

Misrah Mohamed was an expert by experience on this project. Please read her insights below.

### **Autism research: Who's in the room?**

When we think about autism research, it's easy to focus on the professionals – researchers, clinicians, academics, policy-makers. These are the people who often lead studies, write papers, and shape the recommendations that guide services. But there's another group of people whose voices are just as vital – if not more so – and they've often been missing from the conversation.

I'm talking about Experts by Experience.

These are the people who live the realities that research seeks to understand: autistic individuals, parents, carers, siblings, and community advocates. People like myself – a parent of an autistic child – who navigate systems daily, not as a job, but as a way of life. And here's the truth: if we're serious about making autism research truly inclusive and impactful, then involving Experts by Experience is not just a nice idea. It's essential.

### **Lived experience adds what research alone can't.**

Too often, research is conducted about autistic people, rather than with them. This creates a gap between what researchers think is important, and what actually matters to the people living with the day-to-day realities of autism. Experts by Experience bring insight into the nuances that aren't always visible in data sets or literature reviews. We see the small, often overlooked moments that can make or break the effectiveness of services. We question language that feels clinical or cold. We challenge assumptions that don't reflect the diversity of real autistic lives.

We also help shape more relevant research questions, design more ethical studies, and ensure that the findings don't just end up in journals, but actually make sense in real-life contexts.

Let's be honest. Co-production may take time. It requires patience, communication, and a willingness to listen – even when it's uncomfortable. But the benefits are immense. Research becomes richer, more grounded, and more useful. It reflects the complexity and beauty of neurodivergent lives instead of reducing them to diagnostic categories or “challenges to manage”. And for those of us contributing lived experience, it's empowering. It reminds us that our voices matter – not just in our own homes, but in shaping systems that can better support all of us.

**It's not always easy, but it's always worth it.**

I've seen and in fact experienced firsthand how powerful it can be when Experts by Experience are meaningfully involved in research. It leads to deeper understanding, stronger relationships, and most importantly, better outcomes for the communities that matter most. So the next time we talk about autism research, let's ask: “Who's in the room?” Because if we're not including people with lived experience at every stage, then we're missing the most important piece.

Misrah Mohamed

A mother to an autistic child