

Peer Support Work: Building Bridges

Truly Listening to and Including Lived Experience Voices

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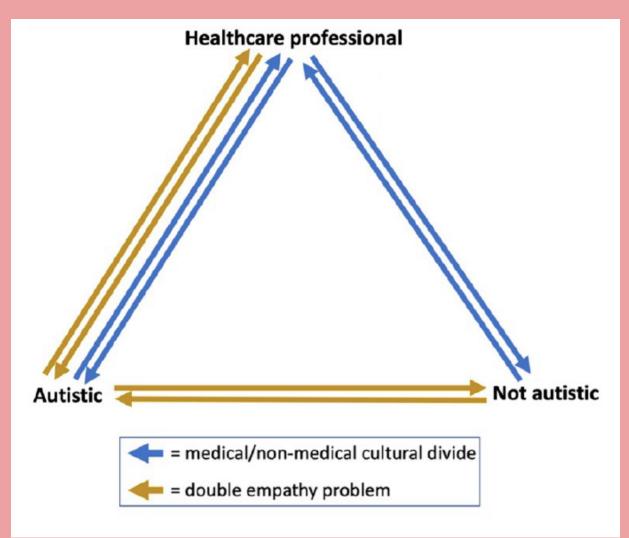


The monumental importance of centring Lived *Experience* in treatment provision...

- Existing, **non-adapted**, evidence-based treatments can be *limited* in their effectiveness for neurodivergent individuals
- Moving away from a 'one size fits all' approach and towards more personalised care
- **Equity** = adapting care and providing adjustments to acknowledge differences
- The PEACE Pathway marks a *significant step forward* in bridging gaps and *including lived experience* directly

Lost in Translation?

"A breakdown in reciprocity and mutual understanding can happen between people with very differing ways of experiencing the world. If one has ever experienced a conversation with someone who they do not share a first language with, or even a shared interest in the topic of a conversation, one may experience something similar (albeit briefly!)" (National Autistic Society)



Shaw et al., 2024

The Courage to Do Things Differently

"Just because something is considered to be the way things are done does not mean it is right."

(The Autistic Survival Guide to Therapy - Steph Jones)



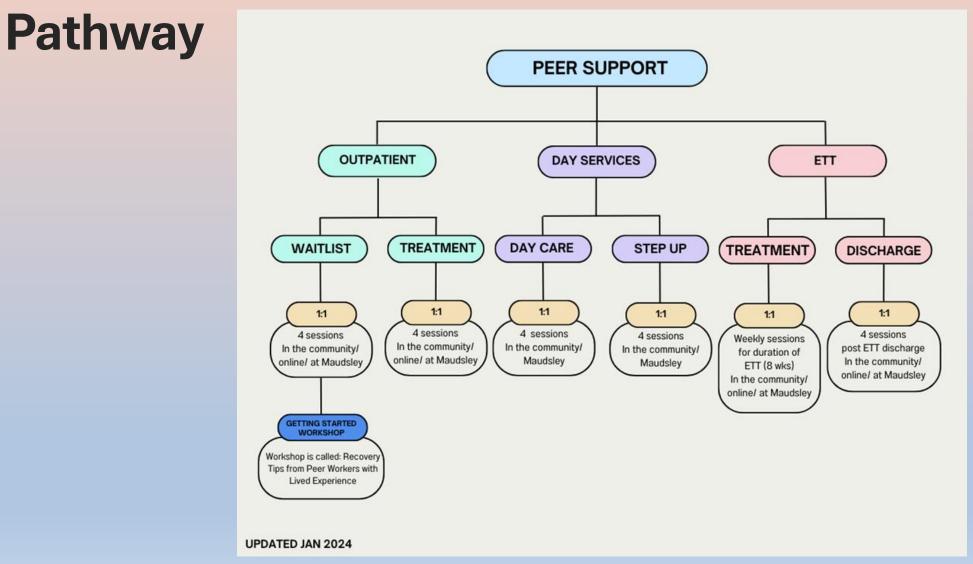
What is

Peer Support?

Peer support is a range of approaches through which people with similar long-term conditions or health experiences support each other to better understand those conditions and aid recovery or selfmanagement.

- NHS England

A New Paradigm: The Peer Support



Peer Support Work – Service User Feedback

"I've been in services for 12 years and this is the first time I feel seen and understood by anyone"

"I didn't think recovery could be possible for me until now. I wanted leave treatment but then I had peer support sessions and **realised that recovery could be for me**"

"I strongly believe peer support should be a mandatory element of every ED service, as it provides a unique and personal form of support that is **more relatable and motivational**"

"Peer support has been the **most useful** part of my treatment"

"I felt that I was being heard. I

didn't have to explain myself, PSW just completely understood what I was talking about. It was a space where I could go in without overthinking what I was going to say and how I was going to say it. I would normally censor myself as I am aware that people who have never experienced an eating disorder would not get what I am talking about. I felt *less alienated* in this often very lonely illness. I think it is a wonderful imitative especially with the crazy long waiting lists for targeted therapy"

The Peer Support Approach - *Themes*

- Understanding, validation and normalisation
- Relatability
- A more **informal** approach (different from other interventions)
- Safe & non-judgmental space
- Sharing knowledge & practical techniques
- Inspiring recovery
- Positive changes in ED symptoms & wider life





Building Bridges

'I'm way more open to my therapist now. I used to be a lot more closed off, not always telling the truth, being quite dishonest and secretive. I'm a lot more open now because I learned you need to be open with your fears to actually get to the root of the issues. Without (*PSW' name*), that wouldn't have happened."

Translating the Patient Voice



Advocacy

More **flexible** weight boundaries in Day Services programmes for autistic patients



Therapeutic Extensions

Discussed + agreed **extensions** in both therapeutic + PSW input for autistic + ND individuals



Adapted Language

Replacing rigid phrases (eg. "Nonnegotiable") with **more sensitive** alternatives, and encouraging this within wider team

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Holistic Approach

More **space** to explore self *beyond* symptoms (eg. sessions in community, creativity)



Improved engagement in other aspects of service

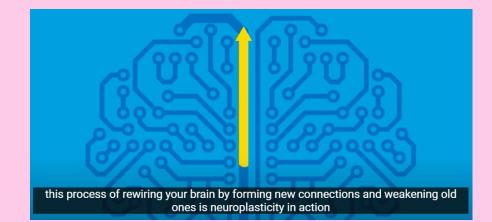
Increased group attendance and trust in wider service following engagement with PSW involvement

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Increased recognition + identification of ND traits

Able to provide neuro-affirming + neuro-inclusive support quickly (eg. recommending use of PEACE resources to clinicians as part of a trait focused approach following PSW intervention)

Sharing *Fragments* of Lived Experience can be *Transformational*





"Between stimulus and response there is a space. In that space is our power to choose our response. In our response lies our growth and our freedom."

VIKTOR FRANKL

Carer Feedback

"I must say X has had the most **positive sessions** with you and you've made him **feel very comfortable** having you for his clinical guidance. As I mentioned before, it's worked **very well** as **you are** <u>neurodivergent</u> and he <u>recognises that connection</u> which has greatly helped." A Less Hierarchical, More Personalised, More Human, More Holistic & Flexible Approach.

Challenges of this Work

- Culture shifts *take time*
- There is a *limited resource* pool vs a growing need for personalised and adapted care
- Additional *emotional toll* on clinicians with *lived experience*

We Are All Learning, and Unlearning.

Strengths and Successes So Far

- The Peer Support Pathway is now **successfully** embedded in EDU!
- Internal and external *recognition* of the PS Pathway is helping to support an ongoing <u>culture shift</u>, improving care
- Supervision and reflective practice in PS Pathway (and wider service) includes explicit lived experience input

The Peer Support Pathway's Hopes for the Future. Reduce stigma around the therapeutic sharing of fragments of lived experience for *all* clinicians.

Center the voices of lived experience, valuing them as equally important other existing treatment modalities.

Increase neurodiversity awareness training for *all* clinicians to bridge the Double Empathy Gap

Develop better support networks for clinicians e.g. 'Community of Practice' to stay connected & support each other.

Develop specialist supervision & competency frameworks to ensure clinicians have adequate knowledge and skills to support ND clients effectively.

Further embed lived experience in treatment provision (supervision, coproduction of resources, & beyond!)

Expand the Peer Support Workforce and complete further research on benefits of lived experience interventions.

Update NICE guidelines with explicit neuro-divergent lived experience input in co-produced manuals



Thank YOU!



Stay connected:

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Useful books (that also feature lived experience) ...

-The Autistic Survival Guide to Therapy - by Steph Jones

-Unmasking Autism: The Power of Embracing Our Hidden Neurodiversity - by Devon Price

-Unmasked: The Ultimate Guide to ADHD, Autism and Neurodivergence - by Ellie Middleton

-Untypical: How the world isn't built for autistic people and what we should all do about it - by Pete Wharmby

-Women and Girls on the Autism Spectrum, Second Edition - by Sarah and Jess Hendrickx

-Autism Is Not A Disease: The Politics of Neurodiversity - by Jodie Hare

-The Neurodivergence Skills Workbook for Autism and ADHD - by Monique Mitchelson and Jennifer Kemp

-The Neurodivergent Friendly Workbook of DBT Skills- Sonny Jane Wise

-Strong Female Character (memoir) - by Fern Brady

-Rediscovered, A Compassionate and Courageous Guide For Late Discovered Autistic Women (and Their Allies) - by Catherine Asta

-Different, Not Less: A Neurodivergent's Guide to Embracing Your True Self and Finding Your Happily Ever After- by Chloe Hayden

-Neuroqueer Heresies: Notes on the Neurodiversity Paradigm, Autistic Empowerment, and Postnormal Possibilities- By Dr Nick Walker

-'It's not a bloody trend': understanding life as an ADHD adult - by Kat Brown

-Now It All Makes Sense: How An ADHD Diagnosis Brought Clarity To My Life- by Alex Partridge

Useful websites

- -The National Autistic Society https://www.autism.org.uk/
- -ADHD UK https://adhduk.co.uk/

-British Dyslexia Association - https://www.bdadyslexia.org.uk/ (coverage of dyscalculia too)

-The PEACE Pathway - https://www.peacepathway.org/ (food and eating issues and tools)

-ARFID Awareness UK - for those with food and drink avoidance - https://www.arfidawarenessuk.org/

-Divergent Voices YouTube channel: https://www.youtube.com/@DivergentVoices



THE AUTISTIC SURVIVAL GUIDE TO THERAPY





THE NEURODIVERGENT FRIENDLY WORKBOOK OF DBT SKILLS

A workbook of Dialectical Behaviour Therapy skills reframed to be neurodivergent friendly with the added benus of accessible mindfulness practices, sensory strategies and managing meltdowns.

> Written & designed by Sonny Jane Wise Olivedexperienceeducator

