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tumbleweed - 1

No help, no guidance for increasing number of children diagnosed with brain-based disabilities

“Tumbleweed” support and funding landscape is “failing young Kiwis”

New Zealand is “decades behind” most First World countries when it comes to diagnosing, treating and supporting children with brain development disabilities, according to a charitable trust working in the field. Acorn Neurodiversity says a significant proportion of young Kiwis living with neurodivergence challenges are never diagnosed and that, for the small proportion that are, there is nearly a two-year gap in some parts of the country between the time they are identified and the start of professional assessment.

The neglect continues even after these children are assessed as living with some form of neurodivergence such as autism or one of the two forms of ADHD. Parents are presented with a diagnosis and nothing more. There is no next step for them to follow, no funding available to help them take that step, no support at all from the health system, and very little help from an education system that is “woefully ill-prepared” to deal with the educational needs of these children.

“It’s like tumbleweed city,” said Acorn chief executive Tami Harris. “Parents are left looking at a completely desolated landscape; uncertain, unsupported and unclear. It’s horrific. It’s unbelievably backward, especially for a socially progressive country like New Zealand.”

Acorn says that more than one in 10 Kiwi children live with, and in many cases struggle unaided with, some form of neurodivergence.

“Sometimes, as in the case of the hyperactive/impulsive variant of ADHD, these children can be reasonably easily identified,” Ms Harris said. “But they’re just the tip of the iceberg. I can guarantee that in any classroom, anywhere in New Zealand, there are at least a couple of children who live with some other form of learning difference or disability like the inattentive form of ADHD, dyslexia or autism.”

Intensive learning, occupational, speech and behavioural therapy are all services that neurodiverse children need, yet very little of this is available or funded through the health system.

The Ministry of Education’s Ongoing Resource Scheme (ORS) does offer some funding to help schools cover the cost of limited educational support for neurodiverse children. But the eligibility thresholds are set so high that only one in every 10 children needing support receive it.

“The burden then falls on individual schools to scrounge for funding for teacher aides and resources,” Ms Harris said. “This is a massive disincentive for schools to be inclusive.”

Barriers between the relevant government departments of health, education and disability are a significant factor hampering effective care for neurodiverse children in New Zealand, Acorn says. Each becomes a silo rather than working together to create a seamless support network.

“One parent told us that she has a small amount of funding from the Ministry of Health which might be enough to fund another hour of teacher aide time to enable her child to attend school for another hour a week,” Ms Harris said. “But she isn’t allowed to use it for that although the money can be used for a carer to take her child for a meal after school, a service she doesn’t need.”

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Acorn says that following assessment, only relatively few families are able to spend the time and money tracking down and accessing the resources and expertise that their newly-diagnosed neurodivergent children need in order to succeed at school, employment and life.

“So, in the end, only a small proportion of a small proportion get the diagnosis, care and attention they need. This compares dreadfully to countries we like to measure ourselves against not only in North America and Western Europe, but elsewhere in the Asia-Pacific region too,” Ms Harris said.

“As a country we like to reassure ourselves on a fairly constant basis that we punch above our weight in various ways. But when it comes to caring for the more than 10 percent of our children who live with some form of neurodivergence, we barely even make it into the stadium, let alone the ring.”

International research repeatedly demonstrates the economic benefits to countries that invest in intensive early intervention. A study in the Netherlands and another in Australia have shown that \$100,000 invested in a child between the ages of 2-5 saves over \$1,000,000 over that child’s adulthood.

The spill-over benefits to society from early intervention include reduced economic burden through a decreased need for special education and long-term residential care, decreased involvement with the justice system and increased resilience and wellbeing in families.

Acorn is using Neurodiversity Celebration Week (18-24 March) to highlight its concerns around the neurodiversity support and funding gap. It is calling for corporate and philanthropic support to step in where government is falling short.

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About Acorn Neurodiversity

Acorn provides the international gold standard model of multidisciplinary support for neurodiverse children, filling a huge gap in service provision. It has grown from two professionals providing speech and language therapy to 22 professionals across two centres providing multidisciplinary services to children from all over Auckland in their homes, schools and Acorn centres.

Acorn is a team of advocates and experts dedicated to providing evidence-based support giving neurodiverse children the tools they need to reach their potential. It provides speech and language therapy, occupational therapy, behavioural therapy, and psychology services all in one place with coordinated care, giving every family a support team.

Originally started as a business, Acorn Autism was transformed into Acorn Charitable Trust in late 2021 to allow it to partner with community stakeholders to increase equitable access to support for more neurodiverse children.