

A flurry of new research has advanced thinking about autism, increasingly co-produced with autistic authors. That swing to more inclusive research is still gaining momentum, Heyworth says. “Once you get research, things trickle down, and the way people talk about it, and universities teach it, changes,” she says. This extends to social media, where the TikTok hashtag #ActuallyAutistic – used to highlight autistic-made content – has more than 7 billion views.

One outcome of this awareness has been a trend towards self-diagnosis. Fraser says it’s most common in women, who were probably missed in childhood, when the diagnostic criteria was limited and it was mainly boys who were identified. (Autism is still diagnosed more in boys, but diagnoses in girls are on the rise).

Many come to the realisation after having autistic children; others arrive through reading, Fraser says. “They get that lightbulb moment of thinking: it’s not that I’m broken, I’m just an autistic person surviving in a predominantly neurotypical world.”

“For most people, that’s enough. They don’t need to go and spend thousands of dollars and time to get the piece of paper,” Fraser says. A clinical diagnosis can provide access to services, and is required to enter the NDIS. “But especially for adults, it may not be necessary that you access those services. You may have worked out other ways to exist.”

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Sharon Fraser

Dissanayake says the neurodiversity movement has given the world a better understanding of what it’s like to view the world through autistic eyes. But it’s not the whole picture.

“That’s also one end of the spectrum; 20 to 30 per cent of autistic people will have an intellectual disability and very limited means of communications. For people with more severe needs, there are parents in their 70s and 80s who have never had a holiday. It’s like another whole job, helping high-needs adults navigate their lives, and I don’t think [these voices] are representing them. What their life is like, I don’t know, because we’re not hearing from them,” she says.

That's where parents like Nicole Rogerson, whose son Jack is autistic but who is not autistic herself, enter the conversation. Rogerson thinks the neurodiversity movement comes from a good place: the idea that the world should be kinder and more supportive of autistic kids, that we need autism acceptance, not just awareness.



Nicole Rogerson and her son Jack, 28, who is autistic. NICK MOIR

“But that social movement glosses over the reality of people with more severe types of autism, and does them a disservice,” she says.

“Have we achieved more awareness of autism? Yes, definitely. In our regular culture we have television, podcasts, books. There are well-known people who identify as autistic. The only downside to all that wonderful awareness and celebration is that it can confuse people.

“For some, autism is something they’re proud of and they wear as a badge of honour. But for 30 per cent of people with autism, it will be a severe disability that affects every aspect of their lives. In the focus on more mild forms of autism, which of course are to be celebrated, people with moderate to profound autism have been overlooked.”

Having that conversation has become taboo, Rogerson says. “It’s like earth and earth two. There’s ‘autism is my superpower’ and there’s ‘my 12-year-old is still not toilet trained’. They both exist and for some reason it’s become a political minefield if you step out there with a view.”

She thinks this also muddies the water for policymakers, pointing to the conversation playing out over access to the NDIS, where 35 per cent of participants in the \$42 billion program have autism as their primary diagnosis.

“Is it a significant disability, or is it not? We know for a significant proportion of those with autism, there are lifelong challenges. And so it becomes tricky. There’s one part of the community that says ‘don’t pathologise us or look at us through a medical model’ but the flipside is we’re talking about an insurance scheme.”

Fraser doesn’t think talking either extreme – of superpowers or deficits – is helpful. But she understands why people have chosen to focus on the positive.

“People tend to be generally uncomfortable with the idea of disability, so that’s where I think that [narrative] comes from. It’s also a resistance to hearing everything about yourself or your child pathologised and seen in a negative light.”

Heyworth, the researcher, thinks there can be a middle ground. She agrees contemporary conversations about disability don’t always acknowledge that some challenges autistic people face are not just environmental.

“For some people, there are elements of their autistic experience that are going to be detrimental to their quality of life, and that’s OK. It doesn’t mean we have to throw away neurodiversity, or the value of autism and the autistic brain.”

The superpower narrative, she says, wipes away the challenges. “It also often allows society to abrogate responsibility for doing too much to meet your needs,” she says.

But while she thinks these are important conversations to have within the autistic community, they’re not ready to hit the mainstream. That’s because stigma persists.

“If we talk about autism in ways that construct us as disordered, we will continue to have a community that doesn’t experience both broader acceptance, as well as self-acceptance. That’s why the conversation still needs to focus on us being proud autistic people.”

Not everyone is sure that autism is even a meaningful label any more. There are different views within the autism community, and among researchers and clinicians, about how to speak about the spectrum. Some want to use functioning terms – such as mild, moderate or profound autism – to differentiate needs and experiences. Others refuse to use this language, because it reduces autistic people to their most challenging characteristics.

Rogerson is in the first camp. She says the 2013 decision to collapse several different childhood diagnoses into “the spectrum” has confused the general population. “If I was to tell you, ‘you’ll meet Billy today, and he has autism’, that tells you nothing about Billy. You just have to acknowledge there are more severe and more mild forms of autism. And if we can’t agree that is true, we are in La La Land,” she says.

But Heyworth isn’t convinced. “The problem with trying to distinguish autistic people from other autistic people – collapsing and separating people back out – is that invariably we reduce people to their most obvious external characteristics of autism,” she says.

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Nicole Rogerson, mother of an autistic son

She says this has happened before: non-speaking autistic people were assumed to have an intellectual disability, which means their strengths and competencies were forgotten.

“On the other hand, our self-proclaimed ‘Aspies’ – [the people who had been given an Asperger’s diagnosis] – weren’t just clever, quirky, strange people who lived in Silicon Valley and probably wouldn’t get married. They had needs too,” she says.

Langston, an artist as well as an advocate, reflects on her own experience and says the idea of labelling someone as high or low functioning doesn’t resonate. “A lot of late-diagnosed women get missed because they can mask. But when you look at their lives, they’ve been in and out of psych wards. It’s life-limiting when you don’t have the support you need; just because someone can be articulate, doesn’t mean they’re fine.”

These are the fault lines that often separate the thinking – and advocacy – of autistic adults and non-autistic parents of autistic children. The NDIS has been a pressure cooker; social media and online forums can be another.

Rogerson regrets that things have become so politicised. “We can have difficult awkward discussions, and we should, without being fearful of using the wrong language. Because at the end of the day, what we desperately care about is people and families, and we need to roll around in the messiness of all the politics of autism to get to that point.”

But in a community that’s taken so long to find its own voice, and still comes up against discrimination and stigma, the input of non-autistic people is not often welcome. Langston acknowledges things can be messy. “I think what’s important is that these conversations should be autistic-led,” she says.

Dissanayake, now in her fourth decade in the field, says she feels sad to see so much tension. She has watched families respond in a range of ways. Some parents are wary of the diagnosis; for others it offers answers. Some families crave support; others reject it, so their children can be their autistic selves. Some clinicians are hesitant to diagnose children so young and set them down a clinical path; she thinks it’s important parents have as much information as possible.

“There’s lots of voices in this space and it sometimes feels intractable. One autistic voice is only one autistic voice. That’s where the need to categorise people and put them in boxes doesn’t serve anybody well ... I think our work needs to focus more on what’s going to be a good quality of life, and how people can have it,” she says.

Whitehouse says we could be approaching a point where we need to re-examine the language we use, particularly as rising numbers of children are diagnosed with autism and policymakers grapple with what this means for government funding and support services such as the NDIS.

“To some extent, we may need new words for what we’re talking about here. It may mean that autism is used as a clinical diagnosis, whereas the term neurodivergence is to talk about people who have a firm belief that they have brains that think differently to other people,” he says.

The idea of taking away autism as either an identity or diagnosis is fraught. Langston, for example, hears that as: “We want to reduce autism diagnoses in the community”. “How are we supposed to feel about that, as autistic people? I think it’s deepening this narrative that autism is bad, when we know it is a normal part of neurodiversity,” she says.

“The idea that we need to create a distinction between the clinical model and ‘mild autism’ to address support needs is politically and commercially motivated. Autistic people are not driving this distinction. The system is overwhelmed, and [we] will also say that. But the answer is not to make less autistic people.”

This is part two of three in a series about how our understanding of autism has changed and what it means for Australia. [Read part one here.](#)

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