

Autism

Beautiful minds: Inside the identity politics of autism

Autism is no longer just a clinical diagnosis. For many, it's an identity, a community and a cause.

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For most of her life, Sarah Langston didn't know why she had so much trouble interacting with the world around her. She chalked it down to being a dysfunctional person. But it took its toll: intense difficulty regulating her emotions led to self-harm and repeat hospitalisations. She found it hard to hold down a job.

"For my whole life I had thought: I am broken, I am a mess, there's something wrong with me, I'm too much, how could anyone love me. I had terrible self-esteem."

That all changed when she was diagnosed with autism aged 38. All of a sudden, she had an explanation for behaviours that other people found puzzling, and decades of feeling on the outer. "I can talk a lot, use long words – I've always been a Scrabble champ – but I didn't realise my bolshiness and wordiness were autistic. We're difficult women. A lot of people don't like us and we experience social discrimination," she says.



Sarah Langston.

The diagnosis has connected Langston with support services that have helped her function day to day. But that hasn't been its most important legacy.

“What my autism diagnosis did was give me knowledge about myself. Knowing there's a reason why I present the way I do, and there's a whole community there for me to connect with, has been life-changing. My self-esteem went from being in the toilet to being pretty good,” she says.

Autism is no longer just a diagnosis. For many, it's an identity: one that has transformed their understanding of themselves and the world, opened up a new community of like-minded people, and changed their lives for the better.

Well-known faces on Australian screens and airwaves – comedians Hannah Gadsby and Josh Thomas, activist Grace Tame and actor Chloe Hayden – are proudly autistic.

Hayden, who played an autistic character in the local Netflix production of

Heartbreak High, has been at the front of this movement locally. “I see autism as a superpower. If you look at people at the top of their fields, so many of them are on the spectrum,” she’s said.



Actor Chloe Hayden plays Quinn “Quinni” Gallagher-Jones in Netflix’s reboot of *Heartbreak High*. LISA TOMASETTI/NETFLIX

This new wave of voices has championed an autistic identity that rejects the old labels.

Many have come to their autistic identity later in life, after the criteria for a diagnosis significantly expanded a decade ago and prompted a new reckoning. One big driver of this has been parents whose children are autistic coming to learn they fit the diagnosis as well. Adults with autism are now one of the fastest-growing groups on the National Disability Insurance Scheme.

Young adults often wear their autism as a badge of pride; an antidote to the discrimination they may have faced when they were younger. Today, identifying as autistic doesn’t necessarily mean you’ve been formally diagnosed. The growing [influence of TikTok](#) also encourages people to self-diagnose, with signs of autism explained in short user-made clips.



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That poses difficulties for policymakers, splits the autism community, and can puzzle others. When a clinical diagnosis takes on a meaning of its own, what do you do? And when an umbrella term like autism – which captures so many different experiences – hits the mainstream, who is left out?

“Autism came into existence as a clinical diagnosis. And what has happened over time – similar to other communities like the deaf community – is that that diagnosis has come to mean a lot more sociologically, particularly in terms of an identity,” says Professor Andrew Whitehouse, head of the autism research team at Telethon Kids Institute.

“People have found enormous purpose and belonging through the diagnosis, and that is a wonderful thing. What it also has done is [that] it’s clouded the differences. It’s made it challenging to differentiate between the clinical diagnosis of autism and the identity label of autism. It’s to be celebrated, but also to be examined.”

For Sharon Fraser, another late-diagnosed autistic mother, there’s a lot to celebrate.

“It’s so much better for your wellbeing to know that your brain is just wired differently. It’s a huge relief and so helpful, when you get your autism diagnosis or realise you’re autistic. You can almost replay your life and go: oh, that’s why that happened,” she says.

”People will use all manner of unpleasant words to describe you, and they tend to be character flaws: you’re lazy, you’re ignorant, you’re rude. Taking on an autistic identity label is something that we can reclaim for ourselves. Identity is so important because it means we get to define who we are. Otherwise other people will give us labels that they think fit us better.“

The advent of the autistic identity is an even newer phenomenon than the diagnosis, which only came into existence in the 1980s.

“When I came into the autistic world, no one talked about autistic identity,” says La Trobe University Professor Cheryl Dissanayake, who’s been researching the condition since then.

“Temple Grandin was the first autistic voice. Now we have many autistic voices. People get a diagnosis because it really helps with their autistic identity. That just wasn’t a thing [before], when people only got a diagnosis because they needed support. It’s a different world, and we need to figure out how we navigate it.”



Temple Grandin, an American academic and animal behaviourist, was one of the first prominent people to disclose that she was autistic.

This has been propelled by the neurodiversity movement, which sees autism and other conditions as natural variations that occur in the human brain, rather than problems to be fixed. It sits alongside the social model of disability, which holds that disabilities arise from the barriers society puts up, rather than inherent personal deficits.

While neurodiversity was coined in the late 90s, it has taken off in the last decade, coinciding with a change to the psychiatrists' manual – known as the DSM – which created a broad diagnosis of “autism spectrum disorder” in 2013, and collapsed a range of conditions such as Asperger's into the one umbrella term.

“I think we started to reassess what it was to be autistic in that moment, when the convenient shorthand [terms such as Asperger's] that we'd used previously no longer worked,” says Dr Melanie Heyworth, an autistic researcher who founded the organisation Reframing Autism.

“And so for us, it's probably in the last 10 years that we've been intensively re-examining what it means to be autistic.”