Parallel Stories: Navigating Neuro-Normative Systems

This reflective piece was originally written as part of a contribution to a presentation to an NHS Trust Executive Board exploring the experiences of autistic staff working within healthcare systems. It reflects on the parallels between the experiences of autistic professionals, autistic children and autistic service users as they navigate environments largely shaped by neurotypical expectations.

Drawing on personal experience as an autistic person, a parent of neurodivergent children and a clinical psychologist, the piece explores autistic burnout, contextual disability and the challenges of creating genuinely neuro-inclusive systems.

I became very aware of a difficult irony while preparing to speak about my experiences as an autistic staff member to senior leadership. At the time, I was on leave due to autistic burnout. The cumulative impact of parenting neurodivergent children, navigating professional demands, and working within largely neurotypical systems had significantly reduced my available bandwidth.

When I was first identified as autistic around two and a half years ago, there was a sense of optimism and relief. Yet there was no sudden reshaping of the world around me into something aligned with my differences, strengths and needs — no keys to a neurotypical city. As a mentor once wisely predicted: *“when it all settles, you will still have to live this life.”* At the time that comment bounced off the armour of my newly forming autistic identity. Looking back, I suspect she could see some of the challenges ahead more clearly than I could.

When contributing to conversations about autistic staff experiences, I realised that I needed to do so in a way that reduced social and sensory load while I recovered. In some ways this felt important to model: that adjustment in response to fluctuating capacity and dynamic disability is part of the autistic experience. Yet this is rarely cost-free. I still feel the shame orchestrated by my internalised ableism — the sense that I should be able to function as I once did, before my circumstances changed.

Part of that experience involves mourning the version of myself who could previously camouflage more successfully. Despite the disconnection that came with living that way, that earlier version of me might have managed to stand in front of a room full of people and speak about these issues without hesitation.

Through my experiences as a parent, psychologist and autistic person, I have increasingly noticed parallels in the stories I encounter. These are stories about autistic people navigating powerful systems — systems that are themselves often overwhelmed and dysregulated, making it even harder for them to flex in ways that might support those who do not conform easily to their expectations.

I will begin with my own story.

It is important to say that I do not experience autism purely as a disability. At the same time, the realities of my current life mean that I am often disabled by context in ways I would not have anticipated a few years ago. My home life is full of energy and movement. My children are wonderful forces of nature who need constant stimulation, activity and sensory engagement in order to regulate and thrive. For my own neurology, however, environments that are predictable, ordered and relatively low in sensory stimulation are far more sustainable.

This creates a daily trade-off. By the time I have navigated the sensory and emotional demands of family life, the number of “spoons” available for professional work can already be significantly reduced. Increasingly I have had to become more intentional about how I manage and replenish those resources in order to live and work sustainably.

The systems we inhabit do not always have the flexibility to accommodate this easily. In those moments the difference between being visible as an autistic professional and truly being *seen* becomes very clear.

Changes in my professional role have also brought new opportunities — particularly opportunities to influence more autism-informed practice across services. Yet these opportunities often come with expectations around networking, visibility and spontaneous social interaction. For me, these forms of engagement carry a high social and sensory cost. If I attempt to participate in them in the same way others might, the result is often another cycle of burnout.

This raises an important question: are there ways of contributing and influencing that allow autistic professionals to participate in these spaces in ways that are more predictable, structured and task-focused? Ways that build working relationships without requiring sustained social camouflaging and the well-documented mental health consequences that can follow.

The echoes of these challenges are also present in my son’s story, which he has given permission for me to share.

As parents we often face a painful dilemma when supporting him to attend school. There are mornings when he sits in the car footwell, distressed and overwhelmed, saying he does not want to go in. Yet we know that if he does not attend, there is a real risk that returning will become even harder — with families often facing punitive consequences when school attendance breaks down.

My son is bright, curious and academically capable. His school understandably wants him to access what is often described as *quality-first teaching* in the classroom. But an important question arises: *quality for whom?*

The language of inclusion is frequently used, yet the reality is that the classroom environment can become so overwhelming that he is unable to access learning at all. Sensory overload, particularly in environments such as communal dining spaces, contributes to cycles of dysregulation and burnout that can prevent him from accessing education for extended periods of time.

Inclusion is not achieved by ensuring everyone experiences the same environment. Sometimes it is precisely the expectation of sameness that becomes the most excluding and harmful factor.

Similar stories emerge within mental health services. For example, autistic individuals receiving treatment for eating disorders may be expected to recover by eating a wide variety of foods in communal environments — an approach that may not align with their sensory or neurological needs. In inpatient settings, policies such as locking bedrooms during the day can remove access to the very spaces autistic individuals rely on for regulation and recovery.

Interventions intended to support recovery can inadvertently become graded exposure toward the very neuro-normative expectations that contributed to distress in the first place.

As Chapman and Botha (2020) argue in their work on neurodivergent-informed therapy, there is a need to move away from the “tyranny of neuro-normativity.” When systems remain rigidly normative, those who cannot conform are disproportionately drawn into mental health services and risk being further harmed by the systems meant to support them.

To paraphrase Desmond Tutu, our systems often become very good at fishing people out of the river — while doing far less to stop them falling in.

For autistic people, that rescue operation can become even more complicated when the systems themselves are inadvertently pushing them under while offering help from the riverbank.

What strikes me most in these situations is that there is often agreement about the desired outcome. Parents want their children to learn and flourish. Professionals want to contribute meaningfully to services. Clinicians and service users want to reduce suffering and support recovery.

Yet the barrier frequently lies not in *what* we want to achieve, but in *how* systems expect those outcomes to be reached.

The result can be situations where an autistic professional feels forced to choose between sustaining a career and being present for their family. Where an intellectually curious child becomes labelled as “below expectations.” Where autistic service users experience escalating distress within environments intended for healing.

These outcomes are not inevitable. They are often the result of rigid expectations about how participation, learning or recovery should look.

If we want meaningful cultural and clinical change, an essential question becomes: how do we ensure that the voices of people with lived and carer experience are included in shaping the systems around them?

The autistic community often requires allyship to ensure those voices are heard and not pushed to the margins. Perhaps an even more important question is this: what is the cost of failing to listen?

My son recently asked me a question during one of his more difficult periods at school. After explaining that I was speaking to people about these issues, he asked:

“Are you telling them, Dad? Well, why isn’t anything changing? Why don’t they understand?”

I hope to continue “telling them” — for my son and for others like him. I hope that in some small way these conversations contribute to the changes that are needed.

The difficulty, of course, is that those changes rarely come quickly enough for the people who need them most.