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

Final Report

Dr Larah van der Meer, Chanelle Moriah, Lee Patrick, Dr Hannah Waddington

September 2023

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

Dr Larah van der Meer
Autism New Zealand | Victoria University of Wellington

Chanelle Moriah
Autism New Zealand

Lee Patrick
Autism New Zealand

Dr Hannah Waddington
Victoria University of Wellington

ISBN: 978-1-922365-61-3

Citation: : van der Meer, L., Moriah, C., Patrick, L., & Waddington, W. (2023). *How do we get autism support right in Aotearoa New Zealand? Final Report.* Autism CRC

Copyright and disclaimer

Acknowledgements

The authors acknowledge the financial support of Autism CRC. Staff and non-staff in kind were provided by Autism CRC members, including Autism New Zealand, Victoria University of Wellington, and wider project team.

We would like to thank our research advisory groups – the Autistic Advisory Group, including Joanne Dacombe, Rei Denei, Kris Finlayson, Gabby Hogg, Nan Jensen, Seth Killick, and Ruth Monk, and the Partnership Advisory Group, including Rebekah Corlett, Sharon Du Preez, Trisha Mariota, Pip McDowall, Erin Raynor, Hilary Stace, and Jess Tupou. We would also like to acknowledge Altogether Autism, Insight Research and Whaikaha. Each of these groups provided input and feedback throughout all stages of this project, including development of the survey. Their input has been fundamental to producing a project that is inclusive, accessible, and guided by the needs and preferences of the autistic community.

Thank you to the autistic individuals, parents of autistic children, family/whānau, professionals, and researchers who completed the survey and shared their experiences of the autism support system in Aotearoa and suggestions for how we can get autism support right in the future.

Autism CRC

Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum.

We provide the national capacity to develop and deliver evidence-based outcomes through our unique collaboration with autistic people, families, professionals, services providers, researchers, and government. Together, we are addressing agreed needs and co-producing outputs with these stakeholders for the benefit of the community.

Autism CRC was established in 2013 as the world’s first national, cooperative research effort focused on autism under the Australian Government’s Cooperative Research Centres (CRC) Program. We receive funding from a number of sources, including the Australian Government. Autism CRC is no longer part of, or associated with, the CRC Program.

autismcrc.com.au

A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, we use the terms 'autistic person', 'person on the autism spectrum' or ‘person on the spectrum’. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector and is used in the context of a person being ‘diagnosed with Autism Spectrum Disorder’.

Table of contents

1. Background and rationale

Aotearoa is in a unique position to shape the future of autism support, with the overhaul of its health system and establishment of Whaikaha – the new Ministry of Disabled People (https://www.whaikaha.govt.nz). Aotearoa has the Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau ('the Guideline') (Whaikaha – Ministry of Disabled People and Ministry of Education, 2022), which provides evidence-based information and recommendations for autistic people, their families/whānau, practitioners, educators, and organisations. However, implementation of the Guideline historically has been mixed (see e.g., research on autism diagnosis in Aotearoa).

With international moves to establish national autism strategies and legislation (e.g., 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.

1.1 Current policy, legislation and accountability for autism in Aotearoa

Aotearoa takes a general approach to disability with:

- The newly created Whaikaha - Ministry for Disabled People (whaikaha.govt.nz)
- Minister for Disability Issues (odi.govt.nz/about-us/our-minister/)
- New Zealand Disability Strategy (odi.govt.nz/nz-disability-strategy/)
- Disability Action Plan (odi.govt.nz/disability-action-plan-2/)
- Enabling Good Lives approach (enablinggoodlives.co.nz/about-egl/egl-approach/principles/).

1.1.1 Autism, neurodiversity and neurodivergence

Within this general approach to disability there is increasing understanding of neurodiversity and how autism fits within this. The term 'neurodiversity' refers to the understanding that there is a range of different ways for human brains to function, and that falling outside of the norm should not necessarily be pathologised. 'Neurodivergent' is an umbrella term for brains that process, learn, or function differently than what is considered 'typical'. It is a distinct category that differs from mental health conditions or disorders in that many neurodivergent people consider their neurodivergence a core part of their identity and take pride in their neurodivergence. Conditions that fall under the neurodivergent umbrella include autism, attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), borderline personality disorder (BPD), dyslexia, dyspraxia, Down syndrome, and many others. There is a move for disability support to understand and take a neurodiversity-affirming approach to better meet the needs of these communities.

1.1.2 Māori perspectives

Takiwātanga is a kupu (word) Māori for autism. The term was coined by Keri Opai after consultation with tāngata whenua (Māori people) and tāngata whaitakiwātanga (autistic people). It means 'in my/their/his/her own time and space' (Opai, 2020). Other terms for autism are also emerging from the community. This includes kura urupare, which means 'gift of the sensories'. The kupu Māori for neurodiversity are kanorau ā-roro (kanorau = diversity, ā-roro = of the brain) and kanorau ā-io (kanorau = diversity, ā-io = of the nerves) (Whaikaha – Ministry of Disabled People and Ministry of

Education, 2022). However, it is important to respect every individual's right to self-refer and be referred to as they choose.

It is additionally important to acknowledge that the process of colonisation has separated many Māori from Te Ao Māori (the Māori world). As a result many Māori have lost their connection with mātauranga Māori (Māori knowledge) including te reo Māori (Māori language) and tikanga Māori (Māori customs and protocols). It is also common to see differences in language across iwi. This may explain why there are now several different kupu Māori for autism and neurodiversity emerging. Autism and neurdoversity are in fact foreign terms for Māori and it is important to consider that these are Western concepts which have been placed upon Māori whether they want it or not.

Te reo Māori and mātauranga Māori shape how takiwātanga is understood, attitudes towards it, and how tāngata whaitakiwātanga Māori and their whānau are supported. Kaupapa Māori services and frameworks, such as Mason Durie's Te Whare Tapa Whā model (Durie, 1984), can be used to guide supports for tāngata whaitakiwātanga and their whānau. Te Whare Tapa Whā includes four dimensions of wellbeing for Māori. These are: taha tinana (physical wellbeing), taha hinengaro (mental wellbeing), taha wairua (spiritual wellbeing), and taha whānau (family wellbeing). Culturally responsive supports for tāngata whaitakiwātanga Māori need to incorporate all four of these dimensions.

1.1.2.1 Te Tiriti o Waitangi

It is imperative 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. These include:

1. Recognition and protection of **tino rangatiratanga**: The right of Māori to live in whatever way they choose - whānau, hapū, iwi or other form of organisation and to exercise autonomy and self-determination.
2. **Equity**: Equitable outcomes for Māori.
3. **Active protection**: Action and leadership to ensure the right to tino rangatiratanga and to achieve equitable health and social outcomes for Māori.
4. **Partnership:** Involve Māori at all levels of decision making to allow self-determination in relation to resources, people, language, and culture (tino rangatiratanga).
5. **Options:** Where kaupapa Māori services exist, Māori should have the option of accessing them as well as culturally appropriate mainstream services. They should not be disadvantaged by their choice (The Policy Place, 2019).

Consistent with Whāia Te Ao Mārama 2018-2022: The Māori Disability Action Plan, autism supports need to be led by tāngata whaitakiwātanga Māori (Māori autistic people) to uphold the significance of Te Reo Māori and Te Ao Māori principles (Ministry of Health, 2018). This includes tāngata whaitakiwātanga Māori having leadership, genuine choice, and control over the supports which enable them to thrive, flourish and live the life they want.

1.1.3 Navigating the support system

Government support can be fragmented and difficult to navigate, and multiple eligibility criteria for different services makes it difficult for autistic people to know what support services they are entitled to. For example, autistic people may be eligible for funded services via:

- **Whaikaha:** Needs assessments service coordination (NASC) to determine eligibility for disability support services, such as carer support and respite, home and community support services, and individualised funding.
- **Te Whatu Ora:** Needs assessments service coordination (NASC) to determine eligibility for mental health support.
- **Ministry of Education:** Needs assessment to determine eligibility for services such as early intervention services, learning support, ongoing resourcing scheme (ORS), and intensive wraparound service (IWS).
- **Ministry of Social Development:** Including Work and Income New Zealand health and disability related benefits and Community Participation Services such as transition from school and employment support.

Due to the complexity in understanding and navigating the support system the Government created Whaikaha – the Ministry of Disabled People. Key aims of the new ministry are to:

- Lead a true partnership between the disability community, Māori and Government.

Help transform the disability system in line with the Enabling Good Lives (EGL) approach.

1.1.4 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" (Enabling Good Lives, 2023). A principles-based approach is being taken to ensure accountability. The principles are:

- Self-determination.
- Beginning early.
- Person-centred.
- Ordinary life outcomes.
- Mainstream first.
- Mana enhancing.
- Easy to use.
- Relationship building.

Whaikaha will work with the disability community and across Government agencies to drive system transformation in line with the EGL Approach. Implementation of EGL has been piloted in several regions across Aotearoa, specifically Christchurch, Waikato and MidCentral (Mana Whaikaha). While the funded model (individualised funding) is not currently available across the whole country, Whaikaha are charged with leading this implementation over the next few years.

This will work within five characteristics of the EGL approach:

- Self-directed planning and facilitation.
- Cross-government individualised and portable funding.
- Considering the person in their wider context, not in the context of 'funded support services'.
- Strengthening families or whānau.
- Community building to develop natural supports.

1.1.5 Legislation, standards, and policies

There are numerous health, disability, and education legislation and policies relevant to autism (for a full list see the Guideline) (Whaikaha – Ministry of Disabled People and Ministry of Education, 2022). Each of these impact on the provision of supports and services for the autistic and autism communities, including:

- Te Tiriti o Waitangi
- Human Rights Act 1993
- New Zealand Public Health and Disability Act 2000
- Health and Disability Services (Safety) Act 2001
- Education and Training Act 2020
- Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003
- Health and Disability Commissioner Act 1994
- Code of Health and Disability Consumers' Rights 1996
- The Mental Health (Compulsory Assessment and Treatment) Act 1992
- United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 2006
- New Zealand Disability Strategy
- New Zealand Disability Action Plan
- Learning Support Action Plan
- Ka Hikitia.
- Whāia Te Ao Mārama: The Māori Disability Action Plan.

1.1.5.1 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" (Ministry of Social Development, 2016). It will guide government agencies and any individual or organisation's work on disability issues from 2016 to 2026. It covers eight key outcomes:

1. Education
2. Employment and economic security
3. Health and wellbeing
4. Rights protection and justice
5. Accessibility
6. Attitudes
7. Choice and control
8. Leadership

Aotearoa 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/).

1.1.5.2 Disability Action Plan

The Disability Action Plan (Ministry of Social Development, 2019) is around the priorities and government work programmes that advance implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the New Zealand Disability Strategy. The current Disability Action Plan covers 2019 to 2023, and a new plan is currently being workshopped. The Disability Action Plan includes several monitoring mechanisms to ensure agencies are held to account. It also focuses on obtaining disability data and disabled people's involvement in decision making.

1.1.5.3 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 (United Nations, 2006). Central principles include the right to autonomy and self-determination, the right to freedom from coercion and the right to be treated in a non-discriminatory way. It was first established in 2006 and Aotearoa ratified (agreed to) the convention in 2008 meaning the Government must provide regular progress reporting on implementation of the convention. More information about the treaty can be found on the Office for Disability Issues website (odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/).

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

The Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau (the Guideline) describes best practice on how to support autistic people in Aotearoa. It includes recommendations based on research evidence and good practice points on diagnosis, education, and ongoing supportive approaches. The Guideline is for autistic people, their whānau, health and disability professionals, community supporters, employers, policy advisers, and anyone involved in education.

The Guideline is updated annually on specific topics by the Living Guideline Group. Updates are informed by systematic reviews prepared by Insight Research, which leads the living guideline process independently on behalf of Whaikaha. A third edition of the Guideline was released by Whaikaha in partnership with the Ministry of Education in November 2022. Planning is underway towards implementation of the Guideline. However, it is also the responsibility of different organisations to make themselves aware of, consider, and implement the recommendations as they see fit. For more information on the Autism Guideline see whaikaha.govt.nz/about-us/policy-strategies-and-action-plans/nz-autism-guideline/.

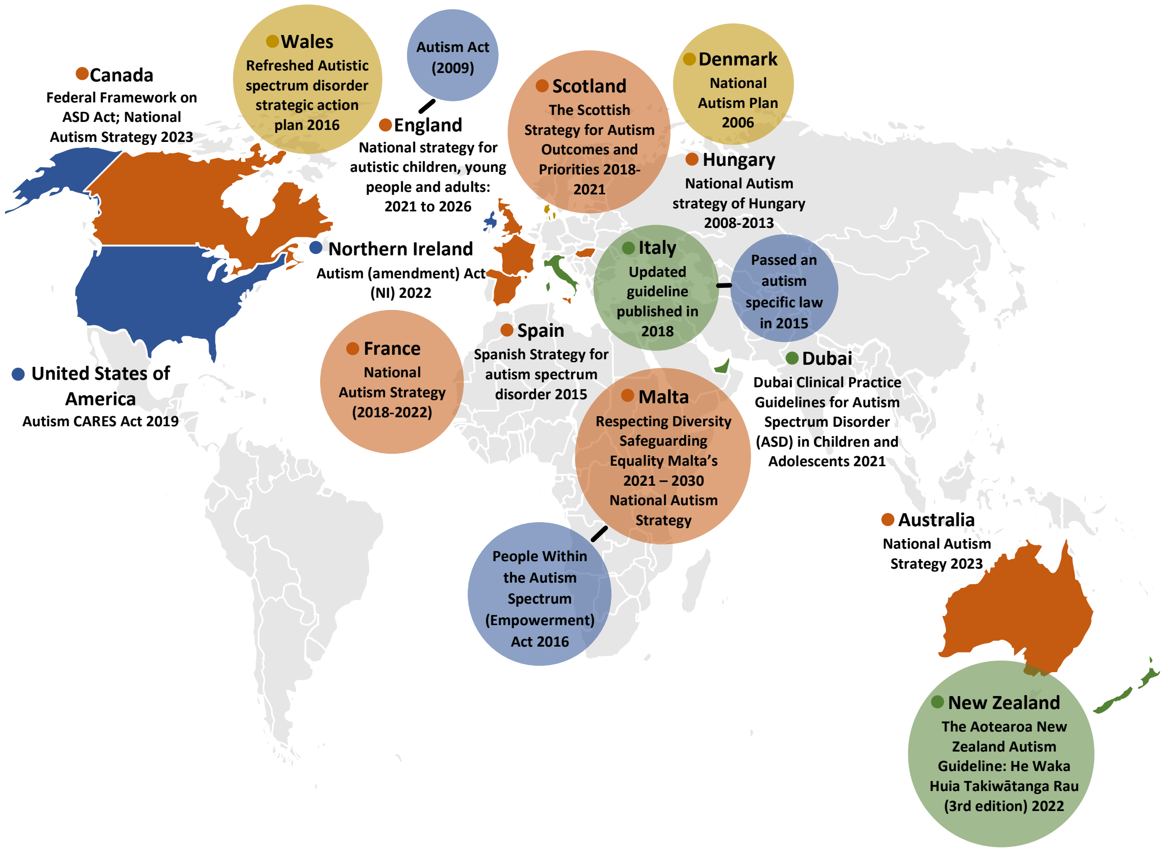
1.1.7 International autism strategies and legislation

There is an abundance of evidence to suggest that we are continually failing to meet the needs of autistic people worldwide. Despite their talents, skills and aspirations, autistic people experience poor educational outcomes, face unemployment at higher rates than other disabled communities, and a significant percentage experience suicidal ideation or mental illness at some point in their lives (Mason et al. 2021). Internationally, it is recognised that general disability approaches have failed to improve services, support, and life outcomes for autistic people (Rees & Long, 2021). To address this need, more than ten comparable countries have a dedicated national autism strategy in place, including England, Wales, Scotland, Northern Ireland, Malta, France, United States, Spain, Denmark and Hungary (see Figure 1). Some strategies are in their second or third iteration and some are underpinned by autism-specific legislation. Australia is currently developing a National Autism Strategy, which will provide a coordinated, national approach to how governments and services can better support autistic people and their families (Australian Government Department of Social Services, 2023).

Evidence suggests these strategies support positive outcomes, including:

- **Long term cost savings** through early investment in evidence driven supports leading to greater productivity and reduced ongoing need for social, health and education support.
- Increased community **awareness and understanding of autism**.
- Improved access to **autism assessment and diagnosis**, which can lead to significant wellbeing benefits and support social, educational, and economic participation.
- More **inclusive and effective education** for autistic children.
- Increased **autism employment outcomes.**
- **Autism responsiveness in the criminal justice system.**
- **Autism responsive health and care services** (Rees & Long, 2021).

Figure 1. Autism legislation, strategies, and other approaches around the world



Effective strategies take a lifespan approach and coordinated action across government, organisations, and individuals. They are autistic-led and involve genuine co-production with the community, including a diverse range of autistic people (e.g., those with complex support and communication needs) as well as parents and families/whānau of autistic people.

Although Aotearoa has an Autism Guideline (Whaikaha – Ministry of Disabled People and Ministry of Education, 2022) and some autism-specific services, the policy and support landscape consists of a fragmented array of small scale and disconnected initiatives. Without specific consideration of the unique differences and barriers that autistic people face, and without suitable accountability to ensure that the rights of autistics are upheld, autistic people will continue to face significant disadvantages that will be detrimental to their wellbeing, and costly to Aotearoa.

2. Aims

Autism is among Aotearoa's biggest disability groups – 35.7% of people accessing Government funded disability support services listed autism as their primary disability category (Heslin, 2023). It is therefore imperative to get autism support right in Aotearoa. To do this, we need to understand community views on current supports and possible future approaches, such as a national strategy and other forms of accountability to facilitate inclusion and the provision of supports for autistic people.

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, and (2) provide suggestions for future approaches to autism support. Findings from the project include recommendations for implementation of the current Guideline (Whaikaha – Ministry of Disabled People and Ministry of Education, 2022) as well other approaches.

The specific research questions were:

- Is the community aware of the Guideline and do they think it is being implemented?
- Is the current approach (the Guideline and wider Disability Strategy) effective in ensuring that the needs of autistic people are being met, including access to assessment and diagnosis, ensuring that autistic individuals have access to suitably trained professionals and services, and ensuring that autistic individuals' rights are being upheld?
- What does the community feel is necessary to ensure the implementation of the Guideline? Do we need an autism strategy? Do we need autism legislation? Do we need an autism commissioner? Do we need some other form of accountability or commitment to measure the effectiveness of autism support?
- If there is a strategy or legislation, does it need to be autism-specific or could it be generic to neurodivergence?
- What would need to be covered in a strategy or in legislation?

3. Methods

3.1 Ethical approval and informed consent

The research was approved by the Victoria University of Wellington Human Ethics Committee (reference number 30857). Participation in the survey was voluntary and anonymous. Participants were presented with an information sheet on the survey website which described the project team, the aims of the project, what participation would involve, use of the data, and dissemination. They then ticked a box indicating that they consented to participate. An easy read version of the consent form was developed by People First and was edited and adapted based on feedback from the team. No participants requested this easy read consent form.

3.2 Eligibility

Participants were eligible to take part in the research if they were 18 years or over and were either currently living in New Zealand or had lived in New Zealand in the past 5 years. They also needed to be autistic or a member of the wider autism community, including parents/whānau of autistic people, professionals (e.g., educators, health professionals), researchers and policy makers.

3.3 Co-production

This project was co-produced alongside two research advisory groups. The first was an Autistic Advisory Group, which consisted of nine autistic individuals who were also professionals, advocates, and/or family/whānau members of autistic individuals. The second was a Partnership Advisory Group which consisted of non-autistic family/whānau, professionals, researchers, and members of the wider community. These research advisory groups included members with diverse, relevant, lived, and professional expertise, including representation of Māori, Pacific Peoples, and other non-Pākehā cultures, as well as complex needs communities. Each meeting was facilitated by several members of the research team, including at least one autistic team member.

The two advisory groups met separately 3 times between January and August 2023. Each meeting was hosted on Zoom and lasted for 1.5 hours. Advisory group members were generally provided with relevant materials a week prior to each meeting. They could participate in a variety of ways, including communicating verbally, using the chat function, and emailing any thoughts prior to, or following, meetings. The content of the meetings was as follows:

- Meeting One – The advisory group members introduced themselves, talked through some guidelines for the meetings, discussed a title for the project and how to represent diverse communities, and provided feedback on draft survey questions.
- Meeting Two – The research team presented preliminary quantitative data and sought feedback on ways to analyse and present the data.
- Meeting Three – The research team presented a draft of the results and sought feedback on ways of presenting the qualitative and quantitative data. Advisory group members also identified key recommendations based on this data.

3.4 Survey development

The survey was drafted by the second author (CM) based on ideas from other team members and those presented in the two advisory groups. Once CM had drafted the survey, they sought feedback from other members of the project team (LP, LvdM, HW) as well as from the two advisory groups, a Māori lecturer at Victoria University of Wellington, and representatives from Altogether Autism, Insight Research, and Whaikaha. After several rounds of feedback and revisions, advisory group members indicated that they were happy with the survey. CM then created an online version of the survey in SurveyMonkey, which was tested by LvdM, HW, and members of the advisory groups. An easy read version of the survey was developed by People First and was edited and adapted based on feedback from the team. Hard copies of the survey were also available on request, and it was also possible to complete the survey with a support person or via an interview with a researcher.

3.5 Survey content

The survey began with eligibility screening questions and those who were not eligible were directed to a message thanking them for their time and informing that they were not able to take part. The rest of the survey had three sections: (a) general demographic information, (b) how things currently are, and (c) what could we do in the future? The survey was estimated to take about 20-30 minutes to complete. Participants were required to complete each question in the survey, but each had a ‘no opinion/not sure’ and/or a ‘prefer not to say’ option. Each section included free-text boxes in which participants could provide more detail about their chosen responses; they were informed that these were not included within the time-limit. A full version of the survey is included in Appendix A.

The general demographic section had questions pertaining to all participants including: (a) age, (b) gender, (c) ethnicity, (d) residency, (e) all relationships to autism, and (f) “primary” identity/role. Primary identity/role was only used for data analysis purposes (i.e., to reduce the already high number of statistical analyses) and the options were ‘autistic adult’, ‘autistic parent’, ‘non-autistic parent’, ‘professional’, ‘researcher/policy maker’, and ‘family/whānau.’ The term ‘autistic people’ is used to refer to qualitative and quantitative data related to the combined ‘autistic adult’ and ‘autistic parent’ primary identity groups. Autistic people were also asked about their employment status, whether they had accessed employment services, their age of diagnosis or self-diagnosis, co-occurring conditions, and modes of communication. Parents of autistic children were asked about their child’s age of diagnosis, co-occurring conditions, modes of communication, and schooling.

The ‘how things currently are’ section examined participants’ experiences with how accessible, available, understanding, and inclusive individuals and services are for autistic people with regard to different areas of life. Participants were asked to rate the understanding/acceptance and their overall experience of various health and therapy, disability, community, education, and ‘other’ individuals and services on a 5-point Likert-type scale from 1 = ‘very bad’, 5 = ‘very good’. They were also asked the extent to which they agreed with the statement “Generally, autistic peoples’ needs are being met in their daily lives” on a scale from 1 = ‘strongly disagree’ to 5 = ‘strongly agree’. Participants then indicated whether they knew anyone who had experienced bullying, harassment, hate crime, and discrimination, and, if they were autistic, whether they had experienced this themselves. Participants rated their satisfaction with the country’s efforts to address issues and disadvantages for autistic people on a scale from 1 = ‘very dissatisfied’ to 5 = ‘very satisfied’.

The next part of this section related to the Aotearoa New Zealand Guideline: He Waka Huia Takiwātanga Rau ('the Guideline'). Participants were informed about the Guideline, and directed to view it, if they so desired, before answering the questions. Participants were asked if they were aware of any edition of the Guideline and if they knew what was included in the current (third) edition of the Guideline. Those who were aware of the Guideline then rated their satisfaction with its recommendations and good practice points, and implementation. They then rated the helpfulness of a variety of strategies (e.g., face-to-face engagement, video summaries) for supporting implementation of the Guideline on a scale from 1 = 'very unhelpful' to 5 = 'very helpful'.

The final section examined what the community would like to see in the future in terms of services and supports. First, participants rated the effectiveness of the current general disability approach to support, an autism-specific approach, and a neurodivergence approach on a scale from 1 = 'very ineffective' to 5 = 'very effective'. Next, they rated the helpfulness of various more specific approaches to supporting autistic people, for example, an autism or neurodivergence minister and a nationwide autism or neurodivergence strategy. Participants then rated the importance of addressing a range of areas in future approaches to autism (e.g., access to therapy and support, transition into adulthood) on a 7-point Likert-type scale from 1 = 'very unimportant' to 7 = 'very important'. Finally, they rated the importance of including various people and groups in decision making and development of future approaches.

3.6 Dissemination

The survey was hosted on the Survey Monkey platform from 3rd April to 15th May 2023. Participants were primarily recruited by snowball sampling. An advertisement for the survey was shared on a variety of autism- and disability-specific community and organisational Facebook pages (e.g., Aotearoa Autism, Autistic Community NZ) and sent out to the Autism NZ Altogether Autism databases. It was also sent to a variety of relevant health, education and disability organisations and Ministries throughout the country, and these organisations were encouraged to share it with relevant members. The information and advertisement were also sent directly to individual members of the autistic and autism community who were known to the team. Again, these individuals were encouraged to further share the information with anyone who might be interested.

3.7 Data management and analysis

3.7.1 Data management

Several steps were taken to manage the data. Those who indicated that they were 'researchers or policy makers' as their primary role were combined with the 'professional' category due to small numbers. Some participants' primary relationship to autism were recoded due to misinterpretation of the options. For example, some non-autistic parents selected 'autistic parent of an autistic child' as their primary relationship. The researchers were able to determine that these responses needed to be changed based on comments in the free text spaces, as well as the responses they selected for the question about 'all relationships to autism'. Some free-text genders were recoded if they were deemed to fit an existing category. Participants who identified as 'white', 'kiwi', 'New Zealander' 'European' and 'other 'European' were combined into the Pākehā/New Zealand European category. For analysis purposes, overarching 'Pacific Peoples' and 'Asian' ethnicity categories were also created. Some participants put their child's age in the participant age demographic question, so these were changed to 'prefer not to say'. Some comments were disregarded as they were not relevant to the research or contained insults. Data was not reported for co-occurring conditions or modes of communication for autistic participants and autistic children because too many participants selected contradictory responses, meaning the data was unreliable. For example, some participants indicated that the question about co-occurring conditions was 'not applicable' to the child and that the child had 'no other diagnoses' and then also selected several specific co-occurring conditions.

3.7.2 Quantitative data analysis

Data across all participant groups and/or for each primary identity group/role were presented descriptively in tables within the appendices. Responses across all participant groups were also presented in figures in-text. For these figures, 'no opinion/unsure' responses were generally excluded, to facilitate comparison across responses. Instead, the number of people who provided a response other than 'no opinion/unsure' was presented on the relevant axis. The percentage of participants providing each response was generally reported on the figures, with the exception of ≤ 3%. The total percentages in the in-text figures varied from 99-101% due to differences in rounding.

Priority rankings for questions related to the perceived importance or helpfulness of different aspects of future support were calculated per primary identity group/role and across all identity groups/roles. Generally, the different options were generally ranked from highest to lowest based on the combined percentage of participants who provided both "very important/helpful" and "important/helpful" responses. Further detail of these calculations is presented in Appendix G.

Statistical analyses were conducted to investigate potential differences in responses across primary identity group/role (autistic adults, autistic parents, non-autistic parents, professionals, and family/whānau) and ethnicity groups (Māori versus non-Māori, Pacific versus non-Pacific Peoples, Asian versus non-Asian Peoples). All statistical analyses were conducted using IBM SPSS statistics. Due to the number of analyses, significance was set at $p \leq .01$. This decision was made a priori to balance the risk of Type I (false positive) and Type II (false negative) errors. Bonferroni-adjusted pairwise comparisons (adjusted $p \leq .05$) were used for all post-hoc analyses.

As most response data were not normally distributed, non-parametric tests were used for Likert-type outcomes. Specifically, Kruskall-Wallis tests were conducted to explore differences between primary identity groups, and Mann Whitney-U tests were conducted to explore differences between ethnicity groups. For analyses related to satisfaction with, and implementation of, the Guideline, autistic parents were combined with autistic adults to create an "autistic people" group, and family/whānau were removed due to having ≤ 20 individuals per group. Chi square tests were used for categorical outcomes, specifically, experiences of bullying, harassment, or hate crime and discrimination, and awareness of the Guideline between primary identity and ethnicity groups.

Friedman's Analyses of Variance (ANOVAs) were also conducted to investigate potential within-group differences in ratings of satisfaction and implementation of the Guideline, future approaches to support, and important areas to address and people to include in all future approaches. This was a result of the data not being normally distributed.

3.7.3 Qualitative data analysis

Qualitative responses to the free-text questions in each section were analysed using conventional content analysis (Hsieh & Shannon, 2005). This coding was conducted in Excel, with one row per statement by each participant. The analysis involved the following steps:

- Reading and re-reading data as a whole.
- Reading statements word-for-word and developing noting keywords and phrases.
- Developing codes.
- Sorting codes into categories and meaningful clusters depending on links between them.
- Naming and creating definitions for the categories and clusters.
- Reporting the findings with example quotes.

LP conducted the majority of this analysis, with CM checking codes for 10% of the statements. Agreement between raters was 94.4% on the codes provided by LP, and CM also identified an additional 168 codes across statements (<1% of total possible additional codes). HW and LvdM provided feedback on the codes and categories developed by LP and CP, who modified them accordingly.

A specific analysis was conducted for codes and ideas that were mentioned by Māori and Pacific participants. For Māori, these were woven into existing themes. The Pacific Peoples group was small and mostly comprised of non-autistic parents. There did not appear to be any differences between the codes identified by Pacific Peoples and non-Pacific Peoples.

Example quotes were selected for each theme and presented with the participant's primary identity/role.

3.7.4 Development of recommendations

The following process was taken in development of recommendations arising from this research project:

- The research team and advisory groups read through all qualitative and quantitative data.
- The advisory groups made suggestions for recommendations in the third advisory group meeting.
- The research team reflected on possible recommendations.
- The research team wrote recommendations based on data and suggestions from the advisory groups.
- Recommendations reflected overarching themes rather than specific quantitative values or frequency of comments. Given the quantity of data it was not realistic to include all possible recommendations, so they were developed to reflect practical, high priority changes.
- The draft recommendations were sent to the advisory groups and were adapted based on feedback.

4. Findings

4.1 Who participated?

A total of 1472 participants consented to take part in the survey. Of these, 43 were ineligible on the basis of not living or having had lived in New Zealand in the last 5 years, 16 were under the age of 18, and 22 indicated that they did not have any relationship to autism, either personally or professionally. A further 386 participants did not complete the full survey and were therefore excluded from data analysis. A total of 1043 participants completed the whole survey. However, one participant was excluded from the data analysis due to not providing a primary identity/role, resulting in a final sample of 1042 participants for analysis. Full details of participants characteristics are presented in Appendix C, Tables 1-3. No participants requested the easy read version of the survey.

4.1.1 All participants

4.1.1.1 Identities and roles

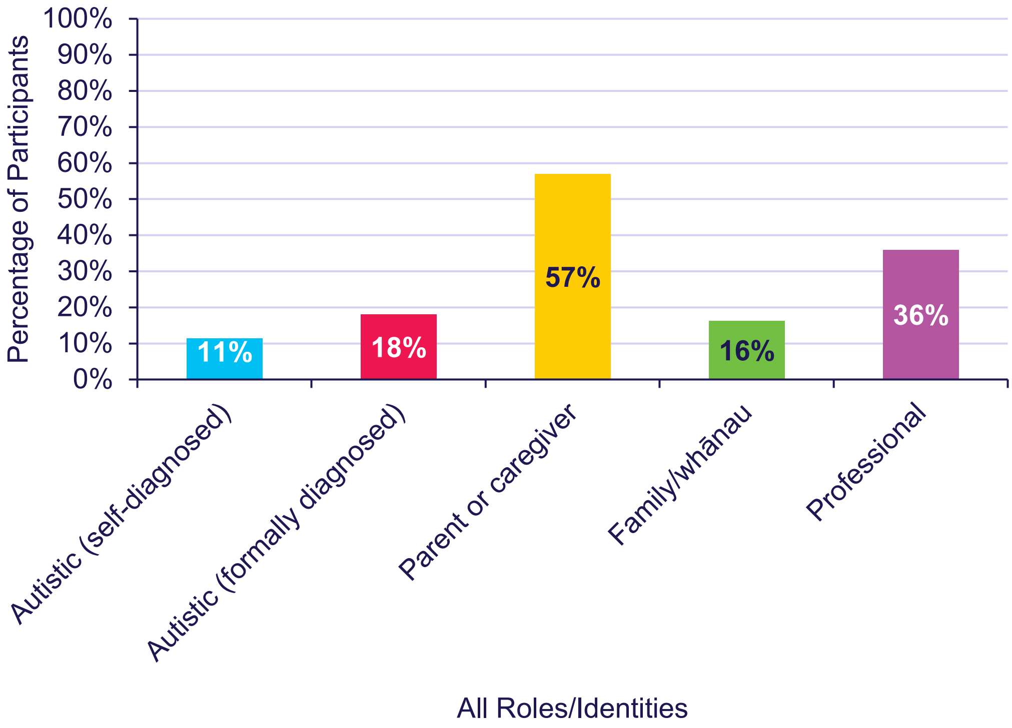


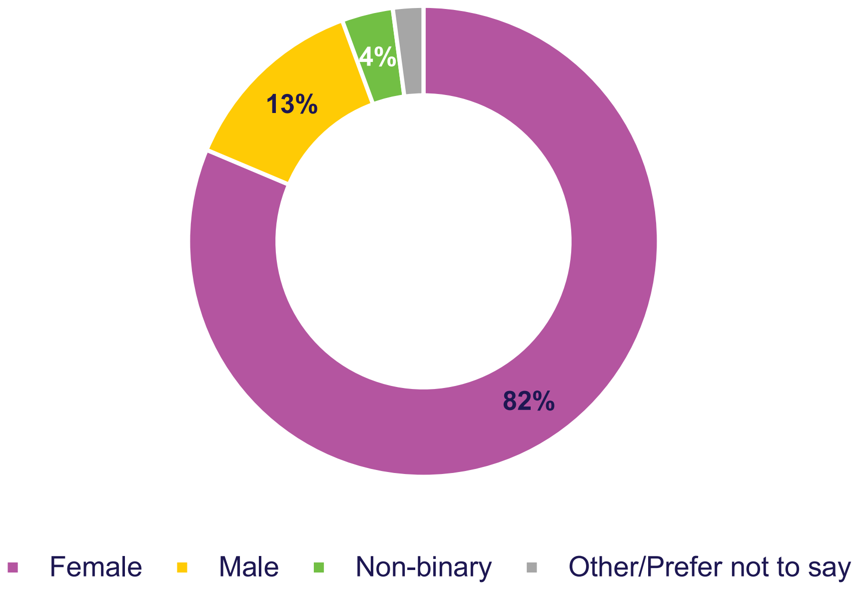
Figure 2. All participant relationship/s to autism (identities and roles) across groups.

Participants were asked to select all of their relationship(s) to autism in terms of their various identities and roles. The figure above shows all participants' identities and roles. The most common relationship was parent or caregiver (this included both autistic and non-autistic parents or caregivers) of an autistic person, while the least common was family/whānau. The majority of autistic people were formally diagnosed.

For analysis purposes, participants were asked to select a primary identity/role (not shown in figure). A total of 217 participants selected 'autistic' either self-diagnosed or formally diagnosed, 79 selected autistic parent/caregiver, 462 selected non-autistic parents/caregiver, 43 selected family/whānau and 242 selected professional.

4.1.1.2 Gender

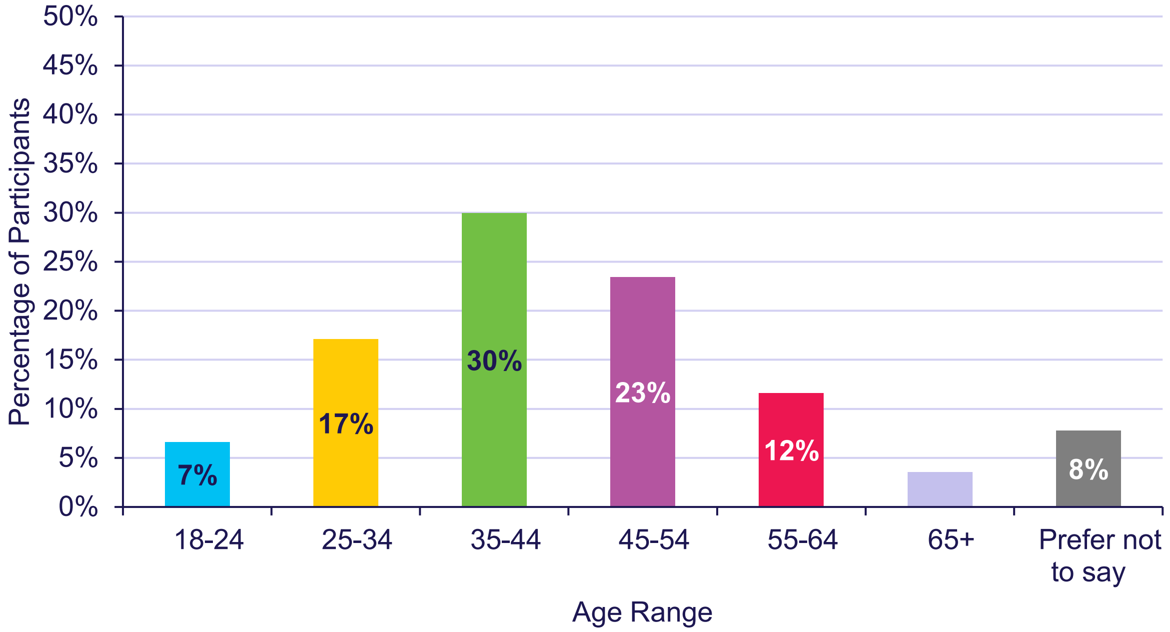
Figure 3. Participant gender identity across groups.



Across participants, the most common gender was female. This was also the case for all primary identity groups/roles. See Appendix C (Table 1) for a summary of gender distributions for each primary identity group/role.

4.1.1.3 Age

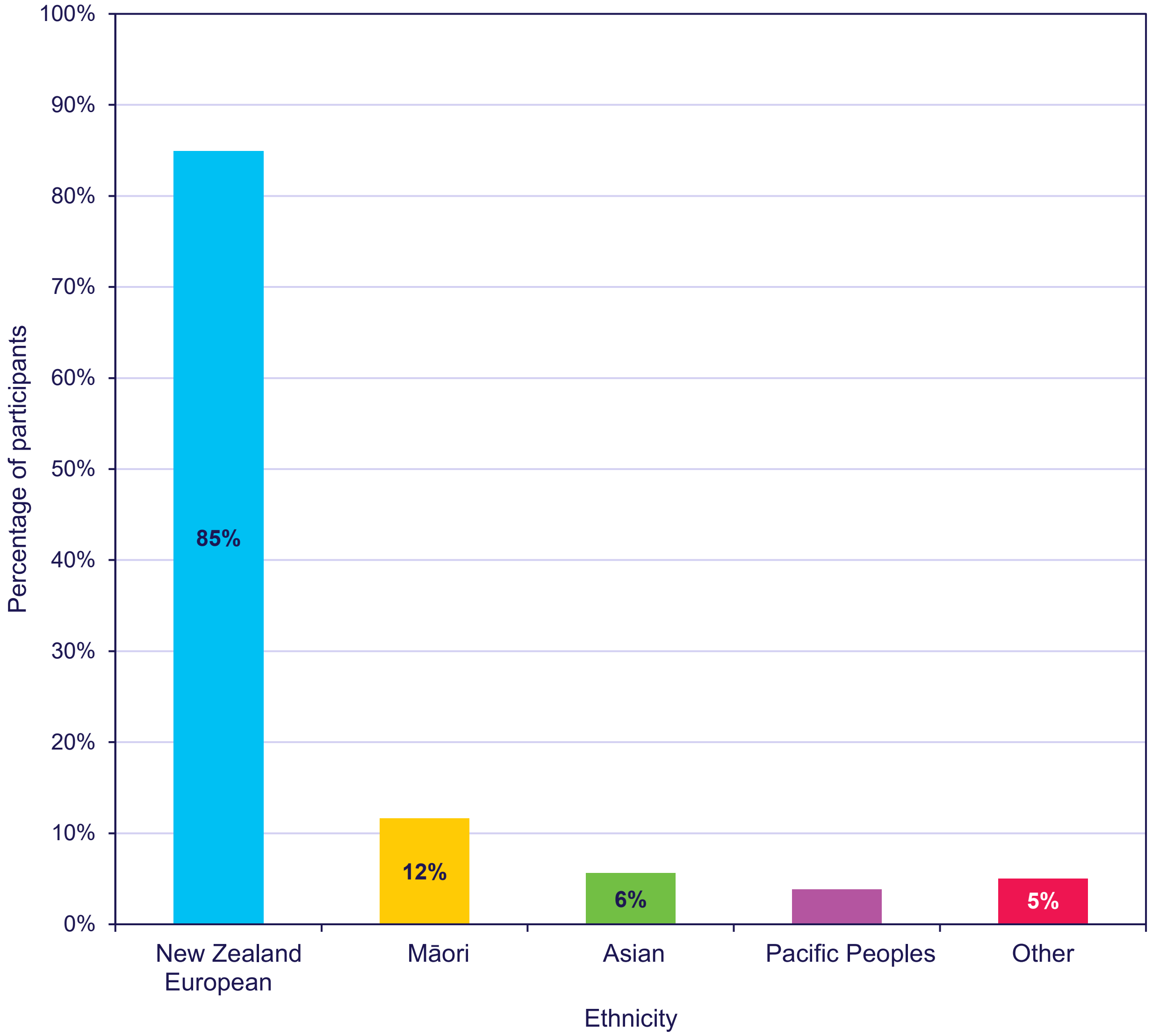
Figure 4. Participant age ranges across groups



Across participants, the most common age range was 35-44. This was also the case for all primary identities except autistic adults for whom the most common age range was 25-34 and professionals for whom the most common age range was 45-54. See Appendix C (Table 1) for a summary of age distributions for each primary identity group/role.

4.1.1.4 Ethnicity

Figure 5. Participant ethnicity across groups.



Participants could select all ethnicities that were relevant to them. Across participants, the most common ethnicity was Pākehā/New Zealand European followed by Māori. This was also the case for all primary identity groups. See Appendix C (Table 1) for a summary of ethnicity distributions for each primary identity group/role.

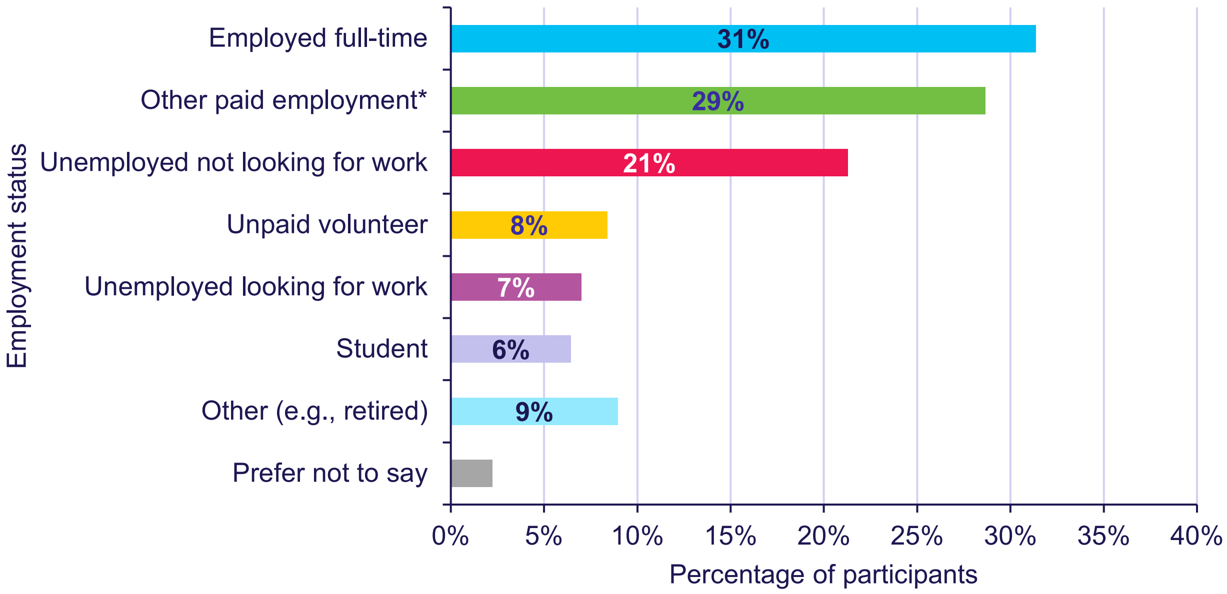
4.1.2 Autistic participants

4.1.2.1 Age of diagnosis

The average age of diagnosis (or self-diagnosis) for autistic adults was 30 years. The average age of diagnosis (or self-diagnosis) for autistic children was 7 years. See Appendix C (Table 2) for a summary of age of diagnosis for each primary identity group/role.

4.1.2.2 Employment

Figure 6. Autistic participant employment status.



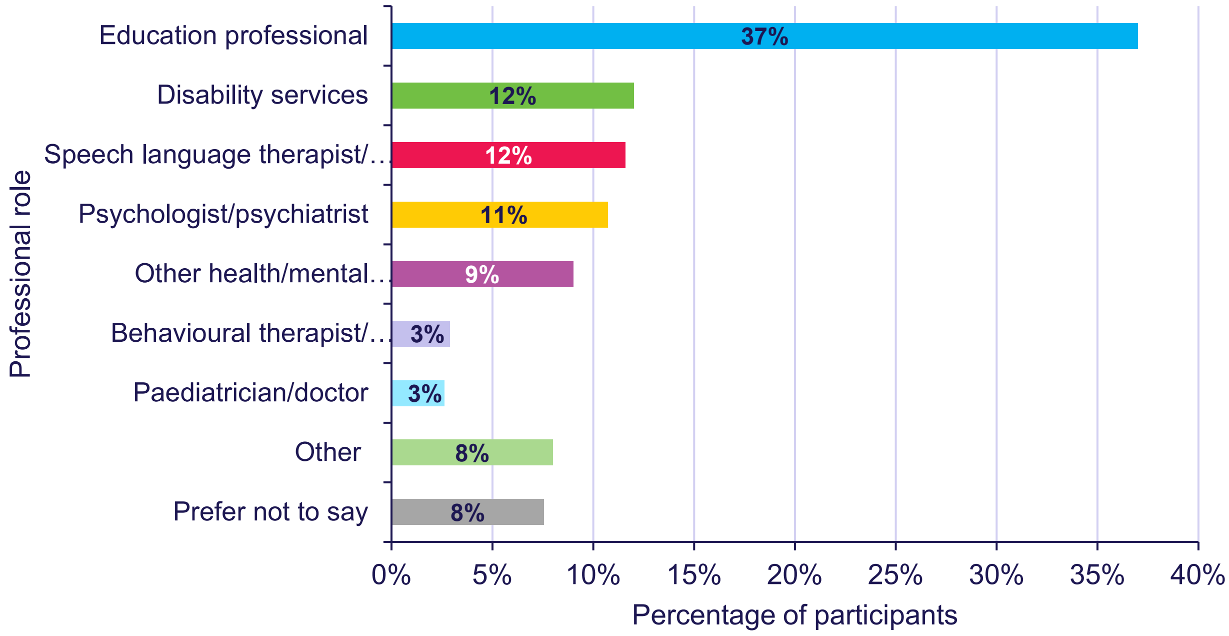
* Other paid employment includes part-time work, casual work, and self-employment

About a third of autistic participants were in full-time employment and other paid employment. This was followed by unemployed and not looking for work.

4.1.3 Professionals

4.1.3.1 Role

Figure 7. Professional roles.



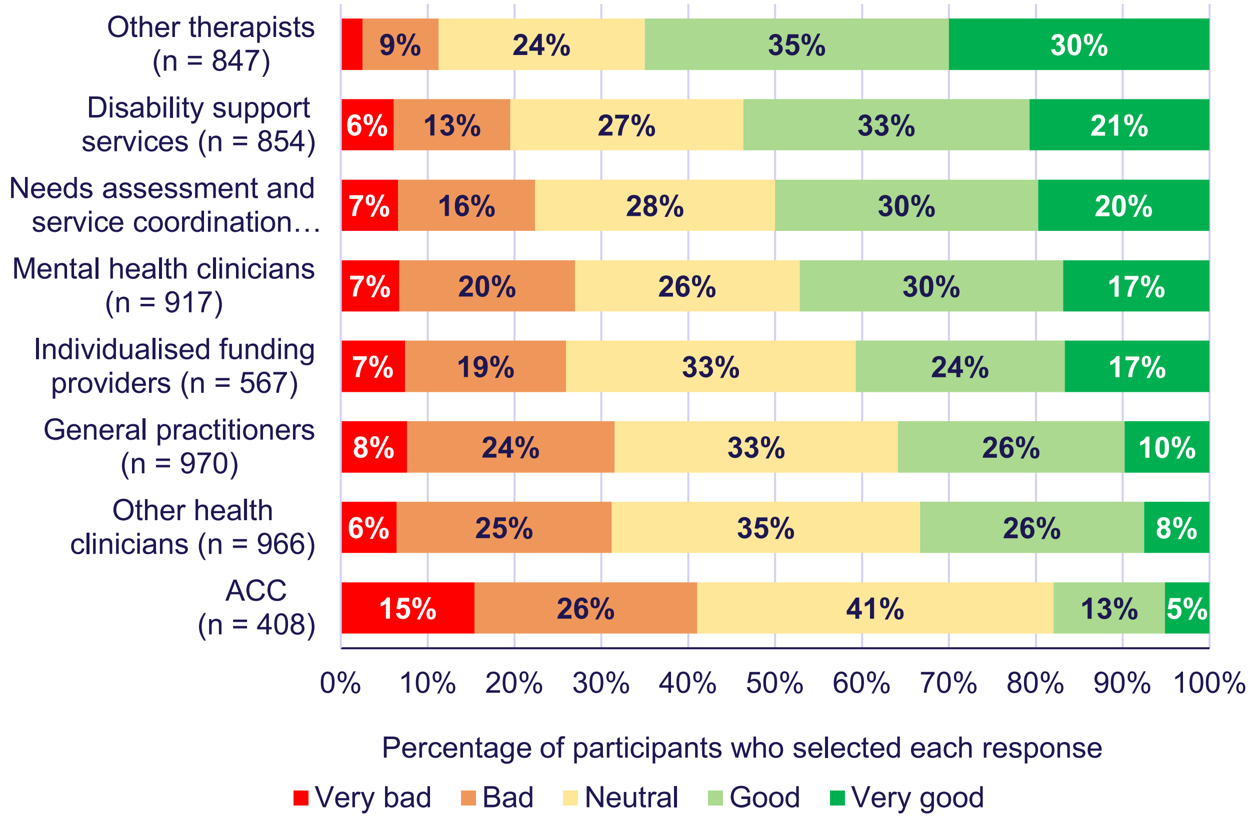
About a third of professionals worked in education. This was followed by disability services and speech language therapists/occupational therapists.

4.2 How things are now

4.2.1 Understanding and acceptance

4.2.1.1 Understanding and acceptance in health and therapy

Figure 8. Participant-rated (across all groups) understanding and acceptance of autism in health and therapy services.



Participants rated understanding and acceptance of autism for a variety of health and therapy services. Understanding of autism for general practitioners, other health clinicians, individualised funding providers, and Accident Compensation Corporation (ACC) was most commonly rated as ‘neutral,’ while the understanding and acceptance of autism for mental health clinicians, other therapists, disability support services and needs assessment and service coordination (NASC) was most commonly rated as ‘good.’

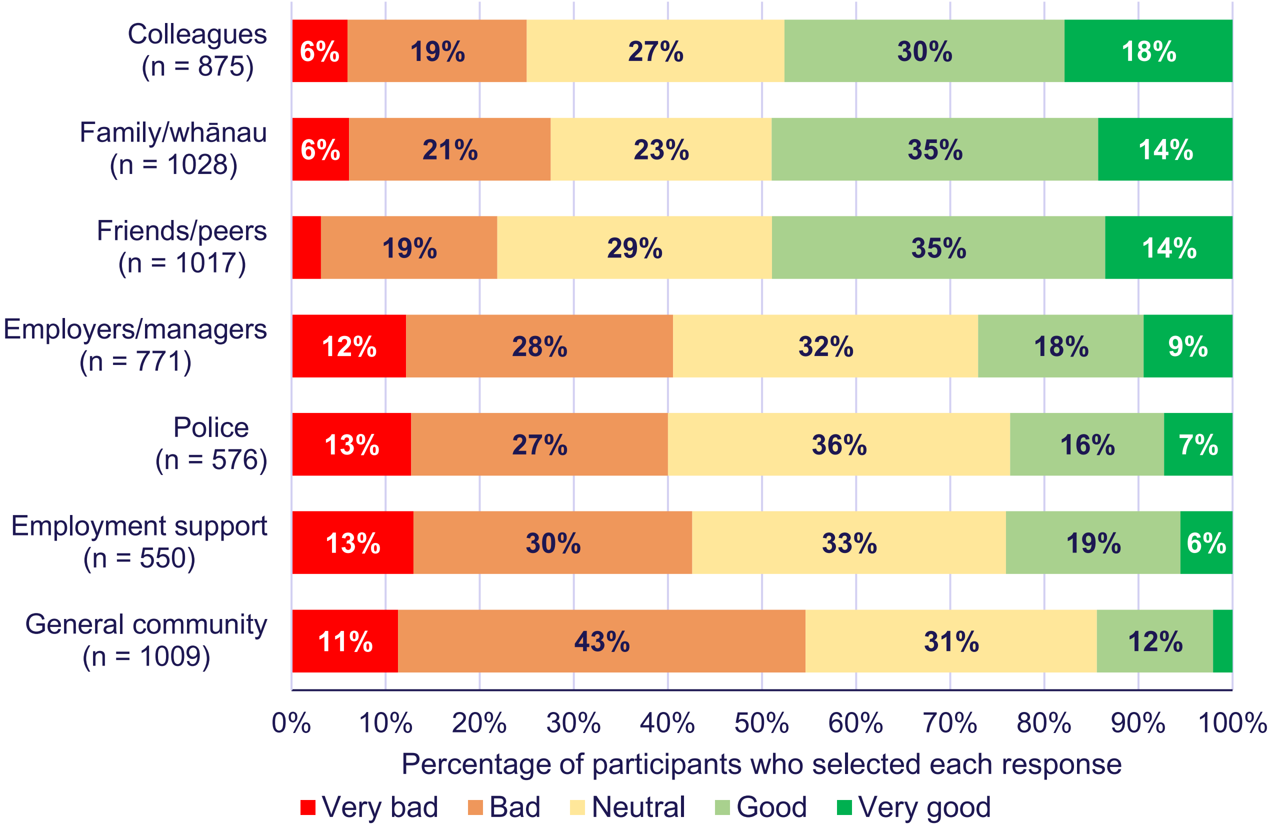
The understanding and acceptance of autism for other therapists such as occupational and speech therapists was rated as ‘good’ or ‘very good’ by a higher percentage of participants (65% total) than the other health and therapy services. The understanding and acceptance of ACC was rated as ‘bad’ or ‘very bad’ by a higher number of participants (31% total) than the other health and therapy services. See Appendix C (Table 1) for a summary of ratings across participant groups.

Statistical analyses for primary identity/role indicated that autistic people rated the understanding and acceptance of some health and therapy services **lower** than other identity groups (see Appendix D, Table 1). Non-autistic parents rated the understanding and acceptance of mental health clinicians **lower** than professionals.

Asian Peoples rated the understanding and acceptance of ACC **higher** than non-Asians (see Appendix F, Table 1).

4.2.1.2 Understanding and acceptance in the community

Figure 9. Participant-rated (across all groups) understanding and acceptance of autism in the community.



Participants rated the understanding and acceptance of autism in the community. The understanding of the general community was most commonly rated as ‘bad,’ with the understanding and acceptance of police, employers/managers, and employment support services was most commonly rated as ‘neutral,’ and the understanding and acceptance of family/whānau, friends/peers, and colleagues most commonly rated as ‘good.’

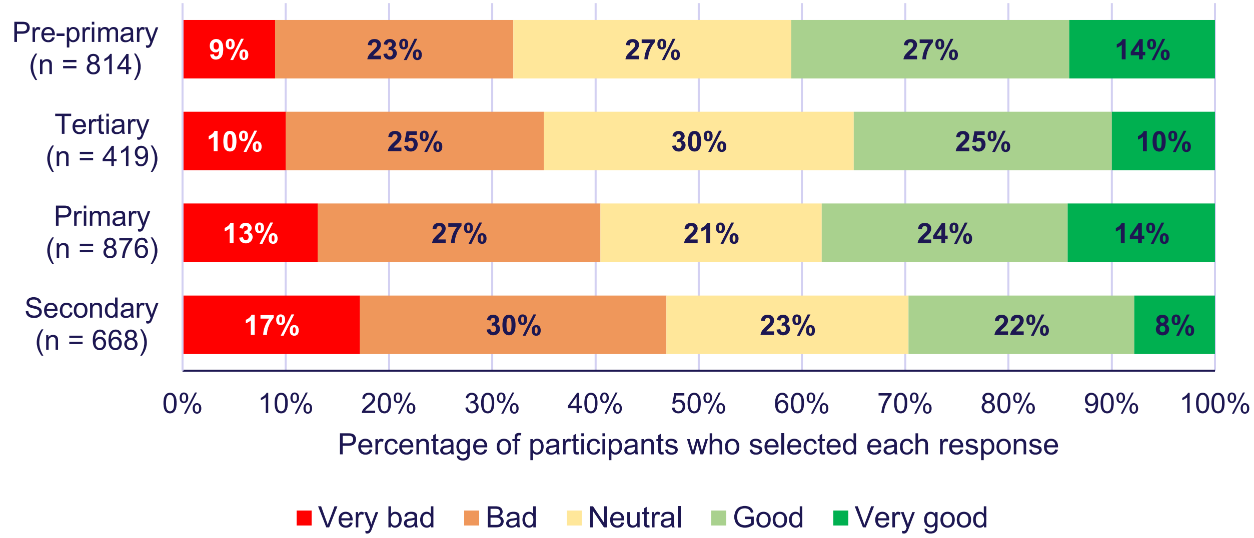
The understanding and acceptance of both family/whānau and friends/peers was rated as ‘good’ or ‘very good’ by a higher percentage of participants (each 49% total) compared to the rest of the community. The understanding and acceptance of general community was rated as ‘bad’ or ‘very bad’ by a higher percentage of participants (54% total) compared to the rest of the community. See Appendix D (Table 1) for a summary of ratings across participant groups.

Statistical analyses for primary identity/role indicated that autistic people rated the understanding and acceptance of some aspects of the community **lower** than at least one other identity group (see Appendix D, Table 2). Non-autistic parents rated the understanding and acceptance of colleagues, the general community, and employment support services **lower** than professionals and the understanding and acceptance of friends/peers significantly **lower** than autistic adults.

There were no significant differences in perceptions of the understanding and acceptance of autism in the community between ethnicity groups (see Appendix F, Table 2)

4.2.1.3 Understanding and acceptance from teachers

Figure 10. Participant-rated (across all groups) understanding and acceptance of autism by teachers.



Participants rated the understanding and acceptance of autism by teachers. The understanding and acceptance of primary and secondary teachers was most commonly rated as ‘bad,’ the understanding and acceptance of tertiary teachers was most commonly rated as ‘neutral’, and the understanding and acceptance of pre-primary teachers received equal ‘neutral’ and ‘good’ ratings.

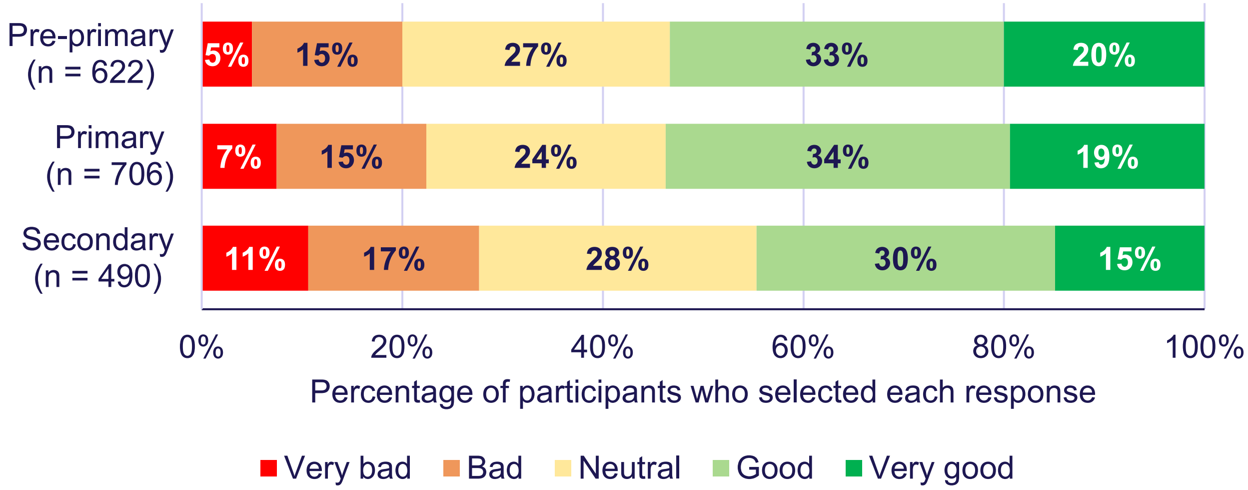
The understanding and acceptance of pre-primary teachers was rated as ‘good’ or ‘very good’ by a higher percentage of participants (41% total) than teachers at other levels. The understanding of secondary teachers was rated as ‘bad’ or ‘very bad’ by a higher percentage of participants (47% total) than teachers at other levels. See Appendix D (Table 1) for a summary of ratings across participant groups.

Statistical analyses for primary identity/role indicated that autistic people rated the understanding of pre-primary, primary, and/or secondary teachers significantly **lower** than at least one other identity group (see Appendix E, Table 3). Non-autistic parents also rated the understanding and acceptance of primary teachers significantly **lower** than professionals.

There were no significant differences in perceptions of the understanding and acceptance of autism by teachers between ethnicity groups (see Appendix F, Table 3).

4.2.1.4 Understanding and acceptance from teacher aids

Figure 11. Participant-rated (across all groups) understanding and acceptance of autism by teacher aides.



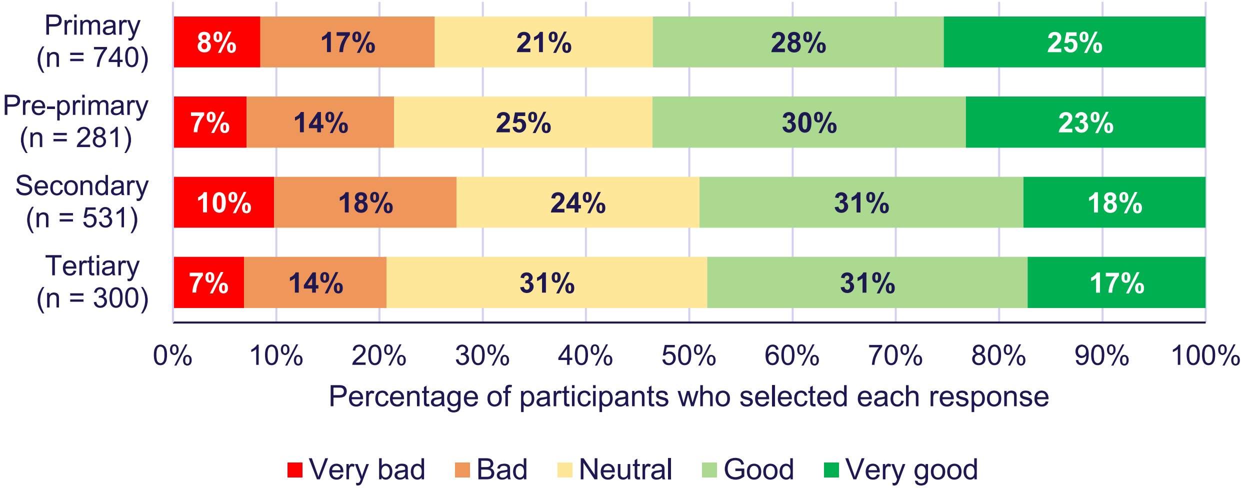
Participants rated the understanding and acceptance of autism by teacher aides and education support workers. The understanding and acceptance of teacher aides/education support workers at all levels was most commonly rated as ‘good’.

The understanding and acceptance of both pre-primary and primary teacher aides/education support workers was rated as ‘good’ or ‘very good’ by a higher percentage of participants (both 53% total) than secondary teacher aides. The understanding and acceptance of secondary teacher aides was rated as ‘bad’ or ‘very bad’ by a higher percentage of participants (28% total) than pre-primary or primary teacher aides/education support workers. See Appendix D (Table 1) for a summary of ratings across participant groups.

Statistical analyses for primary identity/role suggested that autistic people rated the understanding and acceptance of primary school teacher aides significantly **lower** than professionals and non-autistic parents (see Appendix E, Table 3). There were no significant differences in perceptions of the understanding and acceptance of autism by teacher aides between ethnicity groups (see Appendix F, Table 3).

4.2.1.5 Understanding and acceptance from specialist school support

Figure 12. Participant-rated (across all groups) understanding and acceptance of autism by specialist school staff.



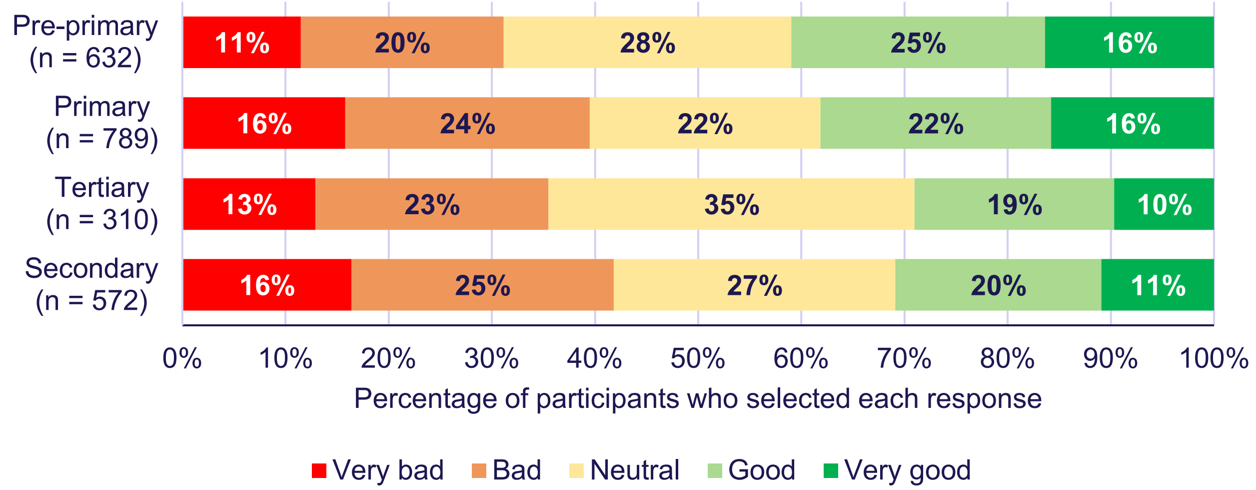
Participants rated the understanding and acceptance of autism by specialist educational support such as Special Education Needs Coordinators (SENCOs), learning support, disability support, resource teachers learning and behaviour (RTLB), and educational psychologists.
The understanding and acceptance of specialist support in pre-primary, primary, and secondary was most commonly rated as ‘good’, while tertiary had an equal percentage of ‘neutral’ and ‘good’ ratings.

The understanding and acceptance of both pre-primary and primary specialist support was rated as ‘good’ or ‘very good’ by a higher percentage of participants (both 53% total) than secondary and tertiary specialist support. The understanding and acceptance of secondary specialist support was rated as ‘bad’ or ‘very bad’ by a higher percentage of participants (28% total) than specialist support at other levels. See Appendix D (Table 1) for a summary of ratings across participant groups.

Statistical analyses for primary identity/role suggested that autistic people and non-autistic parents rated the understanding and acceptance of specialist support in primary and/or secondary significantly **lower** than professionals (see Appendix E, Table 3). There were no significant differences in perceptions of the understanding and acceptance of autism from specialist school support between ethnicity groups (see Appendix F, Table 3).

4.2.1.6 Understanding and acceptance from educational leadership

Figure 13. Participant-rated (across all groups) understanding and acceptance of autism by educational leadership.



Participants rated the understanding and acceptance of autism by educational leadership such as principals, deans, and school boards. The understanding and acceptance of primary leadership was most commonly rated as ‘bad’, while leadership at other levels was most commonly rated as ‘neutral.’

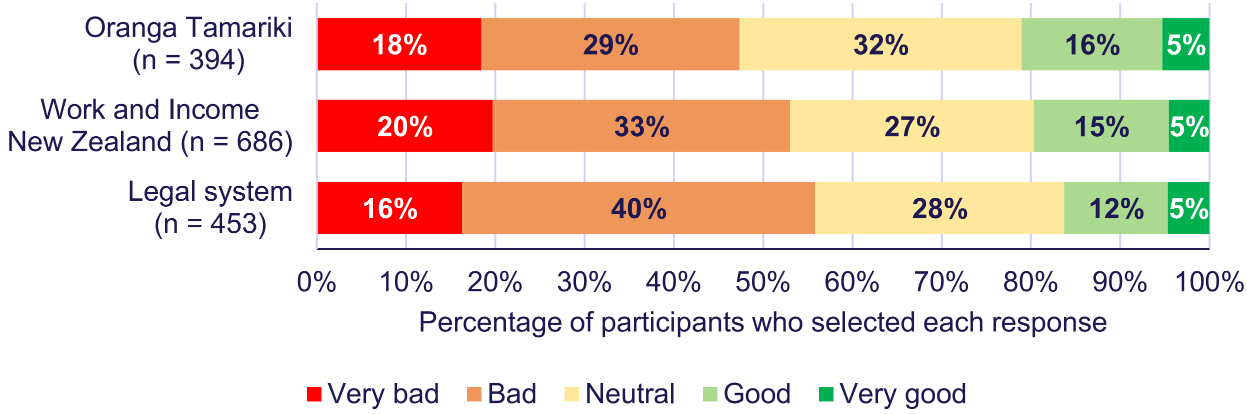
Pre-primary leadership was rated as ‘good’ or ‘very good’ by a higher percentage of participants (31% total) than leadership at other levels. Secondary leadership was rated as ‘bad’ or ‘very bad’ by a higher percentage of participants (41% total) than leadership at other levels. See Appendix D (Table 1) for a summary of ratings across participant groups.

Statistical analyses for primary identity/role suggested that autistic people rated the understanding and acceptance of educational leadership at some levels significantly **lower** than at least one other identity group (see Appendix E, Table 3). Non-autistic parents also rated the understanding and acceptance of primary leadership significantly **lower** than professionals.

There were no significant differences in perceptions of the understanding and acceptance of autism from educational leadership between ethnicity groups (see Appendix F, Table 3).

4.2.1.7 Understanding and acceptance in other contexts

Figure 14. Participant-rated (across all groups) understanding and acceptance of autism in other contexts.



Participants rated the understanding and acceptance of autism in other contexts. The understanding and acceptance of the legal and justice system and Work and Income New Zealand were most commonly rated as ‘bad’, while the understanding and acceptance of Oranga Tamariki was most commonly rated as ‘neutral.’

The understanding and acceptance of the legal and justice system was rated as ‘bad’ or ‘very bad’ by a higher percentage of participants (56% total) than Oranga Tamariki and Work and Income. The understanding and acceptance of Oranga Tamariki was rated as ‘good’ or ‘very good’ by a higher percentage of participants (21% total) than the remaining groups. See Appendix D (Table 1) for a summary of ratings across participant groups.

Statistical analyses for primary identity/role suggested that autistic adults and/or autistic parents rated understanding and acceptance in other contexts significantly **lower** than non-autistic parents and/or family/whānau (see Appendix E, Table 4).

Māori rated the understanding and acceptance of Oranga Tamariki significantly **lower** than non-Māori. There were no other significant differences in perceptions of the understanding and acceptance of autism in other contexts between ethnicity groups (see Appendix F, Table 4).

4.2.1.8 Qualitative 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

> "Most clinicians in the public sector have a limited or surface level understanding of autism"
> – Professional

Participants across groups indicated that professionals, organisations, the public, and some family and friends had little to no knowledge and understanding of autism. This included limited understanding of the need for supports and accommodations for autistic people. Non-autistic parents also identified a general unwillingness to understand or learn more about autism.

Participants shared that most professionals had limited or out-of-date training and education in autism. Autistic adults also reported that professionals generally did not understand the lived experience of autism. Autistic people and non-autistic parents associated this lack of knowledge with an ongoing need for themselves to educate professionals and services about autism. The lack of understanding amongst professionals was sometimes linked to participants' hesitancy or mistrust around services, as well as poor quality service provision.

Some participants highlighted that certain professionals, organisations, and/or family and friends did have positive understandings and up-to-date knowledge of autism. Autistic people and non-autistic parents particularly emphasised the greater level of understanding at specialist compared to mainstream schools.

Participants noted that autistic individuals themselves and autistic behaviours such as stimming, meltdowns, and communication differences were frequently labelled as "bad", "difficult" or "naughty" and that these behaviours were also linked with 'bad parenting'. Parents also felt judged and "told how to parent" by requirements to attend parenting courses instead of, or prior to, providing support for the child.

Autistic adults commented on the lack of understanding of masking across professionals and employers and mentioned that they were not believed when they were in pain or overwhelmed due to masking. Non-autistic parents and professionals also supported the idea that school and legal staff do not understand masking.

Professionals were reported to lack knowledge of the characteristics of autism, including how these may present in non-Pākeha people. Those involved in assessment and diagnosis were reported to misdiagnose autistic people with mental health conditions or personality disorders. Autistic people and non-autistic parents also pointed out that some health professionals continue to use outdated diagnostic terminology. Autistic adults and professionals indicated that few mental health professionals understood the interactions between mental health and autism and how to adjust support for autistic people.

Autistic people stated that some professionals did not understand communication differences or the need for clear language when communicating with autistic clients. This was linked with frequent misunderstandings and difficulties in making their needs understood. Autistic parents emphasised the lack of understanding of non-spoken and augmentative and alternative communication.

4.2.1.9 Qualitative comments: Stereotyped understandings

> "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. Participants shared that they were often told that they, or their child, did not 'look' or 'seem' autistic. 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.

Participants across groups also shared that many professionals and community members associated autism with lower levels of intelligence and treated all autistic people accordingly. Some non-autistic parents commented that many also think that all autistics are 'savants.'

Autistic adults and professionals emphasised poor understanding of autism in adults, as well as a perception that autistic people are "dangerous", particularly when they are in a state of overwhelm or meltdown.

4.2.1.10 Qualitative comments: Acceptance

> "My daughter and I both 'mask' to exist, we both put ourselves through extra stress/work to fit in as best we can without showing our autistic needs."
> – Autistic parent

> "This is a lonely journey where it's in the too hard basket for everyone"
> – Non-autistic parent

Participants expressed conflicting opinions regarding acceptance of autism. Individuals across groups expressed that autistic people felt judged and sometimes afraid to go out in public, while professionals indicated that the public try to avoid interacting with, and are afraid of, autistic people. By contrast, some non-autistic parents indicated that members of the community were generally accepting.

Autistic people and non-autistic parents identified general hesitancy to provide a diagnosis due to autism being a 'negative label'. Parents sometimes felt that health professionals 'pitied' them or their child due to an autism diagnosis. Non-autistic parents and professionals also shared that family/whānau can struggle to come to terms with a diagnosis, which can lead to a delay in seeking assessment. Autistic people also reported not disclosing their diagnosis to avoid the stigma associated with autism.

Participants felt that autistic people were expected to 'fit in' rather than receive accommodations. Autistic people linked this expectation to fit in with feeling that they could not be themselves and being pressured to mask, particularly in the workplace. The identified consequences of choosing not to, or being unable to, mask included punishment, shaming, bullying, and loss of employment.

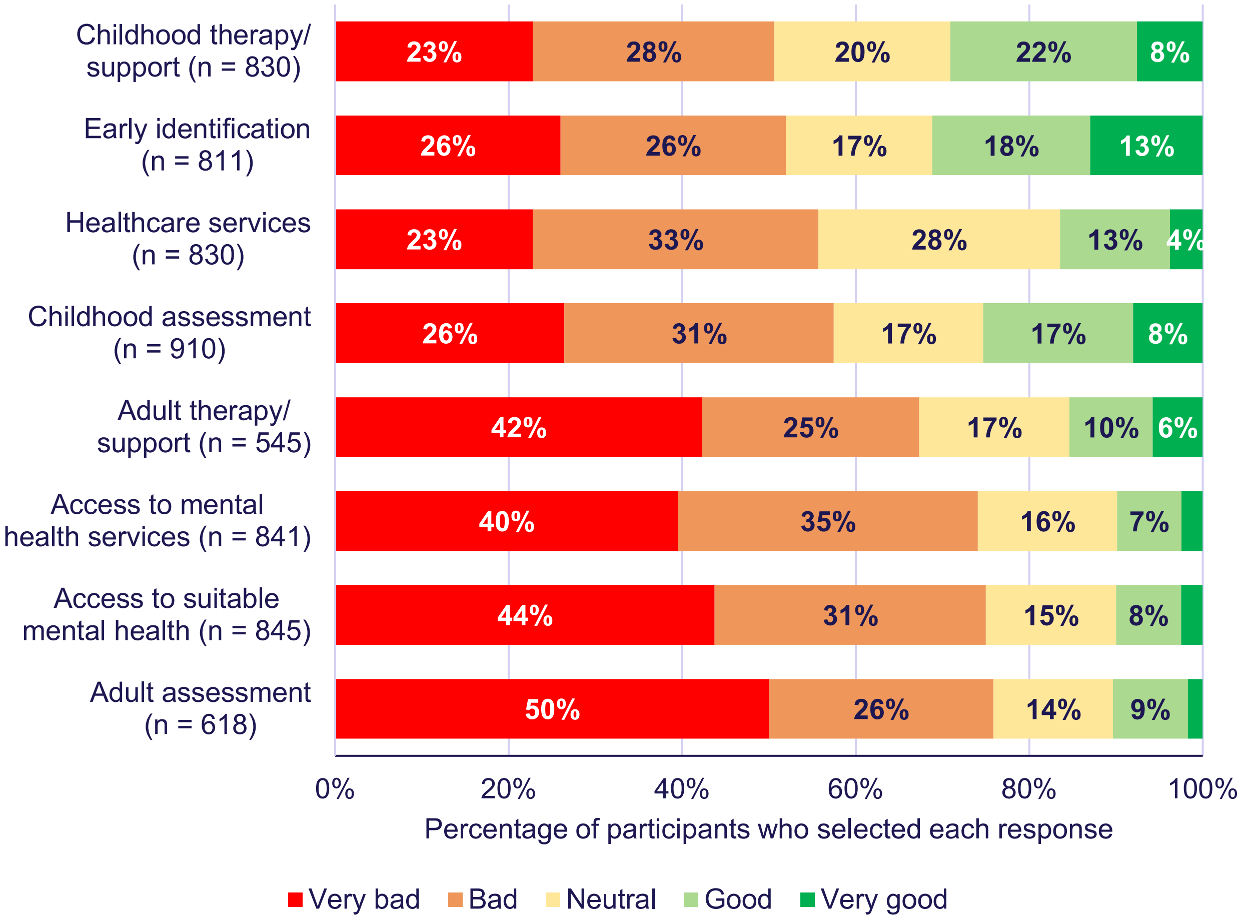
Across groups, autism was associated with feelings of loneliness and isolation for autistic people of all ages and, sometimes, their parents. Non-autistic parents shared that no one wanted to talk about autism or difficulties with their autistic child. Autistic people commented on current or previous exclusion by friends and the community and that they felt alone or like they didn't 'fit in.' They also shared that most or all their friends were neurodivergent.

Some participants indicated that acceptance of autism and neurodivergence was growing, due in part to increasing advocacy from autistic people and awareness of autism. Autistic adults wrote that the current generation of children is more accepting of neurodiversity. Participants identified positive aspects of autism, including seeing solutions others can't, bringing joy to parents' and family members lives, and that autism was a 'superpower.'

4.2.2 Overall experience of services

4.2.2.1 Experience of health and therapy

Figure 15. Participant-rated (across all groups) experiences of health and therapy services.



Participants provided ratings of their overall experience of health and therapy services. Participants most commonly rated their experience of adult assessment, adult therapy and support, access to mental health services, and access to *suitable* mental health services as 'very bad', while they most commonly rated their experience of assessment in children, therapy and support in children, and healthcare services as 'bad.' Early identification received an equal percentage of 'bad' and 'very bad' ratings.

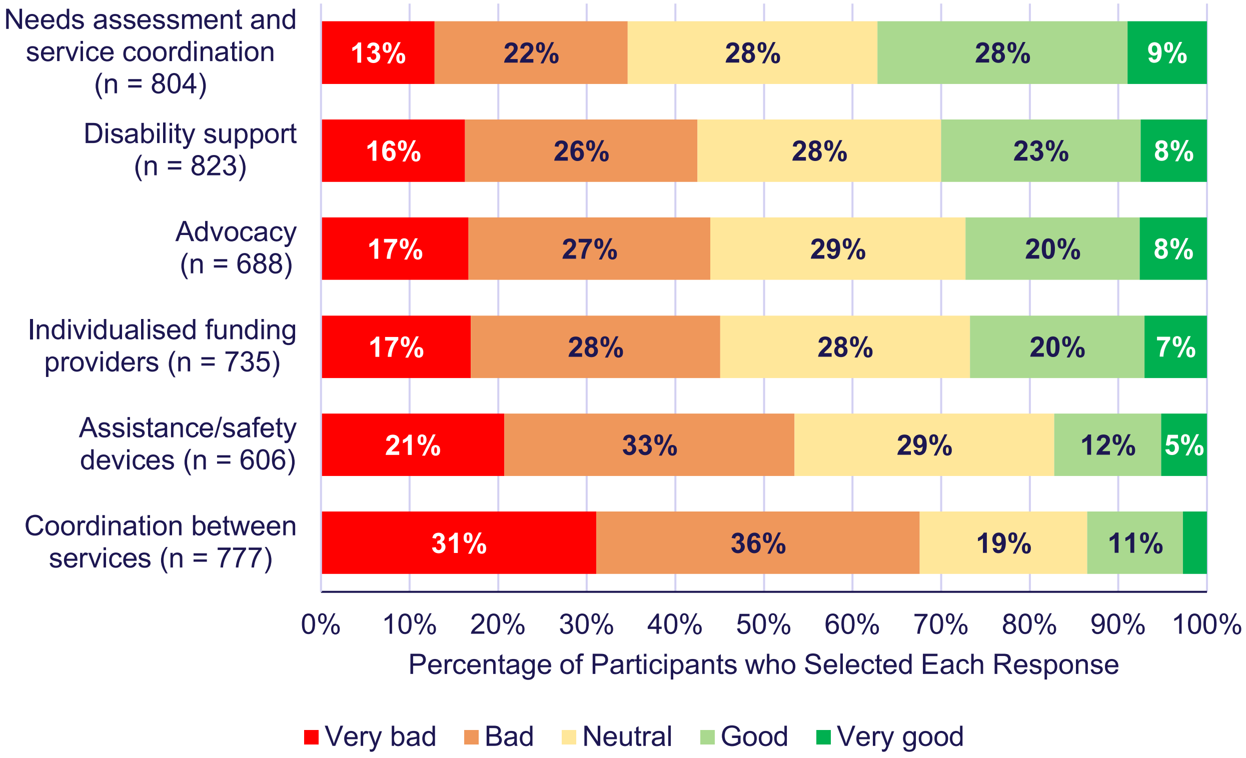
The experience of adult assessment was rated as ‘bad’ or ‘very bad’ by a higher percentage of participants (76% total) than the other health and therapy services. The experience of early identification was rated as ‘good’ or ‘very good’ by a higher percentage of participants (31% total) than the other health and therapy services. See Appendix D (Table 2) for a summary of ratings across participant groups.

Statistical analyses for primary identity/role suggested that autistic adult and/or autistic parents rated their experience of all health and therapy services, except access to autism assessment and diagnosis for children, significantly **lower** than at least one other identity group (see Appendix E, Table 5). Non-autistic parents and professionals rated their experience with access to adult assessment and diagnosis **lower** than family/whānau. Non-autistic parents also rated their experience with therapy and support at all ages significantly **lower** than family/whānau.

There were no significant differences in the experience of health and therapy services between ethnicity groups (see Appendix F, Table 5).

4.2.2.2 Experience of disability supports and services

Figure 16. Participant-rated (across all groups) experiences of disability supports and services.



Participants rated their overall experience of disability supports and services. Participants most commonly rated their experience of assistance and safety devices, individualised funding providers, and coordination between services as ‘bad’, while they most commonly rated their experience of advocacy, disability support, and the Needs Assessment Service Coordination (NASC) as ‘neutral.’

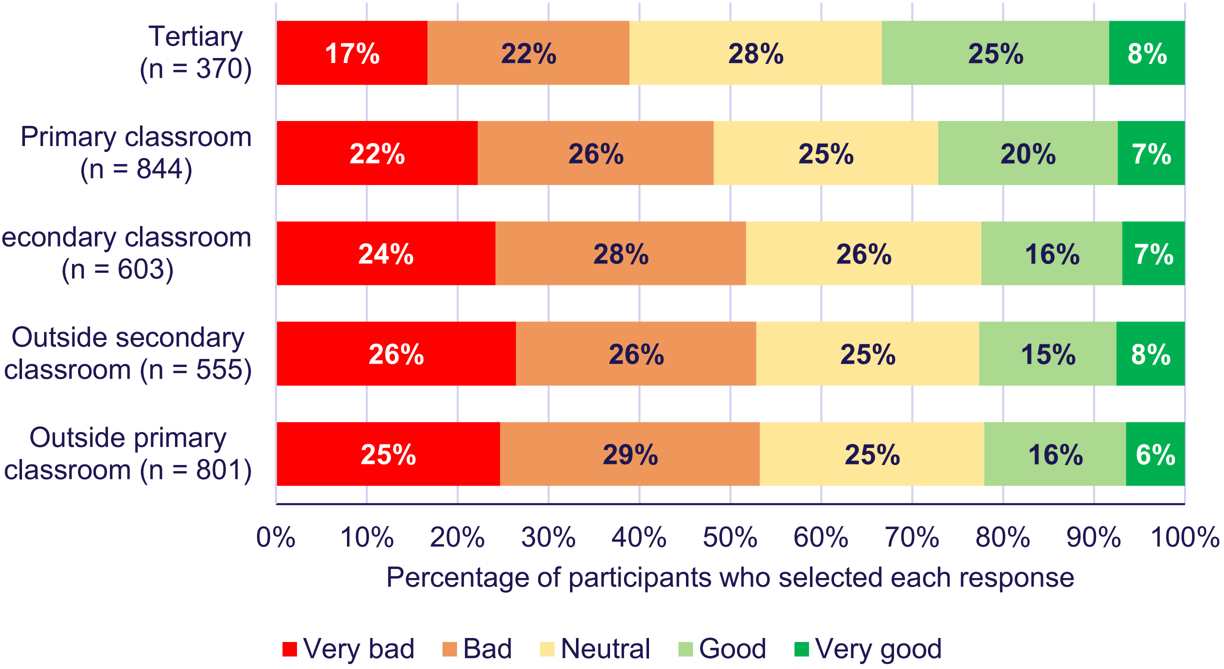
The experience of coordination between services was rated as ‘bad’ or ‘very bad’ by a higher percentage of participants (67% total) than other disability supports. The experience of the NASC was rated as ‘good’ or ‘very good’ by a higher percentage of participants (37% total) than other disability supports. See Appendix D (Table 2) for a summary of ratings across participant groups.

Statistical analyses for primary identity/role indicated that autistic parents rated their experience of coordination between services significantly **lower** than professionals and/or family/whānau (see Appendix E, Table 6). Non-autistic parents rated their experience of advocacy services significantly **lower** than professionals.

There were no significant differences in the experience of disability supports and services between ethnicity groups (see Appendix F, Table 6).

4.2.2.3 Experience of support in education

Figure 17. Participant-rated (across all groups) experiences of support in education.



Participants rated their overall experience of support in education. Participants most commonly rated their experience of support in tertiary education as ‘neutral’, while the most commonly rated their experience of support in all other areas of education as ‘bad.’

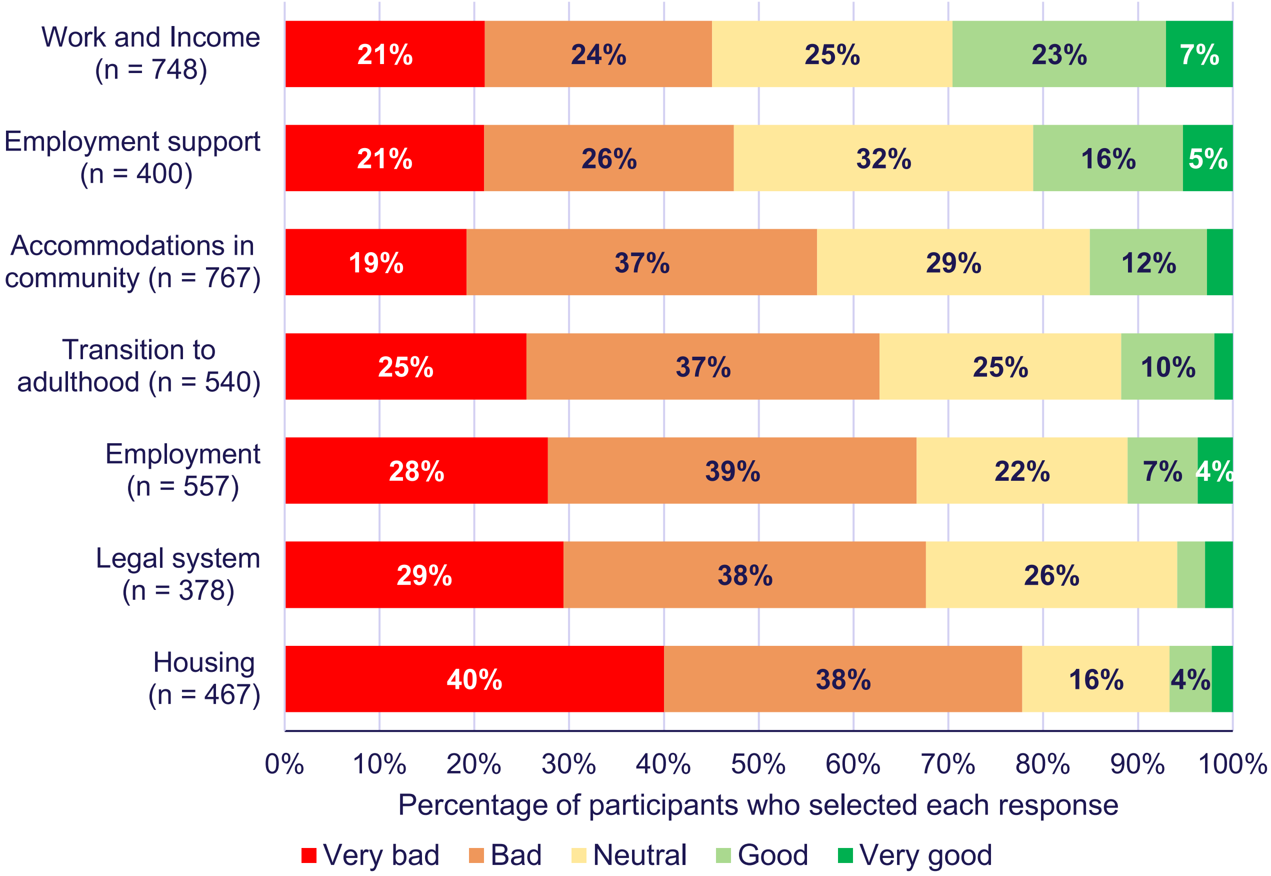
The experience of support outside the primary classroom was rated as ‘bad’ or ‘very bad’ by a higher percentage of participants (54% total) than other supports in education. The experience of support in tertiary education was rated as ‘good’ or ‘very good’ by a higher percentage of participants (33% total) than other supports in education. See Appendix D (Table 2) for a summary of ratings across participant groups.

Statistical analyses for primary identity/role indicated that autistic people and/or non-autistic parents rated their experience with most aspects of support in education significantly **lower** than professionals and/or family/whānau (see Appendix E, Table 6). Professionals also rated their experience of support and adjustments outside the secondary classroom significantly **lower** than family/whānau.

There were no significant differences in the experience of support in education between ethnicity groups (see Appendix F, Table 6).

4.2.2.4 Experience of living and community

Figure 18. Participant-rated (across all groups) experiences of living and the community.



Participants rated their overall experience of living and the community. Participants most commonly rated their experience of housing as 'very bad', accommodations in the community, transition to adulthood, employment, and the legal and justice system as 'bad', and Work and Income New Zealand and employment support services as 'neutral',

The experience of housing was rated as 'bad' or 'very bad' by a higher percentage of participants (78% total) than other aspects of living and the community. The experience of Work and Income New Zealand was rated as 'good' or 'very good' by a higher percentage of participants (30% total) than other aspects of living and the community. See Appendix D (Table 2) for a summary of ratings across participant groups.

Statistical analyses for primary identity/role indicated that autistic people and/or non-autistic parents rated their experience with most aspects of living and the community significantly **lower** than professionals and/or family/whānau (see Appendix E, Table 6). Professionals also rated their experience of the legal and criminal justice system significantly **lower** than family/whānau.

There were no significant differences in the experience of living and the community between ethnicity groups (see Appendix F, Table 6).

4.2.2.5 Qualitative comments: Awareness and information around supports and services

> “The systems there to help us are… hugely difficult to navigate. And help is not easy to find”
> – Autistic adult

> “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. That meant that people were not offered or aware of any supports. They also did not know what support might look like, or what they might benefit from. Some autistic people reported being too scared or stressed to access ambiguous services. Parents reported that this lack of knowledge extended to professionals, who also do not know what is available, so are not able to pass on the information.

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 they may have qualified for individualised funding but they did not know how to use it or were not aware of it until it was close to expiring.

4.2.2.6 Qualitative comments: Waitlists and delays

> “The current MoE 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

> “Incredibly challenging, isolating and depressing as a parent just wanting to help their child”
> – Non-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. Long waiting lists were associated with frustration and delays in accessing support.

4.2.2.7 Qualitative comments: Funding

> “Diagnosis has become a privilege”
> – Autistic adult

> “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

Participants identified funding as a barrier to diagnosis and support. 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.

Professionals felt that funding was limited for children who could speak and who did not have aggressive or disruptive behaviour.

Regarding schooling, participants emphasised a general lack of funding, particularly 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. Some non-autistic parents mentioned financial struggles due to homeschooling their child. Professionals reported that those without Ongoing Resourcing Scheme (ORS) funding did not get any support, while support for those with ORS funding was insufficient. Multiple parents indicated that a lack of their own, or government, funding prevented their child from attending a specialist school – their preferred educational option.

4.2.2.8 Qualitative comments: Lack of supports and options

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

> “I believe the education system is failing our kids”
> – Non-autistic parent

Participants across groups commented on a lack of supports and options across services. Some participants emphasised that there was a greater lack of support in smaller or regional communities. These issues ranged from shortages of trained professionals to a total lack of support in some areas, such as autism-specific mental health and aged-care services. There was also reported to be an absence of support for transitions, particularly transitions to adulthood. Several non-autistic parents also shared difficulties or concerns about support for the transition from intermediate to high school.

Participants noted a general absence of diagnostic and support services for autistic adults, as most services were for autistic children and/or their parents. Participants commented on persistent unemployment or underemployment for themselves or their adult autistic child. There was also a reported lack of workplace support for those who could find employment, which was sometimes associated with job losses. Some parents also reported that they had stopped or reduced their employment to care for their autistic child.

Participants indicated that housing support was similarly lacking, with few affordable options available, particularly for those who needed to live alone or had pets. Non-autistic parents reported that their adult autistic children continued to live with them because of a lack of other options. Autistic adults emphasised that they often needed to rely on their parents for support and advocacy due to a lack of formal support options.

Non-autistic parents remarked upon a lack of culturally responsive services and resources about Māori approaches to autism support. Autistic people indicated that supports were catered towards those with higher support needs and that there was limited support for those who did well academically or were “high masking.” In contrast, some non-autistic parents and professionals felt that services catered for “high functioning” autistic adults at the expense of those with higher needs.

Autistic people and non-autistic parents reported that, despite having funding, they could not find suitable support workers or respite carers to hire. Shortages in educational settings were linked to professionals providing support for a limited amount of time, being “spread too thinly”, and being too overworked to provide meaningful support.

Some Māori participants particularly felt that the Government denies equal treatment and rights to autistic people. They indicated that certain policies are either discriminatory or uninformed and therefore unhelpful. They further indicated that legislation positions autism and autistic people as a burden on society.

4.2.2.9 Qualitative comments: Accommodations and adjustments

> "Pretty much every clinical setting is a sensory nightmare for autistic people"
> – Autistic parent

> "[Work and Income has] zero understanding of how traumatising their offices are"
> – Family/whānau member

Participants across groups commented on the ability of professionals, services, and the broader community to make accommodations and adjustments for autistic people. In general, participants shared that most services 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 noted a lack of accommodations for communication differences. This included professionals who did not communicate clearly, an over-emphasis on verbal communication, and limited time to process communication. Autistic adults reported that professionals and services frequently did not accommodate preferred communication methods, including texting, providing pre-written information, and allowing use of augmentative and alternative communication devices. The need to book appointments and communicate over the phone was identified as a significant barrier to accessing some health and therapy services, as well as Work and Income.

Autistic participants reported that school settings, particularly open-plan classrooms, are not well-equipped for those who do not learn well in busy mainstream environments. Professionals similarly reported that the lack of structure and routine at school was unhelpful. Parents also mentioned encountering some school staff who were unable or unwilling to adapt their teaching approach to suit autistic children. Some participants felt that primary schools were more flexible and accommodating than secondary school, while some autistic participants noted that university was more accommodating than school.

Participants did also identify positive interactions with individuals who were flexible and willing to accommodate their, or their child's, needs in healthcare environments, school settings, and employment. Participants further commented on positive actions taken by the community including, for example, sensory-friendly or low sensory events and sessions. By contrast, some aspects of the community were reported to remain inaccessible, such as the inability to catch buses using a mobility scooter and to access housing that is suitable for co-occurring disabilities.

4.2.2.10 Qualitative comments: Processes for accessing support

> “I personally find my needs hard to meet with all the obstacles and complicated processes”
> – Autistic adult

> “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, and stressful. The specific challenges identified, depending on the service, included the need to complete lengthy and complicated or paper-based forms, separate diagnostic pathways for co-occurring conditions, excessive bureaucracy, unclear eligibility criteria, and frequent rejections. Professionals indicated that the need to manage staff and budgets in order to use individualised funding was a significant responsibility and barrier which resulted in inequitable access.

Some participants indicated that they were unable, or stopped trying, to access diagnosis or support for the reasons outlined above. Others shared that most individuals, particularly those with cognitive difficulties or mental health problems, were unable to navigate some systems without assistance. Even advocates and other professionals were noted to struggle with understanding and navigating these complex processes.

4.2.2.11 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 emphasised the need to strongly advocate for themselves, or their child, to access diagnosis and support. They reported that this was due, in part, to not being heard or taken seriously, or being dismissed by professionals across health, mental health, the Ministry of Education, Work and Income, and individualised funding providers. Participants also discussed not being believed by various services. For example, some autistic adults and parents shared that health and education professionals denied or diminished their experiences. Autistic people also mentioned that health professionals did not believe they were in pain due to their ability to mask. This need for persistent advocacy was associated with exhaustion and burnout, which sometimes led to giving up.

4.2.2.12 Qualitative 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”
> – Professional

Participants expressed that they, or their child, was frequently denied access to, or continuation of, services because of strict or inequitable eligibility criteria. For example, autistic adults mentioned being denied access to disability services because they were concurrently accessing mental health support. Participants across groups identified difficulties with accessing services such as Work and Income and Needs Assessment and Service Coordination without proof of an autism diagnosis.

Sometimes the eligibility requirements and reasons for allocation of support were unclear. For example, parents mentioned that individualised funding appeared to be unevenly allocated across individuals and regions without any clear reason.

Some health and education services were reported to only be accessible to those with Ongoing Resourcing Scheme (ORS) funding, aggressive behaviours, visible impairments, or ‘severe’ impairments. 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.

4.2.2.13 Qualitative 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 and that services often appeared to be working against, rather than with, each other. Examples included poor coordination between mental health and disability services and between the Ministries of Health and Education. 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. Non-autistic parents also reported that they were contacted by multiple different agencies following their child’s diagnosis, who did not appear to be communicating with one another. There was also reported to be inconsistency in services across regions.

4.2.2.14 Qualitative comments: Wellbeing and mental health

> "If we are not safe to be ourselves, our needs cannot be met"
> – Autistic adult

> "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 services on family and child mental health. This included the effects of supports and services which were indicated to be harmful and/or traumatic for autistic people. Participants identified that some professionals used inappropriate and harmful strategies for supporting autistic children, including those aimed at reducing the child's autism characteristics in an attempt to make them appear more 'normal'.

A few participants raised serious instances of abuse or neglect by professionals. For example, parents shared that their autistic child had either been physically assaulted, restrained, or kept in exclusionary environments, such as locked rooms, by school staff. Some autistic parents reported similar instances in the community, including with police. Multiple parents reported that schools were not held accountable for these incidents and autistic adults emphasised the courts would not press charges for assaults.

Autistic people linked mental health issues to the need to mask their autism. Non-autistic parents also associated schooling with long-term negative effects on their child, particularly reduced self-esteem. Participants also felt that modern and open learning environments were harmful for autistic children. Non-autistic parents reported that some school staff made autistic children feel unsafe.

Autistic people and parents linked the search for supports for themselves and their autistic children with poor parental mental health outcomes, including burnout and stress. Parents associated interactions with Work and Income and, particularly the pressure to work when their children needed extra care, with reduced mental health. They also shared instances of feeling threatened or intimated by Oranga Tamariki staff. Professionals and non-autistic parents also linked poor parental mental health outcomes with autistic child behaviour.

4.2.2.15 Qualitative comments: Exclusion from mainstream schooling

> "Years of battles to get any educational placement"
> – Autistic parent

> "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 ("Kiwi stand-downs") and being required to reduce their child's school hours without following any formal process.

The identified reasons for exclusions and standdowns included punishment for meltdowns and other autistic behaviours, and a lack of support or access to safety equipment. Parents and professionals also reported instances of autistic children being banned or discouraged from attending school trips and after-school activities.

Participants across groups shared the need to home-school autistic children because of an inability to enrol a child in school or to find a school that could meet their child's needs. They also linked this with bullying at school and the child's anxiety and poor mental health.

4.2.3 Bullying and discrimination

Figure 19a. Autistic peoples' (n = 307) personal experiences of bullying/harassment/hate crime and discrimination.

Figure 19b. Reports of knowing at least one autistic person who had experienced bullying/harassment/hate crime and discrimination across participant groups (n = 1042).

Most autistic participants (all identities/roles included) had personally experienced bullying, harassment or hate crime, and discrimination. Most participants across groups also knew at least one autistic person who had experienced bullying, harassment or hate crime, and discrimination. See Appendix D (Table 4) for a summary of ratings across participant groups.

While most participants in each primary identity group/role knew someone who had experienced bullying, harassment, or hate crime and discrimination, statistical analyses suggested that autistic adults were significantly **more likely** to know someone than at least one other identity group (see Appendix E, Tables 9 -10). There were no differences in experiences of bullying, harassment or hate crime and discrimination of autistic people across ethnicity groups (see Appendix E, Tables 9 -10).

4.2.3.1 Qualitative comments: Bullying and harassment

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

> “Bullying has been a huge problem for my child over the years”
> – Non-autistic parent

> “[We] prefer not to disclose our diagnosis, knowing the potential harassment we could face as a result”
> – 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. This included being verbally abused for being “weird” or “different”, and for meltdowns. There were also reported instances of racial abuse, including racially motivated vandalism. It is important to note that the most severe incidents of bullying and abuse were reported by Māori participants.

Participants across groups reported that schools often took no action against bullies, or that the child themselves was punished for responding to bullies. A couple of non-autistic parents also reported that their child’s school had responded proactively and well to instances of bullying.

4.2.3.2 Qualitative comments: Discrimination

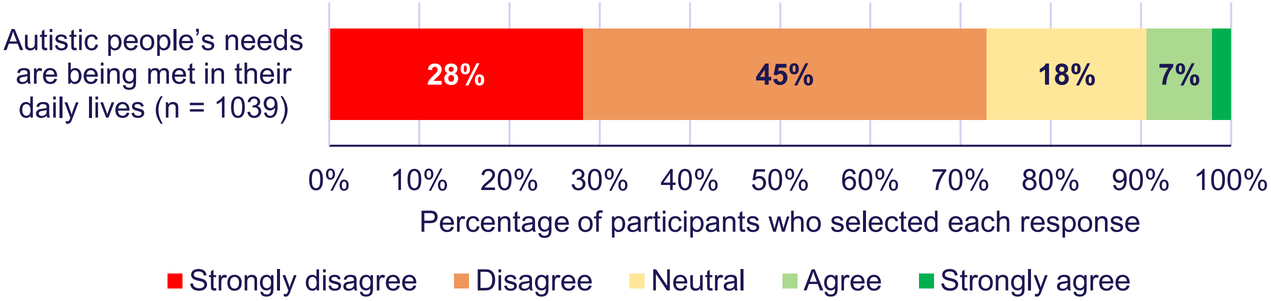
> “Until we get rid of laws and policies that see autism as a burden on society... we will still be ruled by the majority wanting the minority to be more like them”
> – Autistic adult

> “Autistic people should not have to hide who they are in order to obtain employment”
> – Non-autistic parent

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 felt that job interviews were designed to screen out autistic people and non-autistic parents indicated that employers did not want to ‘risk’ hiring autistic people. Participants across groups also commented that it was discriminatory that an autism diagnosis could affect immigration status.

4.2.4 Meeting autistic peoples' needs

Figure 20. Participant-rated (across all groups) agreement that autistic people's needs are being met in their daily lives.

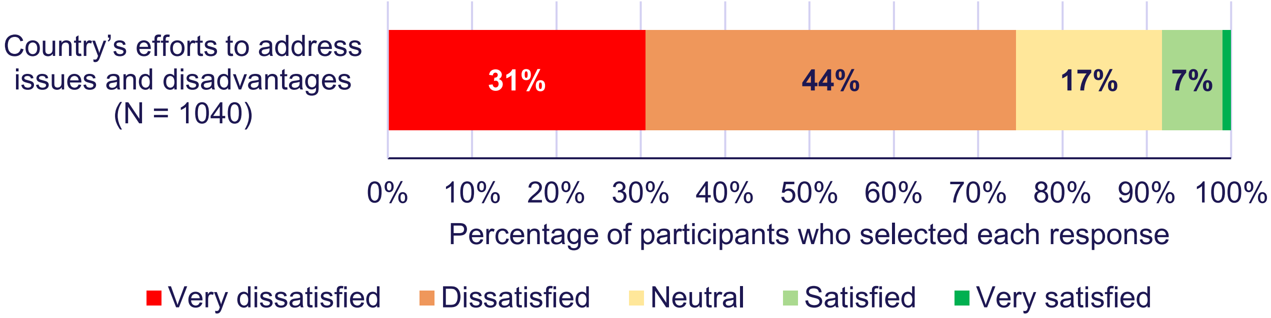


Autistic people and parents linked the search for supports for themselves and their autistic children with poor parental mental health outcomes, including burnout and stress. Parents associated interactions with Work and Income and, particularly the pressure to work when their children needed extra care, with reduced mental health. They also shared instances of feeling threatened or intimated by Oranga Tamariki staff. Professionals and non-autistic parents also linked poor parental mental health outcomes with autistic child behaviour.

While all primary identity groups at least 'disagreed' that autistic people's needs are being met, statistical analyses indicated that autistic parents were **more likely to disagree** than non-autistic parents, professionals, and family/whānau (see Appendix E, Table 11). Non-autistic parents and autistic adults were also **more likely to disagree** than professionals and family/whānau. There were no differences in perceptions of whether autistic people's needs were being met across ethnicity groups (see Appendix F, Table 11).

4.2.5 Addressing issues and disadvantages for autistic people

Figure 21. Participant-rated (across all groups) satisfaction with New Zealand's efforts to address issues and disadvantages for autistic people.



The majority of participants were 'dissatisfied' or 'very dissatisfied' with the country's efforts to address issues and disadvantages for autistic people (75% total). See Appendix D (Table 5) for a summary of ratings across participant groups.

While all primary identity groups were, at a minimum, 'dissatisfied' with the country's efforts to address issues and disadvantages, statistical analyses indicated that autistic people and non-autistic parents had **lower satisfaction** than professionals and/or family/whānau (see Appendix E, Table 12). There were no differences in satisfaction across ethnicity groups (see Appendix F, Table 12).

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

4.3.1 Awareness of the Guideline

Figure 22a. Participant-rated (across all groups) awareness of any edition of the Guideline (n = 1042).

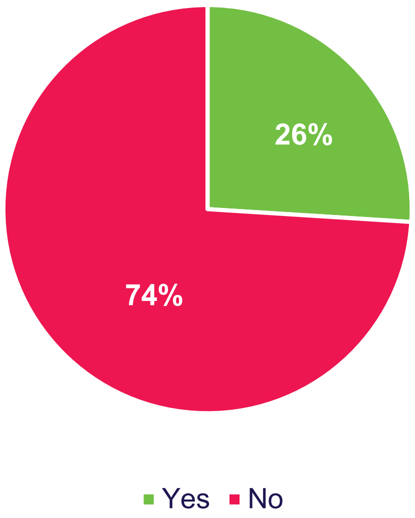
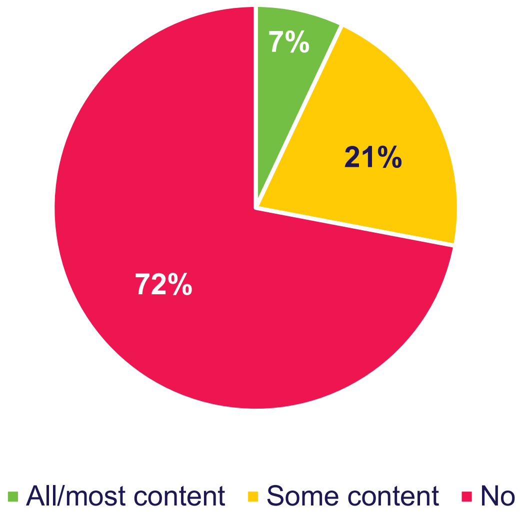


Figure 22b. Participant-rated (across all groups) awareness of the current Guideline (n = 1042).

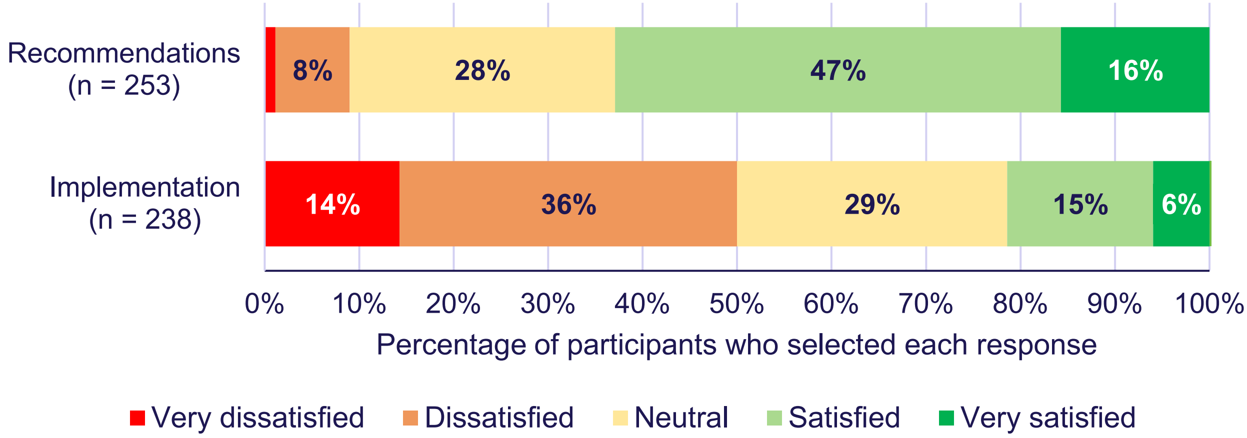


Participants were provided with information about the Guideline and were asked whether they were aware of any edition of the Guideline, and if they had knowledge of what is included in the current (third) edition of the Guideline. Most participants were not aware of any version of the Guideline, including the current Guideline. See Appendix D (Tables 6 and 7) for a summary of ratings across participant groups.

While all primary identity groups were generally unaware of the Guidelines, statistical analyses indicated that autistic people and non-autistic parents were **less aware** of any version of the Guideline and the current Guideline than professionals (see Appendix E, Table 13). A total of 46% of professionals were aware of any version of the Guideline, while 45% of professionals were aware of some to all of the contents of the current Guideline. Māori were **less aware** of any edition of the Guideline than non-Māori (see Appendix F, Table 13).

4.3.2 Satisfaction with the Guideline

Figure 23. Participant-rated (across all groups) satisfaction with the Guideline.



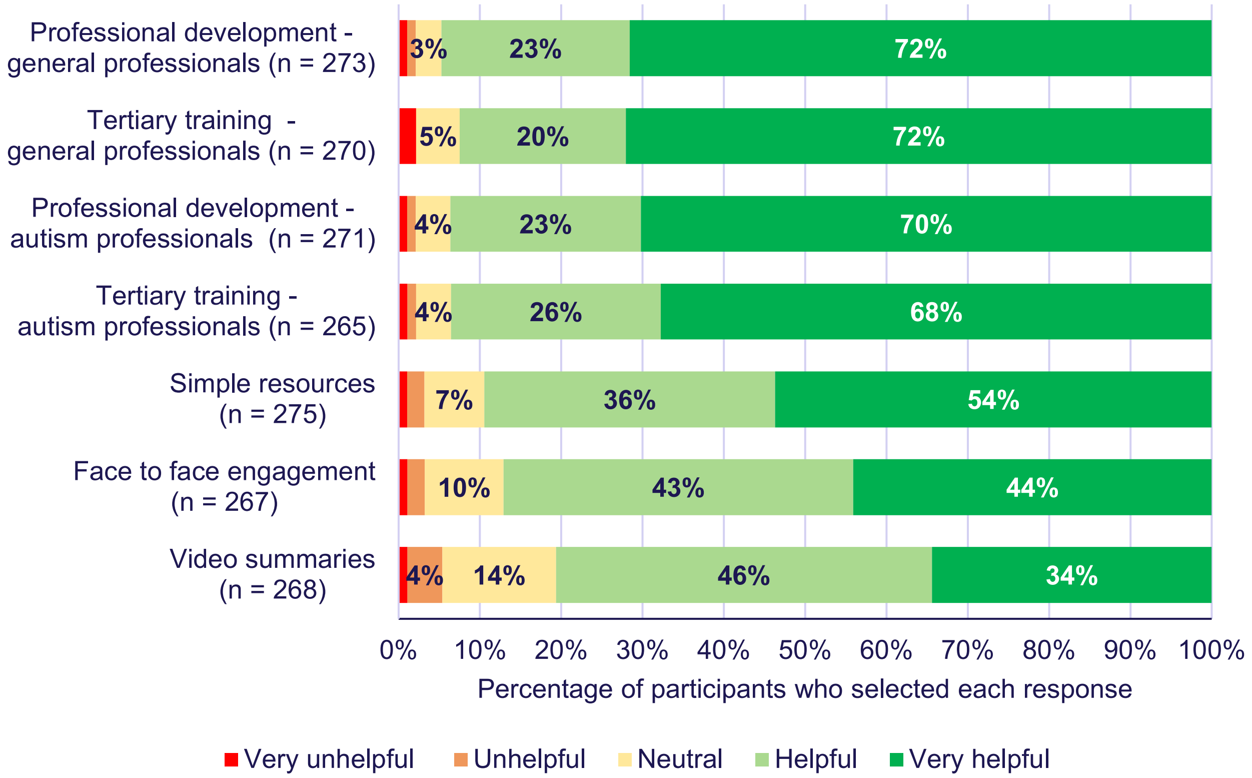
Participants who were aware of the Guideline and its contents were asked to rate their satisfaction with its recommendations, good practice points and implementation. Participants most commonly indicated that they were 'satisfied' with the Guideline recommendations and good practice points, while they were most commonly 'dissatisfied' with the implementation. See Appendix D (Tables 8) for a summary of ratings across participant groups.

Statistically, participants were **more satisfied** with the Guideline recommendations and good practice points than they were with its implementation (See Appendix G, Table 1). A total of 68% of professionals were 'satisfied' or 'very satisfied' with the recommendations and good practice points in the Guideline, while only 14% of professionals were 'satisfied' with its implementation, and none were 'very satisfied'.

Statistical analyses for primary identity/role indicated that autistic people had **lower satisfaction** with the Guideline's recommendations and good practice points than non-autistic parents (See Appendix E, Table 14). There were no significant differences in satisfaction with the Guideline's recommendations and good practice points across ethnicity groups (see Appendix F, Table 14). There were no significant differences in satisfaction with the Guideline *implementation* across primary identity or ethnicity groups.

4.3.3 Suggestions to help implement the Guideline

Figure 24. Participant-rated (across all groups) helpfulness of approaches for supporting the implementation of the Guideline.



Participants who were aware of the Guideline and its contents rated the helpfulness of various suggestions for supporting its implementation. All approaches were most commonly rated as 'very helpful', except video summaries which were most commonly rated as 'helpful'.

Statistically, tertiary training and professional development for general professionals (e.g., general practitioners, dentists, counsellors) and/or the autism professional were rated significantly **more helpful** than the other suggestions (See Appendix G, Table 2). Video summaries were rated significantly **less helpful** than all other suggestions except face-to-face engagement.

Autistic adults, non-autistic parents, and whānau/family rated professional development for the general public as the single most helpful approach, while autistic parents and professionals rated professional development for the autism sector as the most helpful. See Appendix D (Table 9) for a summary of ratings across participant groups and Appendix H (Table 1) for the ranked order of helpfulness of each approach across groups.

While all primary identity groups generally found each approach at least 'helpful', statistical analyses indicated that autistic people rated the helpfulness of face-to-face engagement, and tertiary training and ongoing professional development for the autism sector significantly **lower** than professionals (see Appendix E, Table 15). There were no differences in perceived helpfulness across ethnicity groups (see Appendix F, Table 15).

4.3.3.1 Qualitative comments: Guidelines

> "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

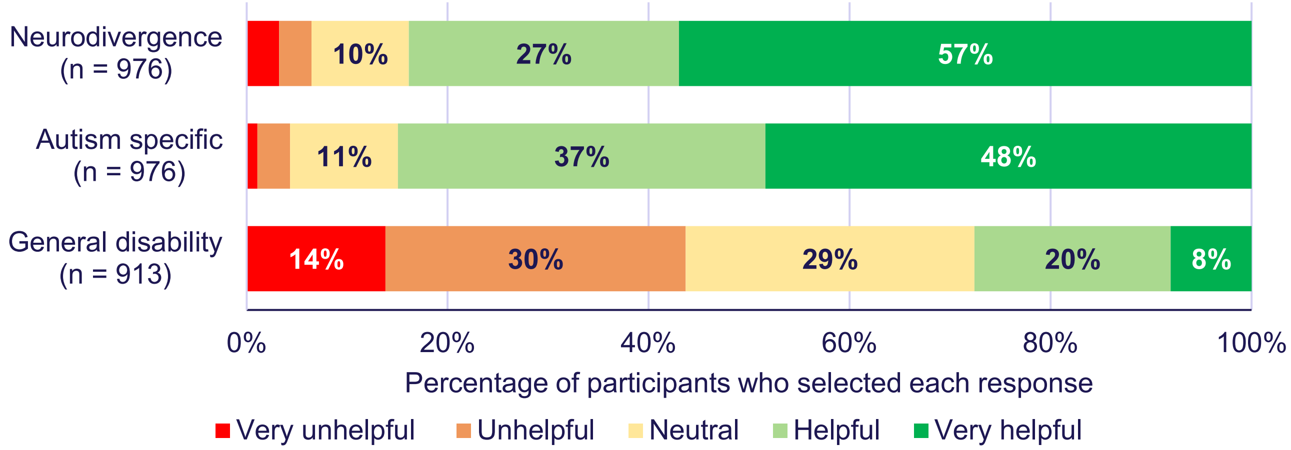
Participants across groups commented on various aspects of the contents and implementation of the Guideline. Some autistic adults commented that the Guideline is a valuable resource, however, participants also identified varying issues with the length and wording used in the Guideline, as well as the practices that are and are not supported or emphasised within 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.

4.4 Looking to the Future

4.4.1 Neurodivergence, autism specific, and general disability approaches

Figure 25. Participant-rated (across all groups) helpfulness of neurodivergence, autism-specific, and general disability approaches.



Aotearoa New Zealand currently takes a general disability approach to supporting autistic people, but some other countries have autism-specific or neurodivergence approaches. Participants rated the perceived helpfulness of each of these approaches. Both the neurodivergence and autism-specific approaches were most commonly rated as 'very helpful', while the current disability approach was most commonly rated as 'unhelpful'. Statistically, the disability approach was rated as significantly **less helpful** than both the neurodivergence and the autism specific approaches, which did not significantly differ from one another (See Appendix G, Table 3).

There were no differences in the ranked order of helpfulness of each approach across primary identity groups, with all groups rating the neurodivergence approach as the most helpful. See Appendix D (Table 10) for a summary of ratings across participant groups and Appendix H (Table 2) for the ranked order of helpfulness of each approach across groups.

Statistical analyses for primary identity/role indicated that professionals rated the helpfulness of the general disability approach and the neurodivergence approach significantly **higher** than autistic parents and non-autistic parents respectively (see Appendix E, Table 16).

Ethnicity analyses indicated that Asians rated the helpfulness of the current disability approach significantly **higher** than non-Asians (see Appendix F, Table 17).

4.4.1.1 Qualitative 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

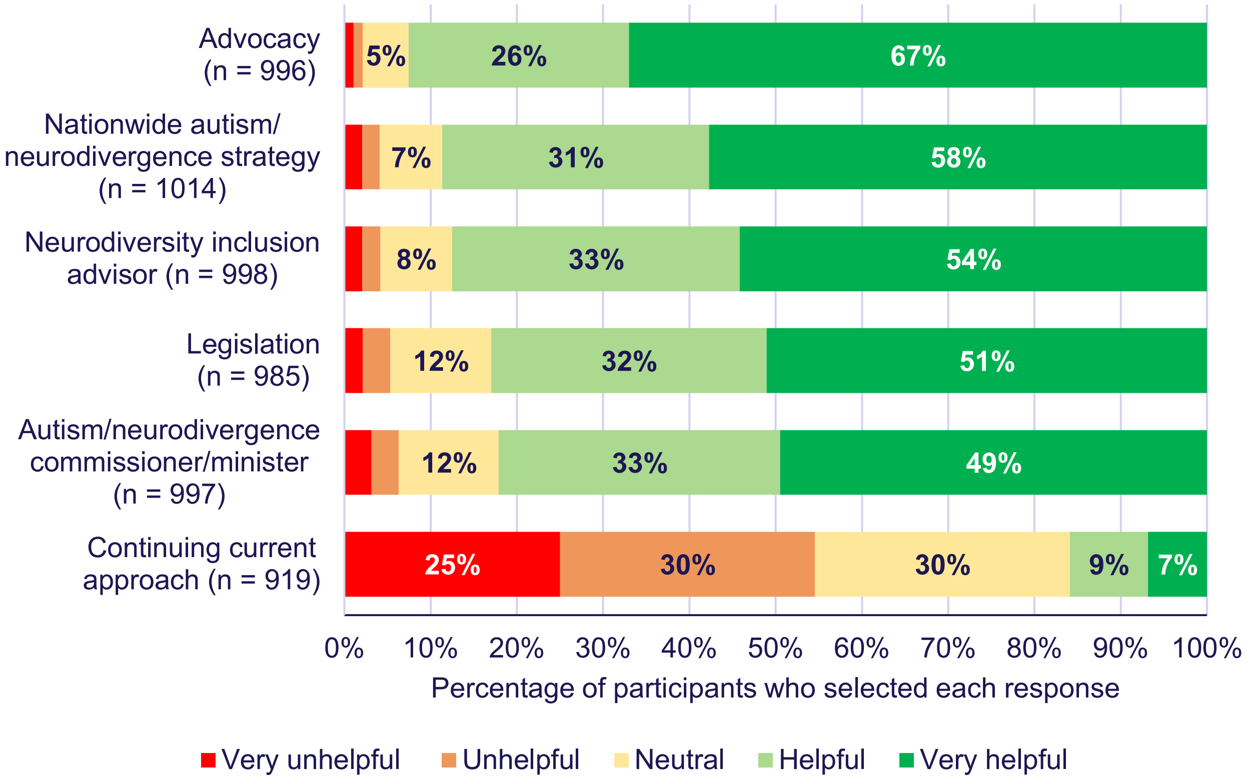
Participants across groups identified strengths and challenges of both the autism-specific and neurodivergence approaches to support. Some autistic adults also suggested that an autism-specific approach within a broader neurodivergence umbrella would be best.

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. They suggested that this approach would allow support to be better tailored to autistic people and would better emphasise communication support needs in particular. Autistic people and parents indicated that terms associated with neurodivergence were euphemistic and would not contribute to decreasing stigma around autism.

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. They indicated that an autism-specific approach could encourage 'one size fits all' supports. Participants suggested that this approach was better suited to supporting the high number of autistic individuals with co-occurring conditions. Some participants associated a neurodivergence approach with 'strength in numbers' and an ability to collectively seek funding and support.

4.4.2 Future autism support

Figure 26. Participant-rated (across all groups) helpfulness of potential future supports for autistic people in New Zealand.



Participants rated the helpfulness of potential future supports for autistic people. Participants most commonly rated all future supports as ‘very helpful’, except continuing the current approach for which the most common ratings were both ‘unhelpful’ and ‘neutral’. Statistically, advocacy was perceived to be significantly **more helpful** than all other future supports except a nationwide autism and neurodivergence strategy (see Appendix G, Table 4). Continuing with the current approach was perceived to be significantly **less helpful** than all other approaches.

All participants rated advocacy as the single most helpful support except family/whānau who rated neurodiversity inclusion advisors as the most helpful. See Appendix D (Table 10) for a summary of ratings across participant groups and Appendix H (Table 3) for the ranked order of helpfulness of each support across groups.

Statistical analysis for primary identity indicated that family/whānau rated the helpfulness of continuing with the current approach significantly **higher** than all other groups, while professionals also rated this significantly **higher** than autistic parents (See Appendix E, Table 17). 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.

Ethnicity analyses indicated that, while still rated as generally unhelpful, Pacific and Asian Peoples rated continuing with our current approach **higher** than non-Pacific and non-Asian Peoples (see Appendix F, Table 17).

4.4.2.1 Qualitative comments: Overall support needs

> "What matters most is that ND [neurodivergent] people define our own support"
> – Autistic adult

> "Māori have their own approach which works for Māori"
> – Non-autistic parent

Participants across groups identified helpful qualities of future autism support. Autistic people emphasised the importance of society as a whole valuing diversity and shared that services should honour autistic peoples' special interests, talents, and unique ways of thinking. Similarly, 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. Māori participants expressed particular opposition to referring to autism as disability. They instead favoured a strengths-based approach and promotion of the positive aspects of autism and autistic achievements.

Participants also stressed the importance of lived experience and that there should be more autistic-led support. Autistic adults also indicated a need for more realistic media representations of autistic people. Autistic people suggested that education, health, and policy systems should employ more autistic people and that the Guidelines should be autistic-led. Non-autistic parents also wanted to work with professionals who were themselves parents of autistic children.

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. However, some non-autistic parents and professionals did indicate that supports should not be 'race based.' Autistic people also noted the importance of catering for all autistic people, including those with 'marginalised identities' such as gender diverse individuals and those from non-Pākehā cultures.

4.4.2.2 Qualitative 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

> "Autism… should be compulsory learning for all Govt agencies involved in public service i.e. police, teachers, nurses"
> – Professional

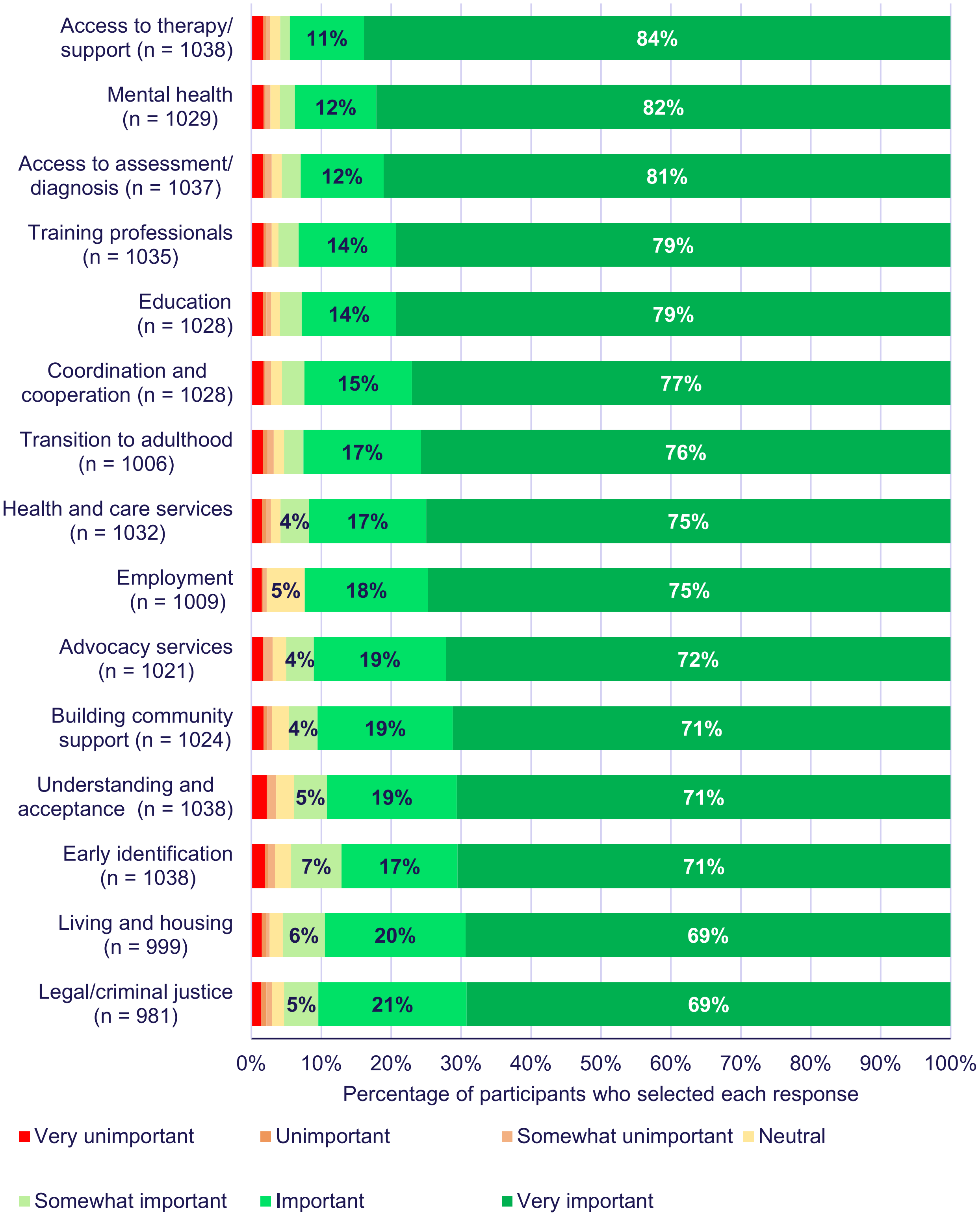
Participants across groups emphasised the need for further training and education around autism for professionals, services, government organisations, and the public. The identified areas in which further training was required, either overall or for specific professionals and groups, included:

- Neurodiversity.
- Autism presentation in girls, women, and non-binary people.
- The contents of the Guideline.
- Autistic masking and catatonia training for general practitioners.
- Augmentative and alternative communication training for speech language therapists.
- Training in hiring neurodivergent individuals for employers.
- Training in the relationship between autism and parenting for Oranga Tamariki.
- Training in meltdowns and how to resolve situations with autistic people for the police.

Autistic adults and professionals indicated that the public needs more information and education on autism to move away from stereotypes. Parents shared that young children should be educated about neurodiversity so that autism is normalised from an early age.

4.4.3 Areas to address in future approaches

Figure 27. Participant-rated (across all groups) importance of areas to be addressed in future approaches to providing support for autistic people.



Participants rated the importance of addressing a variety of different areas in any future approach to autism support. All 15 areas were most commonly rated as 'very important' to address. Statistically, mental health services/outcomes and access to therapy and support were rated as significantly **more important** to address than all other areas (see Appendix G, Table 5). While still 'very important', early identification, living and housing, and support with the legal and criminal justice system were all rated as significantly **less important** to address than access to therapy and support, mental health services/outcomes, access to assessment and diagnosis, training for professionals, and education/inclusion outcomes.

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. See Appendix D (Table 11) for a summary of ratings across participant groups and Appendix H (Table 4) for the ranked order of importance of each area across groups.

While all primary identity groups most commonly perceived each area as 'very important' to address, autistic adults rated the importance of the following areas significantly **lower** than non-autistic parents, autistic parents, and/or professionals (see Appendix E, Table 18):

- Early identification of autism.
- Access to assessment and diagnosis.
- Access to therapy and support.
- Education inclusion/outcomes.
- Transition into adulthood.
- Training for professionals.
- Coordination and cooperation between types of services.
- Support within the legal and criminal justice system.

There were no differences in the importance of areas to address across ethnicity groups (see Appendix F, Table 18).

4.4.3.1 Qualitative 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

> "I do think the current approach of changing autistic behaviour so that they fit in better is potentially damaging for individuals"
> – Professional

Participants across groups identified improvements to healthcare and disability support. Non-autistic professionals and parents felt that services should either be coordinated by one person or that there should be a centralised database of all services. Non-autistic parents emphasised the importance of support throughout the lifespan, including appropriate support and care for autistic adults.

Participants also indicated a need for funding 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 needs assessment should focus on actual support needs, rather than eligibility for existing services, and 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 supress autistic behaviours or make autistic people seem more neurotypical. While some non-autistic parents wanted behaviourally-based approaches to be banned, others advocated for increased access to, and funding, for this type of support.

4.4.3.2 Qualitative comments: Improving education

> "I would've loved to have had my youngest at a specialist school but he won't get ORS [ongoing resourcing scheme] so will be mainstream and I'm not happy about it"
> – Autistic parent

> "I do think the current approach of changing autistic behaviour so that they fit in better is potentially damaging for individuals"
> – Professional

Participants had several suggestions for improvements to the education system. 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. A couple of parents felt that every class should have a permanent, full-time teacher aide. Two non-autistic parents also mentioned the need for autism-specific sex education and the importance of teaching informed consent.

4.4.3.3 Qualitative 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

> "Individuals that have the potential to be employed and live independently are in reality denied this opportunity"
> – Non-autistic parent

Participants across groups identified a variety of improvements to autistic adults' experiences of living and the community. This included 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.

4.4.3.4 Qualitative comments: Improving research

Autistic people wanted to have greater input into research. They also wanted more research into the differential effects of mental illness 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.

4.4.3.5 Qualitative comments: Improving government and legislation

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

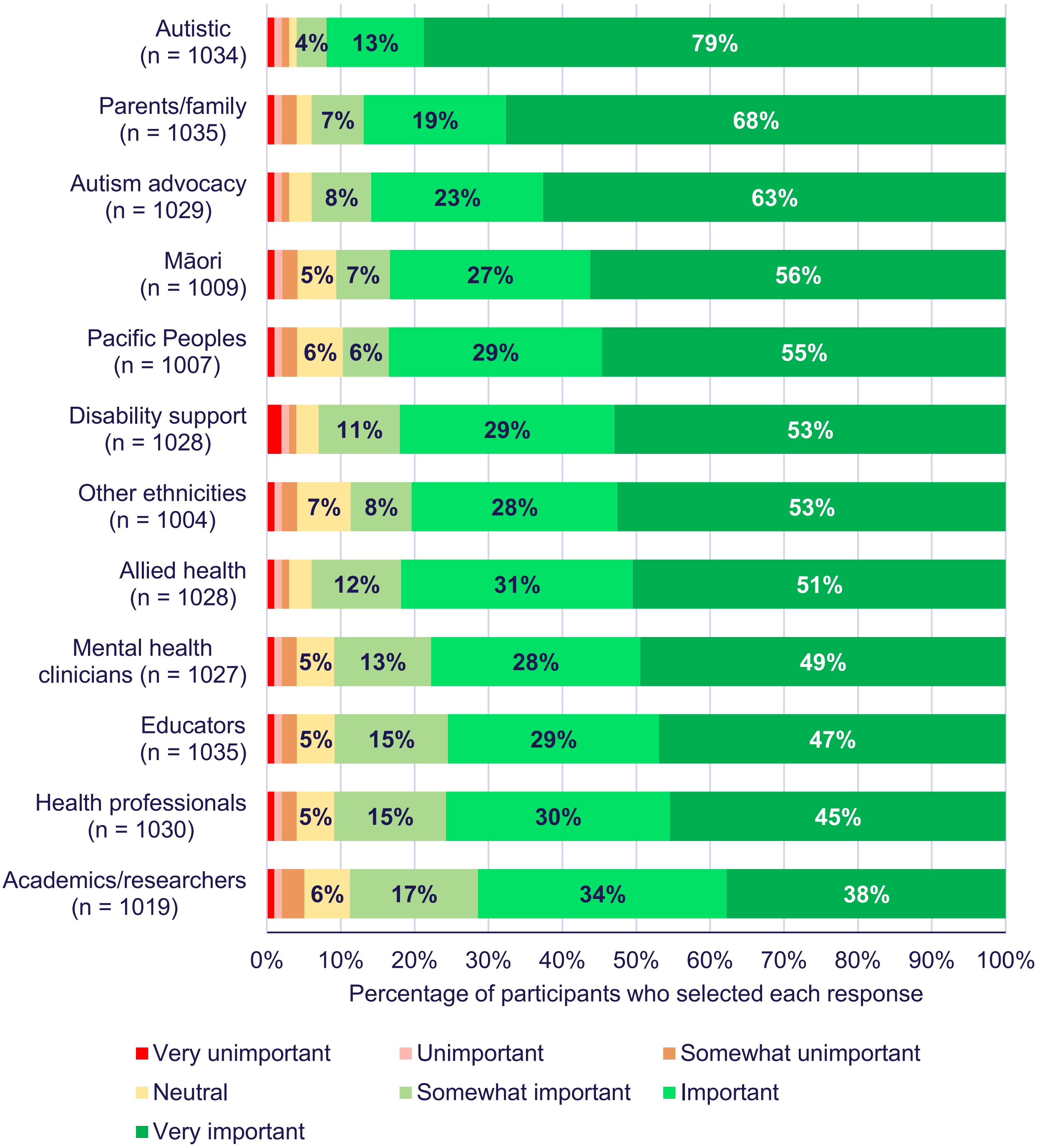
> “Immigration NZ… places awful horrible stress on families who cannot risk getting a dx [diagnosis] (and thus access to services) because they fear they'll be deported. It's a terrible thing to do to families”
> – Family/whānau member

Participants noted multiple improvements to government and legislation. 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 including, for example, administration of the Work and Income database and increasing oversight of the education system. Multiple autistic parents suggested changing the taxation system to redistribute funding from large corporations to health and education. Autistic adults and family/whānau wanted changes to immigration rules which currently frame an autism diagnosis as a burden.

4.4.4 People to include in future development

Figure 28. Participant-rated (across all groups) importance of people to be included in decision-making and the development of future approaches.



Participants rated how important it would be to include various groups of people in decision making and development of future approaches to autism support. All 12 groups of people were most commonly rated as ‘very important’ to include. Statistically, autistic people were rated as **more important** to include than any other group, followed by parents/family, who were themselves **more important** to include than any of the remaining groups (see Appendix G, Table 6). Whilst still ‘very important’, academics and researchers were rated as **less important** to include than all other groups.

Autistic people and professionals rated autistic people as the single most important group to include, while non-autistic parents and family/whānau rated parents/family as the most important. See Appendix D (Table 12) for a summary of ratings across participant groups and Appendix H (Table 5) for the ranked order of importance of each group of people to include across groups. While all primary identity and ethnicity groups rated each type of person as at least ‘somewhat important’ to include, the results of statistical analyses (see Appendices C and D, Table 19) indicated that:

- There was no significant difference between primary identity groups in the importance of including autistic people.
- Autistic adults rated the importance of including all groups except autistic people and other ethnicities significantly **lower** than at least one other group.
- Autistic parents rated the importance of including all groups except autistic people, parents/family, academics/researchers, Māori, and other ethnicities significantly **lower** than non-autistic parents, professionals and/or family/whānau.
- Non-autistic parents rated the importance of including Māori and Pacific Peoples **lower** than professionals and including other ethnicities **lower** than non-autistic parents.
- Māori rated the importance of including Māori and Pacific People **higher** than non-Māori.
- Pacific People rated the importance of including Māori, Pacific People, and other ethnicities **higher** than non-Pacific People.

4.4.4.1 Qualitative comments: Important voices

> "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 across groups commented on the essential people to include in decision making and future approaches. They 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. Autistic adults wanted to lead the decision making and change process by, for example, writing future legislation and strategies themselves.

Autistic people generally positioned themselves as the most important voices and some felt that non-autistic input should be minimised. In contrast, non-autistic parents and professionals emphasised the importance of collaboration between autistic and non-autistic people but often positioned autistic people as consultants, rather than taking a leading role.

Autistic parents wanted a variety of autistic people to be involved in decision making, rather than just one 'token person.' 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 rainbow community and autistic women in the development of future initiatives.

Autistic adults felt that autistic Māori and Pacific Peoples should also 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. Professionals also supported including Māori in policy decisions, as well as other ethnicities such as Asian and Pacific Peoples. Parents and professionals touched on the importance of including parents and/or family/whānau. Some non-autistic parents indicated that parents should be leading the decision-making process as those who best understand the issues facing autistic people. Some parents specifically wanted parents of very young children and older autistic adults to be included.

4.5 Limitations

Several limitations should be considered when interpreting the findings presented in this report. Although the survey was completed by a large number of people, it was not equally representative of all groups. Groups that were comparatively underrepresented included males (particularly in the non-autistic groups), young and older adults, and Pacific Peoples. Non-autistic parents were the most well-represented, with over 40% of participants selecting this as their primary role/identity. Thus, results may be skewed in favour of the perceptions of this group. The survey also employed Pākehā research approaches. Kaupapa Māori frameworks, led by Māori researchers, would have been preferable for eliciting the perspectives and experiences of Māori participants.

Individuals may have been more likely to participate in the survey and, subsequently, to complete the optional open-ended questions if they had strong feelings about the topic. This means that responses, and particularly qualitative responses, may not be representative of all members of the autistic and autism community in Aotearoa. The open-ended questions were broad and mostly elicited negative responses relating to the current state of services in Aotearoa. Results may have been different if the survey had included an explicit question related to examples of positive experiences of supports.

While easy read versions of the survey were available, none were requested. This suggests that the opportunity to engage in the survey may not have been accessible to those with lower literacy skills. Further, participants provided conflicting responses to questions about co-occurring diagnoses and modes of communication, rendering these data unusable. This meant that it was not possible to determine whether autistic people with complex communication needs and co-occurring diagnoses were well represented. The recruitment approach included considerable dissemination through relevant health, education and disability organisations and Ministries, so the percentage of autistic participants in this survey who were employed may be higher than in the general population.

Online questionnaires can be subject to selection bias against those with limited internet access and cultural or linguistic diversity. For this reason, the online questionnaire was made accessible through hardcopy and interview. However, given that the questionnaire was hosted and completed online, the study sample may not include many individuals who do not have relatively easy access to internet. Other research methods such as interviews and focus groups may have been more appropriate for these individuals. It was not possible to determine the perspectives and experiences of autistic children regarding supports in Aotearoa as individuals under the age of 18 were not eligible to participate in the survey.

The survey also focused on participants’ retrospective experiences of supports with no time limit, including parents recalling experiences of accessing childhood supports for their now-adult autistic children. Further, participants may have responded to the questions about the importance of future supports based on their own experiences and perspectives. For example, prioritising areas which relate most directly to their own needs rather than those of the whole community, such as employment for autistic adults and education for parents of autistic children. Findings may have been different if the questions focussed solely on participants’ experiences and perceptions of supports that they were currently accessing.

5. Recommendations and Future Directions

Overall, findings from this project indicate the autistic and autism community are generally dissatisfied with efforts to address issues and disadvantages for autistic people in Aotearoa. They typically perceived the understanding and acceptance of autism across services as ‘neutral’ to ‘good’, but their personal experience of services was generally ‘bad’.

Autistic respondents and non-autistic parents indicated instances of bullying and discrimination, including racial biases held by professionals and disproportionate barriers for Māori. Participants across groups also identified a range of services and professionals that caused harm. This included reports of inappropriate use of restraint, practices that caused trauma and deteriorating mental health, and a focus on reducing the child’s autism characteristics in an attempt to make them appear more ‘normal’. Autistic people and non-autistic parents reported avoiding some services altogether because of the potential for harm.

Participants expressed that they, or their child, were not able to access services in a manner consistent with their needs. These included reports of services that were not designed or appropriate for autistic people, practitioners with limited knowledge and understanding of autism, and an inability to support co-occurring conditions. Parents reported that there was limited quality and continuity across services due to high staff turnover and limited collaboration. Parents also commented on their children being illegally excluded or blocked from enrolling in school.

While the community were generally satisfied with recommendations contained within the Guideline, they were not satisfied with its implementation. Participants rated tertiary training and professional development for professionals as more helpful than other suggestions for implementation of the Guideline.

An autism-specific and/or neurodivergence approach to autism support was rated as significantly more helpful than the current general disability approach taken in Aotearoa. Specifically, advocacy and a national autism/neurodivergence strategy were rated as the most helpful future approaches. Autistic people were rated as significantly more important to include in decision making and development of future approaches than any other group, followed by parents and family/whānau. These findings suggest it is essential for autistic people to lead decision making and development of any future approaches to autism support.

It is clear extensive work is needed to get autism support right in Aotearoa. Recommendations from this project align with previous recommendations in autism diagnosis and support (Evaluation of New Zealand’s diagnostic process) (Autism New Zealand, 2020) as well as education for neurodivergent learners (Neurodiversity in Education Coalition, 2023).

Autism CRC emphasises that all strategy initiatives and related resources should be **explicitly informed by evidence**.

5.1 Awareness and education campaign

Government funding for a multi-year national autism awareness and education campaign. Key features of this campaign should include **a focus on understanding and acceptance of autism in society**:

- **Led by a diverse range of autistic people,** including those with co-occurring conditions, complex support and/or communication needs across the lifespan. This would ensure outdated stereotypes and common myths are replaced by a neurodiversity-affirming paradigm where autism is understood as a brain difference and accepted as a valuable form of human diversity.
- **Targeting key groups** including:
    - Professionals working in the general public (e.g., GPs, dentists, counsellors) and those who interact with autistic people less frequently.
    - Autism sector professionals.
    - The legal and justice systems and organisations such as Oranga Tamariki, Work and Income New Zealand, Accident Compensation Corporation (ACC), and Police.
    - The education system, including educational leadership (board of trustees, principals etc) and teachers.
    - Employers and workplaces.
- **Changing attitudes** and challenging stereotypes with a focus on understanding –
    - **Lived experience.** Listening to, believing, and respecting the autistic person as the expert on their own experiences.
    - **Meeting the needs of all autistic people across the lifespan.** All autistic people have different support needs throughout their life.
- Specifically, increasing awareness in the following areas –
    - **Levels of bullying, harassment and discrimination** faced by autistic people and approaches to reduce this.
    - **Early signs of autism** both for professionals frequently working with children and for the general public to facilitate early identification of autism.
    - How to **identify and avoid harmful or potentially harmful services**.
    - Respect for **augmentative and alternative communication** as a valid form of communication including for partially speaking autistic people.
    - Identifying **autism in women, trans, and gender diverse populations**.
- Increasing awareness of the current **Aotearoa New Zealand Autism Guideline** and how it can be used to support autistic people in Aotearoa, including summaries written for, presented by, and promoted amongst different audiences such as specific professional groups, autistic people, family/whānau, Māori and Pacific Peoples, and the general public.

5.2 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** across health, disability, education, and social services as well as government and NGOs, with value placed on lived experience.
- **Tertiary training and professional development** for professionals working in the autism sector and professionals working in the general public (e.g., GPs, dentists, counsellors), specifically including –

  - **Autistic voices** and autistic conceptions and understanding of autism.
  - Understanding and implementation of the **Aotearoa New Zealand Autism Guideline.**
  - Ensuring these programmes are **free and accessible** (e.g., online) and are available and distributed through relevant professional boards.
  - **Funded internship placements** in key allied health areas, such as Speech Language Therapy, Occupational Therapy, and Psychology.
- **Implementation of existing autism-specific workforce development frameworks** (for example, Te Tau Tītoki [Te Pou, 2019] and Equitable Access to Wellbeing [Te Pou, 2022]), including ensuring autistic people are involved in training professionals.
- Competitive salaries for professionals working in the public sector, manageable workloads, and regular access to professional development and supervision to **ensure staff retention**.

5.3 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:

- Commitment to a **human rights and inclusion framework** in the provision of services, rather than a deficit-based approach of 'fixing' or 'combatting' autism.
- Services to be **tailored and flexible to the individual needs of autistic people**, ensuring services are accessible to people with varying communication needs and preferences (e.g., discomfort and inability with talking on the phone, need for providing information in written form) and cognitive abilities (e.g., simple and clear processes, language, and forms).
- Ensuring **access** in the following areas –
  - **Autism assessment and diagnosis, particularly for adults**. Ensure adequate funding for the creation of multidisciplinary teams to support implementation of best-practice recommendations.
  - **Mental health services** tailored to autistic people's unique experiences and needs. This includes **mental health support** for families and whānau of autistic children, particularly when awaiting diagnosis, and when the child is newly diagnosed.
  - **Therapy and support** (e.g., occupational therapy, speech and language therapy, etc.) for autistic people across the lifespan.
  - **Affordable and accessible housing options** that are fit for autistic people's needs (e.g., if an autistic person can't live in a flatting or boarding situation in relation to being autistic, ensuring there are other equivalent options).
  - **Advocacy services** so that individuals, families and whānau have greater support in advocating for their needs. This may include developing and promoting the role of **autism/neurodiversity inclusion advisors** in a wide range of services and sectors.
  - **Supportive educational settings** including non-mainstream school options (e.g., specialist schools, home-based education) and the removal of modern learning environments.
  - Autism-affirming and autism-specific **aged care services**.
- Increase funding for key services to **reduce waitlists**. While waitlists exist, provide **low-intensity support as an interim measure**.

5.4 Coordinated support system

Previous research has highlighted the need to develop a strategic and long-term approach to autism in Aotearoa involving inter-ministry, interdisciplinary, cross-sector, and consumer-oriented collaboration (Autism New Zealand, 2020). The current project builds on the need for a **coordinated approach** within the autism support system, including:

- Rolling out the **Enabling Good Lives (EGL)** approach across the country.
- Ensuring every autistic person, family and whānau has a **Navigator** to help them navigate the system, as is being piloted by Whaikaha –
    - One central database of supports and services to ensure information about services is clear, consistent, easy to find, and region specific. Responsibility and accountability for awareness of the database and ensuring it is up to date.
- **Streamline the needs assessment (outcome planning) process** with one assessment across disability support services, education, and other social services to ensure equitable access across support areas. This should include incentives for services to provide complementary rather than competing services.
- **Consistency of services across regions** to reduce 'postcode lottery'. This may include increasing telehealth service delivery when appropriate and travelling assessment and diagnosis for people who live in areas without access to diagnosis.

5.5 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 (Rees & Long, 2021), key components to consider include:

- Broader in-depth consultation with the autistic and autism community about whether to take an **autism-specific or neurodivergence approach**. An autism and 'neuro-disability' approach with intentional consideration of co-occurring conditions (e.g., ADHD, Foetal Alcohol Spectrum) may be recommended. Further considerations include –
    - Removing the need for an official diagnosis for accessing services and using needs-based assessments instead. This is particularly relevant for Māori due to cultural barriers in the diagnosis and assessment process.
    - Reducing exclusive entry criteria such as the need to be in crisis, to be showing violent behaviour, or to have visible impairments.
- **Adequate and coordinated funding for implementation.** Responsive funding mechanisms to ensure demand is met, particularly if broader entry requirements are applied.
- **Autistic-led and genuine co-production** with the community, including a diverse range of autistic people (e.g., those with co-occurring conditions, complex support and/or communication needs) as well as parents and whānau of autistic people and autism organisations.
    - Genuine engagement with **tāngata whaitakiwātanga Māori** to ensure leadership and development of an approach that fits within Te ao Māori principles and understanding of takiwātanga.
- **An action/implementation plan with accountabilities for delivery,** including –
    - Clear and tangible objectives, targets, measures, and indicators to track progress.
    - Timelines and processes for eliciting reviews of services and supports, particularly from autistic people, family and whānau.

  - **Incentives, sanctions, and accountability** to ensure people get what they are entitled to, that the quality is acceptable, and that the service is not likely to lead to harm. Examples include the Tertiary Education Commission Disability Action Plans for tertiary institutions or Neurodiversity in Education Coalition proposed Neurodiversity and Disability Action Plans for schools (Opai, 2020).
- **Effective governance** to lead and coordinate implementation of the strategy and action plan. This could involve establishment of an **autism or neurodivergence commissioner** to drive and monitor coordinated implementation across ministries, organisations, and individuals.
- **Coherent linkages to the broader policy and legislation context.** This would mean ensuring key policy and legislative areas (e.g., education, employment, legal and justice systems) include an autism and/or neurodivergence focus. This includes integration with the:
  - Aotearoa New Zealand Autism Guideline.
  - Disability Strategy and Disability Action Plan.
  - United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

6. References

Whaikaha – Ministry of Disabled People and Ministry of Education. (2022). *Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau* (3rd edition). Wellington: Whaikaha – Ministry of Disabled People.

Opai, K. (2020). *From autism to takiwātanga: An origin story* [Online conference presentation]. Australasian Society for Autism Research Conference, Wellington, New Zealand 2020.

Durie M. (1984). Te taha hinengaro: An integrated approach to mental health. *Community Mental Health in New Zealand, 1,* 4-11.

Beri, K (2019). *Learning from the Waitangi Tribunal Māori health report*. The Policy Place. https://thepolicyplace.co.nz/2019/07/the-ps-are-out/

Ministry of Health. (2018). *Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan.* Wellington: Ministry of Health.

Enabling Good Lives. (2023). *About Enabling Good Lives*. https://www.enablinggoodlives.co.nz/about-egl/

Ministry of Social Development. (2016). *New Zealand Disability Strategy 2016-2026.* https://www.odi.govt.nz/nz-disability-strategy/

Ministry of Social Development. (2019). *Disability Action Plan 2019-2023: Putting the New Zealand Disability strategy into Action.* https://www.odi.govt.nz/disability-action-plan-2/

United Nations. (2006). *Convention on the Rights of Persons with Disabilities (CRPD).* http://www.un.org/esa/socdev/enable/rights/convtexte.htm

Mason D., Capp S. J., Stewart G. R., Kempton M. J., Glaser K., Howlin P., & Happé, F. (2021). A meta-analysis of outcomes studies of autistic adults: Quantifying effect size, quality, and meta-regression. *Journal of Autism and Developmental Disorders, 51,* 3165–79.

Rees, N. & Long, T. (2021). *Towards a national autism strategy: International lessons for Australia.* https://www.amaze.org.au/wp-content/uploads/2021/10/Towards-a-national-autism-strategy-international-lessons-Oct-2021-Amaze.pdf

Australian Government Department of Social Services. (2023). *Developing the national autism strategy*. https://engage.dss.gov.au/developing-the-national-autism-strategy/.

Heslin, P. (2023). *Principle Disability Category and percentage of Disability Category (SOCRATES Disability Support Services data 30 June 2023).*

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative health research*, *15*(9), 1277-1288.

Autism New Zealand. (2020). *Autism/Takiwātanga: The pathway to diagnosis and supports in New Zealand.* https://autismnz.org.nz/wp-content/uploads/2021/05/Autism-NZ-Diagnosis-Report-Final.pdf

Neurodiversity in Education Coalition. (2023). *Unlocking the enormous potential of neurodiverse learners: White Paper*. https://www.neurodiversity.org.nz/white-paper

Te Pou. (2019). *Te Tau Tītoki: A framework for supporting people on the autism spectrum.* https://www.tepou.co.nz/resources/te-tau-t%C4%ABtoki-a-framework-for-supporting-people-on-the-autism-spectrum

Te Pou. (2022). *Equitable Access to Wellbeing.* Te Pou https://www.tepou.co.nz/resources/equitable-access-to-wellbeing-framework-pdf

Our values

Inclusion
Valuing lived experience

Innovation
Solutions for long term challenges

Evidence
Truth in practice

Independence
Integrity through autonomy

Cooperation
Capturing opportunities together

AutismCRC

Independent national source of evidence for best practice

autismcrc.com.au