

Autism

## The steps being taken to get better treatment for Australia's autistic people

Australia has its first assistant minister for autism and is crafting its first national autism strategy. How the rest of society steps up will be crucial.

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**S**outh Australian politician Emily Bourke didn't realise she was taking on a world first when her government created an Office for Autism just over a year ago. But the more she talked to people and families around the state, the more she knew it was needed.

It started on the campaign trail in 2022. "We were holding lots of community forums, and it kept coming up naturally: my child can't get through school; I'm an autistic adult and can't get into the workplace," she says. So she started holding specific autism forums; they kept getting booked out.

"That's when we realised we needed someone solely focused on these autism policies. We didn't realise no one had a position like this in the world."

Bourke is now Australia's first assistant minister for autism, but she probably won't be the last. She's tapped into something all policymakers in the country must grapple with: our improved awareness of autism [and rising diagnosis rates](#) mean our systems must change, from schools to workplaces.

All governments need to act. Federal Social Services Minister Amanda Rishworth will

release the country's first draft national autism strategy on Tuesday, promising to create a "whole-of-life plan for all autistic Australians" that spans reform to healthcare, education and employment.

The spiralling price tag of the NDIS, now one of the country's fastest-growing budget pressures, only adds to the urgency. With more than a third of participants reporting autism as their primary disability, the condition has come under the national spotlight. What it has shown us is that people – especially children – are flocking to the scheme because there's not enough support for them outside it.

Bourke has done a lot of learning in the past year. "If you're autistic, you're half as likely to complete year 10. You're three times more likely to be unemployed than someone else with another disability. And if you get to 50 years old, there is a higher suicide rate for the autistic community. That stems from all those other things: not getting through [school], not getting into employment and not having knowledge in the broader community about what it is to be autistic," she says.

"The autistic community have done lots of research into this and found 84 per cent of people know the word autism, but only 29 per cent have knowledge of autism. These were concerning statistics to us."



Social Services Minister Amanda Rishworth will announce the government's draft strategy surrounding autism on Tuesday. ALEX ELLINGHAUSEN

The federal government's new autism strategy, which will be finalised with an action plan by the end of this year, takes all those statistics into account. Developed in consultation with autistic Australians, it vows to boost the understanding of autism among key professions and the wider community, to make education and employment more accessible, and to provide better support for families.

Under this vision for Australia, there would be more autistic faces in Australian sport and media, while public spaces and transport would cater to the sensory differences autistic people experience. Getting assessed for autism would be cheaper and easier, and there would be better access to health services through Medicare. Teachers would all undergo autism training, people in service roles would be upskilled, and workplace recruitment processes would be improved.

Clare Gibellini, an autistic advocate who helped oversee the strategy, says it is "hugely significant". "This is the first step in a longer journey towards better lives for autistic people."

The most pressing policy issue is what comes next with the NDIS.

About 35 per cent of participants in the \$42 billion program, which has been growing at around 16 per cent a year, have autism as their primary diagnosis. That's more than 215,000 people, a number which grew by 18 per cent last financial year, and 21 per cent the year before. Almost 80 per cent of autistic participants are 18 or younger.

The average annual payment to someone with autism was \$33,800 in the 2022-23 financial year, up 7 per cent from the year before. Altogether, \$6.73 billion in support was paid to autistic participants; a year-on-year increase of 28 per cent. Even [the scheme's architects say those rising costs are not sustainable](#) for a social policy that needs public support to endure.

Almost everyone with an autism diagnosis who applies for the scheme is successful because people with a level two or three autism diagnosis are automatically eligible. Last year, 97 per cent of people with autism who applied for the NDIS were accepted, compared with 76 per cent of all applicants.

But that will change under a series of [major changes that will remove the diagnosis list](#) and refocus eligibility on people's needs. Those changes, to be rolled out over the next five years, will reduce the number of children, in particular, who can access support packages with an autism diagnosis alone.

Most people have welcomed that move, which was recommended by a major review of the scheme. First, because looking at a person's specific needs is more insightful than their diagnosis. And secondly, because the NDIS, which often funds siloed clinical services like speech pathology and occupational therapy, is probably not the best way to help children on their development journeys.

Professor Cheryl Dissanayake, the founding director of La Trobe University's autism research centre, says the NDIS has fed an environment where "everyone's in private practice and they're charged top dollar".

"I don't think children should get one hour of therapy here and there. Parents can't work, they're constantly dropping their kids off," she says. Principals are often asked to accommodate this, with kids leaving class to see their private therapist on school grounds in whatever space is available. This isn't ideal for the child or the school. "Support should be provided where they are. Every school should have access to allied health so that kids get the support where they are."

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**T**f families are going to stop using the NDIS to get support for their kids, they

┆ need other avenues. The classroom is the obvious place to start. But as Nicole Rogerson, the founder of parent advocacy group Autism Awareness Australia, has discovered, there is a long way to go.

A survey of parents published by her organisation on Tuesday shows 35 per cent of families of autistic children said they were discouraged or refused enrolment for their child at school, half of whom were in the public system.

Forty-five per cent said their schools were unwelcoming or reluctant to accommodate their kids. Half of parents have considered school alternatives, such as home-schooling or remote learning, because of those difficulties. Only 16 per cent were happy with how their schools managed funding to support their child.

“The federal government wants schools to step up and better support children with disabilities. We don’t disagree that this should be a goal,” Rogerson says.

“But this report illustrates the reality facing autistic children in schools today. It’s a call to action for enhanced teacher training, better communication and a commitment to inclusive education.”

While some families gave examples of supportive teachers and positive adjustments in the classroom, “they are contrasted starkly against widespread reports of inadequate support, bullying, and systemic failures to understand and include autistic students effectively”, the report says.

Professor Andrew Whitehouse, head of the autism research team at Telethon Kids Institute, says Australia’s school systems have not evolved to support autistic children. “We need a better understanding of what true inclusion in the classroom looks like. We also need an understanding that we’re not teaching kids towards the average child: we need to teach kids around all the different methods of learning and different neuro-types that might be within that class. That’s what I see as the major evolution that needs to happen in every school in Australia over the next 20 years.”

It’s a daunting task for education ministers, whose systems are already stretched by workforce shortages. But in South Australia, Emily Bourke has had a few ideas, starting with getting an autism inclusion teacher into every public primary school.

“We have taken one teacher out of the classroom and are now training them in autism, inclusive studies, disability studies, so that they actually have that skill set and can share it with their peers and fellow teachers,” she says.

She also persuaded all four universities in South Australia to change their teaching degrees and introduce six new modules on autism, disability and inclusion, including practical training.

“[Before,] you might do one module on disability. That’s alarming because one in four kids that start school have a learning disability, which includes autism. So this is 1300 teachers that will graduate each year with new knowledge,” she says. A research team will follow that project starting this year, to ensure it’s making a difference.

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**E**mployment is the other big-ticket item. “Because if we can get people working, a job is more than just a pay packet,” Bourke says.

Her Office for Autism has launched an “Autism Works” campaign to guide employers on best practice. It’s being pushed on tram wraps, at Adelaide Oval, in newspapers. A workplace audit, [available online](#), is where they can start.





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Companies are encouraged to build their knowledge. They should consider their physical environments, and whether they are prone to causing sensory overload that autistic people might struggle with: think bright lights, loud noises, kitchen smells. It's important to use clear, plain English, and accept that autistic people might not want to make direct eye contact, or prefer written communication to one-on-ones.

This extends to hiring processes. "We know the biggest barrier for the autistic community in employment is often [getting] the job itself, because it's written in a way that seems black and white to someone who is autistic," Bourke says. One-on-one interviews with surprise questions are often not the best format. One of Bourke's