



Speech block a parental nightmare

Children who have problems speaking their own language get little help from existing services, reports **Heather Stewart**

NATHAN Cole visibly shrinks when someone tries to have a conversation. He can hear perfectly and understands what's being said, but he finds it hard to formulate a response. Every attempt he makes is a struggle.

Cole's condition, a primary language disorder, makes life difficult for those it affects. Four years ago, when 13, he became the subject of teasing and bullying at his school. The incidents culminated in an attack in which he was held on the ground and a white substance was poured down his throat by classmates at his Brisbane state school.

"As Nathan got older the social gap with his peers became harder, and there was teasing and bullying," recalls his mother, Dianne. "That continued right through until about grade seven and eight when we had a very serious assault, where Nathan was injured and bruised."

Police were called. The white substance turned out to be citric acid, but Dianne felt she had no choice but to find somewhere else to school her son. The problem was where. Private schools she approached told her they didn't have the resources for someone with his condition.

However, he became one of the lucky ones. He found a place at The Glenleighden School in Brisbane's western suburbs — the only school catering for children with speech and language disorders in Australia.

They are known as "gap kids" because they fall between federal and state health and education departments. It's a term used to describe the 13 per cent of children who have difficulty using their native language.

A study last year of 14,000 students in a NSW Catholic diocese found communication disorders were the second highest learning disability. Speech Pathology Australia president Cori Williams says this highlights the need for improved access to, and funding for, speech pathology services. "There's a lot of dissatisfaction because funding levels aren't high enough to allow for a meaningful service," she says.

Brisbane developmental paediatrician Michael McDowell says life is hell for these children, who struggle with frustration and their inability to communicate. "Your brain's ability to manipulate the words and combinations of words is where the problem lies ... commonly people won't even notice a child has a language disorder," he says.

In infancy, symptoms include little or no babbling and few consonants. As children get a bit older, they are better at understanding language than at producing it. They have a slow, laboured or halting speech that is hard to understand.

But McDowell says children with developmental language delays are missing out on crucial care. He knows at least four paediatricians who are electing not to take the cases.

"I would hate to be a parent of a child with a language disorder at the moment, because the marketplace is so fragmented," McDowell says. "The people who do know what they're doing often have waiting lists up to two years long, or more — so if you've got a child and you're worried about them today, can you imagine having to put your name down and wait for more than a year? If you get seen and you want an intervention from the public system, the speech pathologist will say, 'We'll see you for six weeks, but that's all we can do because we're so booked out'. The response of the system to your needs just really isn't there, and it's just terrifying for parents — not only for now but looking into the future."

McDowell says doctors don't have the skills

to handle children with specific language disorders — the problem takes them too long to manage and they consider it unviable to take on the cases.

"I see a child with asthma, it's usually quite straightforward and it feels successful, but to sort out and help a child with a child with a developmental disorder like a language problem, it's hard work," he says. "They don't have the support of the resources and paediatricians now are just voting with their feet. "I know of a number in Queensland that have said 'We just don't do this any more, it's too hard, we don't get paid enough, we don't like doing it, we're just not going to see these kids any more'."

Like Dianne Cole, doctor Bev Rowbotham counts herself as one of the lucky ones. Her 15-year-old son Daniel also attends Glenleighden. But the school only has places for 70 children, and families move from across Australia and south-east Asia to attend.

"It's a drop in the bucket," says Rowbotham, a leading Brisbane haematologist, who admits to what she terms "survivor's guilt" because she believes Daniel is getting the best help there is. But she says arriving at a diagnosis was difficult.

"He had this strange disorder nobody could put a name to, and nobody could give you a forward plan on, and so you just wallowed — and with that comes tremendous anxiety because you imagine the worst," she says. "I think the key thing is it's a very difficult disorder to understand, as you cannot conceive the child can't converse with their native language.

"You can understand a child is deaf and can't hear, is blind, or can't see, but this is a leap. They can be looking at you, apparently hearing you, but don't understand what you've just said to them — and I think that's the fundamental issue. It's too strange, it's not something we've can wrap our minds around."

Associate professor Kate Taylor is heading



a decade-long study into specific language disorders in Western Australia. She says these children require daily early intervention with speech and occupational therapy, physiotherapy and psychology.

“There’s been a common belief that children with early language delay will grow out of their difficulties, but we know this isn’t the case and children who start off late to talk continue to have difficulties with language development over time right through adolescence and adulthood,” she says.

She is recommending preschool screening and toddler screening so help can begin early. But school students are lucky to receive a diagnosis, or even see a speech pathologist.

UK professor Dorothy Bishop says it’s disturbing that Australia is three decades behind in helping children with primary language disorders. “It doesn’t look very favourable, and I was really quite surprised that was the case,” she says.

A United States study concludes it costs between \$US150 billion and \$US180 billion a year to support people with communication difficulties. It found appropriate early intervention specific to a child’s needs could result

in a substantial saving to the community.

Australia has no comparative study.

Melbourne paediatric speech pathologist professor Sheena Reilly says Australia will bear the brunt if deficiencies in service provisions are not met.

“The long-term consequences of not intervening early with these children are really dire,” she says. “That’s without going into the issues around delinquency and our prison population, where people with language disorders are over-represented.”

Glenleighden’s principal Vikki Rose Graydon says within just one year at the school, some students start to speak in sentences. While cautious about outcomes, she believes the whole-of-school approach is working.

“I believe we can make a difference, and ultimately it is about them believing in themselves, and that they have a future and the same opportunities to the same sorts of things we take for granted,” she says.

“If we can provide that opportunity for a handful of kids then it has made it worthwhile. The reality is there is a lot more than a handful out there.”



One of the lucky few: Speech pathologist Annalee Aleligay works with Daniel Tomlinson at Glenleighden School, Brisbane
Picture: Lyndon Mechielsen