

VIEWPOINT

Weaponized heterogeneity only harms the most vulnerable autistic people

BY MARY DOHERTY

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Autistic people as a group are heterogeneous, with a wide range of presentations, challenges and support needs. That heterogeneity is commonly weaponized against more able autistic people, often by autism researchers or parents who wish to highlight the needs of their autistic children who have higher support needs. This tactic, however, can backfire and increase harm to the most vulnerable autistic people because it separates this group from the insights gained from autistic scholarship. Focusing on aspects of autistic experience that we all share may be more fruitful and lead more quickly to our shared goal of improved outcomes for all autistic people.

As I write this, I have no access to fluent speech. I am autistic: an able, high-achieving, highly accomplished autistic woman. A medical professional who teaches peers about autism. Yet if you saw me in a difficult moment — such as at Gatwick Airport last night — or indeed during an INSAR [International Society for Autism Research] planning meeting today, you might not recognize me. An intensive day of interaction and teaching at the Royal College of Psychiatrists' **National Autism Training Programme for Psychiatrists** yesterday, followed by a difficult journey home and a trainee support workshop this morning, which I didn't feel able to cancel, has left me completely spent and, as we say in the autistic community, totally "out of spoons." Luckily, our neurodivergent family functions perfectly well without the need for spoken words, and my autistic teenager can empathically say, "It's OK, Mum. Don't try to talk." At other times, I'm the one saying the same to him.

Darkness, a complete lack of interaction (even online), favored comfort items, intense stimming and time is what it will take for me to regulate to the point at which I can once again communicate using spoken words. I hope it happens overnight — because I have a meeting with my occupational therapist tomorrow, which I badly need in order to plan out my next few days. But this is not within my control.

We need to recognize these challenges, which are common among autistic people. Unreliability of

speech for usually fluent autistic people, and the speed at which we can go from articulate and competent to completely unable to access speech, is not generally appreciated. Would I prefer that this aspect of my life was not shared publicly? Yes, of course. I spend quite a lot of time and effort ensuring that I am not seen in such a state except by those who know and love me unconditionally. But if we are to address the needs of the entire autistic community, we should consider those aspects of autistic experience that we all, or most of us, share.

Attempts to subgroup autistic people have been largely unsuccessful and generally unwelcomed by autistic people who can communicate a preference. Parent and author **Amy Lutz** and her colleagues contend that “studies focusing on those most disabled by autism ... should be **of paramount concern** to everyone in the autism community.” I agree, and I contend that they already are. Despite the underrepresentation in research, and indeed the challenges of including those with higher support needs in research, I contend that autistic people with the greatest challenges and support needs benefit from autistic-led research, when those caring for them are open to autistic community wisdom and scholarship.

Autistic-led research is increasingly shining a light on previously unknown aspects of autistic experience. It is also highlighting the risks and dangers of approaches previously considered to be “gold standard,” such as **applied behavior analysis** (ABA). Who among us are at the greatest risk of harm from such approaches but the most vulnerable of autistic people?

How do we know about the impact of **sensory issues**, which are ubiquitous among autistic people but only recently recognized, except that autistic people who have the capacity to speak can describe them? Those of us who can communicate our experiences watch nonspeaking autistic people experience the same sensory challenges, and we understand in ways non-autistic people simply never will, no matter how close their relationship. We notice things in the environment that you’ll never see if you are not autistic. We know how lights hurt our eyes, how sounds hurt our ears, how aversive casual touch can be and how awful certain fabrics make us feel. We understand that the texture of food can affect us far more than taste — and we don’t just know this cognitively, we experience it.

What you might see as rigid inflexibility, we experience as a need for predictability. We appreciate the comfort of familiar routines, and we know the intense pleasure of our passions. We know that what might seem to you to be inexplicable and inappropriate laughter is nothing of the sort. It may be the exquisite pleasure of replaying a favorite cartoon or comedy sketch in our minds as vividly as if on a movie screen, with little regard for social conventions. We **know how soothing stimming is** and how effectively it helps us to self-regulate. More importantly, we know the negative impact of being forced to suppress it. Consider how suppressing visible stimming was, until quite recently, integral to the common therapeutic goal of becoming “indistinguishable from peers.” Why do practitioners who previously saw this as a goal no longer recommend it? Only because autistic people who can speak about such things actually did so, and the risk-benefit ratio was finally appreciated by non-autistic practitioners and parents who listened.

How do we know about the trauma experienced by autistic people subjected to ABA, never mind the lack of any meaningful benefit? This has been known about in the autistic community since the earliest days of autistic self-advocacy, but only when autistic-led research started to shine a light on it did larger, funded studies follow to validate that community wisdom. How do we know about the increased risk of sexual exploitation for autistic women and girls? Only because autistic people who can speak say out loud that compliance-based behavioral techniques, such as those used in ABA and positive behavior support, set us up for such exploitation.

How do we know about **autistic inertia** or **autistic burnout**? Without autistic scholars such as **Leneh Buckle** and **Dora Raymaker**, autistic people would continue to experience hermeneutical injustice, experiencing these phenomena without any way to describe them, even if they had the words. Those who do not have words likely have the same experiences. Only by listening to the autistic community, and the growing ranks of autistic researchers and neurodiversity-affirmative allies in academia, can we start to approach research in a way that has the potential to meaningfully improve the lives of all autistic people.

How do we know that some autistic people who appear to have co-occurring intellectual disability actually do not? What if some have a keen intellect that is only apparent when they are given effective means of communication? How many illiterate nonspeaking 11-year-old autistic children have the potential to become university professors? The truth is that we simply don't know. But we know how to provide the best environment to optimize outcomes: by listening to those who have travelled that path, such as the sociologist Jason Arday, the youngest Black person ever **appointed to a professorship** at Cambridge University in the United Kingdom. Would his potential have been recognized and supported by the proponents of "profound autism"? Hardly.

Splitting the autistic community in two based on level of disability or support needs is a false dichotomy. If you are not autistic, it may seem inimical to suggest that autistic people should not be considered as two separate groups, but those of us who live this reality know that we have far more in common across the spectrum than our differences might suggest. This is not to deny the wide range of challenges and support needs, but clinicians, researchers and caregivers who listen to autistic people describe similar issues stand to gain a far deeper understanding of them.

Attempting to split us up and using those differences against us in an attempt to deny the needs of some — thus weaponizing our heterogeneity — only harms those in greatest need. For researchers and caregivers whose goal is prevention and cure, this insight is unlikely to change their perspective, but increasing numbers of clinicians and researchers are appreciating the value of a neurodiversity-affirmative approach to autism.

The way in which autism is framed will have a profound effect on individual outcomes, and there is a profound need to deliver effective supports for all autistic people, regardless of phenotype. In my view, these are the only two contexts in which the word "profound" should be used in relation to autism or autistic people. Focusing on our shared experiences of the world, I believe, will bring us

closer, and more quickly, to our shared goal of healthier, happier lives for all autistic people and their families.

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