

How do we get autism support right in Aotearoa New Zealand?

Background and rationale

With international moves to establish national autism strategies and legislation (for example, [Australia's National Autism Strategy](#)), it is a good time to explore community support for a similar move in Aotearoa. Based on international approaches and current community engagement we aim to understand the importance of a national autism strategy and other forms of accountability to ensure inclusion and the provision of supports for autistic people in Aotearoa.

Autism, neurodiversity and neurodivergence

Neurodiversity: This refers to the range of different ways for human brains to function

Neurodivergent: An umbrella term for brains that process, learn or function differently than what is considered typical. There are many types of neurodivergence, including:

- Autism
- Attention deficit hyperactivity disorder (ADHD)
- Obsessive compulsive disorder (OCD)
- Borderline personality disorder (BPD)
- Dyslexia
- Dyspraxia
- Down syndrome
- Fetal alcohol spectrum disorder

There is a move for disability support to understand and take a neurodiversity-affirming approach to better meet the needs of these communities.

Māori perspectives

Kupu (word) Māori for autism:

Takiwātanga:

Meaning 'in my/their/his/her own space and time'

Kura urupare:

Meaning 'gift of the sensories'

Kupu Māori for neurodiversity:

Kanorau ā-roro:

kanorau = diversity, ā-roro = of the brain

Kanorau ā-io:

kanorau = diversity, ā-io = of the nerves

Te reo Māori (Māori language) and mātauranga Māori (Māori knowledge) shape how takiwātanga is understood, attitudes towards it, and how tāngata whaitakiwātanga Māori (Māori autistic people) and their whānau are supported.

Te Tiriti o Waitangi

It is essential for current and future approaches to autism support in Aotearoa to uphold the principles of Te Tiriti o Waitangi (The Treaty of Waitangi), the founding document of Aotearoa.

Autism supports need to be led by tāngata whaitakiwātanga Māori to uphold the significance of Te Reo Māori and Te Ao Māori principles.

Enabling Good Lives

Enabling Good Lives (EGL) is a new approach to supporting disabled people that offers greater choice and control over the supports they receive, so that they can “plan for the lives they want”. This includes a partnership between government agencies and the disability sector to provide funding to disabled people, which is currently available in some regions of New Zealand.

Legislation, standards, and policies

New Zealand Disability Strategy

The vision of the New Zealand Disability Strategy is: “New Zealand is a non-disabling society – a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen”.

Aotearoa takes a general approach to disability. Aotearoa has the newly created Whaikaha – Ministry for Disabled People (whaikaha.govt.nz).

Aotearoa also has a Minister for Disability Issues whose role is to advocate for disability issues and to establish and report on the New Zealand Disability Strategy (odi.govt.nz/about-us/our-minister).

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The UNCRPD is an international treaty which gives guidance on how to implement the rights of disabled people.

Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau (the Guideline)

The Guideline describes best practice on how to support autistic people in Aotearoa. It includes recommendations based on research evidence and good practice points.

International autism strategies and legislation

Worldwide, evidence suggests that autistic people experience poor educational outcomes, face unemployment at higher rates than other disabled people, and a large percentage experience suicidal thoughts or mental illness at some point in their lives. Internationally, it is recognised that general disability approaches have failed to improve services, support, and life outcomes for autistic people. To address this need, more than ten countries have a dedicated national autism strategy in place.

Evidence suggests that these strategies support positive outcomes including:



More **inclusive and effective education** for autistic people.



Increased **awareness and understanding of autism**.



An **autism responsive criminal justice system**.



Increased **autism employment outcomes**.



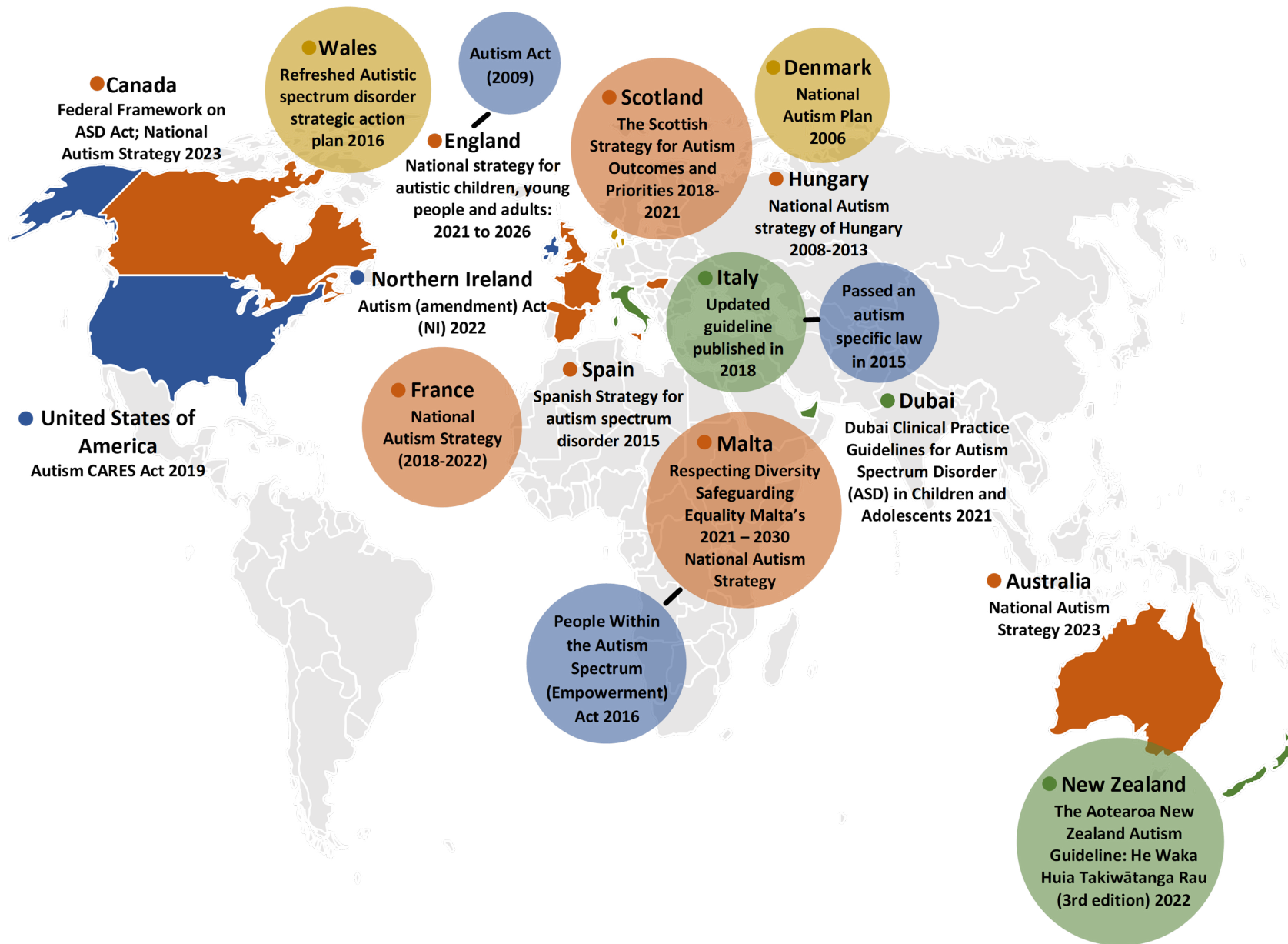
Autism responsive health and care services.



Long term cost savings due to reduced ongoing need from social, health and education support.



Improved access to **autism assessment and diagnosis**, which can improve wellbeing and community participation.



Aims

This project aimed to gain perspectives from autistic people, parents, professionals and family/whānau members to:

1. Understand the nature of existing supports for autistic people
2. Provide suggestions for future approaches to autism support.

Findings from the project include recommendations for implementation of the current Guideline as well other approaches.

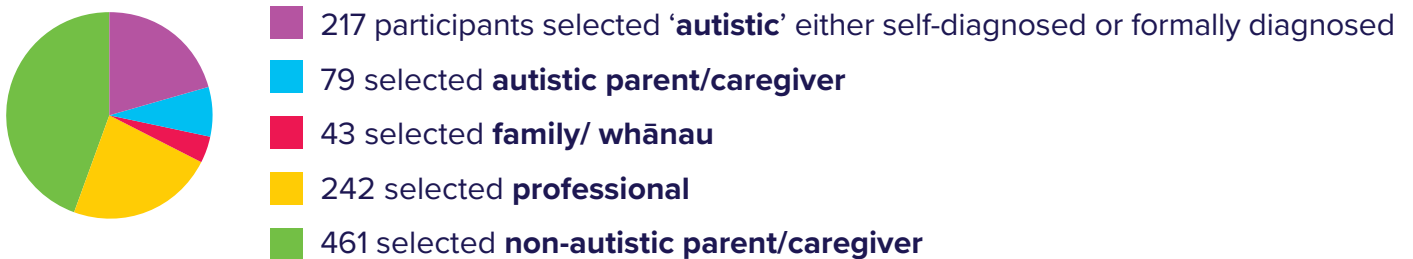
Findings

Who participated

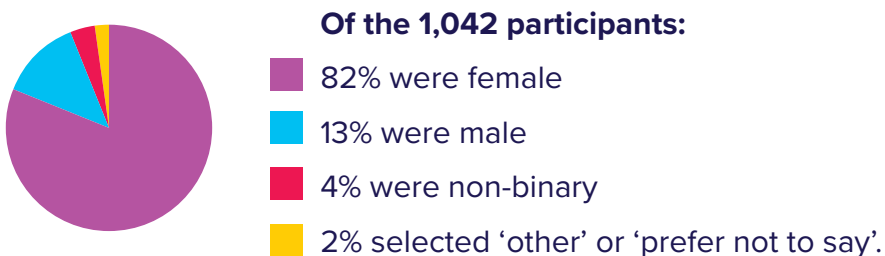
A total sample of 1,042 participants were included in the results.

Identities and roles

Participants were asked to select a primary identity/role.



Gender



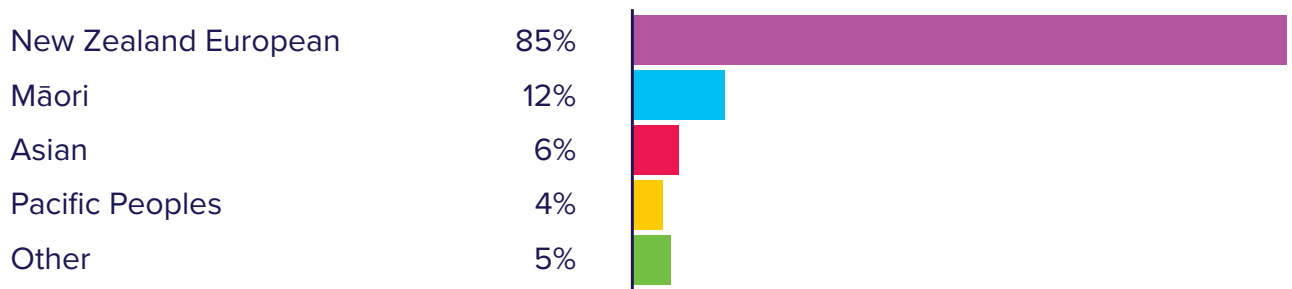
Age

Participant age ranges across groups:



Ethnicity

Participant ethnicity across groups:



How things are now

Understanding and acceptance

Most common ratings for understanding and acceptance:

Good



Mental health clinicians

Rated 'good' by 30% of participants



Family/whānau

Rated 'good' by 35% of participants



Disability support

Rated 'good' by 32% of participants



Friends/peers

Rated 'good' by 35% of participants



Needs Assessment and Service Coordination (NASC)

Rated 'good' by 31% of participants



Teacher aides

Rated 'good' by 31-34% of participants



Other therapists

Rated 'good' by 35% of participants



Specialist school support

Rated 'good' by 28-31% of participants



Colleagues

Rated 'good' by 30% of participants

Neutral



Individualised funding hosts

Rated 'neutral' by 33% of participants



Police

Rated 'neutral' by 36% of participants



General practitioners

Rated 'neutral' by 33% of participants



Employment support

Rated 'neutral' by 33% of participants



Other clinicians

Rated 'neutral' by 35% of participants



Pre-primary and tertiary teachers

Rated 'neutral' by 27-30% of participants



Accident compensation corporation (ACC)

Rated 'neutral' by 41% of participants



Pre-primary, secondary and tertiary educational leadership

Rated 'neutral' by 25-35% of participants



Employers/managers

Rated 'neutral' by 32% of participants



Oranga Tamariki

Rated 'neutral' by 32% of participants

Bad



General community

Rated 'bad' by 43% of participants



Work and Income (WINZ)

Rated 'bad' by 33% of participants



Primary and secondary school teachers

Rated 'bad' by 27-30% of participants



Legal system

Rated 'bad' by 40% of participants

Note: Tertiary specialist school support had equal "neutral" and "good" ratings (31% each), and primary school educational leadership had equal 'bad' and 'neutral' ratings (24% each).

- **Autistic people** rated the understanding and acceptance of some supports lower than other participant groups.
- **Non-autistic parents** rated the understanding and acceptance of some supports lower than professionals.
- **Māori** rated the understanding and acceptance of Oranga Tamariki significantly lower than non-Māori.

Comments: Knowledge and understanding



“It is the people who are willing to understand me as a person and work with me on the things I need that have been the most helpful. It’s not so much about their understanding of autism – it’s more about how willing they are to work with any patient as a unique individual.” – **Autistic adult**

Participants felt that there was limited understanding of the need for supports and accommodations for autistic people. Autistic people stated that some professionals did not understand communication differences.

Participants shared that most professionals had limited or out-of-date training and education on autism and generally did not understand the lived experience. They commented on the lack of understanding of masking and autistic adults mentioned that, due to masking, they were not believed when they were in pain or overwhelmed.

Autistic people were reported to be misdiagnosed with mental health conditions or personality disorders by professionals involved in assessment and diagnosis. Autistic adults and professionals indicated that few mental health professionals understood the interactions between mental health and autism and how to tailor support for autistic people.

Comments: Stereotyped understanding



“Many think of autism as Dustin Hoffman in Rain Man” – **Family/whānau member**

Participants across groups reported that many people have a stereotyped understanding of autism. This included a limited understanding of autism in females and a narrow view of how autism can present. They indicated that adults and children who did not align with these stereotypical understandings of autism were denied access to diagnostic assessment and/or accommodations and supports.

Comments: Acceptance



“[Medical staff] often say to me how sorry they are that my life must be so hard... My life and my kids are amazing” – **Autistic parent**

Autistic people and non-autistic parents identified general hesitancy from professionals to provide a diagnosis due to autism being a ‘negative label’. Participants felt that autistic people were expected to ‘fit in’ rather than receive accommodations. The identified consequences of choosing not to, or being unable to, mask included punishment, shaming, bullying, and loss of employment.

Across groups, autism was associated with feelings of loneliness and isolation for autistic people of all ages, and sometimes, their parents.

Overall experience of services

Most common ratings for overall experience

Neutral



Needs Assessment and Service Coordination (NASC)
Rated 'neutral' by 28% of participants



Support in tertiary education
Rated 'neutral' by 28% of participants



Disability support
Rated 'neutral' by 28% of participants



Work and Income (WINZ)
Rated 'neutral' by 25% of participants



Advocacy
Rated 'neutral' by 29% of participants



Employment support
Rated 'neutral' by 32% of participants

Bad



Childhood therapy/support
Rated 'bad' by 28% of participants



Coordination of services
Rated 'bad' by 36% of participants



Legal system
Rated 'bad' by 38% of participants



Support in primary school
Rated 'bad' by 26-29% of participants



Healthcare services
Rated 'bad' by 33% of participants



Support in secondary school
Rated 'bad' by 26-28% of participants



Childhood assessment
Rated 'bad' by 31% of participants



Accommodations in community
Rated 'bad' by 37% of participants



Individualised funding hosts
Rated 'bad' by 28% of participants



Transition to adulthood
Rated 'bad' by 37% of participants



Assistance and safety devices
Rated 'bad' by 33% of participants



Employment
Rated 'bad' by 39% of participants

Very bad



Adult therapy/support

Rated 'very bad' by 42% of participants



Adult assessment

Rated 'very bad' by 50% of participants



Access to mental health services

Rated 'very bad' by 40% of participants



Housing

Rated 'very bad' by 40% of participants



Access to suitable mental health services

Rated 'very bad' by 44% of participants

Note: Early identification had equal 'very bad' and 'bad' ratings, (26% each), support outside of the secondary school classroom had equal 'bad' and 'very bad' ratings (26% each), and Needs Assessment and Service Coordination (NASC) had equal 'neutral' and 'good' ratings (28% each).

Autistic people and/or **non-autistic parents** rated their experience with many services significantly lower than **professionals** and/or **family/whānau**.

Comments: Awareness and information around supports and services



"Can't ask for things you don't know exist" – **Non-autistic parent**

Participants across groups reported that information about services was inaccessible, hard to find, incorrect or unclear. Autistic people and their families shared that they did not know how to access individualised funding or were not made aware that it was an option. Some commented that while they may have qualified for individualised funding that they did not know how to use it or were not aware of it until it was close to expiring.

Comments: Waitlists and delays



"The current MoE [Ministry of Education] systems appear to largely consist of shuffling you from one waiting list to another, until the kid ages out and is no longer their problem"

– **Autistic parent**

Participants across groups commented on the long delays to access a wide range of services, including diagnosis, health, mental health, disability, education, and supports with living and the community such as Work and Income New Zealand and housing support.

Comments: Funding



“I am constantly frustrated at the lack of support and funding for my own child and for the children I work with. We can’t just blame teachers for not having enough understanding when we don’t train, support, educate and resource them properly” – **Non-autistic parent**

Many private services were reported to be too expensive, while many public services were reported to be underfunded, resulting in low staff pay, high turnover, a lack of available professionals and limited hours of support. Participants reported that diagnosis was a financial burden or inaccessible due to the cost.

Participants emphasised a general lack of funding for Special Education Needs Coordinators (SENCOs) and teacher aides. This sometimes led to restricted attendance for children who were required to have a teacher aide present.

Comments: Lack of supports and options



“There is nothing for adults. You’re just left to suffer” – **Autistic adult**

Participants across groups commented on a lack of supports and options across services. These issues ranged from shortages of trained professionals to a total lack of support in some areas.

Comments: Accommodations and adjustments



“Pretty much every clinical setting is a sensory nightmare for autistic people” – **Autistic parent**

Participants shared that most services and school settings were not well set up for autistic people. This included overstimulating, overwhelming, or chaotic environments and/or limited access to sensory accommodations and low sensory settings. Many participants also noted a lack of accommodations for communication differences, which created barriers to accessing certain services.

Comments: Processes for accessing support



“The pathway to service provision is unclear even to professionals, so how can we expect parents to navigate such a tangled path?” – **Professional**

Participants across groups commented on difficult, lengthy, and confusing processes for accessing diagnosis and support. They reported that these processes were often exhausting, overwhelming, stressful, and inaccessible.

Qualitative comments: Advocacy requirements



“It’s hard to get help when people don’t let me speak” – **Autistic adult**

“People have to fight to be believed” – **Professional**

Participants across groups commented on difficult, lengthy, and confusing processes for accessing diagnosis and support. They reported that these processes were often exhausting, overwhelming, stressful, and inaccessible.

Comments: Strict eligibility criteria



“New Zealand fundamentally does not believe in supporting autistic kids” – **Autistic parent**

“Parents shouldn’t have to continually jump through hoops to gain access to... funding” – **Non-autistic parent**

Participants expressed that they or their child were frequently denied access to services or had services removed because of strict or inequitable eligibility criteria. Participants also indicated that many supports were only available to those who were deemed to be ‘in crisis,’ with support removed as soon as the ‘crisis’ was over.

Comments: Coordination and consistency



“Coordination between the services is terrible and no one can agree on who does what” – **Autistic adult**

“It’s like you have all these agencies working against each other rather than collaborating together” – **Non-autistic parent**

Participants across groups indicated that there was limited coordination between services across health, disability, and education sectors, and that services often appeared to be working against, rather than with, each other. Autistic people and non-autistic parents mentioned that the level and quality of support and funding varied across individuals, families and Needs Assessment and Service Coordination assessors.

Comments: Wellbeing and mental health



“Staff with no proper training or knowledge of Autism... end up causing more harm than good for the child and whānau” – **Professional**

Participants across groups identified negative effects of supports and services which were indicated to be harmful, inappropriate, and/or traumatic for autistic people. Some participants also raised instances of serious abuse or neglect by professionals.

Autistic people experienced poor mental health outcomes due to masking. They, along with other parents, also experienced burnout, stress, and poor mental health from trying to navigate the different support systems.



“Very, very difficult system with a lot of stress for families, having to take kids out of school early, standdowns for meltdowns, punishments for neurology” – **Non-autistic parent**

Participants across groups reported that autistic children were excluded from, or unable to attend, their local school. Parents and professionals identified instances of illegal standdowns and exclusions and being required to reduce their child’s school hours without following any formal process.

Parents and professionals also reported instances of autistic children being banned or discouraged from attending school trips and after-school activities.

Bullying and discrimination



69% of autistic respondents indicated that they had experienced bullying, harassment, or hate crime.



71% of participants knew of an autistic person who had experienced bullying, harassment, or hate crime.



56% of autistic participants indicated that they had experienced discrimination.



70% of participants knew of an autistic person who had experienced bullying.

Comments: Bullying and harassment



“I don’t know of any autistic people who haven’t been bullied” – **Autistic adult**

Many participants commented on issues with bullying and harassment of autistic people in educational, professional, and community settings, including by individuals who were paid to support them.

Participants across groups reported that schools often took no action against bullies, or that the child themselves was punished for responding to bullies.

Comments: Discrimination



“Until we get rid of laws and policies that see autism as a burden on society... we will still be ruled by the majority wanting the minority to be more like them” – **Autistic adult**

Participants reported discrimination and ableism in schools and workplaces. This included children been excluded for after-school activities, fired from their jobs, or denied employment based solely on their autism diagnosis. Participants across groups also commented that it was discriminatory that an autism diagnosis could affect immigration status.

Meeting autistic people's needs



72% of participants felt that autistic people's needs were not being met in their daily lives.

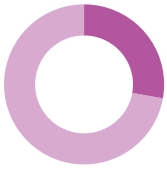
Addressing issues and disadvantages for autistic people



75% of participants were 'dissatisfied' or 'very dissatisfied' with the country's efforts to address issues and disadvantages for autistic people.

Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau (the Guideline)

Awareness of the Guideline



28% of participants were aware of at least some of the content in the current Guideline.

Satisfaction with the Guideline

Participants who were aware of the guideline and its content were asked to rate their satisfaction with its recommendations and implementation.



47% of participants were **satisfied** with the Guideline recommendations.



36% of participants were **dissatisfied** with the implementation of the Guideline.

Autistic people had lower satisfaction with the Guideline's recommendations and good practice points than non-autistic parents.

Suggestions to help implement the Guideline

Participants who were aware of the guideline and its content were asked to rate the helpfulness of possible future strategies to improve implementation of the Guideline.

Most common ratings for helpfulness of approaches for supporting the implementation of the Guideline:

Very helpful



Professional development – general professionals
Rated 'very helpful' by 72% of participants



Tertiary training – autism professionals
Rated 'very helpful' by 68% of participants



Tertiary training – general professionals
Rated 'very helpful' by 72% of participants



Simple resources
Rated 'very helpful' by 54% of participants



Professional development – autism professionals
Rated 'very helpful' by 70% of participants



Face to face engagement
Rated 'very helpful' by 44% of participants

Helpful



Video summaries
Rated 'helpful' by 46% of participants

Comments: The Guideline



“Guidelines are not enough, it needs to be enforceable” – **Autistic adult**

“Guidelines are just lots of words unless there is funding etc. to implement them” – **Professional**

Some autistic adults commented that the Guideline is a valuable resource, however, participants also identified varying issues with the length and wording used in the Guideline. Participants indicated that professionals are unlikely to follow the Guideline because they are not enforceable. They also emphasised the need for funding and work to ensure that the Guideline is implemented.

Looking to the future

Neurodivergence, autism specific, and general disability approaches

Most common ratings for helpfulness of neurodivergence, autism-specific, and general disability approaches

Very helpful



Neurodivergence approach

Rated 'very helpful' by 57% of participants



Autism specific approach

Rated 'very helpful' by 48% of participants

Unhelpful



General disability approach

Rated 'unhelpful' by 30% of participants

Professionals rated the helpfulness of the general disability approach and the neurodivergence approach significantly higher than **autistic parents** and **non-autistic parents**.

Comments: Autism and neurodivergence



“I believe what is good for autistics is generally good for all neurodivergent people” – **Autistic adult**

“Autism spectrum is broad enough without adding other conditions! And the support needs are entirely different, even if there can be some overlap” – **Professional**

Participants across groups identified strengths and challenges of both the autism-specific and neurodivergence approaches to support. Some autistic adults also suggested that an autism-specific approach within a broader neurodivergence umbrella would be best.

Some participants felt that an autism-specific approach would better account for the unique needs and differences for autistic people because the concept of neurodivergence was too wide. In contrast, other participants believed that having a wider neurodivergence umbrella would be more inclusive of different needs and would enable the prioritisation of needs over labels.

Future autism support

Most common ratings for helpfulness of potential future supports for autistic people

Very helpful



Advocacy

Rated 'very helpful' by 66% of participants



Legislation

Rated 'very helpful' by 51% of participants



Autism/neurodivergence strategy

Rated 'very helpful' by 58% of participants



Autism/neurodivergence commissioner/minister

Rated 'very helpful' by 49% of participants



Neurodiversity inclusion advisor

Rated 'very helpful' by 54% of participants

Unhelpful



Continuing current approach

Rated 'unhelpful' by 30% of participants

Note: Continuing with the current approach had equal 'unhelpful' and 'neutral ratings (both 30%).

- **Professionals** rated the helpfulness of continuing with the current approach significantly higher than **autistic parents**.
- Whilst still perceived as very important, **family/whānau and professionals** rated the helpfulness of an autism or neurodivergence Minister significantly lower than **autistic people** and/or **non-autistic parents**.

Comments: Overall support needs



“What matters most is that ND [neurodivergent] people define our own support”

– **Autistic adult**

Autistic people emphasised the importance of society as a whole valuing diversity. Participants generally supported a move away from medical, deficit-focused or cure-based supports and research, favouring a social model in which the environment and society should adapt to better support autistic people. Participants also stressed the importance of lived experience and that there should be more autistic-led support.

Comments: Culturally responsive support



Autistic people and parents highlighted the value of culturally responsive support. They shared that there is a need for greater value to be placed on non-Pākeha and, particularly, Māori understandings and approaches to autism support. Te Ao Māori approaches were identified as more understanding and supportive of autistic people than traditional Western approaches.

Comments: Further education required



“There appears to be little or no training for majority of workers around Autism understanding. Parents/caregivers or the individual are expected to educate many professionals”

– **Autistic adult**

Autistic people emphasised the importance of society as a whole valuing diversity. Participants generally supported a move away from medical, deficit-focused or cure-based supports and research, favouring a social model in which the environment and society should adapt to better support autistic people. Participants also stressed the importance of lived experience and that there should be more autistic-led support.

Participants across groups emphasised the need for further training and education around autism for professionals, services, government organisations, and the public. The identified areas in which further training was required, either overall or for specific professionals and groups, included:

- neurodiversity
- autism presentation in females and non-binary people
- the contents of the Guideline
- autistic masking and catatonia
- augmentative and alternative communication
- training in hiring neurodivergent individuals
- the relationship between autism and parenting
- training the police to understand and respond appropriately to autistic meltdowns.

Areas to address in future approaches

Most common ratings for importance of areas to be addressed in future approaches to providing support for autistic people

Very important



Access to support and therapy

Rated 'very important' by 84% of participants



Employment

Rated 'very important' by 75% of participants



Mental health

Rated 'very important' by 82% of participants



Advocacy services

Rated 'very important' by 72% of participants



Assessment and diagnosis

Rated 'very important' by 81% of participants



Community support

Rated 'very important' by 71% of participants



Training for professionals

Rated 'very important' by 79% of participants



Understanding and acceptance

Rated 'very important' by 71% of participants



Education

Rated 'very important' by 79% of participants



Early identification

Rated 'very important' by 71% of participants



Coordination and cooperation

Rated 'very important' by 77% of participants



Living and housing

Rated 'very important' by 69% of participants



Transition to adulthood

Rated 'very important' by 76% of participants



Legal/criminal justice system

Rated 'very important' by 69% of participants



Health and care services

Rated 'very important' by 75% of participants

Autistic people rated mental health services/outcomes as the single most important area to address while **non-autistic parents, professionals, and family/whānau** rated access to therapy and support as the most important.

Comments: Improving healthcare and disability support



“Rather than have our needs assessed and then matched to suitable supports, we are just assessed to see if we are eligible for any of the supports provided... if your needs are different then you are on your own” – **Autistic parent**

Participants indicated a need for funding for an increased number of autism advocates, as well as assistance in navigating services. They also supported implementing an Enabling Good Lives (EGL) approach across services and regions.

Autistic people felt that diagnostic services should prioritise early identification in females and that self-diagnosis should be seen as a valid form of diagnosis. They shared that autistic people should be trusted to know their own needs. Autistic adults also promoted increased funding and support for implementation of augmentative and alternative communication and suggested that all forms of spoken and non-spoken communication should be equally valued.

Many participants were strongly against including any behaviourally-based or punitive approaches in the future provision of support. They were also opposed to supports which aim to suppress autistic behaviours or make autistic people seem more neurotypical.

Comments: Improving education



“Modern learning environments are not appropriate for many students with autism. It is overwhelming and they can become distressed” – **Professional**

Autistic parents and professionals expressed a need for greater access to alternative education or more support and capacity for specialist schools. Participants indicated that smaller class or school sizes would be beneficial to avoid overload and overwhelm across the school day.

Comments: Improving living and community



“The lack of... true options around housing, support, vocational choices mean that many autistic people are severely restricted in their rights to freedom of choice and to live meaningful lives” – **Autistic adult**

Participants identified a need for more support and social groups for autistic people, including older autistic adults. Autistic parents suggested that autistic children could benefit from learning resilience and how to cope with bullies. Non-autistic parents supported greater investment in employment for autistic people.

Autistic adults advocated for more affordable and safe housing options, emphasising that this was the biggest issue for the adult autistic community. This included housing that was quiet and accessible as well as supporting living options.

Comments: Improving research



Autistic people wanted to have greater input into research. They also wanted more research into the differential effects of mental health conditions on autistic brains and the effects of training professionals to identify autism in girls and women. Several were opposed to genetic research and research into the causes of autism.

Comments: Improving government and legislation



“An autism minister only if they are autistic themselves - no parent, no specialist. Autistic.”
– **Autistic adult**

Several autistic adults felt that legal requirements were essential for ensuring that changes would be implemented and to increase accountability. This included enforceable accessibility legislation and protection of autistic identity under the Human Rights Act. Others indicated that legislation was unhelpful or would lead to resentment and reluctance rather than a willingness to learn.

Regarding changes to government systems, autistic people emphasised that any appointed autism Minister, advisor or commissioner must themselves be autistic or neurodivergent. They also suggested a greater role for Whaikaha – The Ministry for Disabled People.

Autistic adults and family/whānau wanted changes to immigration rules which currently frame an autism diagnosis as a burden and prevent autistic people from immigrating to New Zealand.

People to include in future development

Most common ratings for importance who include in decision-making and the development of future approaches

Very important



Autistic people

Rated 'very important' by 79% of participants



Other ethnicities

Rated 'very important' by 53% of participants



Parents/family

Rated 'very important' by 68% of participants



Allied health

Rated 'very important' by 51% of participants



Autism advocacy

Rated 'very important' by 63% of participants



Mental health clinicians

Rated 'very important' by 49% of participants

Māori

Rated 'very important' by 56% of participants



Educators

Rated 'very important' by 47% of participants



Pacific peoples

Rated 'very important' by 55% of participants



Health professionals

Rated 'very important' by 45% of participants



Disability support

Rated 'very important' by 53% of participants



Academics/researchers

Rated 'very important' by 38% of participants

Autistic adults rated the importance of including all groups except autistic people and other ethnicities significantly lower than other primary groups.



“Autistic adults are the only adults with any right to speak on behalf of autistic people” – **Autistic adult**

“The people who are impacted most (those with autism and the people that support them) should be prioritised for consultation” – **Non-autistic parent**

Participants stressed the importance of “nothing about us without us.” That is, including autistic people in every part of the change-making process and letting them have the final say.

Participants across groups supported the inclusion of those with ‘higher support needs’, particularly non-speaking autistic people, alongside autistic people who are more easily able to advocate for themselves. Autistic people highlighted the importance of including autistic members of the LGBTIQ+ community and autistic women in the development of future initiatives.

Autistic adults felt that autistic Māori and Pacific Peoples should be represented in decision making. They also noted that there is an obligation under Te Tiriti o Waitangi to include Māori in all future approaches.

Recommendations and future directions

It is clear extensive work is needed to get autism support right in Aotearoa. Autism New Zealand stands ready to work with the Government and other key stakeholders to ensure recommendations from this project are implemented.

How things are right now

Government funding for a multi-year national autism awareness and education campaign. Some key features of this campaign should include:



Understanding and acceptance



Led by a diverse range of autistic people



Across the lifespan



Early identification



Reduction of bullying, harassment, and hate crime experienced by autistic people



Identifying harmful services



Alternative communication



Identifying autism in diverse populations



Awareness of the Guideline

Workforce development

Adequate funding for autism-specific training and professional development. This includes a focus on increasing workforce capacity and retention. Specific areas of prioritization should include:



Recruiting and training autistic professionals



Autistic people involved in training professionals



Tertiary training and professional development around autism



Competitive salaries



Autistic voices



Manageable workloads



Implementation of the Guideline



Regular access to professional development and supervision



Funded internship placement

Service provision

Government funding to develop, increase provision of support services where there is high unmet need, and scale up existing programmes that work to ensure equitable access and grow system capability. Service provision needs to focus on:



Human rights and inclusion framework



Advocacy services



Flexibility to the individual needs of autistic people



Supportive educational settings and removal of modern learning environments



Accessibility for communication differences



Therapy and support across the lifespan



Assessment and diagnosis



Autism-affirming aged care



Mental health services tailored to autistic people



Increased funding to reduce waitlists



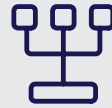
Affordable and accessible housing

Coordinated support system

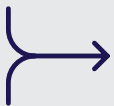
Previous research has highlighted the need to develop a strategic and long-term approach to autism in Aotearoa. The current project builds on the need for a coordinated approach within the autism support system, including:



One central database for supports and services



One needs assessment across disability, education, and social services



Incentives to provide complementary rather than competing services



Rolling out the Enabling Good Lives (EGL) approach



Navigators to help navigate the system



Consistency across regions

Strategy, policy and legislation

Include an autism/neurodivergence-specific strategy and action plan for Aotearoa. Based on findings from the current research and lessons from international autism strategies, policies and legislation, key components to consider include:



In-depth consultation with autistic people about whether to take an autism-specific or neurodivergence approach



Adequate funding for implementation



Reducing exclusive entry criteria



Autistic led and co-production with the autistic community



Removing the need for an official diagnosis and using needs-based assessments instead. This is particularly relevant for Māori due to cultural barriers in the diagnosis and assessment process.



An action plan with accountabilities for delivery

Genuine engagement with tāngata whaitakiwātanga Māori to ensure leadership and development of an approach that fits within Te ao Māori principles and understanding.

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Terminology in this document reflects currently accepted terminology used in Aotearoa.

Download the full report, executive summary, and Easy Read summary on the Autism CRC website: [ADD LINK](#)

