PEACE

FROM INCLUSION TO INFLUENCE

Co-Producing as a Researcher with ADHD

A reflective conference presentation on lived-experience co-production within the PEACE+ Pathway

PEACE+ Pathway | King's College London

KING'S College LONDON

OPENING WITH THE PERSONAL

Starting With My Story

I want to begin not with theory, but with myself.

I am a research assistant working within the PEACE+ Pathway. I am also a person with lived experience of ADHD.

For much of mental-health research history, these two identities have been kept apart. Service users have been positioned as *subjects* rather than knowledge-holders (Beresford, 2002; Rose, 2017). The field is now recognising that *experiential expertise* offers something distinct, especially for neurodevelopmental conditions, where the gap between clinical description and lived reality can be wide (Faulkner, 2017; Pellicano & den Houting, 2022).

WHO I AM IN THIS WORK

Researcher

Neurodivergence and eating disorders within the PEACE+ Pathway

Person with ADHD

Lived experience shapes how I notice, design and disseminate

Beresford (2002); Faulkner (2017); Pellicano & den Houting (2022); Rose (2017).

WORKING CONDITIONS THAT WORK

How My Needs Are Accommodated at PEACE+

Reasonable adjustments grounded in ADHD neuroscience and neurodiversity-affirming practice.

Collegial scaffolding

Consistent peer support functions as external scaffolding for executive function (Barkley, 2012).

Written instructions

Working-memory deficits are robust in adult ADHD (Alderson et al., 2013); written records reduce retention load.

Sensory-friendly space

Sensory differences co-occur with ADHD (Bijlenga et al., 2017); fidget items support attentional regulation.



Flexible hours

ADHD is linked to circadian variability (Hvolby, 2015); flexibility is a reasonable adjustment under the Equality Act 2010.

Being understood

Psychological safety (Edmondson, 1999) underpins neurodiversity-affirming workplaces (den Houting, 2019).

Alderson et al. (2013); Barkley (2012); Bijlenga et al. (2017); den Houting (2019); Edmondson (1999); Equality Act 2010; Hvolby (2015).

THE FRAME BEHIND THE STORY

What Is Co-Production?

A collaborative research approach in which people with lived experience and professional expertise work together to conceptualise, conduct and disseminate research — sharing ownership and decision-making at every stage (Hickey et al., 2018; INVOLVE, 2018).

Six principles of ethical co-production (Boyle et al., 2010):

1. Recognising people as assets
2. Building on existing capabilities
3. Reciprocity and mutuality
4. Peer support and networks
5. Blurring professional / service-user boundaries
6. Facilitating rather than delivering

Quality and transparency in reporting are supported by GRIPP2 (Staniszewska et al., 2017).

Boyle et al. (2010); Hickey et al. (2018); INVOLVE (2018); Staniszewska et al. (2017).

WHAT THE DUAL PERSPECTIVE PRODUCES

Co-Produced Outputs at PEACE+

We have co-produced guidebooks, social media content and accessible resources — not the kind researchers assume patients want, but ones that answer the questions people actually ask when they are scared, confused or exhausted. Those questions did not come from a literature review. They came from the community.

QUESTIONS THAT CAME FROM THE COMMUNITY

> *What is happening to me/my loved one?*

> *What should I expect from services?*

> *What can help day-to-day?*

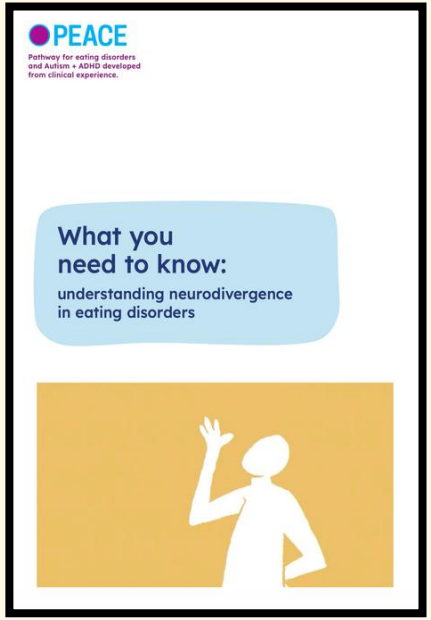
> *How can carers support without escalating conflict?*

Translating research into accessible, usable language is increasingly recognised as essential for real-world impact (Grimshaw et al., 2012).

Grimshaw et al. (2012).

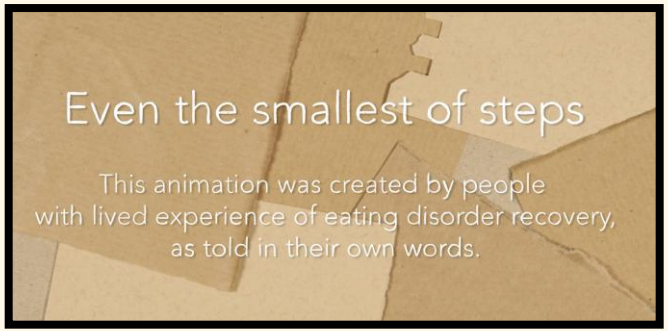

Lived experience perspectives
PEACE
Pathway for Eating disorders and Autism developed from Clinical Experience
01
Meet Emily and Fiona


Lived experience perspectives – ca
PEACE
Pathway for Eating disorders and Autism developed from Clinical Experience
03
Meet Robert


PEACE
Pathway for eating disorders and Autism + ADHD developed from clinical experience.
What you need to know:
understanding neurodivergence in eating disorders


PEACE
Pathway for eating disorders and Autism + ADHD developed from clinical experience.
Caring in context:
A neurodiversity-informed guide to supporting someone with an eating disorder.


Co-Produced: Episode 2.
Navigating ADHD and Eating Disorder Recovery


Even the smallest of steps
This animation was created by people with lived experience of eating disorder recovery, as told in their own words.

POSITIONING MY CONTRIBUTION

How My Dual Perspective Shapes My Work

Holding both insider and researcher positions has reshaped what I attend to, advocate for, and produce.

01

Spotting accessibility barriers

I notice when research outputs assume neurotypical processing — dense text, abstract phrasing, no visual scaffolding. These barriers disadvantage readers with attentional and executive-function differences (Barkley, 1997; Kofler et al., 2020).

02

Advocating for multimodal formats

Animations, podcasts, infographics. Multimedia reduces extraneous cognitive load and supports learners with attentional differences (Mayer, 2014), consistent with audience-tailored knowledge translation (Graham et al., 2006).

03

Naming executive functioning

I bring an embodied understanding of how time perception, working memory and motivational regulation shape engagement — ADHD-relevant dimensions consolidated in the recent international consensus (Faraone et al., 2021).

Barkley (1997); Faraone et al. (2021); Graham et al. (2006); Kofler et al. (2020); Mayer (2014).

A WORKED EXAMPLE

Co-Producing the “Eating With ADHD” Animation

ADHD and eating disorders co-occur at significantly elevated rates (Nazar et al., 2016), yet psychoeducational resources have not kept pace with the evidence. The animation aimed to close that gap: explaining the relationship between ADHD and eating difficulties in ways that are validating, non-stigmatising, and designed for how neurodivergent people actually process information.

> *When the first draft of the animation returned, it was good. But there were things in it I reacted to, not as a researcher reading a script, but as a person with ADHD watching something supposedly about my experience.*
>
> ***That reaction is exactly what co-production is designed to capture.***



PEACE+

Eating with ADHD

An animated explainer

- Recognise ADHD-ED patterns
- Manage difficult environments
- Build supportive habits
- Adapt to your own mind

ACCESSIBLE · SENSORY-AWARE · CO-PRODUCED

Kaisari et al. (2017); Nazar et al. (2016); Tchanturia et al. (2020).

EDITS FROM LIVED EXPERIENCE

What Changed in the Animation — and Why

Each edit was small. Together, they mark the difference between a resource that talks about a community and one that speaks to it.

ORIGINAL DRAFT	REVISED VERSION	WHY THIS EDIT MATTERED
"snacking and bingeing"	**"bingeing"**	For many ADHD adults, snacking is a coping strategy. Pairing it with bingeing imports shame onto a regulatory behaviour.
"small snacks every 2–3 hours"	**"eat something every 2–3 hours"**	Removes minimising, infantilising language for people already carrying shame around food.
Specific image: carrots	**"crunchy foods" (concept only)**	Avoids alienating viewers with ARFID or specific food intolerances.
Sparkling water as sensory regulator	**"Have a bath or shower"**	Removes a food cue from a sensory-regulation strategy.
"low sensory eating options"	**"personalised adaptations"**	Empowering and individualised rather than prescribing a sensory category.

"This kind of sensitivity doesn't come from clinical training. It comes from knowing what those words feel like when you're the one hearing them."

BEING HONEST

Challenges, Lessons, and Reflections

CHALLENGES

- **Time and resource demands**

Co-production done ethically is slow (Hickey et al., 2018).

- **Institutional hierarchies**

Tokenism remains a live risk (Madden & Speed, 2017).

- **Emotional labour**

Drawing on personal experience is itself work (Faulkner, 2017).

- **Accessibility vs. rigour**

Holding both demands continual negotiation.

WHY IT MATTERS

- **Lived experience surfaces blind spots**

It re-shapes both what we ask and how we ask it (Filipe et al., 2017).

- **Neurodivergent perspectives improve accessibility**

End-users benefit when designers share their cognitive style.

- **Ethical co-production strengthens science**

Epistemic rigour and service relevance reinforce one another (Staniszewska et al., 2017).

- **A personal lesson**

Being trusted to bring my whole self into research has been transformative.

Faulkner (2017); Filipe et al. (2017); Hickey et al. (2018); Madden & Speed (2017); Staniszewska et al. (2017).

References

Alderson, R. M., Kasper, L. J., Hudec, K. L., & Patros, C. H. G. (2013). Attention-deficit/hyperactivity disorder (ADHD) and working memory in adults: A meta-analytic review. Neuropsychology, 27(3), 287–302.

Barkley, R. A. (2012). Executive functions: What they are, how they work, and why they evolved. Guilford Press.

Beresford, P. (2002). User involvement in research and evaluation: Liberation or regulation? Social Policy and Society, 1(2), 95–105.

Bijlenga, D., Tjon-Ka-Jie, J. Y. M., Schuijers, F., & Kooij, J. J. S. (2017). Atypical sensory profiles as core features of adult ADHD. European Psychiatry, 43, 51–57.

Boyle, D., Coote, A., Sherwood, C., & Slay, J. (2010). Right here, right now: Taking co-production into the mainstream. NESTA.

den Houting, J. (2019). Neurodiversity: An insider's perspective. Autism, 23(2), 271–273.

Edmondson, A. (1999). Psychological safety and learning behavior in work teams. Administrative Science Quarterly, 44(2), 350–383.

Equality Act 2010, c. 15. UK Public General Acts.

Faulkner, A. (2017). Survivor research and Mad Studies: The role and value of experiential knowledge in mental health research. Disability & Society, 32(4), 500–520.

Filipe, A., Renedo, A., & Marston, C. (2017). The co-production of what? Knowledge, values, and social relations in health care. PLOS Biology, 15(5), e2001403.

Grimshaw, J. M., Eccles, M. P., Lavis, J. N., Hill, S. J., & Squires, J. E. (2012). Knowledge translation of research findings. Implementation Science, 7(1), 50.

Hickey, G., Brearley, S., Coldham, T., et al. (2018). Guidance on co-producing a research project. INVOLVE.

Hvolby, A. (2015). Associations of sleep disturbance with ADHD: Implications for treatment. ADHD Attention Deficit and Hyperactivity Disorders, 7(1), 1–18.

INVOLVE. (2018). Guidance on co-producing a research project. NIHR.

Kaisari, P., Dourish, C. T., & Higgs, S. (2017). Attention deficit hyperactivity disorder (ADHD) and disordered eating behaviour. Clinical Psychology Review, 53, 109–121.

Madden, M., & Speed, E. (2017). Beware zombies and unicorns: Toward critical patient and public involvement. Frontiers in Sociology, 2, 7.

Nazar, B. P., Bernardes, C., Peachey, G., et al. (2016). The risk of eating disorders comorbid with ADHD. International Journal of Eating Disorders, 49(12), 1045–1057.

Pellicano, E., & den Houting, J. (2022). Annual Research Review: Shifting from 'normal science' to neurodiversity in autism science. JCPP, 63(4), 381–396.

Rose, D. (2017). Service user/survivor-led research in mental health. Disability & Society, 32(6), 773–789.

Staniszewska, S., Brett, J., Simera, I., et al. (2017). GRIPP2 reporting checklists. BMJ, 358, j3453.

Tchanturia, K., Smith, K., Glennon, D., & Burhouse, A. (2020). Towards an improved understanding of the anorexia nervosa and autism spectrum comorbidity: PEACE pathway implementation. Frontiers in Psychiatry, 11, 640.