

Autism

Thousand-fold increase: What is driving the rise of autism?

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MARCH 31, 2024



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In the late 1980s, when Professor Cheryl Dissanayake started researching autism, she estimated in her doctoral thesis that three or four babies out of 100,000 would be diagnosed with the condition.

“Now, I’m telling you it’s three in 100,” she says.

That thousand-fold increase isn’t because anything has changed in us, biologically. But our understanding of autism has changed. The evolution of the diagnosis is having a profound influence on Australian society, from our schools and workplaces to our popular culture and policy debates.



There are signs Australia has higher rates of autism than over countries. MARIJA ERCEGOVAC

A massive expansion in the medical criteria means children who were diagnosed with Asperger's syndrome in the late '90s are considered part of the autism spectrum today. Evolutions in research mean children are identified younger, sometimes as early as 18 months. And as awareness has improved and the neurodiversity movement flourished, adults who weren't seen in childhood have figured out they, too, are autistic.

Now, there are signs Australia has higher rates of autism than comparable countries. It's raised thorny questions. Could the \$42 billion National Disability Insurance Scheme have inflated diagnosis rates? On the other hand, rates of diagnosis for women and girls are on the rise, but remain significantly lower than for boys and men. Are true rates of autism higher than we think? And is "the autism spectrum" even a useful term, given it captures such a range of human experiences?

There aren't definitive answers. But most people point to 2013 as the point things really shifted. In the same year that Australia started rolling out a world-first disability insurance scheme, the official diagnostic criteria for autism expanded significantly.

Ten years later, the way those two forces have converged is driving a complex debate

about the NDIS – now one of the federal government’s biggest budget pressures – and how public funding should be delivered to support Australians with autism.



Researcher Cheryl Dissanayake. JASON SOUTH

Autism is a neurodevelopmental disability, which means that the brain develops differently to what we would typically expect. There is no single known cause, but researchers generally accept it’s a genetic condition that may also be influenced by someone’s environment.

But because there’s no genetic giveaway, autism is diagnosed based on behaviour. There are two core traits that autistic people display: they have difficulty with communication and social interaction, and have restricted interests or repetitive behaviours.

It’s a new condition in the scheme of things. The first paper to describe autism was written by Boston child psychiatrist Leo Kanner in 1943. He observed 11 children who were solitary, needed routine and had some language difficulty. This included the first person diagnosed with autism, Donald Triplett, [who died last June](#). Austrian physician Hans Asperger was undertaking similar work at the same time.

But it wasn't until 1980 that a diagnosis called "autism disorder" was added to the psychiatry bible: the Diagnostic and Statistical Manual of Mental Disorders, better known as the DSM. It was mainly children – and mainly boys – with intellectual disability and significant language impairments who were diagnosed, and they needed to have very significant difficulties to meet the threshold.

That stayed true until 1994. Researchers had realised there were some people who showed the core behaviours of autism – communication differences and repetitive interests – but did not have an intellectual or language impairment. Quite the contrary, they could be highly verbal or intelligent. And so several new diagnoses were introduced, reflecting those varying levels of ability.



Hans Asperger with a child patient. FILE

There was Asperger's syndrome for children who became hyper-fixated on certain interests and struggled to interact with others, but could also be highly intelligent. Classic autism was a diagnosis reserved for children who had more difficulty with language and communication. Childhood disintegrative disorder, or Heller's syndrome, described those whose late onset developmental delays might have led to reversals in language, bladder control or motor skills. Children who did not meet the full criteria of those conditions were diagnosed with "pervasive developmental disorder not otherwise specified". Australian children born in the '90s and noughties

were raised in this framework.

Then in 2013, “the spectrum” was born. The fifth and most recent edition of the DSM collapsed all those conditions under the umbrella term autism spectrum disorder, and marked the most significant change yet to how we understand autism.

Some autistic people are intellectually disabled, some are highly intelligent. One person could be non-speaking while another is highly verbal. Autism can present in hundreds of different ways, and no two people are the same. “That’s what we call the autism spectrum. We went from a unitary condition, where everyone had a similar and high level of impairment, to, actually: you can show all these behaviours. And so the numbers of children we diagnosed went from really small to large,” says Professor Andrew Whitehouse, head of the autism research team at Telethon Kids Institute.

But it’s not just children, any more. One of the fastest-growing categories of participant on the National Disability Insurance Scheme is now autistic adults. “Twenty years ago, adult diagnoses were extremely rare. Whereas in our contemporary world, adult diagnoses are almost as frequent as child diagnoses,” Whitehouse says.

“When these adults were children, we had a different conception of autism: that it was only for children who had very significant difficulty, like intellectual disability. As the diagnosis of autism has evolved, all of a sudden, the difficulties that [these adults] have been experiencing are seen in a new light and that they may actually meet criteria for autism.”

Still, there are two fundamental criteria for an autism spectrum disorder diagnosis: certain social and communication difficulties, and patterns of restrictive and repetitive behaviour. The DSM also describes three layers of severity, which are determined by how much support someone requires. These are referenced as level one, two and three autism, providing a shorthand for families to describe the level of disability their child experiences.



Autism expert Professor Andrew Whitehouse. TREVOR COLLENS

Most people in the autistic community, however, don't think of autism as a linear spectrum. Some talk about the condition as a constellation. Others describe a "spiky profile" that mixes incredible strengths and gifts in some areas – such as visual thinking, deep interests, an eye for detail, strong memory – with intense struggles in others.

Dr Melanie Heyworth, an autistic researcher who founded the organisation, Reframing Autism, describes being autistic as having a busy brain, which can affect everything from movement to sensory experiences, communication, emotion and empathy. "Every autistic person's brain is different than the next, and the way those elements interact look different for every autistic person," she says.

"The primary differences that most autistic people would talk about are in the way that we communicate. I use spoken language as my primary form of communication, but other autistic people don't [and are non-speaking], or they are multi-modal communicators."

Heyworth, for example, needs to see a person's face in order to engage with them. "I would not be able to have this conversation with you effectively over the phone," she

says. Some autistic people struggle to understand sarcasm or small talk, or find spoken language takes longer to process altogether. For that reason, they might find public speaking easier than casual conversation because it doesn't require them to digest what they're hearing at the same time as they're trying to talk.

Autistic people often empathise, process their emotions, or show their feelings differently. Some find it difficult to regulate their emotions, which can be intense; others withdraw, and this is a common response spotted in children. Eye contact is often uncomfortable, and for some people it even leads to nausea or dizziness.

Sensory overload is also common. Some people might be hyper-sensitive, "where everything you touch feels like pain", while others are overwhelmed by bright lights. "That's the reason you get the stereotype of the child in school with the big ear muffs. Or you get me rocking back-and-forth at the moment," Heyworth says. Some of those repetitive movements, such as body-rocking and hand flapping, are known as "stimming", and can help autistic people regulate their emotions or cope with anxiety.

Many autistic people "mask", which means they try to hide their unique behaviours, perhaps because they were bullied at school. "Those things impact mental health and it's exhausting, they experience burnout," Dissanayake says. Studies suggest masking is more common in girls, which is why autism in females is identified less frequently.

Children are usually diagnosed with autism following a multidisciplinary assessment, where clinicians from different professions – such as paediatricians, speech pathologists, clinical psychologists – watch them in a range of settings to understand whether they show signs of autism. Dissanayake says the point of treatment is to help children develop ways to communicate and learn from people around them.

"We're not focused on making the child less autistic. What we want to do is improve their cognition. If they don't develop an ability to communicate, it lessens their ability to learn, and they end up with a learning disability."

These days, more autistic children in Australia are getting the help they need much earlier in their lives.

But as more families receive that support by signing up to the NDIS, which offers

automatic entry with a level two autism diagnosis, there have been uneasy questions about whether Australian children are being steered towards a clinical diagnosis for funding in an otherwise expensive and hard-to-access system. More than 9 per cent of five- to seven-year-old children are now on the scheme, mostly for autism or developmental delays.

A research paper published last year, by Australian National University scholar Maathu Ranjan, lit a fuse under that debate.

Ranjan, who is on study leave from her role as a senior actuary at the National Disability Insurance Agency, looked at dozens of studies estimating autism prevalence around the world. While diagnosis rates have gone up everywhere over the past 20 years, she found the Australian growth rate for children was higher than in similar countries.

Her paper, which is not peer-reviewed, quoted international studies that showed autism prevalence rates of one in 36 children in the United States, one in 50 in Canada, and one in 57 in the United Kingdom. In Australia, it was up to one in 25.

She said there was “considerable controversy” around the drivers of rising autism rates worldwide. But in Australia, she pointed to the NDIS. “It is plausible that the growth of prevalence rates above the global average in Australia can be attributed to the financial incentives created by government policy, specifically the implementation of the NDIS.”

Whitehouse agrees that the NDIS has led to more kids being diagnosed and distorted our understanding of true prevalence rates in Australia. “I think it’s without question that the use of an autism diagnosis level two shifted the focus, and the centre of gravity, towards that diagnosis. Clinicians, we all want the best for the kids that we are seeing. And if there are children who require support, there is a focus towards how can we get them that support.”

He says the levels of severity outlined in the DSM were intended for doctors to use, not for policymakers to allocate disability funding. But while the NDIS was rolling out quickly, it was an effective way of identifying people who needed significant support and signing them up to the scheme.

“But as we know with autism, there’s not a simple biological diagnosis, as there is in Down syndrome. There is an observation of behaviour and then a judgment by clinicians. And so the use of autism as one of those automatic entry criteria, unfortunately, was perhaps not the best move.”

Asked if that meant there were children with an autism diagnosis who weren't autistic, Whitehouse says: "It is highly likely that there is a proportion of children who have an autism diagnosis who don't meet criteria for autism but, importantly, they do require support. And this is the great tragedy of the whole thing. These children require support, but they have been provided labels that are not necessarily accurate to their difficulties, just so they can get it."

Many in the autistic community reject that analysis and point to other reasons: the expanded definition, improved diagnostic processes, and more awareness of the different ways that autism presents. [Alternative studies](#) that say Australia has one of the highest reported autism rates in the world have put it down to factors, such as milder cases or subtler signs being diagnosed, and say this trend was detectable even before the NDIS rollout finished.

Dissanayake thinks that sufficient explanations lie outside the NDIS. Even if clinicians are upscaling children to level two, that doesn't invalidate the diagnosis of autism to begin with, she says.

"We diagnose children much earlier and understand how autism presents in infants. The age of diagnosis is going down, and there's greater awareness among maternal and child health nurses, and early childhood workers, which also brings up the diagnosis rate. No longer do we think of autism as a rare condition in childhood."

She points to another important factor that's driving autism rates: an older generation who weren't diagnosed as kids, including parents of autistic children. That so-called lost generation has reshaped how we talk about autism, and what it means to be autistic.

This is part one of three in a series about how our understanding of autism has changed and what it means for Australia.

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