For many Aboriginal and Torres Strait Islander children, delays in diagnosing disabilities are compromising their education and denying their schools the extra funding they need.

BY CHRISTINE LONG

## Disadvantage undiagnosed



or Aboriginal and Torres Strait Islander children in regional and remote communities, having a disability diagnosed is often a difficult, drawn-out process. In the meantime, schools, teachers and parents are left to do the best they can.

"If you're an Aboriginal child with a disability, it's almost a double risk factor for your education," says Scott Avery, policy and research director at First Peoples Disability Network Australia.

Autism is one frequently undiagnosed disability. Autism education organisation. Positive Partnerships says the lack of visibility of Aboriginal people with autism means it's

"mostly unheard of" in many areas. "Lack of appropriate services, appropriate diagnostic assessments and tools, the absence of trusted relationships, and the fear of shame and blame have led to lower numbers of children formally diagnosed with autism."

When Avery visited a school in northern Queensland, teachers were asked if they had taught children with autism. "Two or three put their hand up," he says. "Then we asked how many had taught kids with repetitive behaviours that are impacting on their learning, and half the room put their hand up."

Conversations with community members revealed difficulties in getting assessments for

### BRIEFLY



Aboriginal and Torres Strait Islander children with disabilities are not being diagnosed.

Without a diagnosis there's no access to support and resources.

Without the extra help they need, students with disabilities miss out on a quality education. children with hearing problems, too. A child with a suspected disability can be in primary school before an official diagnosis is made, says Cass Brown, a teacher at Ski Beach, near Nhulunbuy on the Northern Territory's Gove Peninsula.

"I've worked as a preschool teacher and, even though we're not psychologists, we pick up things and we have to note things down," says Brown. "We call in our specialist teacher and do the paperwork - it just seems never-ending. [We need to do that] before we can get to a paediatrician and have that conversation with the parents.

"We find that, if you start in early January in preschool, they probably aren't going to get assistance until they get into the primary school setting. By then you've missed almost two, or even three years, of having assistance for that student."

The delay has significant implications. "It means the child is withdrawn most of the time," says Brown. "They don't have access to good-quality education. Instead of dealing with the issue of the child having the disability, we look at it as a behaviour issue.

"Our struggle in Ski Beach is because we're remote and don't have the resources the cities have. The parents can't just take the child to a paediatrician, and when one does come they're booked up in advance."

In the relatively large township of Nhulunbuy a paediatrician flies

in every two weeks. "But you're not going to get that opportunity out in a remote community," says Brown.

An undiagnosed disability can contribute to "double discrimination" if it's a factor in the expulsion or suspension of a student, says Avery.

"We've heard of things like kids getting suspended for not turning up for school. I can't get my head around that. Is it because they have a disability and they're just not engaging with the practice?

"That's one of the things that bothers me about blanket measures like attendance. We need to be smarter, more nuanced, in understanding some of these factors."

#### **Alcohol-related disorder**

Foetal alcohol spectrum disorder (FASD) can also go undetected. An affected child might be quiet and withdrawn or very violent, because its spectrum is so wide-ranging, says Melanie Baldwin, women's officer at the AEU's NT branch.

"With something like FASD, literacy levels will remain very, very low because they don't have the capacity to retain information," she says.

Teachers who are less aware of how FASD impacts on children may treat it as a behavioural issue. "We're aware of it because we live it," says Brown. "But if someone else has just come up from the southern states, it's not as talked about down there."

The lack of a diagnostic tool is a significant barrier to getting FASD diagnosed. "The science is way behind," says Avery. "The tool is still in the developmental stage and not ready to be rolled out, but everyone in the community knows about FASD." They



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Cass Brown Teacher at Ski Beach in Northern Territory might not use that term, but they can see children with behaviours that affect learning.

There is an assessment tool for hearing, he adds, "but they can't get the assessments done to the level that's needed".

Baldwin says teachers now face a higher level of high-needs and specialneeds children in their classrooms as a result of services being cut and the impact of a "massive drinking culture" that has developed in the past 30 years.

It requires teachers to draw on all their skills to cater to individual children's needs, she says. "Our schools have done a lot of work on FASD and teachers now know there's only so much we can do. We try to do a lot of visual learning. Teachers pull out all the tools they have in their kit."

This goes beyond the classroom, to the sensitive conversations teachers have with parents. Some parents find it hard to acknowledge their child has a disability, says Brown. In one case she had to have five conversations with a mother before she would admit there was an issue that needed addressing.

"That's a skill we have to learn. How do we do this without the parent feeling that you could be picking on their child."

Having a qualified special-needs teacher can help, but they can be difficult to attract and retain. A school in the NT's Barkly region has been trying to recruit one for eight months, says Baldwin, adding that it made a huge difference when a qualified person was in the role. "She knew about networks she was able to get working and she insisted that specialists come. She also sat down with teachers on a weekly basis and supported them in modifying

# It's really about kids having different learning needs, and we need to accommodate that.



Scott Avery
Policy and research director at First
Peoples Disability Network Australia

learning programs for the children."

A student with muscular dystrophy, who was in a wheelchair, was given daily help to improve her fine motor skills. Now she has to wait for fortnightly visits from a physiotherapist who travels from Alice Springs.

"Some of the extra daily routines the special education teacher put in place supported interpersonal, physical and emotional growth," says Baldwin. "That's now fallen back onto families and the above-and-beyond flexibility of classroom teachers."

#### **Conditional hitch**

Many funding structures depend on a child getting some form of diagnosis, which can have a flow-on effect. One child gets diagnosed and receives a certain level of funding, but the teacher intuitively knows there are other children who also need support.

"All the kids get some kind of support rather than it going only to those who've gone through the technical process," says Avery. "Our concern is that a smaller amount of funding gets apportioned among the bigger group."

Baldwin laments the overturning of the Gonski report's position on needs-based funding, noting that change is occurring where it has been implemented in South Australia and NSW.

Avery sees progress being made through Positive Partnerships' work in raising awareness of disability, which is delivered by a consortium known as Partnerships between Education and the Autism Community (PEAC). The government-funded organisation has developed resources, including a behaviour template and a general adjustments checklist, specifically for teachers and schools working with



Aboriginal and Torres Strait Islander students with autism.

Last year it launched a storytelling animation, Finding Out About Kevin, to help raise awareness of autism in Aboriginal and Torres Strait Islander communities. It was developed in conjunction with Jaki French, a Kamilaroi woman from Moree in NSW, who has a son with autism, and in partnership with Aboriginal and Torres Strait Islander communities throughout Australia. The animation, which is used at community get-togethers, has an accompanying resources pack and activity booklet.

Avery says the resources are also aimed at helping schools build an inclusive culture, which is vital to ensuring that children with disabilities have a good schooling experience. The Positive Partnerships resources kit has a whole-of-school audit called 'How inclusive is my school?, a storybook about difference called Djarmbi the Different Kookaburra and resource quide for teachers.

"They also have workshop training modules with strategies for inclusiveness in teaching practices," says Avery. "The teachers who do the training become the champions for their school, and it has a strong community flavour to it.

"You can count the number of days kids go to school, but quality of teaching is a hard thing [to quantify]. But that's what's making the difference."

Christine Long is a freelance writer.