

**Culture
of Care**

National Learning Session 3 **13th January 2025**

Jill Corbyn, Molly Anderton, Lucy Gilbert & Antonia Aluko
NDC Director & Lived Experience Advisors
Neurodiverse Connection

Introductions



Molly Anderton



Lucy Gilbert



Antonia Aluko



Jill Corbyn

Welcome

- 10:00** Welcome & Housekeeping
- 10:15** What is Autism-Informed Care?
- 10:50** Introducing themes from the programme
- 11:00** Positive Behaviour Support (PBS)
- 11:30** BREAK
- 11:45** SPACE framework
- 12:15** Hearing from sites
- 12:30** Question & answer (Q&A) session
- 13:00** Close



Aims for the session

- To build understanding of what autism-informed care is and why we need it
- Reflection on some of the key themes arising from conversations with wards so far
- Reflection on Positive Behaviour Support (PBS)
- Exploring the SPACE framework to support autism informed adaptations
- Learning from other sites and sharing questions, reflections and ideas

Shared principles



Listen with respect and openness

We value learning from all people and remain open to finding new ways of doing things.



Confidentiality

People may share something they wish to be kept confidential. We require your agreement not to share any of the content of this meeting without permission.

Shared principles (II)



Disagree with the point, not the person

We seek to resolve conflicts and tensions, using a constructive approach.



Use plain English

We seek first to understand, then to be understood. Where possible we avoid using jargon, and if we need to use acronyms, we define them.

Shared principles (III)



Collaborate

Everyone's input is valued equally. As a learning community we hope provide a space to learn together, share your ideas, successes and challenges with each other and ask each other questions.



Contribute

We actively share ideas, ask questions and contribute to discussions. We can also choose not to participate if we are unable to or uncomfortable with doing so.



Respect Timing



Recording

We will be recording this event and posting it to the Culture of Care programme webpage.

If there is anything that you would not like to appear on the webpage, please let us know by emailing cultureofcare@rcpsych.ac.uk.



Support Space

On-Call Support Space Facilitator:
Saiqa Akhtar

Join at any time:

[Support space link](#)

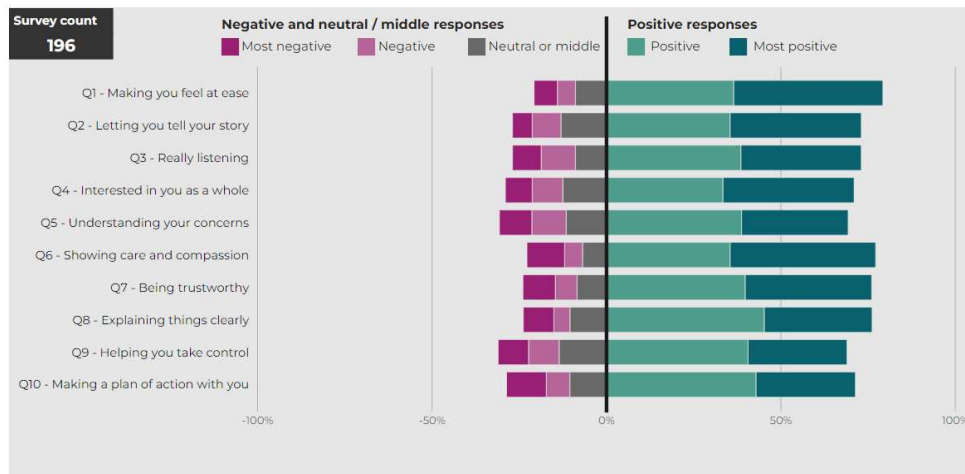
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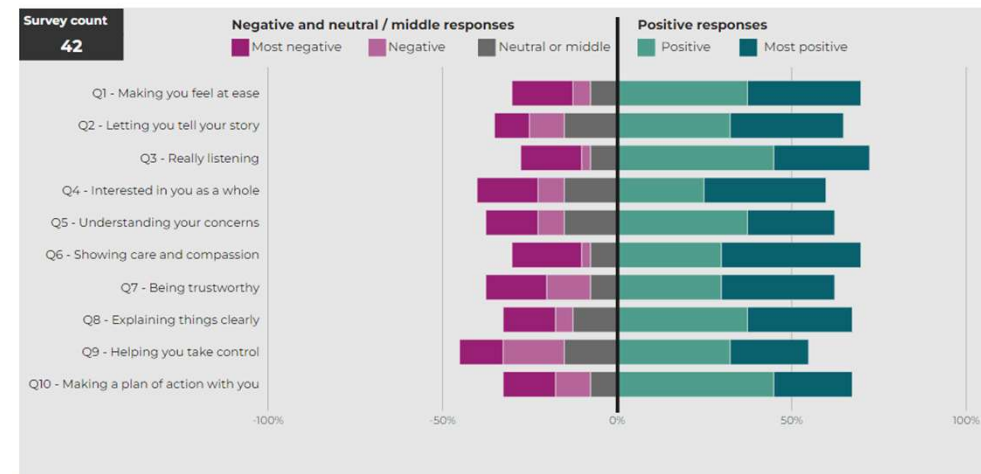
The link to the support space will also be available in the chat.

Results from the CARE survey so far

| Divergent bar chart showing positive and negative responses per question for the CARE survey

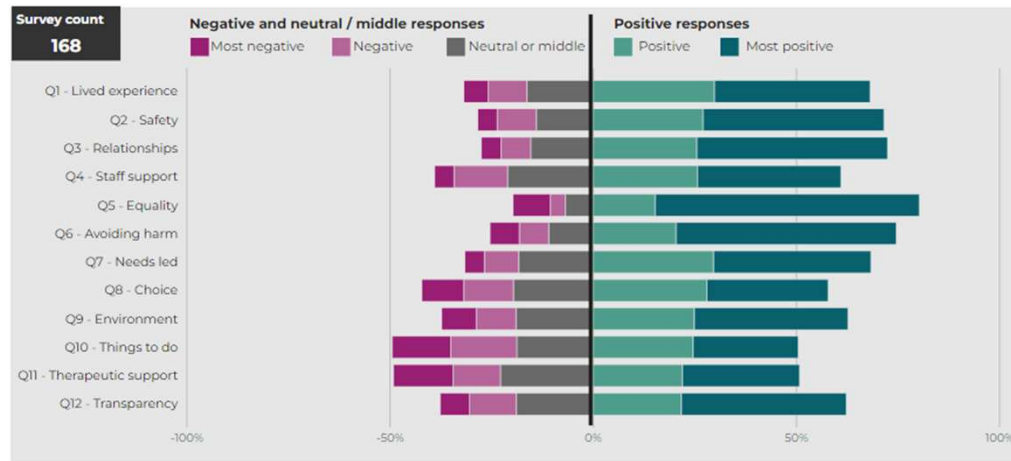


| Divergent bar chart showing positive and negative responses per question for the CARE survey

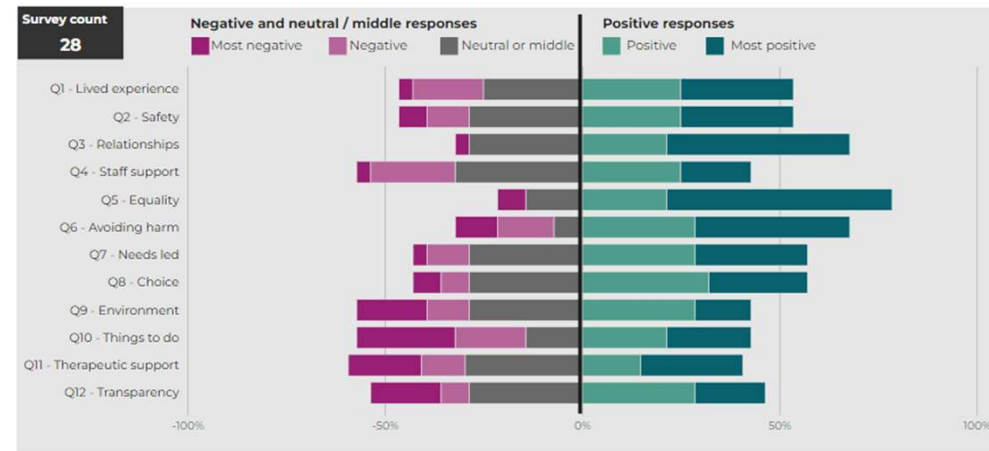


Results from the Patient experience survey so far

| Divergent bar chart showing positive and negative responses per question for the patient experience survey



| Divergent bar chart showing positive and negative responses per question for the patient experience survey



Menti

- How confident do you feel about providing autism informed care?

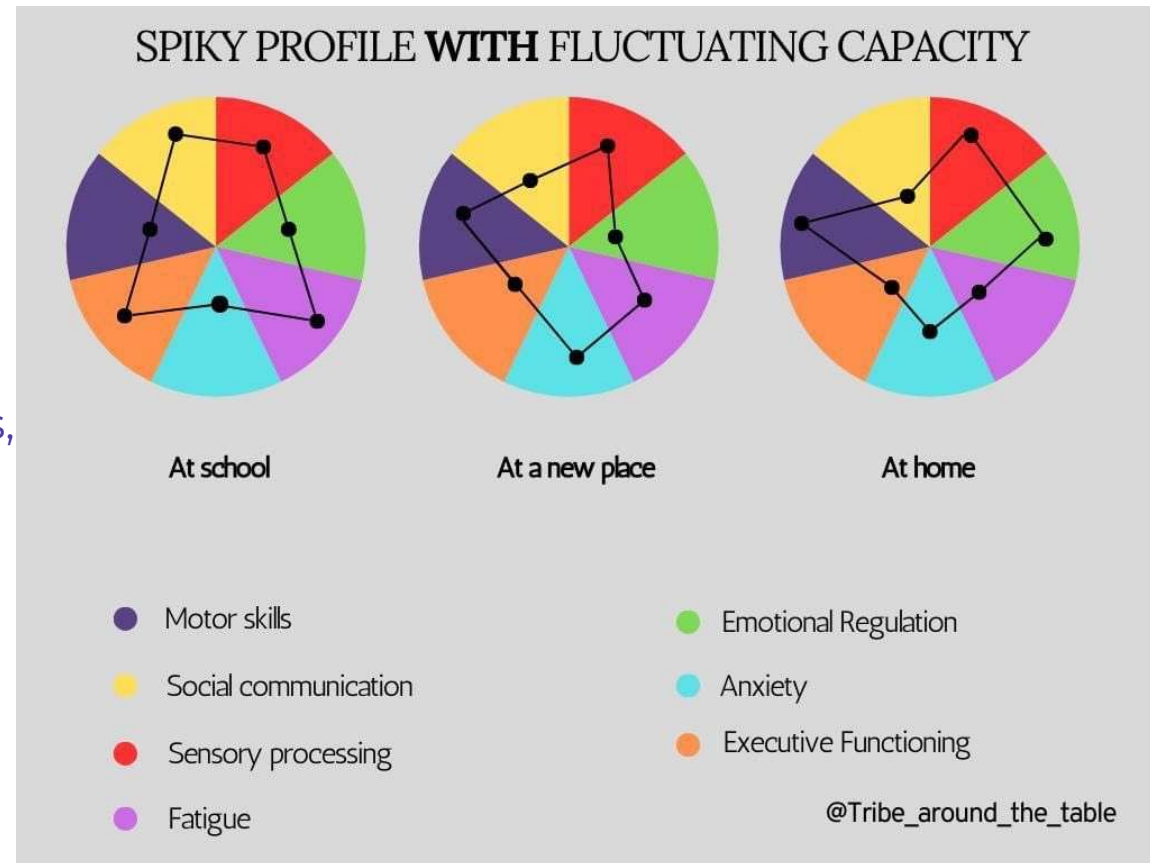




What is Autism-Informed Care?

What is Autism?

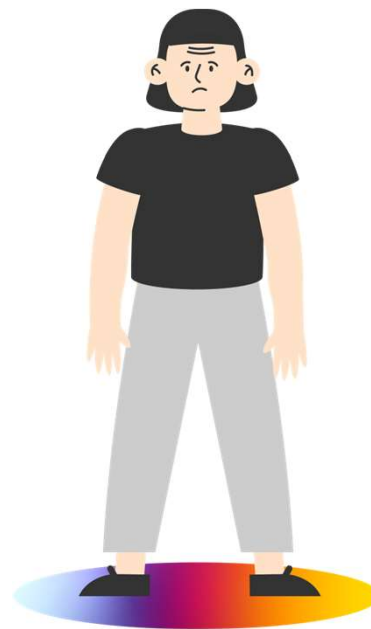
- **Neurodevelopmental**
- **Cognitive, Sensory and Communication Differences**
- **Social processing** = challenges in understanding the social rules, communication styles and interactions that exist in a neurotypical world



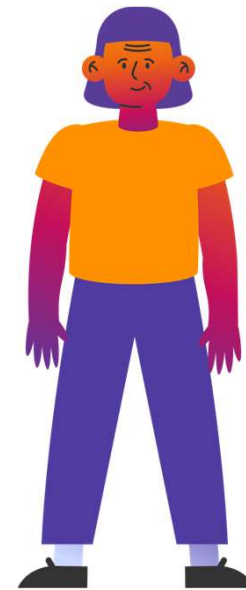
Language



This is a person **with** Autism



This is a person **on** the Autism Spectrum



This is an **Autistic person**

From pathology to neurodiversity

Pathology paradigm



Neurodiversity paradigm

Disorder and deficit

Difference

Behaviour modification and treatments

Neurodivergent affirming approaches to reduce distress and challenges

Us and Them

Everyone is equal

There is a normal brain/neurotype

Normal is socially constructed

Strives for neuronormative standards and goals

Respects individual goals, milestones and needs

Focus on observable behaviours

Seeks to understand internal experience

Sensory differences

- Sensory processing differences to the environment
- Sensory seeking and sensory avoiding, and combinations of both – 'challenging' behaviour in hospital is really people trying to sensory seek or avoid
- Sensory overload
- Stimming
- In an inpatient facility the sensory environment can be overwhelming
- If someone is distressed, then their sensory processing changes – the things we struggle with changes
- Internal and external senses



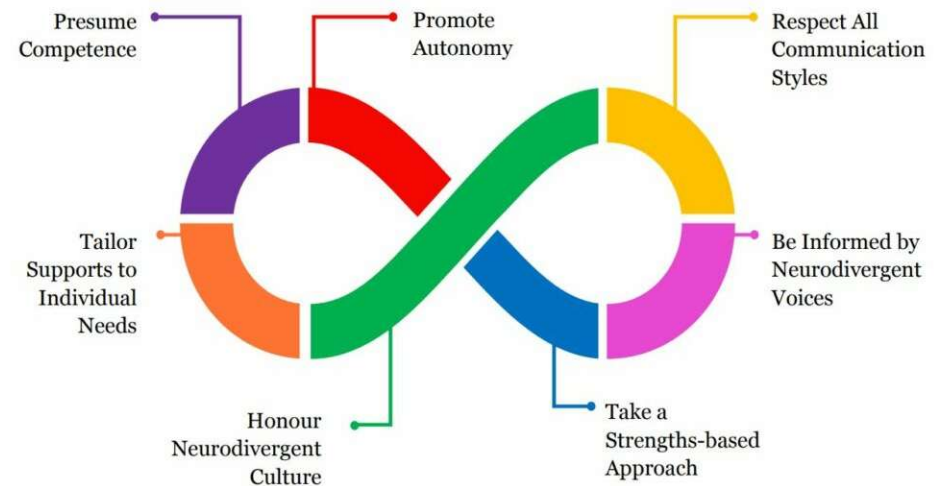
Autistic culture- different but effective

Neurotypical	Autistic
Use of small talk	To the point
Finding common ground	Allowing space for topics of interest
Places value on eye contact for building relationships	Not necessary and often takes away from processing ability
Value on facing each other	Parallel communicating
'Flowery' language with use of linguistic quirks	To the point. Can be perceived as blunt. Focus on honesty.
Tone implies meaning	Less importance on <u>how</u> things are said
Equal give and take	Allowing others to speak at length
Idioms and sarcasm	Literal
Settings often noisy	Low arousal environments
Spontaneous and fast	Require processing time.

- **Autism Informed Care benefits everyone** - not just autistic people
- Autism Informed Care is **everyone's business** not just specialised wards.
- The power of **compassionate curiosity**

Learning disability and autism

- Recent research suggests around 15% of autistic people also have a learning disability
- Consideration of fluctuating support needs
- Consider visual communication support
- Importance of autonomy



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Staff well-being and low-arousal

- We are not neutral in terms of what we bring to an environment
- How can you support yourself and your colleagues to remain emotionally regulated to allow you to co-regulate with patients?
- How can we support each other to provide consistent responses to people in crisis?



2

Introducing themes from the programme

Menti questions

- In your experience, what are the organisational barriers to autism informed care?
- In your experience, what are the organisational enablers to autism informed care?



3

Applied Behavioural Analysis (ABA) and Positive Behavioural Support (PBS)

Content warning for upsetting references (dehumanisation)

Menti question

- Does your ward/organisation have PBS plans for neurodivergent people who don't have a learning disability?



An overview

- Guidance from International Journal of PBS
- Consideration of human rights
- Development and origins of PBS model
- Standards and consistency
- Impact
- Quality of life
- Lived experience perspectives
- Alternative, autism and trauma informed approaches

‘The PBS framework is primarily for individuals with learning disabilities who are at risk of developing or engaging in behaviours that are complex and challenging, and those affected by such behaviour. A proportion of individuals with learning disabilities will additionally be autistic. It should be noted however, that PBS as defined here, and in the past, is not intended for persons identifying as neurodivergent who do not have a learning disability.’

Gore et al. (2022:10)

International Journal of Positive Behavioural Support

ABA and PBS ‘...cannot uphold the UNCRPD principles of autonomy, dignity, right to identity and freedom from non-consensual or degrading treatment.’

Irish Joint Committee on Disability Matters

“You see you start pretty much from scratch when you work with an autistic child. You have a person in the physical sense – they have hair, a nose and a mouth – but they are not people in the psychological sense. One way to look at the job of helping autistic kids is to see it as a matter of constructing a person. You have the raw materials, but you have to build a person.”

Lovaas, 1974

Behaviourism was founded on the belief that only externally observable behaviours count, and that thoughts and feelings ('private events' or 'inner variables') are not always relevant to how to control behaviour (Cooper et al, 2020).

PBS emerged in the 1980s following concerns about punishments used within ABA.

‘Positive behavioural support is a multicomponent framework for (a) developing an understanding of the challenging behaviour displayed by an individual, based on an assessment of the social and physical environment and broader context within which it occurs; (b) with the inclusion of stakeholder perspectives and involvement; (c) using this understanding to develop, implement and evaluate the effectiveness of a personalised and enduring system of support; and (d) that enhances quality of life outcomes for the focal person and other stakeholders.’

Gore et al 2013

- BILD state that ‘PBS and ABA are not the same thing’ (2022). Gore et al. (2022) and MacDonald (2016) note that Positive Behaviour Support is founded on, and still underpinned by, the principles of Applied Behaviour Analysis.
- MacDonald states that Johnston et al. (2006:38) described PBS as ‘...a watered-down or less technical version of ABA, more marketable to service providers without ABA training as it requires less technical expertise, which is less robustly evaluated and involves less vigorous training.’ MacDonald also notes that ‘...when the implementation of PBS is described, it is very difficult to differentiate it from ABA.’
- Many PBS roles advertised by the NHS request a background in ABA.

Standards and consistency

The PBS Coalition write that ‘...many services, agencies and trainers now lay claim to implementing [PBS] when their actual practice bears little or no resemblance to the model...’

‘We know that things are often labelled as PBS that aren’t really PBS at all. Sometimes poor-quality services simply relabel what they do as PBS, without changing their practices or attitudes.’

BILD (2022)

‘...non-academic brief in-service training’ leaving staff largely unmonitored and unevaluated, and poorly equipped to deliver PBS interventions.

Taylor (2021) notes the lack of evidence of improvement in quality of life for those receiving PBS (see also Macdonald 2016) and finds little evidence of reductions in ‘challenging behaviour PBS has been ‘...adopted wholesale and unquestioningly by health and social services...’

“Scientific, evidence based, data led”

‘...there has not been a robust evaluation of a PBS framework in a UK setting to date.’

Gore et al 2022

‘There is limited evidence for the effectiveness of either applied behaviour analysis or antipsychotic medication, or a combination of these in community settings. Little is known about which people respond best to which interventions or about the duration of the interventions. There is considerable evidence of the over use of medication and of limited skills and competence in delivering behavioural interventions.’

The National Institute for Health and Care Excellence guideline on ‘Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges’ (2015:34)

“PBS would never be used, for instance, to address self-stimulatory behaviours that serve the function of self-regulation for the person concerned unless those behaviours meet the definition of behaviours that challenge”

(Gore et al., p9).

Yet two studies referenced in ‘the state of the nation’ and detailed here reference stimming descriptors in their list of challenging behaviour.

Lived experience

It was really hard to find any involvement of people with learning disabilities and autistic people in any of the literature.

Autistic respondents exposed to ABA were 1.86 times more likely to meet the PTSD diagnostic criteria.

Individuals exposed to ABA had a 46 percent likelihood of indicating post traumatic stress symptoms.

Kupfrestein (2018) 'evidence of increased PTSD symptoms in autistic exposed to ABA', advances in autism, vol 4 No 1, pp19-29.

My colleague asked her twitter followers and got 150 responses. Fewer than 1 in 10 people who had experienced PBS would recommend it (2023).

75% of respondents said they wouldn't recommend it.

Human rights

The United Nation's Convention on the Rights of Persons with Disabilities states that the principles of the Convention include:

- a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- b) Non-discrimination
- c) Full and effective participation and inclusion in society
- d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- e) Equality of opportunity
- f) Accessibility
- g) Equality between men and women
- h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Additionally, Article 14 states that 'Parties shall ensure that persons with disabilities, on an equal basis with others:

- a) Enjoy the right to liberty and security of person
- b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.'



Break

11:30 – 11:45



SPACE

Menti - What are your Autism-Informed Care change ideas?



SPACE framework:

AUTISTIC

(Physical

Processing

Emotional)



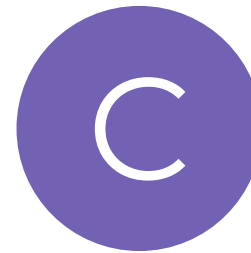
Sensory



Predictability



Acceptance



Communication



Empathy

Doherty, McCowan, Shaw (2023)

Sensory

Recognise the sensory processing differences of Autistic patients.

Consider the impact of the inpatient environment on Autistic individuals.

Address sensory issues to make the ward more accessible.



Suggestions:

- Turn off or dim artificial lights, prevent flickers & offer sunglasses.
- Reduce echoes, prevent slamming doors & offer ear-defenders.
- Avoid wearing strong perfumes & consider ventilation.
- Explore sensory needs around food & offer sensory-friendly meals.
- Consider & adjust temperature where required.
- Consider the need for adjusted pain scales.

Predictability

Autistic people rely on predictability in order to manage anxiety and to regulate.

Unexpected change, lack of structure of change in routine can be distressing.



Suggestions:

Provide as much information as possible, in advance:

- What does the ward look like?
- What does a day consist of?
- Who will my care team be?

Provide information about any changes well in advance.

Provide predictability with staff involved in care (e.g. consistent named nurse.)

Acceptance

Not just Autism awareness, but Autism acceptance.

A holistic approach to care- recognise strengths and challenges.

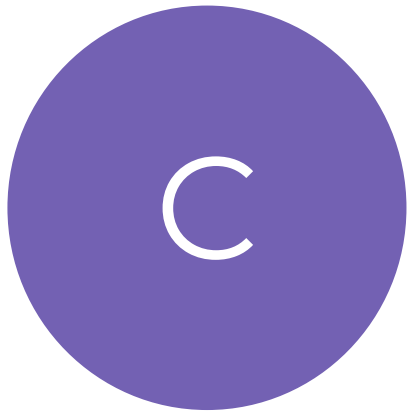


You should:

- Understand differences in communication, monotropism & stimming.
- Recognise that “behaviours that challenge” are usually a response to Autistic needs not being met.

Communication

Autistic people may communicate differently: this can change depending on stress levels or sensory overload.



Suggestions:

- Allow for non-verbal communication (e.g. use communication cards & allow people to write down their feelings.)
- Avoid metaphors, be unambiguous & allow for questions to check understanding.
- Understand non-verbal communication differences (e.g. do not force eye contact or base assessments of mental health solely on body language.)

Empathy

Autistic people do not lack empathy! It may just be expressed differently.

Many Autistic people experience hyper-empathy, which can lead to shutdowns.



You should:

- Recognise challenges in neurotypical staff's ability to have empathy for Autistic patients.
- Work with individuals to understand their experience of hyperempathy- how do they find being on an inpatient ward and witnessing distress?

SPACE framework:

AUTISTIC

(Physical

Processing

Emotional)



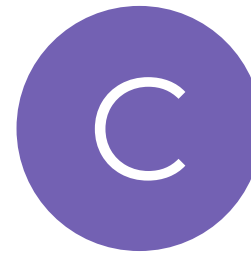
Sensory



Predictability



Acceptance



Communication



Empathy

5

Hearing from Sussex Partnership NHS Trust (Abbey Ward)

*Jess Honeysett (Clinical Specialist Occupational Therapist) &
Sarah-Joe Mohun-Smith (Clinical Psychologist)*

6

Question & Answer session

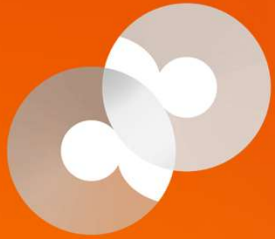


End of session reflections

Menti

- Is there anything you will do differently after the session today?





**Culture
of Care**

Thank you

Please scan the QR code
to share your feedback





Dates for your diary (2025)

- **February: Learning Networks Event**
(see next slide for time/location)
- **11 February: Personalised Approach to Risk (PAR)** – The integrated model of suicidal behaviour (virtual, 10am-12pm)
- **11 March: Learning Networks Workshop** (virtual, 2pm-4pm)
- **17 March: Lived Experience Network** (virtual, 1pm-3pm)

Upcoming learning network events

Learning Network Pairing	Organisations	Date of Event	Location
3 & 10	Black Country, Cygnet, GMMH, Coventry and Warwickshire, Gateshead Health, Herefordshire and Worcestershire, Midlands, CNTW, Birmingham, Cheshire and Wirral, Lancashire and South Cumbria, North Saffordshire, Merseycare	05/02/2025	Newcastle
2 & 5	Oxford, Norfolk and Suffolk, Northamptonshire, Nottinghamshire, Cambridgeshire and Peterborough, Berkshire, Lincolnshire, Essex, St Andrews Healthcare, Leicestershire, Derbyshire	12/02/2025	Oxfordshire
1 & 6	Elysium, Gloucestershire, Hampshire and Isle of Wight, Dorset, Devon, Livewell Southwest, Avon and Wiltshire, Somerset, Bramley Health, Cornwall	13/02/2025	Bristol
8 & 9	Hertfordshire, NELFT, North London Partnership, SABP, SWLSTG, CNWL, Kent and Medway, Oxleas, SLaM, Sussex, West London	14/02/2025	Royal College of Psychiatrists, London
4 & 7	Humber, TEWV, Pennine, Navigo, SW Yorkshire, Leeds and York, Sheffield, The Priory, Rotherham Doncaster and South Humber, Bradford, Northumbria	20/02/2025	Darlington

Upcoming Training

Event Name	Type	Format	Length	Cycle	Design and Delivery
Dialogical and Relational Training Taster Days (DARTT)	Ward-level sign-up	Virtual	7 hours	Monthly	NELFT (North East London NHS Foundation Trust)
Autism informed training	Ward-level sign-up	Virtual	3 hours	Bi-monthly	Neurodiverse Connection
Anti Racism Training	Ward-level sign-up	Virtual	TBC	TBC	Black Thrive Global
Preventing Sexual Harm	Ward-level sign-up	Virtual	TBC	TBC	Trauma Informed Collaborative