

# Nāfanua

O galuega mamana ia ale Atua The holy works of God

Filiomanaia Levaopolo Laga'aia Dr Akata Galuvao

#### Acknowledgments

Malo le soifua ma le lagi e mama

*Nāfanua* is a Pacific resource that shares the stories of Pacific families with neurodiverse children, and enables schools to better understand the experiences and needs of neurodiverse learners.

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E moni lava, osi o tatou va'a e fau tele. la saga viia le Atua i mea uma.

Ma lou fa'aaloalo tele

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## Glossary

#### assistive technology

tools and technologies designed to support individuals who need it within their day-to-day tasks, for example, text-to-speech software for individuals who need support with reading and writing, noise-cancelling headphones for people sensitive to sound, or apps that help individuals with time management

#### diagnosis

the identification of a particular condition by examining the symptoms

#### holistic approach

a way to provide support that considers the whole of a person and includes everyone involved in their lives – parents, families, teachers, and communities

#### inclusion

the practice of ensuring that people of all abilities and backgrounds feel valued, respected, and supported

#### Individual Education Plans (IEPs)

a plan that outlines a child's educational needs and how those needs will be met

#### inequity

unfairness, favouritism, or bias that results in people not being treated fairly

#### Learning Support Coordinator (LSC)

a member of a school's teaching staff who manages the learning supports within a school

#### nonverbal

a word to describe a person who does not speak

#### **Ongoing Resourcing Scheme (ORS)**<sup>1</sup>

provides support for learners with the highest level of need if they meet ORS criteria – learners must have either have significant ongoing needs in learning, hearing, vision, physical, or communication; or they may have moderate to high needs across several areas

#### pathologised

to treat someone as abnormal

#### Resource Teachers: Learning and Behaviour (RTLB)

specialist teachers who provide learning and behaviour support to a number of schools

#### satellite class

a small, specialised class for learners with specific learning support needs

#### strength-based

focusing on a person's strengths and potential to overcome challenges

#### Support for inclusion funding<sup>2</sup>

it can be difficult to access funding supports, which means that neurodiverse support for inclusion is part of school operational funding that is designated to help schools support learners with learning support needs

<sup>1</sup> Your Way | Kia Roha. (2023). Support and funding for students with disabilities. https://www.yourwaykiaroha.nz/ learning-information/online-information-hub/connections-and-funding/support-and-funding-for-students-withdisabilities

<sup>2</sup> Ministry of Education. (2024). Support for inclusion funding. https://www.education.govt.nz/education-professionals/schools-year-0-13/funding-and-financials/operational-funding/support-inclusion-funding

## Foreword

A learner is neurodivergent if their mind works 'differently' from what society regards as normal.<sup>3</sup> According to medical research, the brain is different in every individual, and every brain processes information differently.<sup>4</sup> Many forms of neurodivergence are part of how the brain develops and functions. While these differences may go unrecognised or undiagnosed in childhood, that does not mean they are not there.<sup>5</sup>

#### THE CURRENT SITUATION IN AOTEAROA NEW ZEALAND

In Aotearoa New Zealand all learners, including neurodivergent learners, are catered for through a system of 'inclusive education', where teachers and other specialists integrate neurodivergent children into local classrooms as much as possible. This system utilises a range of supports and services including Resource Teachers: Learning and Behaviour (RTLB), the Ongoing Resourcing Scheme (ORS), and Support for inclusion funding, and other forms of support for communication and behaviour. A range of supports and services help neurodivergent learners with the most significant needs to access local education, with individualised support and specialist teachers when necessary. While in local classes, each neurodivergent learners is individually assessed and catered for.

Research into the experiences of neurodivergent individuals in Aotearoa New Zealand has found that the education system is failing many learners. The ongoing disconnect between what research says best supports neurodivergent learners and the actual support available is 'concerning'.<sup>6</sup> This can lead to significant pressure on schools and growing rates of burnout among teachers and support staff.<sup>7</sup>

The difficulty can be in accessing funding supports, which can mean that neurodivergent learners miss out on valuable resources. Parents often feel like they are left on their own and their feelings of hopelessness and despair can lead them to question the current approach to inclusion or local education in Aotearoa New Zealand.<sup>8</sup>

The research also found that some teachers lack knowledge and understanding about neurodivergent learners.<sup>9</sup> Many teachers are keenly aware of the gap between their desire to support neurodivergent learners and their ability to do so.

<sup>&</sup>lt;sup>3</sup> Hood, N. And Hume, R. (2024). The Illusion of Inclusion: The experiences of neurodivergent children and those supporting them in Aotearoa New Zealand's education system. The Education Hub. https://theeducationhub.org. nz/neurodiversity-research-report

<sup>&</sup>lt;sup>4</sup> Ako Aotearoa. (2025). What is neurodiversity and neurodivergence? https://ako.ac.nz/manako/manakoresources/what-is-neurodiversity

<sup>&</sup>lt;sup>5</sup> Resnick, A. (2023). What does it mean to be neurodivergent? Verywell Mind. https://www.verywellmind.com/ what-is-neurodivergence-and-what-does-it-mean-to-be-neurodivergent-5196627

<sup>&</sup>lt;sup>6</sup> Hood, N. and Hume, R. (2024).

<sup>&</sup>lt;sup>7</sup> Ministry of Health. (2024). Briefing: Overview on neurodiversity. https://www.health.govt.nz/system/ files/2024-08/h2024036865-briefing-overview-on-neurodiversity.pdf

<sup>&</sup>lt;sup>8</sup> Education Gazette. (2021). Evolution of learning support in Aotearoa. https://gazette.education.govt.nz/articles/ evolution-of-learning-support-in-aotearoa

<sup>&</sup>lt;sup>9</sup> Hood, N. and Hume, R. (2024).

This resource offers valuable insights and practical ideas to foster an inclusive supportive environment for Pacific neurodivergent learners. It focuses on Pacific children and their families. This resource may also provide useful information and strategies for non-Pacific neurodiverse learners. It is designed to empower teachers and families to work together to support neurodivergent learners<sup>10</sup> in school, at home, and in the community.

Every school in Aotearoa New Zealand is required to be safe, inclusive, and free from racism and discrimination for all learners.<sup>11</sup> To maintain these qualities, every learner, regardless of their diverse abilities, must have barrier-free and equitable access to quality education opportunities with high expectations and effective teaching and learning practices.<sup>12</sup> Equally important, learners and their families must be at the centre of learning where they feel safe and appreciated for who they are, including their culture, identities, and learning needs.<sup>13</sup>

#### HOW THE RESOURCE IS SET OUT

The subtitle 'O galuega mamana ia a le Atua' is a Samoan sentence that was chosen to challenge persistent deficit thinking that many Pacific peoples have about neurodivergent children. This includes cursed,<sup>14</sup> a sin,<sup>15</sup> sick, and disabled.<sup>16</sup> 'O galuega mamana ia a le Atua' translates to mean the 'holy works of God' and reminds us of our blessing. Each of us is unique, and our brains process information differently.

In this resource, parents spoke of their faith, the blessings they experienced, and the transformative shift in their beliefs – from traditional Pacific views that associated neurodiversity with sin, sickness, or disability, to a renewed understanding that their child was, in fact, a blessing.

- <sup>12</sup> Ministry of Education. (2007). High expectations principle. https://newzealandcurriculum.tahurangi.education. govt.nz/5637210590.p
- <sup>13</sup> Ministry of Education. (2007). Community engagement principle. https://newzealandcurriculum.tahurangi. education.govt.nz/community-engagement/5637168721.p
- <sup>14</sup> Nafatali, R. (2023). "E lē ma'i, o le malosi!" = (He's not sick, he's strong!): Pacific parents' journey of raising autistic children in Aotearoa. Thesis. https://mro.massey.ac.nz/items/7beaf5ec-e2d0-4c73-8d81-9430a82c0334
- <sup>15</sup> Dyches, T., Wilder, L., Sudweeks, R., Obiakor, F., and Algozzine, B. (2004). Multicultural issues in autism. Journal of autism and developmental disorders. https://www.researchgate.net/publication/8543383\_Multicultural\_ lssues\_in\_Autism
- <sup>16</sup> Kokaua, J., Kolose-Pulefolau, B., Ruhe, T., Aldridge, F., Foliaki, S., Kokaua, L., Mapusua, T., Dacombe, J., Richards, R., Blakelock, R. and Bowden, N. (2024). Is parent education a factor in identifying autism/takiwātanga in an ethnic cohort of Pacific children in Aotearoa, New Zealand? https://journals.sagepub.com/doi/pdf/10.1177/13623613231217800

<sup>&</sup>lt;sup>10</sup> Dyson, C. (2024). Supporting neurodivergent students by developing the home-school partnership. The Education Hub. https://theeducationhub.org.nz/supporting-neurodivergent-students-by-developing-the-homeschool-partnership

<sup>&</sup>lt;sup>11</sup> Ministry of Education. (2007). Inclusion principle. https://newzealandcurriculum.tahurangi.education.govt.nz/ inclusion-principle/5637158087.p

This resource includes:

- » Information about neurodivergence
- » Pacific views and beliefs about neurodiverse learners
- » Family stories and testimonies
  - > Real-life experience from parents of neurodivergent children
  - > Insights into the challenges and successes they have faced
- » Ideas for schools and families
  - > Prompts to help teachers and parents reflect on their approaches
  - > Opportunities to consider the impact of their practices on neurodivergent learners

The ideas and activities in this resource are designed to be used by the families and teachers of neurodivergent children in a flexible way. There are also links to resources that parents and teachers can access for further support.

#### PARENT VOICE

This resource highlights three key areas from talanoa with parents of neurodiverse children.

- Parents highlight the need for teachers and other specialists working with neurodivergent learners to be well-equipped to cater for learners' diverse needs. This includes the appropriate knowledge, skills, patience, and empathy to provide support for learners and to have access to resources and external support systems.
- 2. Parents acknowledge they need to learn more about neurodiversity so they can become more confident and effective in their role as caregivers.
- 3. Pacific neurodivergent learners need a strong partnership with their teachers, parents, families, and communities to help them feel valued and supported to thrive in school and life.

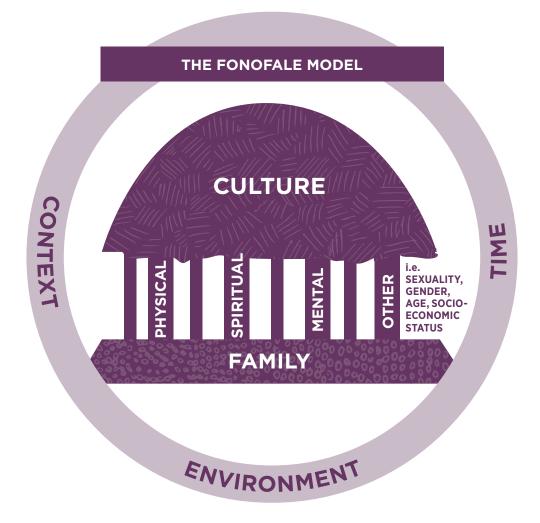
#### OUR ADOPTED FRAMEWORKS

The shared knowledge, ideas, and suggestions presented in this resource highlight the need to acknowledge our neurodivergent children as 'galuega mamana a le Atua', the mighty works of God. Although they are indeed different, they are our children and it is our duty as teachers, parents, families, and communities to understand and seek effective and inclusive ways to appreciate and cater for their diverse needs. To achieve this goal, two Pacific models were adopted as frameworks.

#### The Fonofale model

The Fonofale model was created by Fuimaono Karl Pulotu-Endemann (2009)<sup>17</sup> as a Pacific model of health in the Aotearoa New Zealand context. It incorporates values and beliefs such as family, culture, and spirituality, which are important to many Pacific people. In this resource, the Fonofale model guides and emphasises a holistic and inclusive support system for Pacific neurodivergent children.

#### Figure 1: The Fonofale model



Source: Pulotu-Endemann, 2009

<sup>&</sup>lt;sup>17</sup> Pulotu-Endemann, F. K. (2009). Fonofale model of health. [Workshop]. Health Promotion Forum of New Zealand conference, Wellington, New Zealand. https://d3n8a8pro7vhmx.cloudfront.net/actionpoint/pages/437/ attachments/original/1534408956/Fonofalemodelexplanation.pdf

The roof of the fale shelters our children's wellbeing and represents their Pacific cultural values and beliefs. Such beliefs include trusting and accepting both Western and Indigenous methods of learning and healing. As Pacific people in Aotearoa New Zealand, our constantly evolving and adaptive cultures also influence the decisions we make regarding our children's wellbeing.

The foundation of the fale is family. For neurodivergent children, family includes immediate and extended family, friends, neighbours, members of church communities, teachers, and education and medical specialists and the neurodivergent community.

Between the roof and the foundation are four pou (poles). The pou not only connect culture and beliefs with family, but are but are continuous and interactive with each other. The pou represent our **spiritual, physical, and mental strengths**, as well as **gender, sexual orientation, age, social class, employment**, and **educational status**. These all contribute to the holistic approach we need to care for neurodivergent children. The environment we live in – **time and context, politics**, and **socioeconomic status** are also acknowledged as influences in the Fonofale model.<sup>18</sup>

In this resource, Fonofale is demonstrated in the pursuit of ideas and suggestions to strengthen the relationship between families and schools and better cater for the needs of neurodivergent children. The ideas are flexible and can be adopted to suit a child's unique learning and health needs, as well as their own environment, time, and space.

#### Tofā'a'anolasi

Tofā'a'anolasi<sup>19</sup> is the identification of practices and systems from a Pacific perspective. It ensures that Pacific ways and funds of knowledge are considered valid in their own right. It involves Pacific collective vision and aspirations for the good of our Pacific community.

In this resource, Tofā'a'anolasi guides the process of identifying families' concerns and challenges as they experience neurodivergence from a first-person perspective. This approach highlights how the current system can lead to unintentional inequality for neurodivergent children in education, medical, and community settings.

Tofā'a'anolasi gives neurodivergent children and their families a 'voice' to collectively construct the knowledge necessary to navigate a way forward as 'galuega mamana a le Atua', the mighty works of God.

#### Talanoa

The methodology used in this project to gather family stories was Talanoa. Talanoa is rooted in Pacific cultures. It involves inclusive and participatory dialogue to explore authentic knowledge and perspectives. It is a way to create a space for sharing, analysing diverse viewpoints, and producing knowledge grounded in Pacific values like love, respect, humor, and warmth.

The talanoaga plays a crucial role in understanding the role of parents and families in how they support their neurodivergent children at home. During the talanoaga, ideas were shared about what worked, when, and why. Based on parents' responses, some questions were adjusted to gather detailed insights into possible reasons why some ideas and strategies did not work, and the possible 'where to next'. The talanoaga helped to facilitate the exchange of ideas and expertise to support participants in their roles as parents and supporters of neurodivergent children.

<sup>&</sup>lt;sup>18</sup> Open Polytechnic of New Zealand. (2025). The Fonofale model of health. https://www.openpolytechnic.ac.nz/ current-students/wellbeing/the-fonofale-model

<sup>&</sup>lt;sup>19</sup> Galuvao, A. (2016). Filimānaia: A Samoan critique of standardised reading assessment in New Zealand primary schools. https://openrepository.aut.ac.nz/items/5e560291-9599-439d-b443-d96edc83f80f

#### SEARCHING FOR A PACIFIC TRANSLATION FOR 'NEURODIVERGENCE'

Neurodivergence is a new term, and there is no Pacific translation for it. For this resource, a Pacific word is needed to explain neurodivergence to ensure Pacific are visible. The author, who is Samoan, researched academic and historic literature to put together and justify a Samoan word to translate the concept of neurodivergence.

According to Samoa's former Head of State, Tui Ātua Tupua Tamasese, living languages are shaped by their users to suit their needs. Language has an elastic quality that allows it to stretch with new demands. He affirmed that the Samoan language is growing and the coining of new words to capture new contexts or usages is encouraged.<sup>20</sup>

One Indigenous language example is 'takiwātanga', the Māori word for autism.<sup>21</sup> The word was coined by Keri Opai, a Māori linguist, educator, and author. 'Takiwātanga' was created based on his interpretation that people with autism tend to have their own timing, spacing, pacing, and life-rhythm. Takiwātanga is derived from the phrase tōku/tōna anō takiwā, which means 'in my/ his/her own time and space'. It is a relatively new term in Aotearoa New Zealand, and it was chosen to best convey the concept of autism from a Māori worldview.<sup>22</sup>

Neurodivergence is about the differences and unique ways in which our brains work, due to the presence of various neurodivergent traits. Some differences are obvious, hence the diagnosis, others are obscure and quietly hidden (nānā or nā). Some of us are aware of having these traits but choose to hide them. However, most of us are unaware of their existence, which means these traits are safely sheltered in our bodies, in our own personal space and 'fanua'. This understanding led the author to the story of Nāfanua, a Samoan warrior.

According to Samoan history, Savea Siuleo and Tilafaiga were a couple. One day, when Savea was out on a walk, Tilafaiga gave birth to a clot of blood, and to hide it she pushed it under a stone on their land (fanua). When Savea returned, he asked about it and she pointed out that 'it was hiding in the ground'. Savea became angry and asked her to call it. When Tilafaiga called, a little girl came out. They named the girl Nāfanua, which means 'hidden on the land'. Nāfanua grew up to be a formidable force who used her supernatural powers to defend her tribe, village, and family.<sup>23</sup>

Choosing 'Nāfanua' as a Samoan translation (representative for Pacific) for 'neurodivergence' highlights the differences that are mostly hidden (nānā) within our bodies (our fanua). As a title, it also encapsulates the meaning of this resource. It is about the journey to support our neurodivergent children. They may have been born different, but with a holistic approach that connects schools and families, neurodivergent children can succeed and be warriors in their own way, just like **Nāfanua**.

<sup>&</sup>lt;sup>20</sup> Tui Ātua, T. T. T. E. (2005). Clutter in indigenous knowledge, research and history: A Samoan perspective. https:// www.msd.govt.nz/about-msd-and-our-work/publications-resources/journals-and-magazines/social-policyjournal/spj25/clutter-in-indigenous-knowledge-25-pages61-69.html

<sup>&</sup>lt;sup>21</sup> Ministry of Education. (2023). Takiwātanga - in your own time and space. https://www.education.govt.nz/news/ takiwatanga-your-own-time-and-space

<sup>&</sup>lt;sup>22</sup> Bowden, N., Thabrew, H., Kokaua, J., Audas, R., Milne, B., Smiler, K., Stace, H., Taylor, B. and Gibb, S. (2020). Autism spectrum disorder/Takiwātanga: An Integrated Data Infrastructure-based approach to autism spectrum disorder research in New Zealand. https://pmc.ncbi.nlm.nih.gov/articles/PMC7542998

<sup>&</sup>lt;sup>23</sup> Steubel, C., Kramer, A. and Herman, B. (2010). Tala o le vavau. Myths, legends and customs of old Samoa. Auckland, New Zealand: Pasifika Press.

# Section 1 What is neurodivergence?

### What is neurodivergence?

The term neurodiversity was first used in 1997 by an Australian sociologist, Judy Singer, to describe autism characteristics. The term is now used to describe the differences in how our brains develop and engage, which can affect how an individual learns, communicates, and behaves.<sup>24</sup> There is no 'correct' way for the brain to work. Instead of viewing differences in the brain as disorders, neurodiversity recognises the unique strengths and perspectives that neurodivergent individuals bring to society and the countless conditions included in neurodiversity.<sup>25</sup>

#### THE SPECTRUM OF NEURODIVERSITY

Figure 2: A representation of neurological diversity



Source: Living on the Spectrum<sup>26</sup>

<sup>&</sup>lt;sup>24</sup> Ministry of Health. (2024).

<sup>&</sup>lt;sup>25</sup> Miller, C. (2025). What is neurodiversity? Child Mind Institute. https://childmind.org/article/what-is-neurodiversity

<sup>&</sup>lt;sup>26</sup> Living on the Spectrum. (2022). https://www.livingonthespectrum.com/education/the-spectrum-ofneurodiversity

#### Definitions of neurodiverse conditions

#### Anxiety

a difference that causes excessive and uncontrollable fear or worry that can significantly impact a person's life

#### Attention Deficit Disorder (ADD)

a difference that makes it hard to focus and pay attention

#### Attention Deficit Hyperactivity Disorder (ADHD)<sup>27</sup>

a difference that makes it difficult to stay focused, be still, and control impulses

#### Autism

a difference that affects the way a person perceives the world, behaves, and interacts with others – includes what was previously called Asperger's syndrome

#### **Bipolar Disorder**<sup>28</sup>

a difference, also known as manicdepressive disorder, that involves extreme mood swings, from mania to depression

#### Depression

a difference that can cause low mood, loss of interest, withdrawal from activities, affecting a person's thoughts, behaviour, and sense of wellbeing

#### Dyspraxia (DCD)

a difference that affects a person's ability to coordinate their movements and learn new skills

#### Dyscalculia<sup>29</sup>

a difference that impacts on how people process mathematics

#### Dysgraphia<sup>30</sup>

a difference that makes it difficult to physically write words, and to organise and express thoughts in written form

#### Dyslexia<sup>31</sup>

a brain-based lifelong learning difference, characterised with reading and writing caused by impaired phonological processing

#### Epilepsy<sup>32</sup>

a difference that causes seizures

#### Intellectual disability

a lifelong difference that impacts on everyday learning and participation

#### **Mental health**

a person's state of wellbeing that affects how they think, feel, and act – especially when feeling stressed

#### **Obsessive Compulsive Disorder (OCD)**<sup>33</sup>

a difference that involves obsessive thoughts and compulsive repetitive behaviours

#### **Post-Traumatic Stress Disorder**

a difference that can develop after experiencing or witnessing a traumatic event

#### Social Anxiety Disorder (SAD)<sup>34</sup>

a difference that causes people to fear social situations and avoid them to prevent feeling embarrassed or humiliated

#### **Tourette Syndrome**<sup>35</sup>

a difference that involves the involuntary movements and vocalisations

- <sup>27</sup> Ministry of Education. Guide to ADHD and learning. https://inclusive.tki.org.nz/guides/adhd-and-learning
- <sup>28</sup> Mental Health Foundation of New Zealand. Bipolar disorder. https://mentalhealth.org.nz/conditions/condition/ bipolar-disorder
- <sup>29</sup> Tertiary Education Commission. Dyscalculia resources. https://www.tec.govt.nz/oritetanga-learner-success/neworitetanga-tertiary-success-for-everyone/resources-to-help-support-your-learners/neurodiversity-resources/ dyscalculia-resources
- <sup>30</sup> Dyslexia Support South. Specific learning difficulties and processing disorders. https://www. dyslexiasupportsouth.org.nz/school-toolkit/specific-learning-difficulties-and-processing-disorders
- <sup>31</sup> Ministry of Education. Understanding Dyslexia. https://inclusive.tki.org.nz/guides/dyslexia-and-learning/ understanding-dyslexia
- <sup>32</sup> Epilepsy New Zealand. About Epilepsy. https://epilepsy.org.nz/understanding-epilepsy/about-epilepsy
- <sup>33</sup> The Education Hub. An introduction to Obsessive Compulsive Disorder. http://theeducationhub.org.nz/anintroduction-to-obsessive-compulsive-disorder
- <sup>34</sup> Mental Health Foundation of New Zealand. Anxiety. https://mentalhealth.org.nz/conditions/condition/anxiety
- <sup>35</sup> Britannica. Learn about Tourette syndrome. https://www.britannica.com/video/overview-Tourettesyndrome/-218153

#### COMMON TRAITS OF NEURODIVERGENT CHILDREN

Some of the strengths we see in neurodivergent children <sup>36</sup>	Some of the challenges we see in neurodivergent children <sup>37</sup>
<ul> <li>» good at analysing, thinking critically, and problem-solving</li> <li>» creativity</li> <li>» identifying patterns</li> <li>» good at engaging with active learning strategies</li> <li>» empathy, intuition, honesty</li> <li>» great attention to detail</li> <li>» an ability to memorise</li> <li>» able to focus intently on a task or interest</li> </ul>	<ul> <li>» difficulty picking up social cues or communicating in social situations</li> <li>» problems with speech and language</li> <li>» sensitivity or insensitivity to external stimuli</li> <li>» physical tics or behaviours, such as rocking or excessive movement</li> <li>» difficulty paying attention or having poor memory</li> <li>» having high energy even when they should be tired</li> <li>» struggling with behaviour at school.</li> </ul>

#### AUTISM

This resource aims to support schools and families to understand, appreciate, and cater for neurodivergent children. Autism is a neurodiverse condition that was prevalent in the stories shared by families for this resource. In 2018, Statistics New Zealand concluded that 1.3% of all learners in Aotearoa New Zealand are autistic. Research has also found that autistic children are almost three times more likely to be stood down or suspended from school than other children.<sup>38</sup>

A 2024 study found that many New Zealanders with autism do not feel accepted by society, or by their colleagues.<sup>39</sup> Autisim is most often noticed by people when they see differences in personal appearance, behaviour, and language. Autistic children have active brains in terms of how they sense and react to situations. This may lead to sensory and emotional experiences that are overwhelming and painful. Children may then manage this by limiting themselves to a small range of secure behavioural routines<sup>40</sup> that can affect relationships with teachers and their peers.

Common traits of autism include but are not limited to:41

- » intense, narrowly-focused interests
- » difficulty interpreting and using nonverbal communication
- » a strong need for routines and predictability.

<sup>&</sup>lt;sup>36</sup> Ako Aotearoa. (2025).

<sup>&</sup>lt;sup>37</sup> Holmes, K. (2023). Is My Neurodivergence a Gift or a Curse? https://www.kdholmeslpc.com/en/blog/is-myneurodivergence-a-gift-or-a-curse

<sup>&</sup>lt;sup>38</sup> Crawshaw, M. (2022). Autistic students in NZ three times more likely to be stood down or suspended: new research. https://www.abetterstart.nz/2022/05/17/autistic-students-in-nz-three-times-more-likely-to-be-stooddown-or-suspended-new-research

<sup>&</sup>lt;sup>39</sup> Ingoe, M. (2024). 'We're often presumed to be incompetent' - only 1 in 5 autistic NZers feel accepted. RadioNZ. https://www.rnz.co.nz/news/national/512278/we-re-often-presumed-to-be-incompetent-only-1-in-5-autisticnzers-feel-accepted

<sup>&</sup>lt;sup>40</sup> Kéri, S. (2023). Autism and religion. https://pmc.ncbi.nlm.nih.gov/articles/PMC10453845/pdf/children-10-01417.pdf

<sup>&</sup>lt;sup>41</sup> Autism New Zealand. https://autismnz.org.nz/definitions

Figure 3: The three levels of autism and some specific traits and supportive ideas THE THREE LEVELS OF AUTISM **REQUIRING SUPPORT** » Trouble understanding and following social rules LEVEL 1 » Rigid or inflexible behavior » Some stress during transitions » May benefit from therapy or life skills coaching **REQUIRING SUBSTANTIAL SUPPORT** » Atypical social behavior, like walking away mid-conversation LEVEL 2 » High interest in specific topics Noticeable distress when faced with change May need school accommodations like reading help or social skills support **REQUIRING VERY SUBSTANTIAL SUPPORT** Severe communication deficits, such as being nonspeaking » Repetitive behaviors like rocking or spinning » Extreme distress when asked to switch tasks May need one-on-one time with an education assistant » and may use augmentative and alternative communication (AAC) tools, for example, picture symbols

Source: PsychCentral<sup>42</sup>

#### EARLY INTERVENTION FOR NEURODIVERGENT LEARNERS

Parents as carers for children are often the first to notice differences in their child's development. Health care providers and teachers also play a vital role in monitoring and supporting children's development. Parents and teachers can use the milestone charts (see Figure 4, 5, and 6) to note any significant delays in their child's development.

If parents are concerned about their childs development, it is important to discuss their observations with their family doctor and/or other health providers, and their early learning teachers. Prompt identification and intervention are crucial for children with developmental delays. Early support can improve longer term outcomes.

#### DEVELOPMENTAL MILESTONES AND DIAGNOSIS

To understand neurodivergence, a knowledge of developmental milestones and diagnosis can be helpful. These are the specific skills or abilities that most children can achieve at certain age ranges. They provide guidelines to track a child's development across various areas such as physical movement, language, cognitive skills, and social interaction.

The milestones are based on an understanding of what is expected as neurotypical and what is not neurotypical in a child's progression These developments are influenced by factors including the development of a child's nervous system, and their physical and social environment.

<sup>42</sup> Lovering, N. (2022). What are the three levels of autism? https://psychcentral.com/autism/levels-of-autism

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A diagnosis of developmental delay is made when a child significantly lags in reaching these expected milestones in one or more areas.

Figure 4: What we can expect and see in our children to show how well their speech and language skills are developing

AGE	MILESTONE TRICK	SPEECH/LANGUAGE	HEARING/UNDERSTANDING
3 months	3 letter word i.e. Coo	<ul> <li>» Coos and smiles</li> <li>» Cries differently for different needs</li> </ul>	<ul> <li>» Recognises your voice</li> <li>» May stay quiet/smile when spoken to</li> </ul>
6 months	6 letter word i.e. Babble	<ul> <li>» Babbles; laughs and giggles more</li> <li>» Vocalises excitement and displeasure</li> </ul>	<ul> <li>» Notices sounds, music, changes in tone of voice</li> <li>» Moves eyes towards sound</li> </ul>
9 months	9 letter word i.e. Imitation	<ul> <li>» Imitates speech/non-speech sounds</li> <li>» Babbles longer strings of sounds</li> </ul>	<ul> <li>» Imitates actions and gestures</li> <li>» Looks at objects when talked about</li> </ul>
12 months	1-2 words	<ul> <li>» 1-2 word vocabulary</li> <li>» Meaningful use of 'mama' and 'dada'</li> </ul>	<ul> <li>» Understands simple phrases</li> <li>» Recognises words for common items</li> </ul>
18 months	18 words	<ul> <li>» Vocabulary of 18 words (10-20 words)</li> <li>» Repeats words overheard in conversation</li> </ul>	<ul> <li>» Follows simple commands/ questions</li> <li>» Points to pictures/objects in book</li> </ul>
2 years	2 word phrases	<ul><li>» Uses 2 word phrases</li><li>» Vocabulary of 50 words or more</li></ul>	<ul> <li>» Follows 2 step directions</li> <li>» Uses gestures during pretend play</li> </ul>
3 years	3 word phrases	<ul><li>» Uses 3 word phrases</li><li>» Vocabulary of 200 words or more</li></ul>	<ul> <li>» Understands spatial/time concepts</li> <li>» Understands pronouns/plurals</li> </ul>
4 years	4 or more word sentences	<ul><li>» Uses 4 or more word sentences</li><li>» Uses 4 or more sentences to tell a story</li></ul>	<ul> <li>» Understands how/why questions</li> <li>» Groups objectives; identifies colours</li> </ul>

#### **PEDIATRIC MILESTONES – SPEECH/LANGUAGE**

\*Milestones may occur sooner or later than shown

Source: EZmedlearning <sup>43</sup>

<sup>43</sup> EZmed. (2024). Speech and Language Pediatric Milestones.

Figure 5: What we can expect and see in our children to show how well their thinking skills are developing

#### **COGNITIVE DEVELOPMENT MILESTONES**

AGE 2	AGE 3
<ul> <li>» Repeats finger plays (Itsy Bitsy Spider, Wheels on the Bus) with words and actions</li> <li>» Can tell own age</li> <li>» Tries to use switches, knobs, or buttons on a toy</li> <li>» Plays with more than one toy at the same time, like putting toy food on a toy plate</li> <li>» Uses things to protond like faciliar a black</li> </ul>	<ul> <li>» Draws a circle, when you show how</li> <li>» Understands 'same' and 'different'</li> <li>» Matches objects that have the same function (fork and spoon)</li> <li>» Understands 'more' and 'less'</li> <li>» Sorts objects by colour and shape</li> </ul>
<ul> <li>» Uses things to pretend, like feeding a block to a doll as if it were food</li> <li>» Shows simple problem-solving skills, like standing</li> </ul>	AGE 4
on a small stool to reach something » Follows two-step instructions like "Put the toy down and close the door."	<ul><li>» Names a few colours of items</li><li>» Tells what comes next in a well-known story</li></ul>
» Shows he knows at least one colour, like pointing to a red crayon when you ask, "Which one is red?"	<ul> <li>» Draws a person with three or more body parts</li> <li>» Can copy own name</li> <li>» Distinguishes between real and make-believe</li> </ul>

Source: Early Childhood Center, Union R-XI School District<sup>44</sup>

Figure 6: What we can expect and see in our children to show how well their social skills are developing

#### SOCIAL-EMOTIONAL DEVELOPMENTAL MILESTONES

AGE 2	AGE 3	AGE 4
<ul> <li>» Notices when others are hurt or upset, like pausing or looking sad when someone is crying</li> <li>» Looks at your face to see how to react in a new situation</li> <li>» Plays next to other children and sometimes plays with them</li> <li>» Shows you what they do by saying, "Look at me!"</li> <li>» Follows simple routines when told, like helping to pick up toys when you say, "It's clean-up time"</li> </ul>	<ul> <li>» Calms down within 10 minutes after you leave her, like at a childcare drop off</li> <li>» Notices other children and joins them to play</li> <li>» Changes activities when requested</li> <li>» Repeats rhymes, dances, or songs for others</li> <li>» Shares</li> <li>» Shows concern for a crying friend</li> <li>» Plays make believe with dolls, animals, and people</li> </ul>	<ul> <li>» Pretends to be something else during play (teacher, superhero, dog)</li> <li>» Asks to go play with children if none are around, like "Can I play with Alex?"</li> <li>» Comforts others who are hurt or sad, like hugging a crying friend</li> <li>» Avoids danger, like not jumping from tall heights at the playground</li> <li>» Likes to be a "helper"</li> <li>» Changes behaviour based on where she is (place of worship, library, playground)</li> </ul>

Source: Early Childhood Center, Union R-XI School District<sup>45</sup>

<sup>&</sup>lt;sup>44</sup> Early Childhood Center - Union R-XI School District. (2025). Early Childhood Developmental Milestones. https:// www.unionrxi.org/o/ecc/page/developmental-milestones

<sup>&</sup>lt;sup>45</sup> Early Childhood Center - Union R-XI School District. (2025).

# Section 2 Neurodivergence

and Pacific families

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## **Neurodivergence and Pacific families**

Pacific people in Aotearoa New Zealand continue to experience longstanding and unacceptable health inequities.<sup>46</sup> Contributing to this inequity is a lack of information about Pacific experiences of neurodiversity, and their needs and outcomes.<sup>47</sup>

Fewer Pacific children are diagnosed with neurodivergence than non-Pacific children.<sup>48</sup> This suggests a systemic failure to support Pacific parents and communities to navigate the health and education systems. Obtaining a neurodivergent diagnosis for a child is a complex process, and a specific diagnosis is usually required to qualify for government support. In 2019, it took approximately three and a half years for children in Aotearoa New Zealand to receive their first neurodivergence diagnosis.<sup>49</sup>

Researchers found that Pacific children who had parents with higher levels of education were more likely to be diagnosed as neurodivergent.<sup>50</sup> Parents who have higher levels of health literacy are more likely to recognise signs of neurodiversity. They also face less barriers when accessing healthcare and other support systems.

Early support for neurodiverse children and their families is essential to their long-term success. However, access to this support often depends on receiving a formal diagnosis. To address inequities, especially for Pacific children, it is critical that the diagnostic process is both timely and accessible. Without appropriate support in place, neurodivergent children are at greater risk of experiencing academic challenges, social exclusion, and behavioural difficulties.

To support the needs of children who have not received a formal diagnosis, the Ministry of Education developed the *He Pikorua in Action<sup>57</sup>* approach. This approach focuses on responding to the individual needs of mokopuna, their whānau, educators, support teams, and communities. It promotes an inquiry-based model grounded in continuous reflection and improvement, ensuring that support is holistic and responsive regardless of whether a formal diagnosis is present.

<sup>&</sup>lt;sup>46</sup> Kokaua, J. et al. (2024).

<sup>&</sup>lt;sup>47</sup> Ministry of Health. (2024).

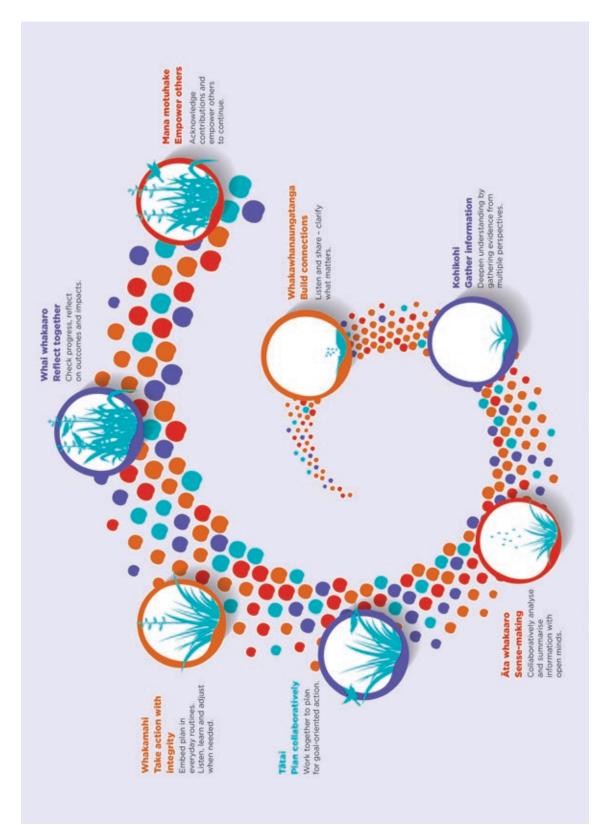
<sup>&</sup>lt;sup>48</sup> Kokaua, J. et al. (2024).

<sup>&</sup>lt;sup>49</sup> Kokaua, J. et al. (2024).

<sup>&</sup>lt;sup>50</sup> Eggleston, M., Thabrew, H., Frampton, C., Eggleston, K. and Hennig, S. (2019). Obtaining an autism spectrum disorder diagnosis and supports: New Zealand parents' experiences. https://www.sciencedirect.com/science/ article/pii/S1750946719300297

<sup>&</sup>lt;sup>51</sup> Ministry of Education. He Pikorua in action. https://hepikorua.education.govt.nz/he-pikorua





#### A GLIMPSE INTO PACIFIC VIEWS AND BELIEFS

#### **Cultural integrity**

Pacific families have their own cultures and ways of doing things at home and in their communities. In addition to traditional communal cultures, they have also adopted unique ways of living as they strive for successful lives in Aotearoa New Zealand. Those children who have a neurodivergent sibling also develop understanding, empathy, and acceptance of their sibling's diverse needs.

Pacific people are proud of 'who' and 'what' they are. This is seen in community gatherings such as birthdays, weddings, and funerals, when families demonstrate fa'aaloaloga (giving gifts such as money and food to show respect). Families and communities feel pride when children are successful in life.

However as children are also expected to be like 'everyone else in the community', difference is not seen as desirable. Instead of pride, families and communities may feel shame. These children can become the target of negative attitudes and labelling, such as ma'i (sick), fasia (to become sick with ghost sickness). This negativity is the reason some parents choose not to draw attention to their child's difference.

However, there are expectations of Pacific cultures that can be wrongly misinterpreted as neurodivergence, for example, looking down and avoiding eye contact during a face-to-face interaction is a sign of respect in Samoa, as well as a symptom of autism. A child who is playing independently in a corner during a large family gathering may be viewed as a 'good' child who is quiet while adults talk, rather than a marker of limited social engagement. A child who can recite scripts from their favourite TV show or movie may be perceived as clever, rather than displaying traits of verbal behaviour in autism.<sup>52</sup>

Pacific parents of neurodivergent children who are firm believers in their cultural and traditional beliefs may be more likely to accept a child's differences and not pursue a medical diagnosis. Others may choose to seek a medical diagnosis and external support for their child.

Parents of neurodivergent children hold expert knowledge about their child and the context of their family. As primary carers, mediators, and advocates for their child, they can inform schools about the support that is needed.

#### **Religion and neurodiversity**

Many Pacific people are Christians. This belief system means they live by the teachings in the Holy Bible. This is evident in the stories told by parents in the next section. They know that God created man in his own image.<sup>53</sup> According to 1 Corinthian 12, 22-26: 'The parts of the body that seem to be weaker are essential, and those that we think less worthy we give greater honour, and our unpresentable parts are treated with greater dignity, which our more presentable parts do not require. God composes the body, giving greater honour to the part that lacked it, that there may be no division in the body, but that the members may have the same care for one another. If one member suffers, all suffer together, if one member is honoured, all rejoice together.'<sup>54</sup> These Bible teachings emphasise supporting those who are 'different'.

For some neurodivergent people, religion can be beneficial as it is part of their family and community culture.<sup>55</sup> Religious communities can provide a sense of belonging, understanding, and support. Acceptance and inclusion within these communities can benefit neurodivergent children who may feel marginalised in other social settings.

To participate in religious rituals, a neurodiverse individual doesn't need to rely on processing nonverbal communication, such as reading facial emotions, intonation, expressive body posture, and gestures. Instead, taking part requires chanting together and a shared sense of rhythmic coordination. Through these spiritual experiences, neurodivergent children can experience social bonding.

However, religious settings often involve unspoken social norms, which can be challenging for some neurodivergent children. It is essential to approach the situation with sensitivity, respect, and an open mind.

Teachers and specialists working with Pacific children should accept and respect the diversity of religious beliefs and practices among families of neurodiverse children. Each family may have unique religious values and customs that influence their approach to classroom teaching. It is also important to support families in advocating for their child's needs within their religious community.

#### **Changing views on neurodiversity**

Pacific language and words to describe neurodiversity have often been very negative. Since the term is very new, many Pacific families are still struggling with the stigmatising labels. However, Pacific communities are becoming more appreciative of neurodivergence as understanding about it grows.<sup>56</sup> The Bible also supports Pacific parents who refer to their neurodivergent children as 'blessings'.<sup>57</sup> They argue that 'God loves us, and to think that God would put a 'curse' on a child, is wrong'.<sup>58</sup>

The changing views on neurodiversity among Pacific communities is heartening for learners, their families, and their schools who are who are working together to support neurodiverse learners.

<sup>&</sup>lt;sup>53</sup> BibleGateway. https://www.biblegateway.com/passage/?search=Genesis%201&version=NIV

<sup>&</sup>lt;sup>54</sup> ESV Bible. https://www.esv.org/1+Corinthians+12

<sup>&</sup>lt;sup>55</sup> Kéri, S. (2023).

<sup>&</sup>lt;sup>56</sup> Mila's Books. (2023). vAsifika - Our autism journeys. https://milasbooks.com/products/vasifika

<sup>&</sup>lt;sup>57</sup> Nafatali, R. (2023).

<sup>&</sup>lt;sup>58</sup> F. Luātua, personal communication, 20 December 2024.

Section 3 Families tell their stories llh.

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## Families tell their stories

These stories give voice to the families of Pacific neurodivergent learners. In this section, parents share their experiences of raising their children, who are now young people and young adults. All participant names are anonymous.

The families are from South Auckland in Aotearoa New Zealand. Their children are members of the Special Olympics Māngere Team. They range in age from 15 to 24 and in these stories the families talk about their experiences with doctors, schools, and government and support agencies.

As part of the Special Olympics Māngere Team, the neurodivergent athletes participate in sports such as ten pin bowling, basketball, bocce, and athletics. They compete in regional and national sporting events. Parents and family members, including the author of this book, support the team by volunteering as coaches and managers.

The families' membership of the Special Olympics Māngere Team provided the foundation for the talanoa relationship. The talanoa took place in their safest space, the family home. With permission, the talanoaga was recorded using a phone to preserve the wisdom and privileged knowledge shared. During the talanoa, families revealed the ordinary experiences, highlights, and challenges of having a neurodivergent child. These talanoa conversations also captured new knowledge and identified possibilities to address some of the challenges for Pacific families with neurodiverse children.<sup>59</sup>

#### SIX QUESTIONS WERE ASKED TO GUIDE THE CONVERSATIONS.

- 1. What is your understanding of neurodivergence and autism?
- 2. When and how did you find out about your child's condition?
- 3. What impact is this having on your family?
- 4. What ways and ideas are you using at home to support your child?
- 5. What support are you getting from the government, schools, and other agencies?
- 6. How is your child's neurodivergence 'a blessing'?

The stories are written in the way they were shared.

<sup>&</sup>lt;sup>59</sup> Tamasese, K. (2002). Honouring Samoan ways and understandings: Towards culturally appropriate mental health services. International Journal of Narrative Therapy & Community Work, 2002(2), 64-71.

#### SOGALU'S STORY

## 'Why would God curse my daughter? What did she do?'

Autism is a word from the doctor. They told us that. I do not know about it. Even up to now I still do not know that much. My family are saying 'e mai' e leaga le ulu' (bad head). There was a time when my wife suggested we take her to Samoa to a fofō (Samoan traditional doctor) to see if it is a ma'iaiku (ghost sickness). We do not have anyone in my family that is like this. So, we thought maybe she is fasia (to become sick with ghost sickness) from somewhere.



When my daughter was only two months old, we bought our house in Māngere. We bought it from a Samoan family. Their old mother died in the house. My children used to hear things in the house. Even my wife kept saying she could hear footsteps in the house after 11pm every night. So, we thought maybe my daughter was fasiaby bad spirits lingering in the house. My wife still thinks that my daughter's sickness may be a ma'iaiku. But with autism, I do not know.

When she was young, she used to hit her head on the floor whenever she got angry. I never thought it was a problem. We used to scream at her for always playing with the TV. She would turn it on and off and on and off. One day, she climbed through the window and jumped out and hit her head. We did not know she was sick until she went to school and her teachers said she was sick.

## SOGALU'S PARENTS WERE ABLE TO IDENTIFY SIGNS OF NEURODIVERGENCE, INCLUDING:

- » hitting her head on the floor when she is overwhelmed by feelings of anger
- » repetitive actions like turning the TV on and off
- » late development of communication skills.

My daughter's condition is making us very tired. My children are tired too. Sometimes they get angry. The meltdowns. They see it as their sister seeking attention and being spoiled. They do not like it. I do not think they see the difference between themselves and my autistic daughter. Attending to what she needs is very tiring. Sometimes she gets very violent. We got the doctors in. They advised us to take time off work to be with her when she is unhappy. So, I am always away from work, which is not good because we need the money. To support my child, the ways that work with our daughter, we listen to what she says. We do what she wants. We make sure she is safe. We keep her happy.

Is it a blessing. It is not a sin. It is not a curse. We go to church and believe in the love of God. If God loves us, why would he punish my daughter? What did she do so evilly that she deserved to be punished. She was born autistic. Did she commit a crime while inside that womb? If the sin is mine or her mother's, then why would God punish my daughter. Isn't that against what we believe in as the love of God? Labelling autism as a sin is against what we believe and have been taught from the Bible as the love of God. He will not make innocent children suffer. I know that. My last message for other parents who have children with autism is hold your child's hand. Make sure she is safe. The most important thing is her safety. No one can love your child as much as you. Just you.

#### FROM SOGALU'S STORY, WE CAN SEE THAT:

- » maintaining her safety is important
- » listening and hearing what she says is important
- » religious and cultural beliefs play an important part in how her parents support her
- » her parents' jobs and relationships with siblings are affected
- » her parents are tired
- » her parents need to know about autism
- » negative labels are used to explain and describe autism.

#### EPRISTEL'S STORY

## 'Please Mum, please help me.'

Epristel was born and grew up in the most difficult time of our lives, when his father and I had to take turns looking after him after work. I worked during the day, and his Dad, at night. Apart from being the handover child from one parent to the next, which started when he was just one month old, Epristel was raised and grew up just like his three older brothers. They ate the same food, drank the same water, slept in the same home, and followed the same routines. I noticed one thing though – he was very late to talk.



Epristel went to a pre-school in Māngere Central. The staff often complained about his 'weird behaviour'. I would always smile it off and took no notice of them at all. Then in 2005, there was a phone call from Special Education New Zealand, asking for a chance to talk about Epristel's best choice of school. Epristel was autistic. Our doctor had been communicating with Special Education about Epristel's autism without us, his parents, in the picture.

We chose a Samoan Bilingual Unit for our son. I thought he would get the best support from there, but he did not. The teachers asked to have him removed and put him into a school that would cater for his special needs. After a few months in Year 1, Epristel moved to Sir Keith Park school, where he spent the rest of his school years. During these years, I was a punctual but silent attendee in his IEP<sup>60</sup> meetings. Epristel has had support all his school life hence we did not need to have the urgency of being his advocate. However, Epristel grew up and reached the age when he 'had' to leave school. It was only then we had to step up to learn about our 'autistic Epristel'. We grew up in Samoa. There were three labels for those who were different – ma'i (sick), leaga le ulu (bad head), valea (dumb), which all meant the same – sick. There were no distinctions like here in New Zealand. It did not matter which conditions people had, they were all the same, they were 'sick'. So, autism is a very new and strange concept to me. The very strange language specialists and teachers used every time our son's condition was discussed did not help either. Hence the reason why I was always silent during IEP meetings.

I have had to learn about autism by living it. I know it involves extreme anger and meltdowns. There are holes punched into our walls to show autism. It involves running away from home in the middle of the night, attempting to commit suicide several times, and numerous phone calls to the police. It involves tireless walking and driving around the neighbourhood and even shamelessly calling others trying to locate his whereabouts. The numerous sick days we have had to take to cater for his autism. The tears, the worry about his safety, the growing patience and empathy.

When we finally got the support we desperately needed, I realised that autism also involves a lifetime of medication. It is a learning journey for us. We do not really know what may happen in the next few minutes or the next hour or day. However, now with the internet I would look up information and yes, I know now it is a mental disability. It is a mental disability that needs this strong partnership of me, my husband, and God.

## EPRISTEL'S PARENTS WERE ABLE TO IDENTIFY SIGNS OF NEURODIVERGENCE, INCLUDING:

- » late development of communication skills
- » repetitive behaviour and narrow interests
- » struggling outside of daily routines.

Our son's autism was not a problem when he was young. I am not so sure if it was due to the longer time he spent at school, from 8am when he got ready to 3:30pm when he got dropped off. By 9pm he was already asleep in bed. It became hard when he got older and had to leave school. That was when we began to see and experience the difficulties our son is living with. His brothers know about their brother's autism. They see the problems and try to help. But it is and has been mostly his Dad and I who have had to deal with autism. Sometimes I wonder what it is like to have a normal life, without autism. We, his parents, will never be free. We, the parents, are very tired.

To help my child, I keep the sentences short, clear and in simple language. I keep my voice calm and gentle. It works. My aim is to keep my son calm and reassured that I am here. The goal is to make sure he is safe. I watch his body language all the time. I listen to what he says. There are times when I cannot do what he asks and I have to think fast to work out what and where to next, to keep my son calm and happy. We try our best all the time to avoid a meltdown. Keeping to routines seems to work.

Our son gets a benefit. He also gets funding from other organisations such as Taikura Trust and Real World Living. These funds help pay for activities he attends such as PHAB Pasifika, gym, Recreate NZ, Special Olympics, and for his bus card. We have had people from some organisations helping to get him jobs. Vaka Tautua is the other group helping our son.

It is a blessing to know about a condition I never knew before. This condition is expecting me to be gentle, calm, patient, and empathetic. The condition itself is not a blessing, but to live it and to know how to succeed in this journey is a blessing.

My son needs me. Once, after another violent meltdown, I asked my son 'when you are angry, what do you want Mum to do?' He answered, 'Please Mum, please help me.' This often makes me wonder, if we are struggling to cope with this condition, I wonder what it is like living with it.

#### FROM EPRISTEL'S STORY, WE CAN SEE:

- » knowing about autism is a blessing
- » he gets ongoing support from various agencies
- » it helps to keep to routines and attend to what he needs
- » his parents had limited understanding of autism
- » caring for him maintains the strong partnership of his parents and God
- » his teachers were ill-equipped to cater for his needs
- » his parents were not told about the condition by doctors
- » there are negative labels of neurodivergence.

#### SIALEN'S STORY

### 'We see and feel the experience of our son. The blessing is living it.'

It was very hard in the beginning when my son was first diagnosed with autism. It was hard because we did not know what it was. They told us about this 'sickness'. They told us our child was sick. Trying to explain it to Mum and Dad was the hardest thing. They challenged me – they kept asking 'what is it?' It was hard for me to explain in our language. The word I used was 'faamai' (disease) because that was the only word I could come up with.



For me to understand autism was to understand what was involved. In the beginning, Sialen was nonverbal. He would point at everything. His words did not come out right – it was 'gibberish' language. Now he has come a long way. He is now able to verbalise his needs and wants. Autism in my experience is 'black and white'. My son cannot really understand what is there. He cannot really figure out things happening around them. But I believe my son is very much like everyone else. He has things he cannot understand. He experiences things he does not want to touch or even like. To me that's like everybody else. I cannot say he is different, he just needs to be explained about things differently.

Sialen used to hit himself when he was young. He used to scratch himself when he was excited or sad. He would scratch his ears and so I made him stop. I said, 'Son when you are happy clap'. I tried to get him away from hurting himself. I got him to change so now I see him clapping when he is excited.

## SIALEN'S PARENTS WERE ABLE TO IDENTIFY SIGNS OF NEURODIVERGENCE, INCLUDING:

- » late development of communication skills
- » repetitive behaviour and narrow interests.

My son's autism is hard. His autism is not a blessing. The blessing is seeing and experiencing it. The blessing is to be more hopeful and more active and get him through things he cannot go through. The blessing is living through it. We have to be creative. We see and feel the experiences of our son. People who don't have autistic children do not see and experience it. To see the other world is a blessing.

All my other children go through the same as us. They need to be careful with what they say and do. Sialen is the oldest. Even though we had other babies younger than him, we still had to be careful and pay more attention to him. In our culture, since he is the oldest, he is supposed to be responsible, but he cannot be. I explain this expectation to him in the best way I can. He knows he is the eldest, but we cannot take his autism away. My children do say that Sialen is spoiled. Yes, we do have a soft spot for him because of his condition. We can only experience what we experience, and we do not know what is going on in there. So, all the time we had to think of the best way to talk to our children because I do try my best to be equal to them and treat them equally. My second child is a girl. She now has to take on the responsibility of being the oldest because Sialen cannot. In the beginning when Sialen was younger, they gave me a course to attend. That is how I learnt all these things. I sat there listening and talking with others going through the same experience and now they are older, what do they get? Nothing.

Even trying to find a job is hard. They do not tell us anything. They keep saying no to a sickness benefit because he needs to go and work. What work is out there for him? How can I be sure that he is safe out there. What if he has a meltdown or a misunderstanding? Are they going to make sure my child is safe? I am worried. I know there are no places out there to help to keep him safe.

It was like that in school. There is no care at all. When there is a meltdown, they just call you to come pick him up. I have seen there is no caring. You would think that teachers would take care of these children knowing they have special needs, but no. They are supposed to be experienced. So, I guess unless the teachers have children with special needs themselves, then they would not know what the child and their parents are going through. There are people who work in schools who know and treat our children with love and respect and try to cater for their meltdowns. But most of the time, they just call their parents to come in.

When I get called in, I go in and talk to my son. I find that my son's explanations of the incidents are sometimes totally different from what the teachers say. I understand and know my son. Teachers think he does not understand what they are talking about. There have been incidents where teachers would speak very badly about my son in front of him. They think that our children do not know and understand what they are talking about. It is sad because I am not the one hearing it and living it, my son is. So, there is no support environment out there for us. Sialen is picky with food. We listen and respect that to help my son. We work hard and think ten times more to make sure my son is ok. We are taught about autism, but not about what to do and how to cater for their needs. It is like learning on the job.

We need government support or programmes to facilitate it for us and our children. They need to live their lives without worrying. The schools where they go should be more inclusive of them and their needs. They need to look at their systems. I cannot imagine other families who do not have a voice. The families are going through enough already. The schools and system are not helping. I often wonder about others, especially the nonverbal ones. My son is verbal. Others are not. How can they be heard? The school is not catering for their needs. It is very concerning. Parents do not need to be afraid to talk.

#### FROM SIALEN'S STORY, WE CAN SEE THAT:

- » there is negative labelling of autism
- » his school often called his parents to pick him up when he had a 'meltdown'
- » his parents are learning on the job
- » his family is affected
- » it's a blessing is to learn about autism
- » there is a lack of support from the government and agencies
- » his parents worry about safety at workplaces
- » his teachers are often ill-equipped to cater for his needs and safety at school
- » his parents notice similarities between being autistic and being non-autistic.

#### JAYKA AND RIVA'S STORY

## 'It has made me a better person.'

When the boys started at school, the main problem was we could not communicate. They could not communicate in a way that was clear to me. Now they are a little bit OK, although they still struggle to explain some things. At school I would go in to see them. I see how they learn. They were and are still different. At home the boys are always quiet. They keep to themselves most of the time. We rarely talk. I think the school environment helps them a lot. They open themselves up and communicate with others. Now they have some verbal skills. They did not have those when they were young.



At intermediate level we looked at a school that offered transport to pick them up from home and drop them off. That made things easier for us. At home they can do very minor chores. They are never physical problems for me. It is just their mental and speech. They struggle with that.

The biggest problem is the school never tells me anything. But I notice the sadness in my sons. There is a lot of bullying at school and the school is not doing anything to help and prevent it, which is worrying.

When Jayka was young he was able to read and count. But then we noticed him walking back and forth, back and forth and then he began to show severe difficulty in speaking. We took him to the clinic, and they told us the bad news. They told us he is delayed and he has autism. It was the same with his younger brother. They told me I was the carrier of the autism genes. I cried because I knew I did this to my sons. I passed it on to my sons.

## JAYKA AND RIVA'S FATHER WAS ABLE TO IDENTIFY SIGNS OF NEURODIVERGENCE, INCLUDING:

- » repetitive behaviour like walking back and forth multiple times
- » a delay in speech or not speaking at all.

My sons' autism is a blessing. It has made me a better person. I do not regret having my sons at all. I only wish I could have been better. As a single father it is very hard. I know I will not be around forever, and I worry. When I grew up my Dad was not there also. It was just my Mum. I raised the boys all by myself. I watched my mother do it all by herself so I know what to do. I also need to thank the school for their help.

Both boys have calm and happy strains. I know my sons. I know their body language. I know when something is wrong just by seeing their body language. They do not have to say anything. I know when things are not going well for them. I can tell.

We do get some support. However, it is very hard. My sons do not get the benefit. I do go to see the community link about support. They give forms to complete. I struggle to understand the language of those forms. I have the same problems with the doctors. It is hard to get through the system. There were times when we really needed support, but they make things hard for us, then we would just go without. Even the workers at the social welfare office can be mean and not willing to help. They are judgmental. They tell me to go to work. How can I when have two autistic boys to look after at home. They need me to be there for them.

#### FROM JAYKA AND RIVA'S STORY, WE CAN SEE THAT:

- » their father is aware of the boys' body language
- » their family is affected
- » autism is a blessing to the father
- » there is a lack of communication from the school
- » the boys are bullied at school
- » their father is proactive for their safety
- » their father struggles through the system to get support.

#### **MOSAM'S STORY**

### 'I am the chosen one.'

Mosam was born prematurely. He also suffered from a lack of oxygen. However, we did not find out until he started school that he was different. When he started school, they picked up that he was behind in his learning. His speech was not good at that time and he was a bit slow with a lot of things. He was always left behind in the class and that was why they picked it up when he started at school. Then they called me, and they told me there was no satellite class there and so we moved him up to Maungawhau Primary school in Mount Eden. He was put in a satellite class with a lot of teachers there to teach and spend



time with him and so that was how his learning started. When I found out I was really upset because you don't want your child to be like that. But then I accepted it. My husband never ever accepted it. Even when he knew that his son was behind, he never accepted it. He always blamed me that he was behind because I put him in a satellite class.

I was working at the time when Mosam was at school. He went to daycare and then to the babysitter and I did not have that much time to spend with him, but I tried my best to teach him things. I spent all my time on the weekend with him. I taught him the alphabet and 1 to 20 but Mosam could not pick it up. He cannot pick up on money. Money is the problem. If you give him a note, like \$10, he can see and recognise it. But if you give him coins like a dollar and two dollars and ask him to add, he will not know. He does not know how much change he gets after shopping using cash. Because of that he gets cheated quite a lot. One time I gave him and his younger brother \$50 and I was hoping the younger one would help, but no, he did not. He got his ticket, walked away and left Mosam to get the change. Mosam got his ticket and chips, and the shopkeeper did not give him any change at all. When Mosam used his card, he would swipe then call out his pin number. Now he has payWave and I have asked him to always ask for the receipt. He has a HOP card, and one time the driver got him to pay \$30 each way, instead of \$30 for both ways. So he paid a total of \$60. I complained and he was given back his \$30. Now we are having to take him shopping because of the many times others have been stealing from him. We need to be very careful. People can easily see that our children are different, and they steal from them.

Sometimes I worry so much that I cry. I think about what is going to happen if I die, what is going to happen to Mosam. His younger brother has been made his beneficiary, and the will has been set out so that the house is for both of them, and that as long as Mosam lives here, his brother will not sell it. As long as Mosam is living in this house, no one can sell it.

## MOSAM'S MOTHER WAS ABLE TO IDENTIFY SIGNS OF NEURODIVERGENCE, INCLUDING:

- » struggling with life experiences such as money management
- » falling behind at school
- » difficulties with communicating.

Mosam is very calm. He is quiet. He does as he is asked. I talk straight to him. If he does something wrong, I say 'Don't do that again ...' and he would apologise. The family likes him.

They say that they can care for him, but there is something about me. Being a mother, I see everything. I see what others cannot see.

He is very isolated. He likes to do his own thing. When we are all gathering and doing everything together, he always prefers to be isolated. He can judge people too. He sees, listens and watches what they say and do. He would walk away. He has a very good memory, and he reminds me of what to do.

He gets alternative carer support, but he does not want to go away with anyone. This is his space, and he feels safe here.

I am the chosen one. In our Bible it says only the chosen will have a child like this. God picks the mother to have this child. She is the chosen one. No, it is not a curse. We are the chosen ones to have these children. God knows and chooses me to be the mother for this child. In our culture people hide their children if they are different. They never show them. I am not ashamed. He is mine and I love my child. Love them, take care of them, and give them as much love as you can. Praise them for all the effort they put into living and life.

#### FROM MOSAM'S STORY, WE CAN SEE THAT:

- » there were complications at birth
- » there is support from the government
- » being different is seen as a blessing
- » it is important to love our children
- » people are stealing from him
- » there was no communication from the doctor
- » local schools were not prepared to cater for their needs
- » his family is affected
- » his family has already planned for his future.

#### WHAT THE FAMILY STORIES TELL US

- » Listen and hear what our children say.
- » Know our children, including body language.
- » Keep to routines and attend to needs and wants.
- » Religious and cultural beliefs are important.
- » Learn on the job.
- » Watch and notice the neurodivergent behaviours when the children are young. If concerned, talk to are noticed, talk to your child's teacher and family doctor.
- » Praise them for the effort they put into living life.
- » Prepare and plan for the future.
- » Seek help such as funding from the government and other agencies.
- » See the blessing in being parents of neurodivergent children.
- » Love them. If we are struggling to cope with the condition, we cannot imagine what living 'it' is like.

Section 4. Making a change for Pacific neurodivergent learners

# Making a change for Pacific neurodivergent learners

The family stories highlight the need for more information and support for Pacific neurodivergent children. In the stories, parents raise concerns about what happens at home, school, and in the community. This involves teachers, parents, specialists working with neurodivergent children, and members of the public. Parents also describe lapses in the government support systems that impact on the quality of help for neurodivergent children.

This section includes ideas and strategies to address the challenges identified by parents in the family stories. The ideas and strategies are guided by the Fonofale model, a Pacific approach that empowers holistic and strength-based relationships between neurodivergent children, their families, and their teachers.

#### SEVEN KEY THEMES IDENTIFIED IN THE FAMILY STORIES.

- » Communication from doctors and schools can be lacking.
- » Having a neurodivergent child has an overwhelming impact on families.
- » Parents often need to learn about neurodiversity.
- » The way neurodiversity is described is often detrimental.
- » Schools often struggle to meet the needs and safety of neurodivergent children.
- » Parents and families struggle with the system to get support.
- » Neurodivergent individuals are often taken advantage of.

This section includes a list of actions and reflective questions for schools and families to address each challenge. They are designed to be adapted for the unique physical, cultural, mental, and emotional environments that neurodivergent children live in.



## IMPROVING COMMUNICATION

Early identification of neurodiversity is vital. It allows for early intervention, which has been shown to significantly impact developmental outcomes and overall quality of life. By recognising and addressing neurodivergent traits early on, individuals can receive appropriate support that is tailored to their specific needs.<sup>61</sup>

Young children identified as neurodiverse need a consistent and supportive environment that involves regular and up-to-date communication between parents, teachers, and medical practitioners. Clear channels of communication ensure that everyone understands what is happening and what supports are needed. Support systems can then be set up to help them to thrive and contribute to their communities.

## WHAT TEACHERS AND SCHOOLS CAN DO

- » Support parents to gain access to information about neurodivergence and the range of support services available. Parents also need timely information about assessments, IEPs, and the resources that are available for their children.
- » Be sensitive to the cultural context of communication delivery. Being neurodivergent means different things in different cultures. It is important to understand what a child's neurodivergence means to a family in order to understand how you can best support them.
- » Provide information in parents' ethnic languages. Find out if families require a translator during meetings, and written information provided in their home language.
- » Share resources with parents to encourage meaningful conversations at home. Discussing these prompts can provide insights into a child's emotional world and strengthen parent-child relationships.
- » Prior to IEP meetings, provide families with written results of their children's assessment, and a contact person to explain the findings if needed.
- » During IEP meetings, encourage parents to voice their questions, concerns, and perspectives about their child's development and educational programme.

<sup>61</sup> Immersive Psychology Group. (2025).

- » Our neurodivergent children need us. Pay attention to their needs.
- » Make time to learn about specific traits of neurodivergence. If these traits become obvious in your child, make an appointment to see the doctor. Be proactive.
- » Make time to meet with the school if you are concerned about something. Teachers need parents to help as well. Share some strategies that work with children at home.<sup>62</sup>
- » Attend parent and teacher interview nights with a support person if needed. Have your questions ready. Take your child's report with you and be prepared to talk about it. Ask questions such as 'My child did well here, how can I help my child be better at other subjects as well?' and 'My child is dreaming of becoming a ... Can we please put a plan in place to help them get there?'
- » Find out how teachers prefer to communicate about different topics, for example, letting a teacher know about an absence might use a different communication channel than informing them about something that has happened at home.
- » Learn the skills to collaborate in IEP meetings. Do the proposed ideas work with your child's unique personal, family, cultural, religious, and neurodivergent circumstances? Some 'textbook' strategies do not always work. You are the parent who knows your child best. Be a proactive advocate.

For teachers and schools	For parents and families
<ul> <li>» Have I tried to make communication easy with parents?</li> <li>» Have I encouraged families to always</li> </ul>	» Have I talked to my child's teacher about a more accessible way to communicate?
ask if they need support? » Am I aware of families' ethnic and cultural beliefs about neurodivergence?	<ul> <li>» How prepared am I for the parent and teacher interviews?</li> <li>» Do I need help understanding the language of my child's report?</li> </ul>
» Have I sent out the information parents need for their child's IEP meeting?	» Do I need a support person during the IEP meetings?
» How well is the school communicating with parents about their child's education progress, wellbeing, and safety?	» Have I inquired about regular communication with teachers and doctors and why?

<sup>&</sup>lt;sup>62</sup> W. Arp, personal communication, 14 December 2024.



## SUPPORTING THE WELLBEING OF FAMILIES

Having a neurodivergent child is a challenge for any family. Prioritise self-care for all members of the family as living with neurodivergence is a lifelong journey.

#### WHAT TEACHERS CAN DO

- » Make information available to parents to ensure they have an active role in advocacy for their children's education. Explain that neurodiverse learners have different needs that need to be catered for in specific ways.
- » Provide relevant support when parents share concerns during meetings.
- » Be sensitive to family needs. Be attentive and work closely with parents to provide family support.
- » Share resources about neurodiversity with the learner and their family. Check whether the resources are available in Pacific languages.
- » Support siblings of neurodivergent learners who are often enrolled at the same school. They may experience more feelings of sadness and worry than other children, but also benefit from having a neurodivergent brother or sister.
- » Respond to questions from siblings about neurodivergence and be alert to the impact on the child's peer relationships. Let parents know if you have any concerns.
- » Set up sibling support groups to teach play skills, and provide information and peer group support.
  - » Kickstart each day with a prompt to foster a sense of community and selfreflection among siblings. This can help set a positive tone for the day and encourage openness and sharing.
  - » Use prompts as conversation starters in small groups to facilitate deeper discussions about feelings, experiences, and perspectives. This can help enhance empathy, listening skills, and social understanding among peers.
  - » Allocate time for siblings to write journals to allow them to privately explore their thoughts and feelings. This practice supports self-awareness and emotional expression in a safe, personal space.

- » Remind each other of the love and care your child needs. Remember they are the holy works of God, and you are indeed the chosen ones.<sup>63</sup> God gave them to you for a reason. Stay strong. Pray.
- » Get to know your child what they like and what causes pain and anger.
- » Learn to understand your child's body language and non-verbal communication.
- » When attending parent and teacher interviews at school, tell them about your concerns and ask for support with ideas to help you at home.
- » Make an appointment to see your family doctor. Ask about the support available to help you and your family to look after your child at home. It could also include a carer to look after your child<sup>64</sup> or programmes away from home where your child can meet others and make friends while you rest. These include Recreate NZ,<sup>65</sup> PHAB Pasifika,<sup>66</sup> and disabilityconnect.<sup>67</sup>
- » Visit your local Ministry of Social Development Office. They can provide different types of support for families.<sup>68</sup>
- » Connect with your friends, support network, church community, whānau and community trusts for support. Examples include Alofa Tunoa Trust,<sup>69</sup> Vaka Tautua, <sup>70</sup> Kaikaranga,<sup>71</sup> NukuOra,<sup>72</sup> and Special Olympics New Zealand.<sup>73</sup>
- » Look online for ideas to help at home.
- » Set up a comfortable place for your neurodivergent child when attending events such a church service. Provide necessities such as headphones.<sup>74</sup>

- <sup>66</sup> PHAB Pasifika https://www.phab.org.nz/pasifika-2
- <sup>67</sup> Disability connect Activities across Auckland. https://disabilityconnect.org.nz/activities-across-auckland-allages
- <sup>68</sup> Ministry of Social Development. Find out about Disability Support Services. https://www.msd.govt.nz/what-wecan-do/disability-services
- <sup>69</sup> Alofa Tunoa Trust. https://www.alofatunoatrust.com
- <sup>70</sup> Vaka Tautua. https://www.vakatautua.co.nz
- <sup>71</sup> Kaikaranga. https://kaikaranga.org.nz
- <sup>72</sup> Nukuora. Organisations and Support Services. https://www.nukuora.org.nz/assets/Documents/Support-and-Development/Info-on-Disability-Services-Support-2021.pdf
- <sup>73</sup> Special Olympics New Zealand. https://specialolympics.org.nz
- <sup>74</sup> Mila's Books. (2023).

<sup>&</sup>lt;sup>63</sup> Mosam's story

<sup>&</sup>lt;sup>64</sup> Disability Support Services. (2025). How to access carer support. https://www.disabilitysupport.govt.nz/carers/ what-is-carer-support

<sup>&</sup>lt;sup>65</sup> Recreate NZ. https://www.recreate.org.nz

- » Support your child when they're not coping.
  - » Make sure they are safe.
  - » Keep other people away.
  - » Remain calm and speak in a soft voice sudden movements or aggressive actions could be perceived as a threat.
  - » Give your child space and do not touch them, or depending on the child, give them a big hug.<sup>75</sup>
  - » Try to identify (or ask them to tell you) what situations have caused this and reduce or remove them from these situations.
  - » Teach your child calm-down routines, like deep breathing, clapping, or counting to 10.
  - » Help your child to name their feelings with a resource that uses pictures and words to help your child identify their emotions.
  - » Praise them for their behaviour when they calm down.
  - » Ask your child to tell you what they want and/or need you to do to help them.
- » Keep reminding each other, as a family, that if you are struggling to cope with the condition, imagine living it. Our children need us.

For teachers and schools	For parents and families
<ul> <li>» What other support can I give to families who need help?</li> <li>» How can I support the siblings of neurodivergent learners?</li> <li>» What other ideas and activities can I put in place to help learners and their families?</li> <li>» How am I making the classroom and the school safe for all learners?</li> <li>» How am I advocating for the unique needs of neurodivergent children?</li> </ul>	<ul> <li>» How well am I catering for the needs of other members of my family?</li> <li>» Have I communicated with the teachers about the impact of my child's condition on my family?</li> <li>» Have I considered all the support that I have access to, including counselling?</li> <li>» What else can I do to help my family enjoy and appreciate my child's neurodivergence?</li> <li>» How can my church community help me and my family?</li> </ul>

MAKING A CHANGE

## STRENGTHENING KNOWLEDGE AND CAPABILITY

Neurodiversity is about understanding that people's brains work in different ways, and we all experience the world in a different way. For parents of neurodivergent children, knowledge about their child's unique difference is important to provide the best support.

## WHAT TEACHERS AND SCHOOLS CAN DO

- » Participate in professional learning about neurodiversity, such as but not limited to the University of Auckland course 'Inclusive Practices for Neurodiversity (EDUC 759)'<sup>76</sup> and programmes offered by Ako Aotearoa.<sup>77</sup> Share new knowledge with the school community and parents of neurodivergent learners.
- » Organise information evenings to help parents learn about neurodivergence. Include academic research so that parents see the scientific explanations about neurodiversity, as well as practical techniques for teaching their children new skills and reducing behavioural challenges at home. These classes can also play an essential role in helping children transfer learning from school to home.
- » Support parents in their journey of caring for their neurodivergent children. Offer training in advocacy skills, including conflict resolution, to ensure they are well informed and to ease tensions that may arise in their interactions with specialists.
- » Seek parents' perspectives to actively help shape educational plans. A familycentred approach emphasises addressing the needs and desires of individual families, rather than providing predefined services.
- » Make connections with other organisations who support neurodivergent children to create an inclusive community for mutual support.

<sup>&</sup>lt;sup>76</sup> University of Auckland. EDUC 759 : Inclusive Practices for Neurodiversity. https://courseoutline.auckland.ac.nz/ dco/course/EDUC/759/1253

<sup>&</sup>lt;sup>77</sup> Ako Aotearoa. Professional learning. https://ako.ac.nz/professional-learning

- » Observe your children as they are growing up. If you have concerns about your child's development, approach the family doctor to ask questions.
- » Seek support from other parents with neurodivergent children. Join support groups and organisations, for example:
  - » MindfitNZ<sup>78</sup>
  - » Runway Foundation<sup>79</sup>
  - » Pasifika Autism Support Group<sup>80</sup>
  - » New Zealand Down Syndrome Support Group<sup>81</sup>
  - » Altogether Autism<sup>82</sup>
- » Search the internet for credible sources of information about neurodiversity.<sup>83</sup>
- » Contact your child's school to see what information and resources are available.
- Learn how to help your child, for example, give simple instructions, with no distractions. If they can, give your child time to talk and share their own stories. Try to remain calm when your child is not coping. They do not always know how to tell you what they need.

#### **Reflective questions**

For teachers and schools	For parents and families
<ul> <li>» How well do parents understand my explanation of neurodiversity?</li> <li>» Have I prepared leaflets in different languages to help parents understand neurodivergence?</li> <li>» How can I help parents access other support groups available in our area?</li> <li>» How can we make learning about neurodivergence easy and engaging for parents?</li> </ul>	<ul> <li>» What do I know about neurodiversity?</li> <li>» What are the traits of being neurodivergent?</li> <li>» Do I know how to best cater for the needs of my neurodivergent child?</li> <li>» How are my own cultural beliefs helping me understand neurodiversity?</li> <li>» How is my neurodivergent child different from others?</li> </ul>

- <sup>80</sup> Pasifika Autism Support Group. https://www.asdpasifika.org.nz
- <sup>81</sup> New Zealand Down Syndrome Association. https://nzdsa.org.nz
- <sup>82</sup> Altogether Autism Takiwātanga. https://www.altogetherautism.org.nz

<sup>83</sup> Resnick, A. (2023).

<sup>&</sup>lt;sup>78</sup> Mindfit NZ. https://www.mindfitnz.co.nz

<sup>&</sup>lt;sup>79</sup> ADHD New Zealand. (2025).

## **PROTECTING THE LEARNER**

Pacific people have different ideas and interpretations of neurodivergence depending on their life experience and beliefs. Educators and other professionals need to be aware that labelling neurodivergent children as 'vulnerable', 'at-risk', 'risky', 'violent', or 'delinquent' influences how these children are seen in the long-term. When children are framed this way, it sets them up for negative interactions with the services geared up to support them. It can lead to inspection, intrusion, and stigma for families attempting to access services.

## WHAT TEACHERS AND SCHOOLS CAN DO

- » Adapt assessment methodologies to suit the diverse needs of neurodiverse learners. Their success does not have to be defined by standardised assessments.
- » Be attentive to the needs of learners. Provide support, for example, reader-writers during exams.
- » Focus on what learners can do and build on this. Never set a limit on what they can do.<sup>84</sup> For example, provide examples of work that are not perfect (with no names). As a class, brainstorm ideas to make them better.
- » Share new research about neurodivergence with school communities, and describe it as difference not disability.<sup>85</sup> This may include speaking about neurodiversity at school assemblies or prizegiving. Information leaflets can be displayed on community noticeboards.

- » Make changes to accommodate your child's differences. Reshape what success looks like for your child. Learn about their differences and how they prefer to do things.<sup>86</sup>
- » Celebrate your child's achievements (big or small) with family and friends.
- » Build close relationships with communities. Learn, accept, and appreciate neurodivergence together.<sup>87</sup>
- » Reach out and join parent support groups to share the positive experiences of being families with neurodivergent children.
- » Remember that it is ok to be different, and what matters most in life is that things will happen when they happen.
- » Build and maintain a strong partnership between you as parents, families, communities, teachers, and medical professionals. Our children need us.
- » Ask for a chance to share information about neurodivergence at community events such as a church information evening. Others need to know that it is not a curse or a sin that our children are different. It is important for them to be able to help a neurodiverse child if the need arises.

<sup>&</sup>lt;sup>84</sup> Mila's Books. (2023).

<sup>&</sup>lt;sup>85</sup> The Neurodiversity in Education Project. https://www.neurodiversity.org.nz

<sup>&</sup>lt;sup>86</sup> Mila's Books. (2023).

<sup>&</sup>lt;sup>87</sup> Mila's Books. (2023).

For teachers and schools	For parents and families
<ul> <li>» What can I do to change others' views about neurodivergence?</li> <li>» How can I highlight the effect of negative labelling on neurodivergent learners and their families?</li> <li>» Have I adapted classroom ideas, strategies, and assessment methods to suit neurodivergent learners?</li> <li>» How am I building on my learners' strengths in class?</li> <li>» How am I helping my colleagues at work to promote positiveness about neurodivergence?</li> </ul>	<ul> <li>» Have I helped others in my community to understand my child's neurodivergence?</li> <li>» How well am I including my neurodivergent child in family events and meetings?</li> <li>» How can I spread important information about neurodivergence for others to understand and appreciate it?</li> <li>» What else can I do to empower my neurodivergent child to do well in school, at home, and in the community?</li> <li>» What else can I do to change family and community perspectives on neurodivergence?</li> </ul>

MAKING A CHANGE

## SUPPORTS FOR SCHOOLS

Funds are provided for schools to support learners with learning needs. This may include funds for additional staff, to purchase specialised equipment, and provide professional development for teachers.

#### **ONGOING RESOURCING SCHEME (ORS) FUNDING<sup>88</sup>**

The Ongoing Resourcing Scheme provides specialist support for learners with the highest levels of ongoing needs in learning, hearing, vision, physical, language use, and social communication. Applications for ORS funding can be made at any time for children who are age 4 years and 8 months or older. This funding is provided on top of the funding paid to schools for every learner in New Zealand. Learners eligible for the ORS funding continue to receive it as they change schools until they leave the school system.

ORS funding can help school provide services and support including:

- » specialists such as therapists, psychologists, and learning support advisors
- » teachers to provide specialist teaching support
- » a contribution to teacher aides to assist with the student's learning support.

The ORS funding application is completed by someone who is able to work with the parents, families, specialists, teachers, and who knows the neurodivergent learner well and understand their differences. This person is usually:

- » a registered early learning teacher, early intervention teacher, or key worker for a child
- » a class teacher, special education needs coordinator, or learning support coordinator.

#### **ROLE OF TEACHER AIDES**

Teacher aides assist teachers in a classroom by working with learners on a one-to-one basis, or in groups. Teacher aides support neurodivergent learners by:

- » working with them on a one-to-one basis, and in small groups, following a programme prepared by the teacher
- » helping with extra activities such as physical exercise or physiotherapy
- » meeting with teachers and parents to discuss their children's progress
- » helping teachers plan lessons for neurodivergent learners with learning support needs
- » helping learners learn English as a second language
- » giving medication to neurodivergent learners who need it
- » assisting learners with personal care such as toileting or eating.

To effectively cater for the needs of neurodivergent learners, teacher aides need to have knowledge of:

- » how to work with neurodivergent learners and their differences
- » the school curriculum and subject areas in which they work
- » different teaching methods and different teaching and learning styles
- » supporting social and emotional wellbeing

<sup>&</sup>lt;sup>88</sup> Ministry of Education. (2024). Overview of the Ongoing Resourcing Scheme. https://www.education.govt.nz/ school/student-support/special-education/ors

- » child learning and development
- » school rules, policies and procedures, including safety and emergency procedures
- » first aid.<sup>89</sup>

#### Limited ITE training focused on neurodiversity

Research has highlighted the impact of shortage of funding on the support available for neurodivergent learners. According to research, many schools have to raise additional funds, utilise their already insufficient operational funds, or ask parents to cover some of the costs for teacher aides and other specialist services. This shortage of funding can result in a lack of permanent teacher aides and specialists and a lack of professional development. This can lead to the implementation of cookie-cutter advice rather than individualised support for neurodivergent learners in schools.<sup>90</sup>

A teacher's knowledge of best practice for teaching neurodiverse learners is instrumental to the success of neurodivergent learners. This is strongly connected to a teacher's relationship with families. Teachers who view learning as a partnership between the school, family, and support services also see more positive outcomes for learners.<sup>91</sup>

#### WHAT TEACHERS AND SCHOOLS CAN DO

- » Adapt the curriculum, resources, and teaching method to suit the diverse needs of learners. This will allow learners to process information in a mode and at a pace that works for them. Include children's culture and interests in learning and topics.
- » Be creative in how to present information. Some learners learners may have trouble listening to you talking and moving at the same time, while others may be the opposite and tune out when you are talking while sitting still. Get to know learners and be aware of the neurological differences that may affect how they process information.
- » Use strategies when working with learners with specific cognitive needs related to information processing, memory, and organisation.
  - » Have a clear outline and learning objective for each lesson and communicate this to learners both verbally and visually.
  - » Review the learning objective and allow learners to evaluate their own progress at the end of each lesson.
  - » Provide shorter, fast-paced, and interactive learning activities for learners who are active in body and mind.
  - » Be flexible about the time allocated to complete a task for learners who require longer processing time or worry about getting things right.
  - » Use colour coding to organise information.
  - » Use blue and black markers to make text easier for learners to read.

<sup>&</sup>lt;sup>89</sup> Careers.govt.nz. Teacher aide. https://www.careers.govt.nz/jobs-database/education-and-social-sciences/ education/teacher-aide.

<sup>&</sup>lt;sup>90</sup> Hood N. and Hume, R. (2024).

<sup>&</sup>lt;sup>91</sup> Hood N. and Hume, R. (2024).

- MAKING A CHANGE FOR PACIFIC NEURODIVERGENT LEARNERS
- » Design the learning environment to support learners.
  - » Consider how assistive technology and the physical learning space can be used to support neurodiverse learners.
  - » Use tablets and computers to support learning. Learners can read a book on a device or in print. They can also listen to the book, with each word highlighted as it is being read, allowing learners to visually track what they are listening to.
  - » Create follow up activities to allow learners to test their comprehension and practice what they have just learnt.
  - » Use websites and apps to address diverse learning needs, for example, Education Perfect,<sup>92</sup> MANGAHIGH,<sup>93</sup> MyMaths,<sup>94</sup> Prototec,<sup>95</sup> and Kahoot.<sup>96</sup>
- » Set up instructions to teach children to participate independently in typical classroom routines such as hanging up a coat, sitting in a circle with a small group, moving from one area to another, getting materials, using them appropriately, putting them away, and lining up for outdoor time.
- » Scaffold teaching and learning so learners learn to carry out the classroom routine independently.
- » Use strategies to support learners who find social interaction challenging or who have specific emotional needs.
  - » Encourage and facilitate social interaction between learners.
  - » Allow learners who struggle with social interaction to choose who they sit with or engage with in group work.
  - » Implement a buddy system for learners who require prolonged social support.
  - » Provide opportunities for learners to practice appropriate social skills.
  - » Provide safe opportunities for learners to request help.
  - » Communicate clear expectations.
- » Be aware of signs that may indicate a learner is becoming overwhelmed and respond with reassurance and compassion.

<sup>&</sup>lt;sup>92</sup> Education Perfect. https://www.educationperfect.com

<sup>&</sup>lt;sup>93</sup> MANGAHIGH. https://www.mangahigh.com/en

<sup>&</sup>lt;sup>94</sup> MyMaths. https://www.mymaths.co.uk

<sup>&</sup>lt;sup>95</sup> Prototec Maths. https://learning.prototec.co.nz/maths

<sup>&</sup>lt;sup>96</sup> Kahoot. https://kahoot.com

- Support learners who are particularly sensitive to sensory information such as sound, sight, touch, taste, balance, and body awareness (temperature or pain). This includes learners who struggle to process information when there is either too much or not enough noise in the room.
  - » Create a quiet space or allow learners to wear headphones or earplugs while they work.
  - » Be aware of your own volume when speaking and the level of background noise in the environment.
  - » Ask children to turn around to see your mouth as you speak.97
  - » Provide movement breaks for learners who benefit from being physically active or find it hard to stay still for long periods of time.
- » Adapt the physical learning space to suit the needs of diverse learners.
  - » Arrange furniture to limit distractions such as windows or other learners.
  - » Colour code and label different areas of the classroom and match to resources intended for use in those areas.
  - » Provide options for learners to work in other locations when possible, such as the library, gym, or outside.
- » Change schedules, rearrange physical settings, or social groupings to fit learners.98
- » Help learners by identifying challenging behaviour and designing an intervention with them and their parents.
- » Notice when things are not going well for the learner. Ask about how to get them back to their safe and calm selves.<sup>99</sup>
- » Make time for professional learning about supporting neurodivergent learners.<sup>100</sup>

<sup>&</sup>lt;sup>97</sup> Mila's Books. (2023).

<sup>&</sup>lt;sup>98</sup> W. Arp, personal communication, 14 December 2024.

<sup>&</sup>lt;sup>99</sup> Mila's Books. (2023).

<sup>&</sup>lt;sup>100</sup> Ako Aotearoa. Neurodiversity workshops. https://ako.ac.nz/professional-learning/in-house-workshop/ neurodiversity/neurodiversity-workshops

- » Make an effort to learn about your child's difference. This can help you contribute to conversations with teachers.
- » Collaborate with the professionals who are working with your child by learning more about:
  - » the vocabulary of education
  - » the characteristics of your child's neurodivergence and how they relate to your child's educational needs
  - » how treatment techniques work
  - » how to disagree and resolve differences within a constructive atmosphere.
- » Make time to meet with the teachers to ensure that appropriate educational programmes are in place for your child.<sup>101</sup>
- » Be proactive. Make an appointment to see the school's senior leadership team and/ or SENCo or Learning Support Coordinator if needed. Insist that support, such as a reader-writer, is provided for your child.
- » Help your child practice the new skills they are learning at school. This can include simple tasks such as counting or talking about pictures after reading a book.<sup>102</sup>
- » Be your child's voice. You have the right to seek help from other agencies. Your child has the right as the customer in their school setting to be treated with dignity and respect.<sup>103</sup>

<sup>&</sup>lt;sup>101</sup> Ministry of Education. (2024). What to do if you are worried about your child's learning. https://www.education. govt.nz/parents-and-caregivers/early-learning/learning-support/what-do-if-you-are-worried-about-your-childslearning

<sup>&</sup>lt;sup>102</sup> W. Arp, personal communication, 14 December 2024.

<sup>&</sup>lt;sup>103</sup> Code of Health and Disability Services Consumers' Rights. https://www.hdc.org.nz/your-rights/about-the-code/ code-of-health-and-disability-services-consumers-rights

For teachers and schools	For parents and families
<ul> <li>» What can I do to change others' views about neurodivergence?</li> <li>» How can I highlight the effect of negative labelling on neurodivergent learners and their families?</li> <li>» Have I adapted classroom ideas, strategies, and assessment methods to suit neurodivergent learners?</li> <li>» How am I building on my learners' strengths in class?</li> <li>» How am I helping my colleagues at work to promote positiveness about neurodivergence?</li> </ul>	<ul> <li>» Have I asked my child about their learning and safety at school?</li> <li>» What can I do to help my child enjoy learning?</li> <li>» What are the main barriers for my child's learning?</li> <li>» What information do I need to know and learn before I attend the next IEP meeting?</li> <li>» How can I make sure my child is getting the best support at school?</li> </ul>

## NAVIGATING THE SYSTEM

Parents struggle to get support from the health, social welfare, and education systems. Applying for funding and other services can be a hard process to navigate. The language used (jargon and other terminology, as well as language barriers for second language learners) and the rigid application of rules and processes that often require high levels of English literacy skills can can be a barrier to accessing support for neurodivergent children.<sup>104</sup>

## WHAT TEACHERS AND SCHOOLS CAN DO

- » Be prompt with accurate reporting on learners' needs to help initiate the application process.
- » Provide parents with information about the sources of funding they are eligible for.
- » Help parents to navigate their way through the funding process and support them to fill out application forms if needed.
- » Provide parents with information about their child's rights and provide translators from school staff or the community if needed.
- » Teach 'how to stay safe at school, in the community, and at work' in class and in the evenings or weekends so families can attend.

- » Contact a support group for parents with neurodivergent children to ask about the easiest steps to take to access funding. You may be able to get in touch with a person who speaks the same language to help you.
- » Find out about the resources you can access for your child and family needs, for example, Disability Support Services.<sup>105</sup>
- » Connect with supporting groups within the community. For example Alofa Tunoa Trust.
- » Contact Work and Income to find out what support is available.<sup>106</sup> Some neurodiverse individuals are eligible for a benefit, for example the Child Disability Allowance.
  - » Contact Work and Income (phone 0800 559 009).
  - » Provide the requested information.
  - » Complete the application form. Ask Work and Income for a translator if needed.
  - » Ask your child's doctor or specialist to complete the medical certificate.
  - » Submit the application and medical certificate to your local Work and Income office.

<sup>&</sup>lt;sup>104</sup> Hood N. and Hume, R. (2024).

<sup>&</sup>lt;sup>105</sup> Disability Support Services. https://www.disabilitysupport.govt.nz/disabled-people/assessment-and-funding/ how-to-access-support

<sup>&</sup>lt;sup>106</sup> Work and Income. https://www.workandincome.govt.nz

- » Ask your child's school to help find available assistance and to fill out forms.
- » Contact your child's teacher or the school principal, police, or Oranga Tamariki if you feel your child is not safe at work or at school. Your child's safety is paramount.
- » Contact employment companies who specialise in helping neurodivergent individuals get into employment and stay safe in workplaces.<sup>107 108</sup>

For teachers and schools	For parents and families
<ul> <li>» How ready are we with our assessments and reporting systems for funding processes?</li> <li>» Have I prepared sufficient information in various ethnic languages about how to access the funding system?</li> </ul>	<ul> <li>» What other support am I able to get for my child?</li> <li>» Have I contacted a social worker to help me understand and fill in forms?</li> <li>» What can I do to make the system work easily for me?</li> </ul>
» Am I aware of the effect of the lack of support on my learners and their families?	» Is the difficulty in getting support from the system having an impact on the family?
» What else can our school do to help our learners' parents financially?	<ul> <li>Who else in the community can I ask for help to seek support from</li> </ul>
» Are learners aware of safety measures both in school, in the community and at workplaces?	the system?

#### MAKING A CHANGE P

#### PRIORITISING SAFETY AND WELLBEING

For some neurodivergent people, their local communities are the only space they feel safe in outside of their homes. However, their difference can make them an easy target for abuse. Abuse tends to take place in the service providers' own space, such as taxi drivers in their taxis and shopkeepers in their local businesses.<sup>109</sup> The abuse also takes place opportunistically when neurodivergent individuals are alone. This is especially distressing because they are trying to be independent – a life skill and goal they work hard to learn and achieve.

It is vital that teachers and families are aware and do their best to protect neurodivergent individuals and prevent abuse from occurring.

#### WHAT TEACHERS AND SCHOOLS CAN DO

- » Act as the point of contact and support for parents who may need help.
- » Provide community-based workshops for parents on how to support their children who may become victims of these crimes. Topics may include:
  - » guardianship or power of attorney to protect their interests
  - » consulting an attorney to understand the legal options available.
- » Teach learners 'how to stay safe' during class or school community workshops.
- » Teach neurodivergent learners the skills needed to handle money.
- » Teach them about the potential dangers of financial exploitation and how to identify red flags.
  - » Provide regular class sharing sessions to allow learners to talk openly about activities and feelings.
  - » Empower your learners to tell parents and teachers about any suspicious activity.

<sup>&</sup>lt;sup>109</sup> F, Luātua, personal communication, 27 December 2024.

- » Find ways to prevent others exploiting your child.
  - » Teach your child about money (If they can, identifying notes and coins, counting, adding, subtracting, how much change to expect, working out the best deals).
  - » Designate accounts with limited access.
  - » Closely monitor transactions (always ask for receipts).
  - » Teach your child about the potential risks of using cash and/or bank cards.
  - » Report any suspicious activity to authorities.
  - » Consider legal measures like guardianship or power of attorney.
  - » Act promptly if you suspect any wrongdoing.
- » Encourage your child to talk about incidents. Some children may decide to be silent because of:
  - » negative experiences resulting from past complaints being negated
  - » fear of retribution
  - » believing they deserve the abuse
  - » being accustomed to ill-treatment and abusive behaviours
  - » limited understanding and the inability to complain
  - » socially learned avoidance
  - » having to provide evidence.<sup>110</sup>
- » Teach your child strategies to protect their belongings and personal information.
- » Be proactive for their safety. Contact the police or the Health and Disability Commission<sup>111</sup> for further support.

<sup>&</sup>lt;sup>110</sup> Roguski, M. (2013). The Hidden Abuse of Disabled People Residing in the Community: An Exploratory Study. https://communityresearch.org.nz/wp-content/uploads/formidable/Final-Tairawhiti-Voice-report-18-June-2013.pdf

Code of Health and Disability Services Consumers' Rights. https://www.hdc.org.nz/your-rights/about-the-code/ code-of-health-and-disability-services-consumers-rights

For teachers and schools	For parents and families
<ul> <li>» Have I talked to other teachers and senior management about the parents' concern?</li> <li>» Are learners learning about money in class? What else can I do to help?</li> <li>» Am I encouraging learners enough to share about events in their lives?</li> <li>» Are learners learning about staying safe in the community?</li> <li>» What professional development is available to increase teacher knowledge about neurodiverse learners?</li> </ul>	<ul> <li>» Have I taught my child the skills to understand and handle money?</li> <li>» Have I talked to their teacher about my concern?</li> <li>» Have I set up their bank account to help keep their money safe?</li> <li>» Am I closely monitoring transactions and receipts?</li> <li>» Have I considered legal support for my child?</li> </ul>

Figure 8: Ideas to support neurodivergent children

#### LISTEN

People who are neurodivergent may feel misunderstood or left out. Be willing to listen to them. Let them know you hear them and respect them and their choices.

#### COMMUNICATE

Interact in ways that help them. Sometimes, neurodivergent people prefer written communication such as instant messaging, texting, or emails over a phone call or face-to-face conversation. Give them the time and tools they need to communicate.

#### AVOID VALUE-BASED 'LABEL'

Experts recommend against using the terms 'high-functioning' and 'low-functioning' to describe conditions like autism. They often assume a person's level of function based on how much they behave like someone who's neurotypical.

#### NO TWO NEURODIVERGENT PEOPLE ARE THE SAME

The personalities and preferences of neurodivergent people can be widely different, even when they have the same diagnosis.

#### DON'T ASSUME THAT ANYONE IS INCAPABLE OR UNINTELLIGENT

People who are intelligent often have differences and preferences that make them stand out and appear different.

#### TREAT EVERYONE WITH RESPECT

Provide others with accommodations that honour their dignity.

Source: Cleveland Clinic<sup>112</sup>

# Conclusion

Neurodiversity is a normal human brain variability. These variations include the 'usual' (neurotypical) and 'different' (neurodivergent) ways of processing and understanding the world. All these variations should be recognised, accepted, and celebrated as part of the broad spectrum of human diversity. They should not be pathologised or stigmatised as this can affect the ability of our children to do well in school and in life.

This resource is designed to help parents and teachers support Pacific neurodivergent children in school and at home. Using the Tofā'a'anolasi approach enables families to share their experiences in their own words. The family stories highlight both the joys and the challenges of being parents to neurodivergent children.

The parents acknowledge the privilege of learning about neurodiversity and sharing this knowledge with their communities. They know their children and celebrate their strengths.

The stories also highlight the challenge of difference. When compared to societal norms, neurodivergent children can be misunderstood, negatively labelled, and treated unfairly.

Parents also face challenges due to limited resourcing for health, education, and social services. They often struggle to access the support they need.

This resource is underpinned by the Fonofale model that proposes a holistic approach to supporting neurodiverse children. The ideas and strategies included in this resource are designed to encourage strong relationships between a neurodiverse child, their family and community, and their school. The ideas acknowledge children's Pacific cultures, beliefs, and experiences and look for ways to address the systemic and societal challenges identified in the family stories.

This resource is for our children, the holy works of God. They need us to be their advocates and support. It is also for us, their parents and teachers. If we can make our children's lives better, then it is all worth it.<sup>113</sup> O galuega mamana ia a le Atua.

# Support for families and schools

## ADHD NZ

https://www.adhd.org.nz

#### Alofa Tunoa Trust (Wellington based)

https://www.alofatunoatrust.com/ alofatunoatrust@gmail.com

## Altogether Autism | Takiwātanga

0800 273 463 https://www.altogetherautism.org.nz/ enquiries

#### disabilityconnect

09 6360351 https://disabilityconnect.org.nz

#### **Disability Support Services**

0800 566 601 https://www.disabilitysupport.govt.nz

#### Engage Aotearoa https://www.engagenz.co.nz

#### Explore: Hāpainga Ora

0800 605 001 https://explorewellbeing.org.nz/about

#### Health and Disability Commissioner

0800 112 233 https://www.hdc.org.nz/your-rights/aboutthe-code/code-of-health-and-disabilityservices-consumers-rights

#### Mental Health New Zealand

0800 543 354 Free text 4357 (HELP) https://mentalhealth.org.nz/help

#### New Zealand Downs Syndrome

#### Association

0800 693 724 https://nzdsa.org.nz

#### Pasifika Autism Support Group

https://www.asdpasifika.org.nz

#### PHAB Pasifika

09 4887490 https://www.phab.org.nz

#### RecreateNZ

09 6385364 https://www.recreate.org.nz/about

#### **Special Olympics New Zealand**

https://specialolympics.org.nz

#### Vaka Tautua

0800 825 282 https://www.vakatautua.co.nz

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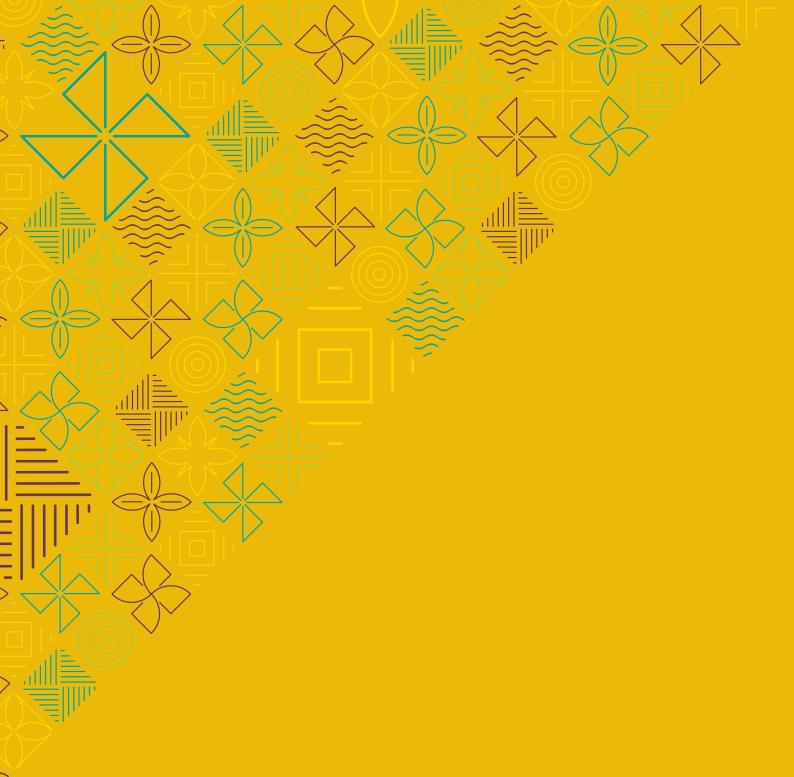
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# Other useful links

ADHD New Zealand. What is ADHD?

https://www.adhd.org.nz/navigating-adhd/what-is-adhd https://www.adhd.org.nz/ navigating-adhd/what-is-adhd

- Mayo Clinic. Understanding bipolar disorder. https://www.youtube.com/watch?v=tKvI0M0JA38
- Edutopia. Supporting with dysgraphia. https://www.youtube.com/watch?v=HPMaxsSJMwI
- Medical Centric. Dyslexia, causes, signs and symptoms, diagnosis and treatment. https://www.youtube.com/watch?v=UBImXpCHV-k
- Children's Hospital Colorado. What is epilepsy and how is it treated? https://www.youtube.com/watch?v=vlwvljpiS-A
- OCD-UK. OCD and me by Josh. https://www.youtube.com/watch?v=Fs4khDNe7FM
- Blue Cross Blue Shield of Michigan. What is social anxiety disorder? https://www.youtube.com/watch?v=87Vdj2vsJ4w





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