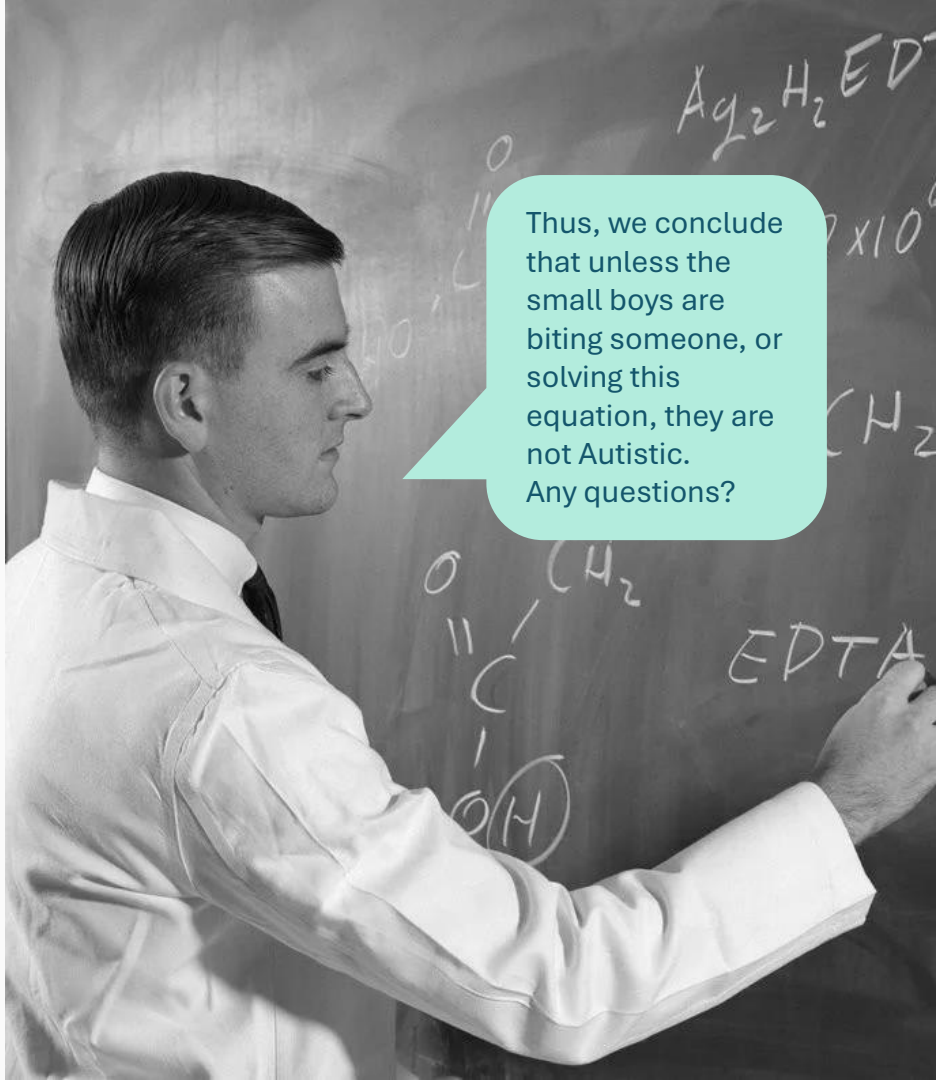
Gender bias in diagnosis

> A young white boy, who may be either misbehaving or exceptionally intelligent, has a passion for collecting traditional "boy" items like trains and cars..



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Autism...

...is a sensory and social processing difference.

...is a neurotype divergent from the current 'norm'.

...differs in presentation from person to person.

...is lifelong.

...impacts how individuals experience, make sense of and interact with the world.

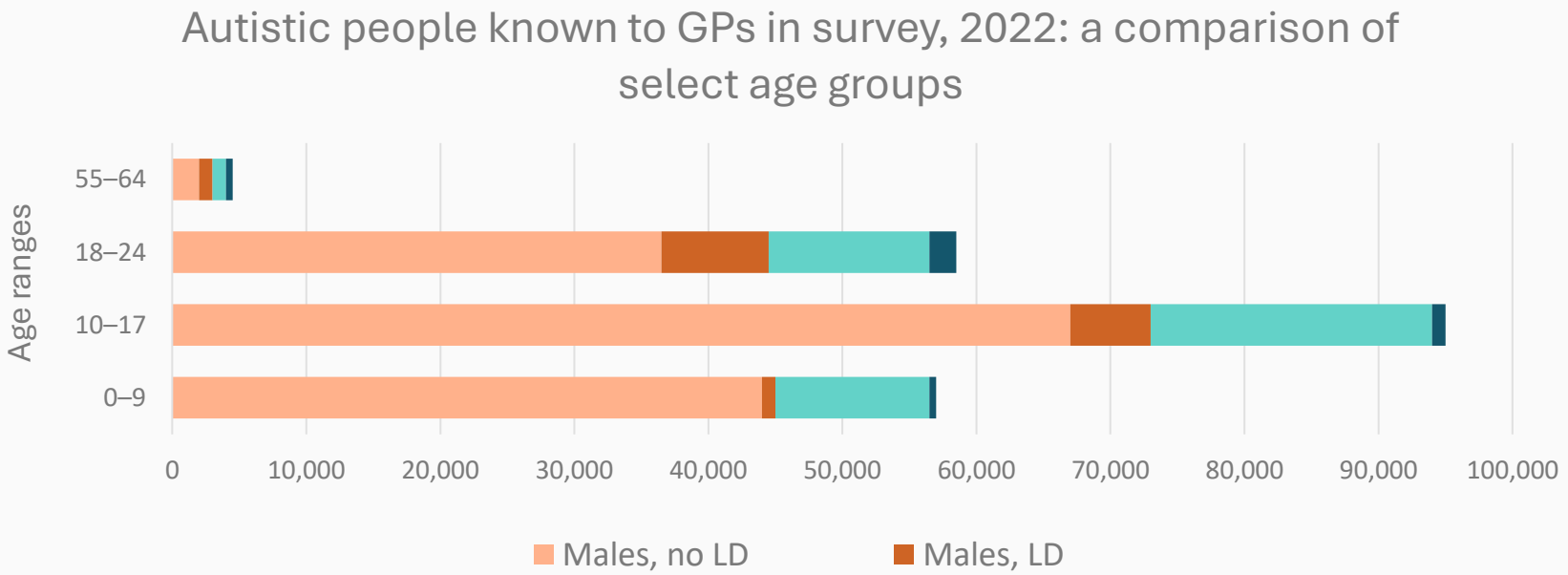
Statistics and myth busting

> All we can really say with certainty is that there are more than you think! This is not because autism has become more prevalent but because it has become better recognised. Girls in the UK are still being diagnosed autistic on average 2-3 years later than boys though (Russell et al., 2021). Given what we are coming to understand about the damage a late diagnosis and subsequent camouflaging of autistic traits can do to an autistic person's mental health, confidence and self-esteem, this is a statistic which needs to change fast. But girls aren't diagnosed later because there is a female phenotype of autism (there isn't), they are missed for complex reasons the largest of which are masking and presenting internally.

https://autisticgirlsnetwork.org/keeping-it-all-inside.pdf

Official statistics still say that 1 in 100 people in the UK are autistic, official figures in Northern Ireland are 1 in 22

What is the effect of those myths on known numbers?



https://www.england.nhs.uk/long-read/autistic-peoples-healthcare-information-strategy-for-england/#number-of-people-with-autism-known-to-gps

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Masking Autism can look like...

Forcing eye contact during conversations

Suppressing stimming behaviours

Adjusting facial expressions to match others

Hiding special interests, or pretending to like others

Being overly aware of the impression made on others

Researching social rules before events

Repeating phrases you have heard others use

Preparing a ‘social script’ before interactions

Sensory Processing

Hypersensitivity: big and enhanced

- Hyper vision (lights flicker, notice specks of dust/fluff)
- Hyper hearing (startled and overwhelmed by phone ringing, sudden noises, crowd sound)
- Olfactory hypersensitivity (gag at smells, eating selective foods)
- Hyper tactile (touch induces panic, temperature sensitive, textile intolerant)
- Vestibular hypersensitivity (fear of jumping, difficulty walking or changing movements)
- Proprioceptive hypersensitivity (hold bodies differently, may struggle with fine motor skills)

Hyposensitivity: small and dulled

- **Hypo vision** (touching objects to settle, attraction to bright lights)
- **Hypo hearing** (seek and stimulate sound—bang doors or tapping)
- **Hypo taste and smell** (chew and smell everything, may mix foods)
- **Hypo tactility** (seem immune to cold, heat and pain, may get injured, may like tight clothes)
- **Vestibular hyposensitivity** (spin, swing, rocking, circular movements)
- **Proprioceptive hyposensitivity** (lean to one side, don’t feel hunger, bump into things, weakened grasp)

Social Processing Differences

Interactions with others

Initiating interactions, responding to others, or using interaction to show people things

Receiving, processing and understanding communication messages.

These differences can impact distress, nervous system arousal levels, and their ability to interact or engage with work.

Understanding Regulation and Dysregulation

Why talk about it?

Having a well-regulated autonomic nervous system, with capacity and flow is crucial for overall well-being.

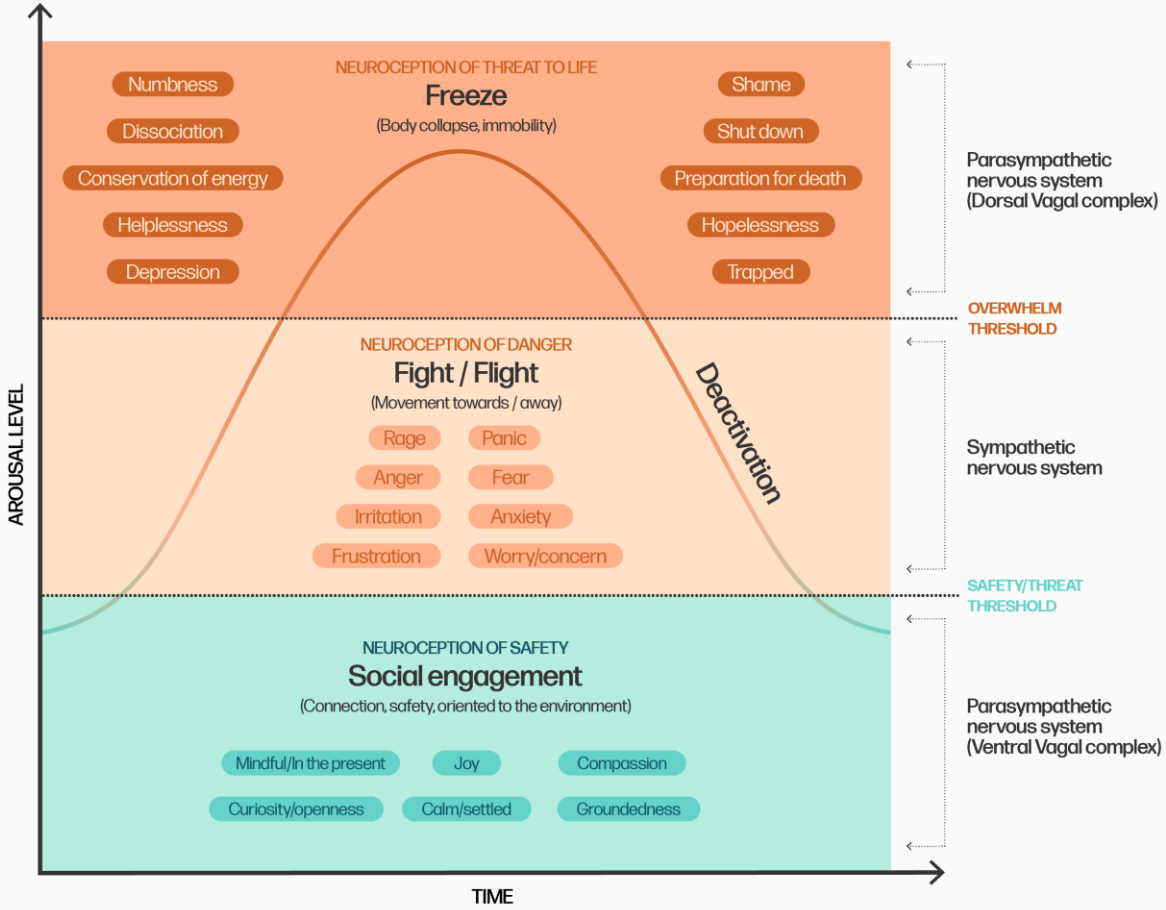
What effect does it have?

In the context of mental health services, it is essential for:

- impulse control – reducing risk
- thought, emotional and sensation tolerance
- therapeutic compliance and engagement

Autonomic Nervous System and The Polyvagal Theory

Dr Stephen Porges
American Neuroscientist
& Psychologist

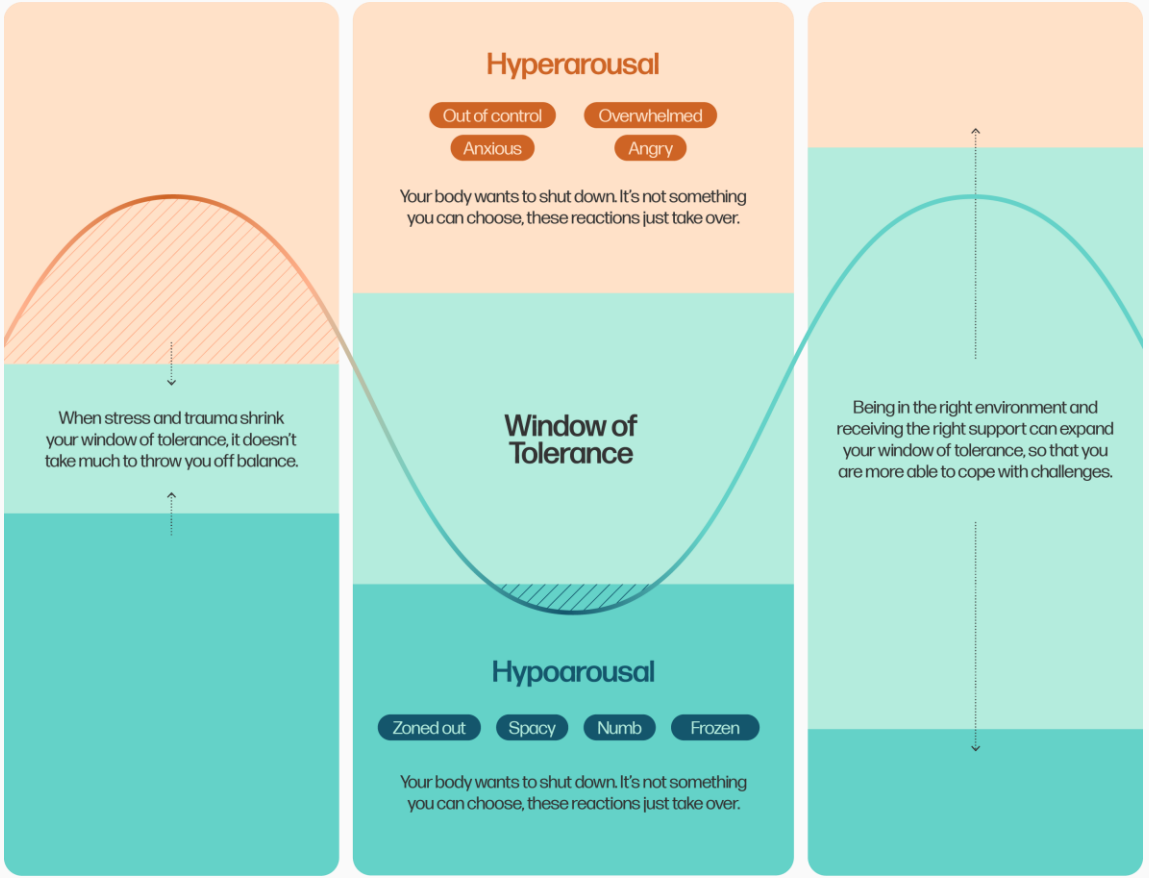


What is meant by regulation?

> “The ability to tolerate stressors and process, digest and complete sympathetic activation without moving beyond capacity and window of tolerance.

Window of tolerance

- Zone of resilience: able to deal with day-to-day living, stressors and function.
- Window in which NS arousal can be processed.
- Window of regulation.
- Neurodivergence and trauma impact on window size.
- Therapeutic engagement happens within window of tolerance.



How sensory and social processing impacts regulation

Individual windows of tolerance vary according to neurology, childhood experiences (including ACE), current environment, social support and coping skills.

Processing speed impacts on regulation—titrated pace of information helps.

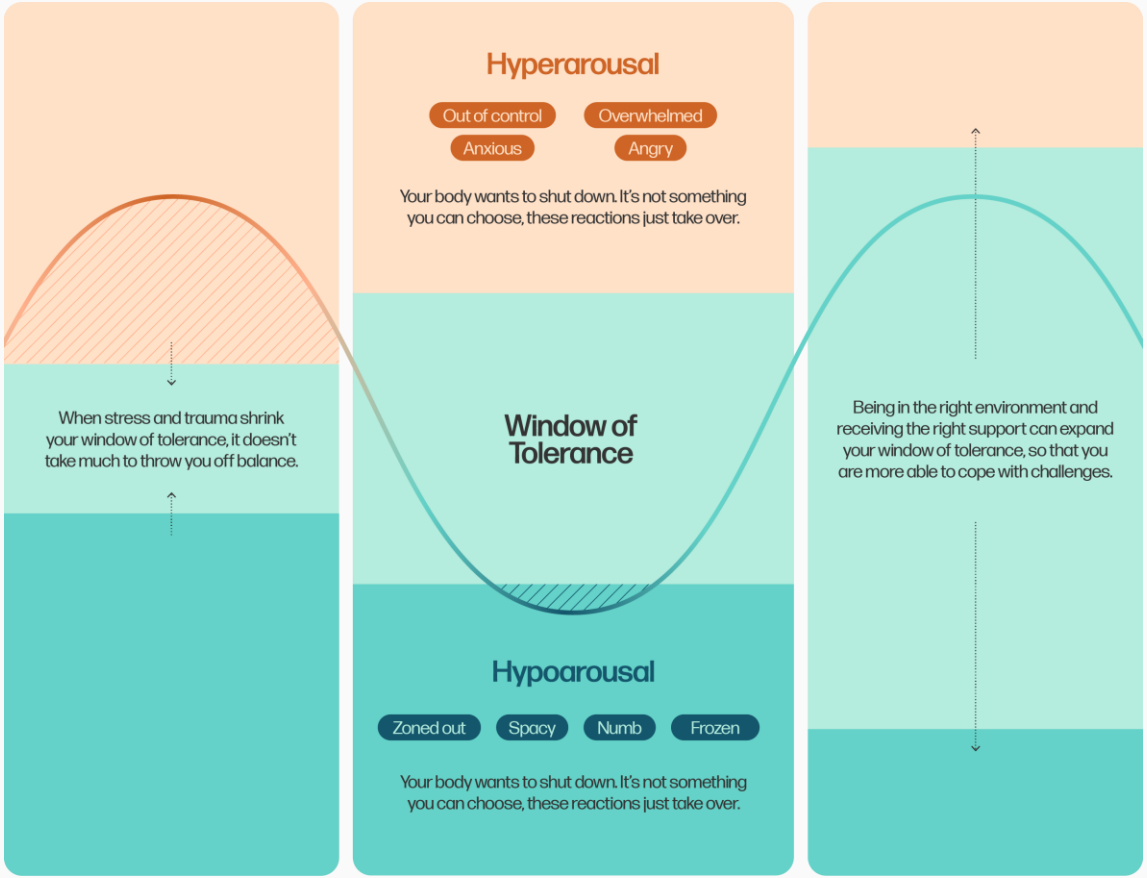
Sensory processing needs of people, either hyper or hypo (sight, smell, sound, touch, taste), impact distress and arousal levels.

Social processing needs impact on regulation. Neurotypical norm dominance of communication and social etiquette creates added stress and burden.

Building capacity and growing the window of tolerance by identifying causes of stress responses and having access to resources to meet sensory, social and processing needs (alongside environmental adaptation) improves regulation

What is dysregulation?

- When the nervous system is out of capacity and beyond the window of tolerance.
- When stressors can't be processed.
- When emotions and sensations can't be contained.
- Increased likelihood of shutdown or meltdown.



Understanding Meltdown and Shutdown Presentations

Meltdown

Fight/Flight (sympathetic activation)

“I can”

Shutdown

Collapse (defensive immobilisation)

“I can’t”

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Presentations of dysregulation

Content warning for self-harm, disordered eating & eating disorders

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How do Autistic people regulate?

Re-regulation may include increasing or decreasing sensory input and arousal.

Stimming

Repetitive behaviors (stimming) can help to either increase or decrease sensory input:

- Jumping/spinning can increase sensory input.
- Hair twirling may help block out surrounding input (eg. bright lights or sudden noises) and reduce arousal.

Stimming behaviours in women are often more ‘subtle’ and may not be conscious.

Returning to the 'window of tolerance'

To **decrease** sensory input and arousal:

- Avoid overstimulating environments
- Noise-cancelling headphones
- Listening to calming or familiar music
- Calming visual displays
- Stimming: helps to block out surrounding input.

To **increase** sensory input and arousal:

- Sensory items (e.g. spiky objects or sour sweets)
- Stimming e.g. spinning or hair twirling
- Some individuals may self-harm

Self-harm

“Up to 50% of Autistic people have engaged in self-harm at least once”

Maddox, B. B., Trubanova, A., & White, S. W. (2017). Untended wounds: Non-suicidal self-injury in adults with autism spectrum disorder.

Why might an Autistic person self-harm?

Self-harm as a repetitive behaviour:

- Overwhelm, meltdown or a shutdown may mean someone tries to regulate by using repetitive behaviours.
- This may include behaviours/actions which cause physical harm.
- E.g. hair pulling or head banging.

Mental health triggers:

- Alexithymia and understanding emotions
- Internalised distress
- High levels of anxiety, depression and isolation
- Physical representation of emotional pain
- Communication

Disordered eating and eating disorders

"70% of Autistic children have atypical eating behaviours"

Mayes, Susan Dickerson, and Hana Zickgraf. "Atypical eating behaviors in children and adolescents with autism, ADHD, other disorders, and typical development." Research in Autism Spectrum Disorders 64 (2019): 76-83.

Disordered eating vs. eating disorders

Autistic eating behaviours which could be seen as 'disordered':

- Preference for 'safe foods' - an identical sensory experiences every time.
- Need for routine and familiarity- e.g. exact meal times or specific cutlery.
- Not eating around others.

These behaviours do not mean a person has an eating disorder.

Eating disorders are serious mental illnesses:

- Significant impact on mental **and** physical health.
- Can be fatal if left untreated – 1 in 5 die from Anorexia.
- Often a coping strategy to 'numb' difficult/overwhelming emotions.

ARFID & sensory based eating disorders

- ARFID: Avoidant restrictive food intake disorder
- Complete avoidance of foods/food groups due to:
  - Aversion to sensory experience (taste/texture etc)
  - Previous trauma (e.g. choking/physical illness)
- No preoccupation with body image or weight
- Low body weight and physical health complications
- Severe impact on daily functioning

Anorexia & autism

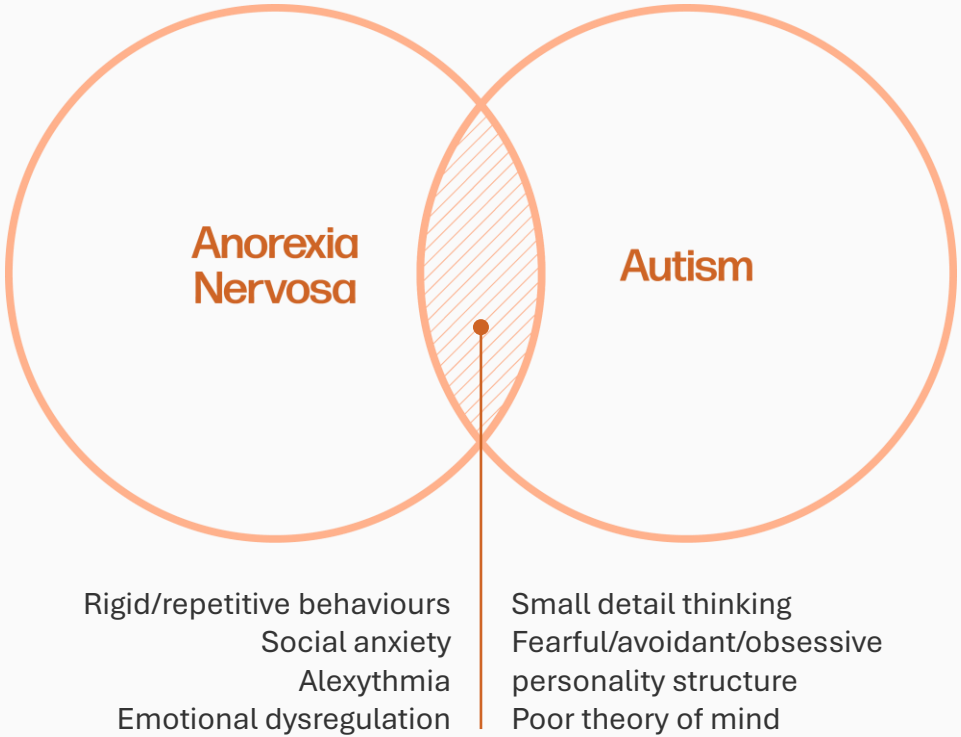
> 20-35% of adults with anorexia are autistic or have elevated autistic traits.

> Autistic people are diagnosed with anorexia at higher rates than non-autistic people and often have worse outcomes when seeking treatment.

Brede, J., Babb, C., Jones, C. et al. “For Me, the Anorexia is Just a Symptom, and the Cause is the Autism”: Investigating Restrictive Eating Disorders in Autistic Women. J Autism Dev Disord 50, 4280–4296 (2020)

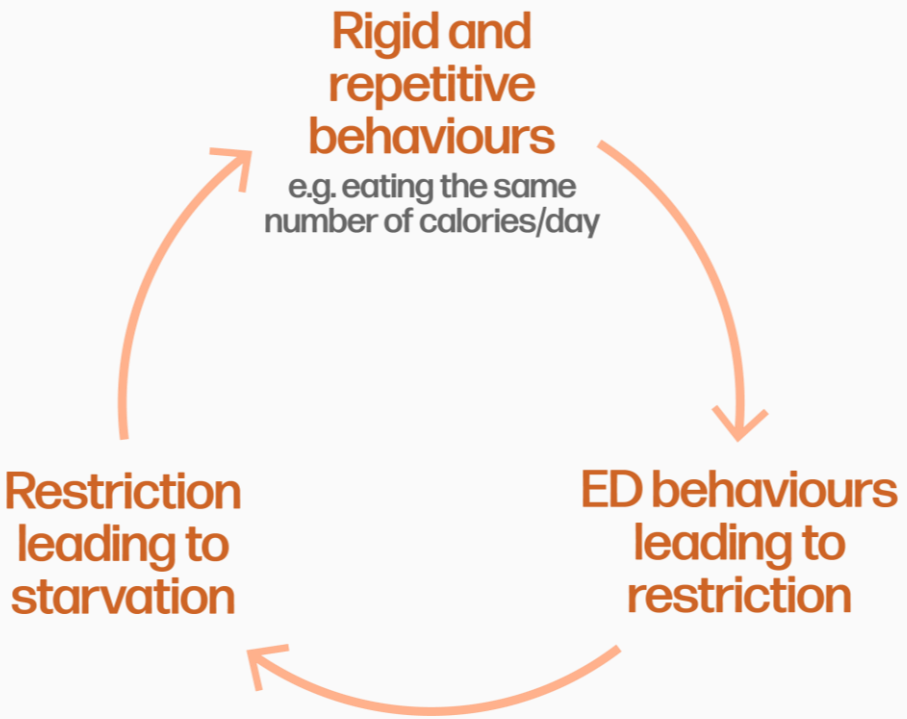
Anorexia Nervosa

- Significant restriction of food intake **and** preoccupation with weight and shape.
- Body image distortion.
- Overwhelming fear of weight gain.
- Frequently a response to trauma-managing emotions.
- Key experiences overlap with those of Autistic individuals



Misdiagnosis of Anorexia instead of ARFID:

- Repetitive and restrictive behaviours worsen with starvation (e.g. ‘fear foods’ vs autistic preferences):
- Obsession with weight or calories: hyperfixations or special interests
- Avoidance of food groups due to sensory experience
- Low body weight → diagnostic overshadowing



Anorexia, mental health and autism: my story

Every individual will have unique experiences and needs.
No two people have the same story.

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(Undiagnosed) autism: a pre-disposition?

Social challenges:

- Feeling ‘different’
- Always an ‘outsider’
- Never good enough
- Strong sense of justice
- Rejection/loss sensitivity

Mental health challenges:

- Grieving differently
- Overwhelm of emotions
- Self-harm
- Processing trauma
- Internalised distress and anxiety

Transitions & change:

- Moving to high school- “no one teaches you how to make friends”
- Puberty: physical and emotional changes
- ‘Growing up’ is uncertain

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Food as a coping mechanism

- Decreasing weight: a sense of achievement, predictability and control.
- Anorexia's 'rulebook' : clear and brings comfort.
- A smaller and more manageable world- overwhelm reduces.
- Numbing of emotions and trauma.
- Physical representation of pain.

Experiences with services

Negative experiences with services

- Alexithymia: I don't know how I feel?
- Too many people: unpredictability
- Removing my 'control' – anger and mistrust
- Labelled as 'difficult' for needing structure
- A "controlling patient" for seeking clarity
- Undiagnosed and misdiagnosed Autistic for 8 years

Supportive experiences with services

- Structure and positive rule
- Negative associations (pattern recognition)
- Consistency and flexibility
- Communicating differently
- Ongoing support > time-limited
- Sensory awareness

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Recovery as an Autistic woman

- Disliking change- a fear of the unknown
- ‘Losing’ routine and predictability
- Increased intensity of emotions
- Fearing rejection
- Changing physical appearance
- Processing more trauma

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Thank you

For additional resources, please visit the Resources Library section of our website.

ndconnection.co.uk
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Please take a moment to share your feedback on this session.

Thames Valley CAMHS Provider Collaborative Hospital at Home Eating Disorder Service

Emily Morgan Clinical Nurse Lead & Lorna McGuigan Modern Matron Child and Adolescent Mental Health Services, Hospital at Home Eating Disorder Service, Oxford Health NHS Foundation Trust

Thames Valley CAMHS PC Hospital at Home Eating Disorder Service

Lorna McGuigan (Modern Matron) and Emilie Morgan (Clinical Nurse Lead)

Thames Valley Provider Collaborative

NHS Oxford Health NHS Foundation Trust

NHS Gloucestershire Health and Care NHS Foundation Trust

NHS Berkshire Healthcare NHS Foundation Trust

Why the service was developed

- Eating disorder referrals to inpatient services increased sharply during the pandemic and continued to rise: 71 in 2019/20, 83 in 2020/21 and 121 in 2021/22.

- Admission to hospital presents potential risks for the young person and their ability to progress with treatment. Autistic young people with AN often require longer inpatient admissions and have poorer outcomes [(1)]. Children and young people with Autistic traits had a greater use of intensive treatments alongside more general difficulties both prior and post treatment [(2)].
- Day patient services may disadvantage those living further away from the treatment centres.
- There remains a large gap between the intensity of input offered by inpatient versus community eating disorder services which can limit the flow of young people in and out of inpatient services.
- The Hospital at Home service was designed to prevent hospital admissions and enable step-down from hospital.

Many psychiatric inpatient units are not designed to meet the needs of CYP with Autism. NICE states that inpatient environments are typically bright, noisy environments with overwhelming smells and no sensory escape areas, whilst the Department of Health and Social Care states that the hospital environment can cause sensory distress which may be overwhelming for individuals with Autism who frequently have sensory hypersensitivities.

Placing autistic females in unfamiliar environments can lead to increased levels of distress. Exposure to the ward milieu and to other patients with self-harm and eating disordered behaviours can increase the risk of iatrogenic harm. The environment can contribute to sensory over stimulation which can lead to; autistic burnout, and/or violence and aggression which in turn may lead to increasing incidents of restrictive practice which can be highly traumatising for all involved.

The NHS in their 2017 document ‘Transforming Care – Model Service Specifications’ highlight the need to decrease length of admissions alongside decreasing the number of admissions in general to inpatient facilities for CYP with Autism. In the 2014 document; ‘Winterbourne view – Time for Change’ it is recognised that many autistic young people could have avoided admission or had a reduced length of stay if community support had been able to meet their needs. However despite this the number of children with diagnosed learning disabilities and/or autism in CAMHS tier 4 units was 205 in March 2020, over double the number in 2015

Tier 4 eating disorder referrals for autistic young people

Referrals	2019-2020	2020-2021	2021-2022	2022-2023	2023-2024
Total referrals	16	31	24	24	44

Service Overview

- Covers Thames Valley CAMHS Provider Collaborative
  - Oxfordshire, Buckinghamshire, Berkshire, Gloucestershire, BSW (BaNES, Swindon, Wiltshire)
- The team supports young people with eating disorders who meet the threshold for inpatient care
- We generally accept young people 11-18 with any eating disorder diagnosis via Thames Valley Single Point of Access (under 11s considered on individual basis)
- We offer an intensive, remote, multidisciplinary service
- Monday-Friday 8am-8pm

Timeline of service

SEP 2021
Team recruited to and gradual launch of pilot service (6 YP) commenced

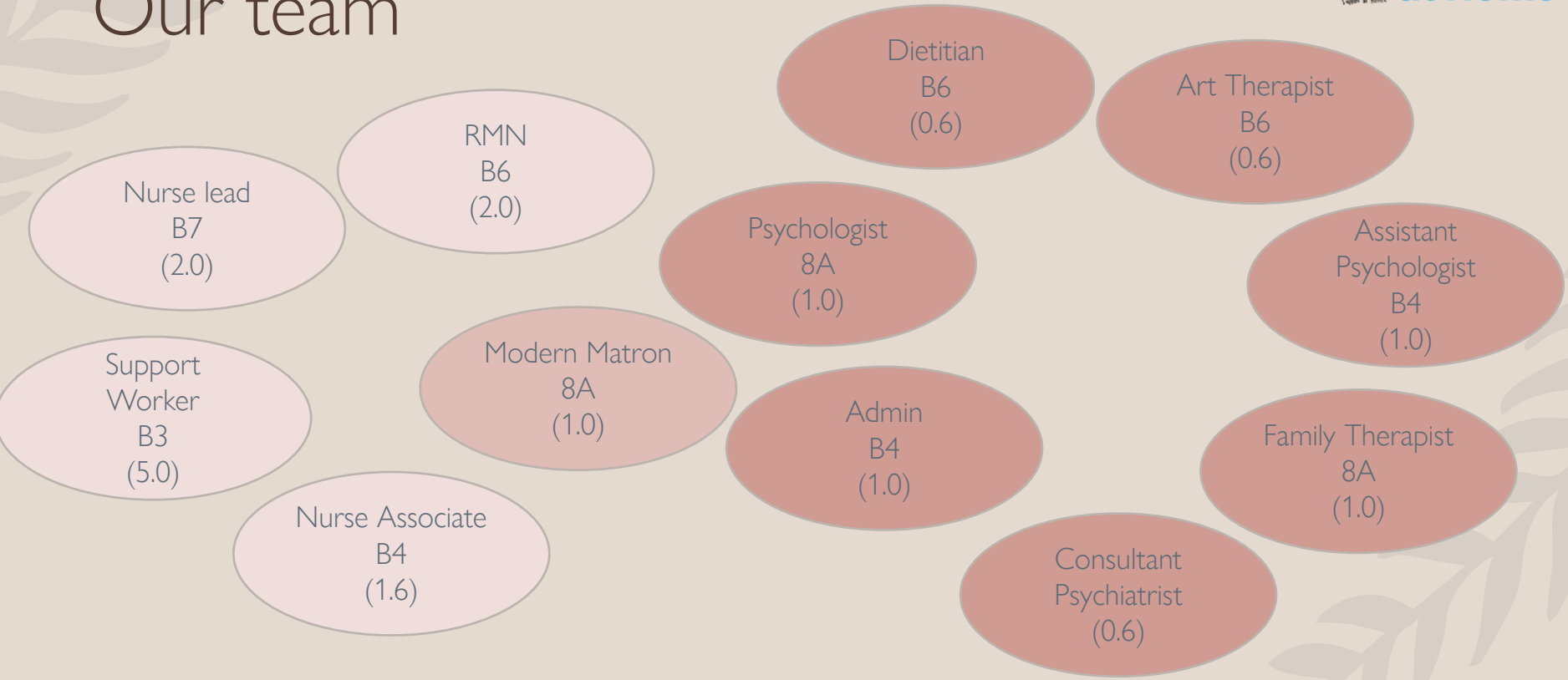
SEP 2022
Review of data and feedback from pilot

DEC 2022
Approval given for substantive service and expansion to 12 YP

JAN-APR 2023
Recruitment

MAY 2023
Gradual expansion of service commenced

Our team


Dietitian
B6
(0.6)
Art Therapist
B6
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RMN
B6
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Nurse lead
B7
(2.0)
Psychologist
8A
(1.0)
Assistant
Psychologist
B4
(1.0)
Modern Matron
8A
(1.0)
Support
Worker
B3
(5.0)
Admin
B4
(1.0)
Family Therapist
8A
(1.0)
Nurse Associate
B4
(1.6)
Consultant
Psychiatrist
(0.6)

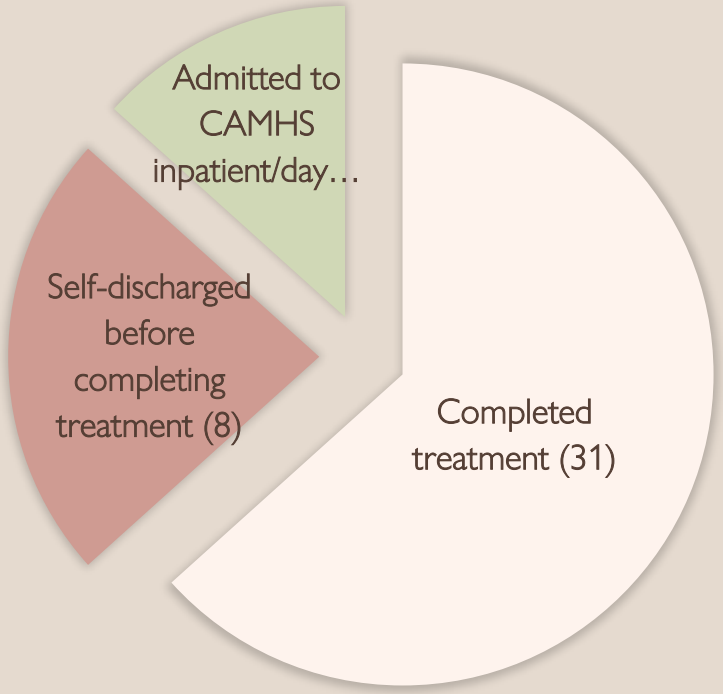
Treatment

- One-to-one sessions with YP - up to daily.
- Parents sessions - up to twice weekly.
- Group sessions for parents – weekly.
- MDT sessions as required (including Psychology)
- Meal support – normally up to 3 times a day.
- Physical monitoring weekly by community ED team.
- Ad hoc support and instant access to team via email 8am-8pm Monday-Friday.

Adaptions we have made

- Informing patients in advance who they are seeing each appointment
- Appointments at consistent time
- Changing our camera settings and backgrounds
- Allowing patient to work with less members of the team
- Getting to know you sessions
- Shorter/longer sessions
- Building up to patients being on camera
- Creating the ideal eating environment
- Processing time for meal plan changes
- Adapted meal plans based on individual needs
- Utilising the PEACE pathway resources
- Respecting individual differences identified in communication passports

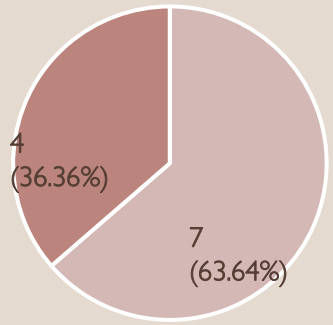
Outcomes so far



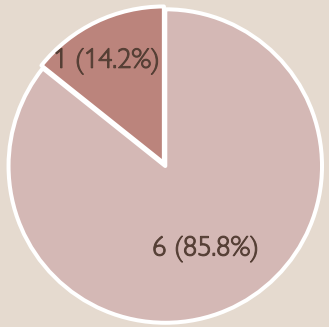
- 45 discharges
- For those that completed treatment there have been no re-referrals to Tier 4.

Comparison

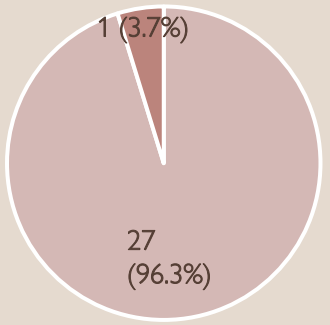
Confirmed Autism

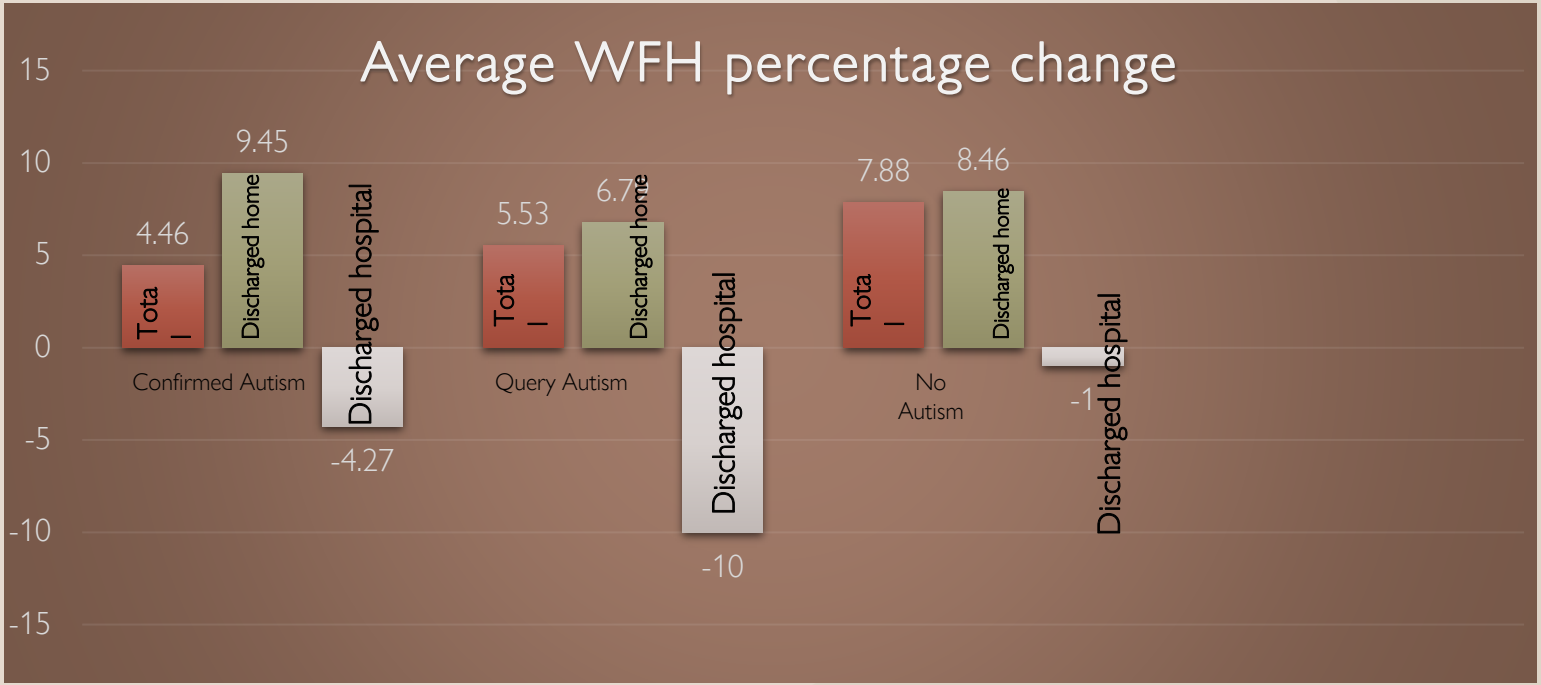


Query Autism

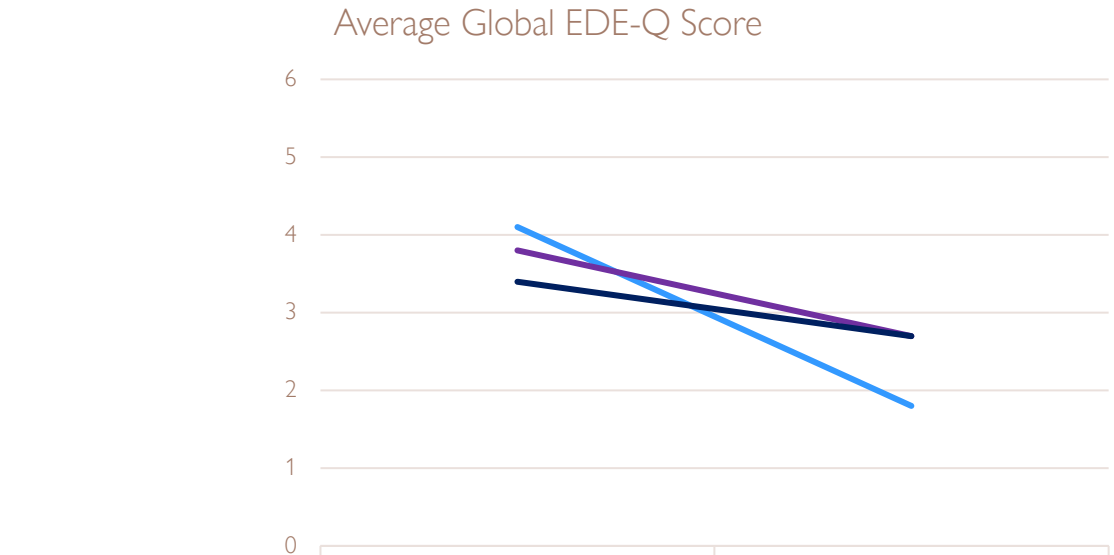


No Autism




Average WFH percentage change
15
10
5
0
-5
-10
-15
4.46
9.45
-4.27
5.53
6.7
-10
7.88
8.46
-1
Total
Discharged home
Discharged hospital
Confirmed Autism
Query Autism
No Autism

Outcome measures



	Average Admission Score	Average Discharge Score
Confirmed Autism (n = 5)	4.1	1.8
Query Autism (n = 5)	3.8	2.7
No Autism (n = 16)	3.4	2.7

- To note: we do not have outcome data for young people who were admitted to inpatient services due to discharge questionnaires not being completed

Preconceptions of services

- People with autism won’t be able to engage
- Virtual meal supports won't work
- A therapeutic relationship won't develop
- Risks are too high
- YP with autism don’t like virtual sessions

Feedback from parents/carers

- “I do think H@H helped get us in a good place to carry on treatment in the community by looking at different ways to tackle fear foods, how to cope with the anxiety and distress around eating food, certainly in public. I think it was the team as a whole as they all think about things in slightly different ways so we got a wide range of help from lots of different perspectives”.
- “H@H offered a buffering transition between admission to a unit and community care”.
- “Some of the parent sessions really helped me to support my daughter emotionally and with weight restoration”.

Training

- 1 staff has completed the Autism master's module
- Whole team 2-day training with the NDTi Team.
- Peace pathway webinars
- ARFID training
- CYP IAPT
- FT AN
- Sensory workshop

What comes next…

- Pathway for atypical anorexia/arfid
- Physical health clinic
- Quality improvement
- Different questionnaires
- Education

Thank you

emily.morgan@oxfordhealth.nhs.uk

lorna.mcguigan@oxfordhealth.nhs.uk

Local Government Association | directors of adass adult social services | Partners in Care and Health

Question and answer session with the presenter panel

Local Government Association | directors of adass adult social services | Partners in Care and Health

Close and thank-you!

Partners in Care and Health:
autistic people
and people with a learning disability team

For more information about our sector-led improvement offer 2022-2025 go to:

www.local.gov.uk/pch/autistic-learning-disabilities