

Why aren't learning disabled adults leading the design of specialist learning disability services?

About me

I am a Highly Specialist Speech and Language Therapist who has specialised in working with learning disabled adults since qualifying in 2011. At the start of my internship with ARC-GM I was employed by Manchester Foundation Trust, working for the Manchester Local Care Organisation (Community services arm) within the Community Adult Learning Disability Service. In July 2025 I moved to Mersey Care NHS Trust, working within mental health teams based in prisons and continue to work with learning disabled adults in prison.

Background

Learning disabled adults have historically been excluded from society and from being involved with decisions which affect their lives. Learning disabled adults on average die 15-20 years younger than the general population. This reality can be attributed to many associative factors, including access to timely and effective healthcare.

Specialist community learning disability services emerged following the closure of long stay institutions in the UK as part of the care in the community initiative in the 1980s and 1990s. There is no single statutory model for how these services are designed and delivered and each service is commissioned based on local needs.

However, the National LD Professional Senate have produced guidance, published via the British Institute of Learning Disabilities website entitled 'Delivering Effective Specialist Community Learning Disabilities Health Teams / Services for Adults with Learning Disabilities and their Families and Carers' in 2023. They cite the following policy drivers which currently underpin delivery of services for people with learning disabilities:

- Building the Right Support; Learning from Lives and Deaths (LeDeR)
- Stopping overmedication of people with a learning disability, autism or both with psychotropic medicines (STOMP)
- Annual health checks;
- the NHS Long Term plan
- CQC Quality of Life Tool and Framework
- Bamford Review of Mental Health and Learning Disability – Equal Lives Learning Disability Report (2005)
- NI Mental Health Strategy 2021-31.

Having worked in several different specialist learning disability health teams across the UK, I have observed a range of '**involvement**' initiatives, which generally felt tokenistic and had little obvious effect on how local services are planned and delivered.

This lead me to ask myself the following questions;

Why aren't learning disabled adults leading the design of specialist learning disability services?

What does 'gold standard' advocacy and leadership for learning disabled adults look like? How can we ensure that learning disabled adults are central to the design and production of research which drives the commissioning of services they use?

Activity

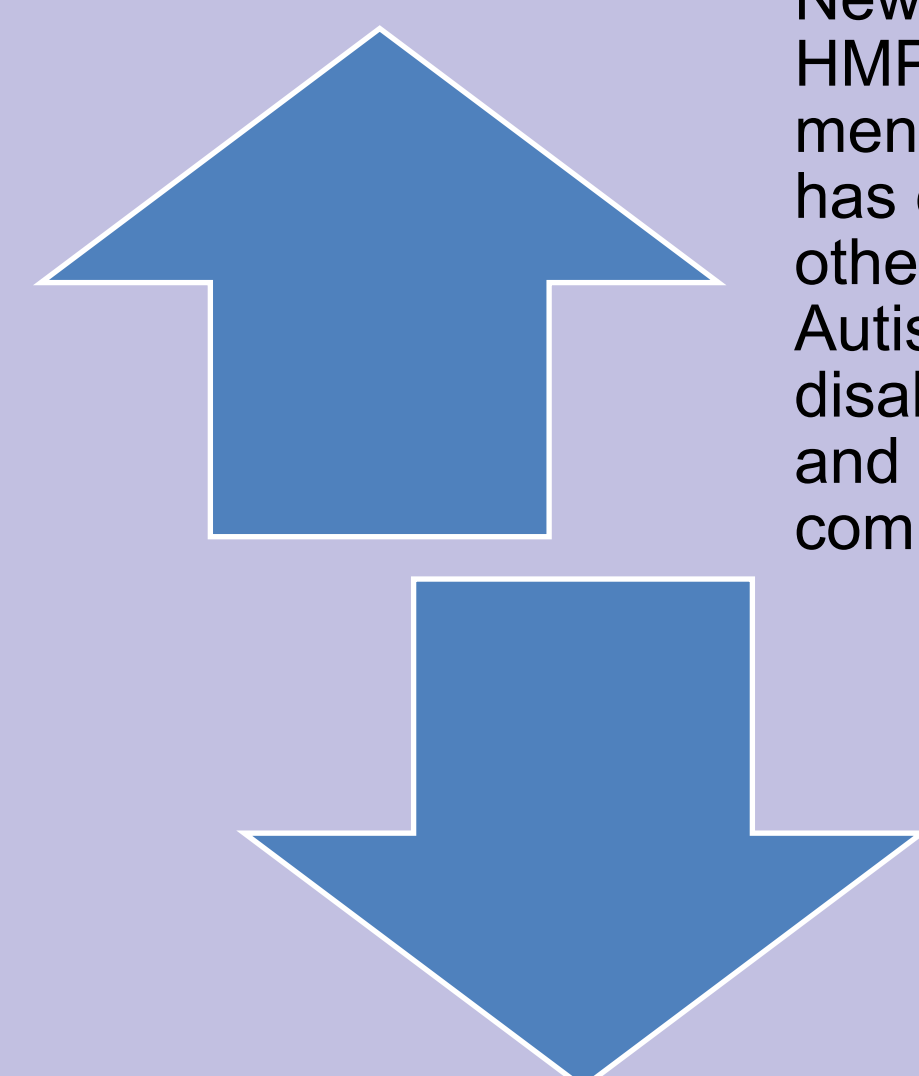
I participated in or observed the following activities during my year long internship with ARC-GM and the University of Manchester;

- ✓ I attended a one-day workshop to learn about the organisation Purple Patch Arts and their arts-based co-production approach to research and education for learning disabled adults. I learnt about the Purple Research Group and met Melissa Kirby who is a researcher now based at the University of Leeds, who works alongside learning disabled adults as part of the Purple Research Group. I learned about their unique model of understanding power structures within research via 'Tiers of participation'.
<https://purplepatcharts.org/research/>
- ✓ I also joined a research group hosted by People First Tameside (a user led organisation speaking up for the rights of learning disabled people in Tameside) alongside Melissa Kirby. They were producing mixed media patient information for Salford Royal NHS Foundation Trust about cervical screening and colposcopy procedures.



- ✓ I learned about the work of the ARC-GM PCIE approach (Public and Community Involvement and Engagement) regarding inclusive research practices more generally, by attending their Research engagement Network event.

Changes in July 2025



New job working within HMP Liverpool and HMP Altcourse as part of the Integrated mental health Team. My scope of practice has expanded to working with adults with other neurodevelopmental conditions such as Autism and ADHD (with and without learning disability) developmental language disorder and stammering, as well as acquired communication and swallowing needs.

No longer based in community services, seeing people in their homes and workplaces.



Academic learning and conferences

- ✓ I completed a course at Kings College London - Advanced Qualitative Short Course: Approaches to Cross-Disciplinary Qualitative Health Research. The course was lead by Sergio Silverio. The course helped me to understand the internal structures within academia which create barriers to inclusion for learning disabled adults, such as methods of rating the 'quality' of interview data based on so-called 'eloquence' and language & communication skills of the participant.
- ✓ I attended the Unlocking Speech and Language Therapy 2025 conference at York St John University. I learned about Speech and Language Therapy current practice and research within the criminal justice system. People with communication needs who had received Speech and Language Therapy within the criminal justice system participated through audio testimonies.



Thanking people

I'd like to thank the following people for supporting me through my research internship journey and signposting me to opportunities to support my learning;

- Dr Jan Owens (University of Manchester) my academic supervisor and mentor.
- Melissa Kirby (University of Leeds)
- All the folks at Purple Patch Arts and People First Tameside