

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

Appendices

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Appendix A

Survey Questions

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

We want to know how you feel about how things are going, whether you feel what we're doing in Aotearoa New Zealand is enough, and if not, what is needed to get things right?

The survey will remain open until 31/05/2023. If you do not finish the survey in one sitting, you can return later by pressing the "Next" button at the bottom of the page to save your responses and then the "Exit" button at the top of the page to leave the survey. Click on the survey link from the same computer or device to go back into the survey to continue your previous answers. Your previous answers will be unchanged. **You need to answer all questions, but each question has an "unsure", "not applicable" or "prefer not to say option".**

Thank you for taking the time to complete this survey.

1. You must meet the below criteria to complete this survey.

- I currently live or have lived in Aotearoa New Zealand at some point in the last 5 years
- I am 18 years or over
- I am one or more of the following:
 - Autistic (Self diagnosed)
 - Autistic (formally diagnosed)
 - Parent/carer of an autistic person
 - Family/whānau member of an autistic person
 - Professional who has worked with at least one autistic person in the last 5 years
 - Researcher or policy maker in the disability sector

If you do not meet all three of the above criteria, you are not eligible to participate in this survey. Thank you for taking the time to consider this research.

Section one: General demographic information

1. What is your age?

- Age (in years):
- Prefer not to say

2. Which gender do you most identify with?

- Female
- Male
- Non-binary
- Other (specify)

- Prefer not to say

3. What is your ethnicity? Select all that apply.

- Pākehā/New Zealand European
- Māori
- Pasifika
- Chinese
- Indian
- Other (specify):

- Prefer not to say

4. What is your residency status in New Zealand?

- Permanent resident
- Citizen
- Other (Specify):

5. What is your relationship to autism? Please select all that apply.

- Autistic (formally diagnosed)
- Autistic (self-diagnosed)
- Parent or caregiver of an autistic person (including parents of autistic adults)
- Family/whānau member of an autistic person (other than parent or caregiver)
- Professional (Please specify – *optional):

- Researcher or policy maker in the autism field
- Other (Specify):

- Prefer not to say

6. We understand that you may belong to more than one of the following groups, however for this survey please indicate one role/identity as your primary relationship to autism

- Autistic (formally diagnosed)
- Autistic (self-diagnosed)
- Non-autistic Parent or caregiver of an autistic person (including parents of autistic adults)
- Autistic Parent or caregiver of an autistic person (including parents of autistic adults)
- Family/whānau member of an autistic person (other than parent or caregiver)
- Professional (Please specify – *optional):

- Researcher or policy maker in the autism field
- Other (Specify):

- Prefer not to say

7. If you are autistic, what is your employment status?

- Employed full time (paid)
- Employed part time (paid)
- Working as a volunteer (unpaid)
- Unemployed looking for work
- Unemployed not looking for work

8. If you are autistic, have you accessed any employment support services?

- Yes
- No
- Prefer not to say

Any further comments (this is optional, and not included in the estimated completion time):

For the following section, if you are a parent of multiple autistic children, please complete questions 8-11 with one of your children in mind. You are welcome to provide further information on your other children in the comment box.

9. If you are autistic or a parent/caregiver of an autistic person:

- **How old were you when you were diagnosed? (If you are self-diagnosed, how old were you when you worked this out?)**

- **How old was your child when they were diagnosed?**

- My age (in years):
- My child's age (in years):
- Prefer not to say

Any further comments (this is optional, and not included in the estimated completion time):

10.If you are autistic or a parent/caregiver of an autistic person, are there any other conditions you/your child have been diagnosed (formally or self) with that you are comfortable sharing? (Data not reported)

| | Me | My child |
|---|-----------------------|-----------------------|
| Not applicable | <input type="radio"/> | <input type="radio"/> |
| No other diagnoses | <input type="radio"/> | <input type="radio"/> |
| ADHD | <input type="radio"/> | <input type="radio"/> |
| Mental health condition (such as depression, anxiety, PTSD, bipolar etc.) | <input type="radio"/> | <input type="radio"/> |
| Learning disability (Intellectual disability) | <input type="radio"/> | <input type="radio"/> |
| Learning difficulty (e.g., dyslexia, dyspraxia, dysgraphia, dyscalculia) | <input type="radio"/> | <input type="radio"/> |
| Speech-language delay | <input type="radio"/> | <input type="radio"/> |
| Developmental delay | <input type="radio"/> | <input type="radio"/> |
| Eating disorder (ARFID, Anorexia, bulimia, binge eating disorder) | <input type="radio"/> | <input type="radio"/> |
| Epilepsy | <input type="radio"/> | <input type="radio"/> |
| Tourette's/tic disorder | <input type="radio"/> | <input type="radio"/> |
| Prefer not to say | <input type="radio"/> | <input type="radio"/> |

Other (specify for yourself and/or your child):

Any further comments (this is optional, and not included in the estimated completion time):

11.If you are autistic or a parent/caregiver of an autistic person, what mode/s of communication do you/your child usually use? Select all that apply. (Data not reported)

| | Me | My child |
|--|-----------------------|-----------------------|
| Speech | <input type="radio"/> | <input type="radio"/> |
| Sign (either NZSL or another sign language) | <input type="radio"/> | <input type="radio"/> |
| A communication (AAC) device (speech-generating device, iPad with communication app) | <input type="radio"/> | <input type="radio"/> |
| Prefer not to say | <input type="radio"/> | <input type="radio"/> |
| Not applicable | <input type="radio"/> | <input type="radio"/> |

Other (specify):

Any further comments (this is optional, and not included in the estimated completion time):

12.If you are autistic or a parent/caregiver of an autistic person, where did you/your child receive most of your/their primary and secondary schooling?

- Mainstream school
- Home-school
- Correspondence school
- Specialist school
- other (please specify)
- Prefer not to say

Any further comments (this is optional, and not included in the estimated completion time):

Section two: How happy are you with how things currently are?

In this section we want to understand your experiences and satisfaction with individuals and services. This includes accessibility, availability, understanding and inclusiveness.

- How would you rate the understanding and acceptance of autism from the following groups?** (We understand that your answers for each statement might vary in different contexts, i.e., you might have had a really good experience in one place but a really bad experience in another. So, for the purposes of this section, rate your experience in general. You are welcome to leave a comment about your different experiences in the comment section at the bottom of this question).

Understanding and acceptance of Autism in health and therapy

| | Very bad | Bad | Neutral | Good | Very Good | Unsure/not relevant |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| General practitioners (GP) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other Health clinicians (e.g., other doctors/nurses/medical professionals) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Mental health clinicians (e.g., psychologists, psychiatrists, counsellors, mental health nurses etc.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other therapists (e.g. Occupational therapists, speech and language therapists) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Disability support services (e.g. support workers, carer support, respite, etc.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| NASC (needs assessment and service coordination) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Individualised funding hosts/providers (e.g. Manawanui, Geneva Healthcare, Mycare, etc.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| ACC | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

If you like, you can tell us more about why you selected your responses (this is optional, and not included in the estimated completion time).

Understanding and acceptance of Autism in the Community

| | Very bad | Bad | Neutral | Good | Very Good | Unsure/ not relevant |
|-----------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------------------------|
| Family/wider whānau | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Friends/peers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Colleagues | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| The general community | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Police | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Employers/managers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Employment support services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

If you like, you can tell us more about why you selected your responses (this is optional, and not included in the estimated completion time).

Understanding and acceptance of Autism in Education

For those who were home-schooled, or are home-schooling, you are welcome to use the comment box to share any relevant information.

| | | Very bad | Bad | Neutral | Good | Very good | Unsure/ not relevant |
|---|----------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------------------------|
| Teachers | Pre-school | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | Primary | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | Secondary | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | Tertiary | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Teacher aides/education support workers | Pre-school | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | Primary | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | Secondary | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | Tertiary (not reported) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Specialist support (e.g., SENCO, learning support, disability support, RTLB, educational psychologist etc). | Pre-school | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | Primary | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | Secondary | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | Tertiary | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Leadership (e.g., Principals, deans, school boards, etc.) | Pre-school | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | Primary | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | Secondary | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | Tertiary | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

If you like, you can tell us more about why you selected your responses (this is optional, and not included in the estimated completion time).

Understanding and acceptance of Autism in other contexts

| | Very bad | Bad | Neutral | Good | Very good | Unsure/ not relevant |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------------------------|
| Legal system/courts/ judges/lawyers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Work and Income New Zealand (WINZ) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Oranga Tamariki | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

If you like, you can tell us more about why you selected your responses (this is optional, and not included in the estimated completion time).

2. How would you rate your overall experience with the following services in Aotearoa New Zealand?

(We understand that your answers for each statement might vary in different contexts, i.e., you might have had a really good experience in one place but a really bad experience in another. So, for the purposes of this section, rate your experience in general. You are welcome to leave a comment about your different experiences in the comment section at the bottom of this question).

Overall rating of Health and therapy

| | Very bad | Bad | Neutral | Good | Very good | Unsure/not relevant |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Early identification of autism (diagnosis under the age of 5) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Access to autism assessment and diagnosis for children | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Access to autism assessment and diagnosis for adults | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Access to public mental health services for autistic people | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Access/availability of mental health services tailored to autistic people's unique experiences and needs (public or private) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | | | | | | |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Health care services (for physical health) suitable for autistic people | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Therapy and support for autistic children (e.g., occupational therapy, speech and language therapy, etc.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Therapy and support for autistic adults (e.g., occupational therapy, speech and language therapy, etc.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

If you like, you can tell us more about why you selected your responses or what your experiences have been (this is optional, and not included in the estimated completion time).

Overall rating of disability supports and services

| | Very bad | Bad | Neutral | Good | Very good | Unsure/not relevant |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Access to assistance and safety devices, such as communication (AAC) devices or safety fences | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Needs Assessment and service coordination (NASC) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Disability support services (e.g. support workers, carer support, respite care) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Accessibility of Individualised funding providers/hosts | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Coordination of different services responsible for supporting autistic people with different challenges (i.e. disability services vs. mental health services) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Advocacy services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

If you like, you can tell us more about why you selected your responses or what your experiences have been (this is optional, and not included in the estimated completion time).

Overall rating of Education

| | Very bad | Bad | Neutral | Good | Very good | Unsure/ not relevant |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------------------------|
| Support and adjustments in the classroom in primary/intermediate education | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Support and adjustments outside the classroom, such as on field trips, in primary/intermediate education | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Support and adjustments in the classroom in secondary education | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Support and adjustments outside the classroom, such as on field trips in secondary education | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Support and adjustments in tertiary education | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

If you like, you can tell us more about why you selected your responses or what your experiences have been (this is optional, and not included in the estimated completion time).

Overall ratings to do with living and community

| | Very bad | Bad | Neutral | Good | Very good | Unsure/ not relevant |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------------------------|
| Accommodations for autistic people in community services, events, and facilities | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Accessibility of WINZ and income tested benefits such as the Supported living payment or Disability allowance | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Transition to adulthood | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Employment for autistic people | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | | | | | | |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Employment support services (e.g., Evaro, Workbridge, etc.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Affordable 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 due to being autistic, are there other equivalent options) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Legal and criminal justice system | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

If you like, you can tell us more about why you selected your responses or what your experiences have been (this is optional, and not included in the estimated completion time).

3. How much do you agree with the following statement:

Generally, autistic people's needs are being met in their daily lives

| Strongly disagree | Disagree | Neutral | Agree | Strongly agree | Unsure/ not relevant |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

If you like, you can tell us more about why you selected your responses (this is optional, and not included in the estimated time limit).

4. Do you know of any autistic person (including yourself if you are autistic) who has experienced bullying, harassment or hate crime? Select all that apply

- Myself
- Someone/people I know
- No

5. Do you know of an autistic person who has experienced discrimination as a result of being autistic? Select all that apply

- Myself
- Someone/people I know
- No

6. Overall, how satisfied are you with the country’s efforts to address issues and disadvantages for autistic people in Aotearoa New Zealand?

| Very dissatisfied | Dissatisfied | Neutral | Satisfied | Very Satisfied | Unsure/ not relevant |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

If you like, you can tell us more about why you selected your responses (this is optional, and not included in the estimated time limit).

The next few questions are about the **Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau (‘the Guideline’)**

The Guideline describes best practice on how to support autistic people in New Zealand. 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. 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.

If you would like to stop at any point and have a look at the Guideline before answering the questions, you can find it here (<https://www.whaikaha.govt.nz/about-us/policy-strategies-and-action-plans/nz-autism-guideline/>), but do not feel obligated to do so.

7. Prior to this survey were you aware of any edition of the Guideline since it was first published in 2008?

- Yes
- No

8. Do you have knowledge of what is included in the current (third) edition of the Guideline?

- Yes, I am aware of most or all of what is included in the current Guideline
- Yes, I am aware of some of what is included in the current Guideline
- No, I do not know what is included in the Guideline

If you selected either of the 'yes' options in the previous question, please continue to question 9. If not, please select "not relevant" for questions 9-11 and proceed to question 12.

9. If you are aware of the Guideline and its content, how satisfied are you with its recommendations and good practice points?

| Very dissatisfied | Dissatisfied | Neutral | Satisfied | Very Satisfied | Unsure/ not relevant |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

10.If you are aware of the Guideline and its content, how satisfied are you with its implementation since it was first published?

| Very dissatisfied | Dissatisfied | Neutral | Satisfied | Very Satisfied | Unsure/ not relevant |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

11.What do you think would help implementation of the Guideline?

| | Very unhelpful | Unhelpful | Neutral | Helpful | Very Helpful | Unsure |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Face to face engagement from key leaders to raise awareness of the recommendations and how to implement them | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | | | | | | |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Video summaries of key recommendations | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Simple resources and handbooks with key recommendations for different audiences, such as clinicians, educators, autistic people, and whānau. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Tertiary training for professionals and clinicians working in the <u>autism sector</u> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Ongoing professional development for professionals and clinicians working in the <u>autism sector</u> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Tertiary training for professionals and clinicians working in the <u>general public (e.g., GPs, dentists, counsellors).</u> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Ongoing professional development for professionals and clinicians working in the <u>general public (e.g., GPs, dentists, counsellors).</u> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Other (Specify):

If you like, you can tell us more about why you selected your responses (this is optional, and not included in the estimated time limit).

Section three: What could we do in the future?

This section is aimed at looking at our future and what the community would like to see.

Aotearoa New Zealand takes a general approach to disability. New Zealand has the newly created [Whaikaha \(Ministry for Disabled People\)](https://www.whaikaha.govt.nz/), [Minister for Disability Issues](https://www.odi.govt.nz/about-us/our-minister/), [Disability Strategy and Action Plan](https://www.odi.govt.nz/nz-disability-strategy/), and [Enabling Good Lives](https://www.enablinggoodlives.co.nz/about-eql/eql-approach/principles/) approach (<https://www.enablinggoodlives.co.nz/about-eql/eql-approach/principles/>).

As well as disability approaches, other countries also have approaches specific to autism and/or neurodivergence to support autistic people.

12. How effective do you think each of the following would be for supporting autistic people in the future?

| | Very unhelpful | Unhelpful | Neutral | Helpful | Very helpful | Unsure/not relevant |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| The current general disability approach | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| An autism specific approach | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| A neurodivergence approach | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

* Neurodivergence: an umbrella term for conditions which differ from what is 'typical'. For example, Autism, ADHD, Dyslexia, Dyscalculia, OCD, Down syndrome, etc.

If you like, you can tell us more about why you selected your responses (this is optional, and not included in the estimated time limit).

As well as autism guidelines, other countries have also established national autism/neurodiversity strategies, legislation and other forms of accountability to ensure inclusion and supports for autistic people.

13. How helpful do you feel each of the following approaches would be for autistic people?

| | Very unhelpful | Unhelpful | Neutral | Helpful | Very Helpful | Unsure |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Developing, or promoting the development, of roles such as autism/neurodiversity inclusion advisors, in a wide range of services and sectors. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| An autism or neurodivergence commissioner or a minister for autistic/neurodivergent people– someone who is a part of city council or government whose primary role is to ensure that autistic/neurodivergent voices are included in policy or decision making, and autistic/neurodivergent rights are upheld at a local level | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| A nationwide autism or neurodivergence strategy that identifies key areas for change, actions/steps required to make those changes and who is responsible for carrying them out. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Autism/neurodivergence legislation or legal requirements for organisations, professionals or individuals to follow rules, processes or plans. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Advocacy services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Continuing with our current approach | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Other (specify):

If you like, you can tell us more about why you selected your responses (this is optional, and not included in the estimated time limit).

14. Please rate the importance of addressing each of the following areas in Aotearoa New Zealand’s future approach to autism

| | Very unimportant | Unimportant | Somewhat unimportant | Neutral | Somewhat important | Important | Very Important | Unsure |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Understanding and acceptance of autism in society | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Early identification of autism | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Access to assessment and diagnosis | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Access to therapy and support | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Education inclusion/outcomes | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Employment inclusion/outcomes | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Transition into adulthood | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Choice and control with living and housing | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Health and care services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Mental health services and mental health outcomes | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Training for professionals within the autism sector and general public (e.g. dentists, doctors, teachers, etc.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Coordination and cooperation between types of services (e.g. mental health vs. disability) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Support within the legal and criminal justice system | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Advocacy services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Building the right support in the community (tailored to the unique needs of autistic people) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Other (specify):

If you like, you can tell us more about why you selected your responses (this is optional, and not included in the estimated time limit).

15. Is there anything that you feel should NOT be included in future approaches to autism?

16. How important is it to include each of the following in the decision making and development of any future approach?

Assume policy makers, politicians, government and leaders are included.

| | Very unimportant | Unimportant | Somewhat unimportant | Neutral | Somewhat important | Important | Very important | Unsure |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Autistic people | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Parents/family of autistic people | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Educators | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Mental health clinicians | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Health Professionals | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Disability support providers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Academics/researchers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Autism advocacy groups | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Allied health professionals (e.g, speech language therapist, occupational therapist) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Māori people/groups with a connection to autism | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Pacific people/groups with a connection to autism | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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| Other ethnicities/groups with a connection to autism | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| | | | | | | | |

○ Other (specify):

If you like, you can tell us more about why you selected your responses (this is optional, and not included in the estimated time limit).

17. What do you feel would be necessary to make any approach to autism successful in New Zealand? For example, anything that would be needed to ensure that plans, changes and recommendations are implemented effectively.
(this is optional, and not included in the estimated time limit).

18. Do you have any further comments around what is or isn't going well in regard to autism and how it's approached and supported in New Zealand? Or anything else you'd like to share with us relating to the topics in this survey? (this is optional, and not included in the estimated time limit).

Thank you for taking the time to complete our survey

We are aware that answering the questions in this survey may have been triggering for some people. If you need support please contact:

- The research team (021 190 6070 or research@autismnz.org.nz)
- 1737 (free text or call)
- Youthline for anyone 12-24 (0800 376 633, text 234, or online chat at youthline.co.nz)
- Lifeline for serious distress (0800 543 354 or text 4357, suicide crisis line 0508 828 865)

- Autism NZ Outreach (<https://autismnz.org.nz/support-from-us/>). If you are in urgent need of help please use one of the helplines above or call 111

Please follow the link below to provide contact details if:

- You would like a copy of the results of the research project
- You would like to go in the draw to win one of 100 \$25 Prezzy Cards
- You would be willing for us to contact you in the future to be invited to participate in other autism-related projects

Your contact details cannot be linked to your survey responses. Your survey responses will remain anonymous and your contact details will remain confidential.

Please follow this link to provide contact details:

Appendix B

Detailed Coding Scheme

Understanding and Acceptance

Knowledge and understanding

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| Overall | <p>Some respondents reported positive interactions with various services; across multiple groups, these interactions were positive because they felt listened to, acknowledged, and understood; because the service took the time to give them information and make sure they understood it; and because individual professionals were knowledgeable.</p> <p>Autistic adults, autistic parents, and non-autistic parents felt that they had to educate professionals and services on autism at a very basic level. These included teachers, school staff, Ministry of Education staff, health professionals, disability workers, mental health professionals, and support workers. One autistic parent felt that even if you could access support, there was no guarantee that the person would be up-to-date or neurodiversity affirming.</p> |
| Healthcare | <p>Respondents across all groups reported that healthcare professionals, including the Accident Compensation Corporation (ACC), had no understanding, or lacked in-depth understanding of autism and neurodiversity. They particularly felt that general practitioners and nurses lacked education and understanding around autism. Non-autistic parents also reported that health professionals questioned patients' diagnosis.</p> |
| Mental health | <p>Autistic adults, non-autistic parents, and professionals said that it was almost impossible to find mental health clinicians who understood autism, and autistic adults believed that psychologists and psychiatrists lacked education about autism. For some, understanding was not the most important thing, and it was more about being willing to work with them as an individual. For others, including autistic and non-autistic parents, lack of understanding from public mental health services meant lack of support for themselves or their child.</p> |
| Other therapies | <p>Non-autistic parents and professionals felt that other therapists such as speech language therapists (SLTs) and occupational therapists did not understand autism or how to interact with autistic individuals.</p> |
| Disability services | <p>Respondents across the autistic adult, autistic parent, and non-autistic parent groups felt that support workers were poorly trained or had little to no training around autism. They felt that this resulted in a lack of understanding around autism and therefore, poor quality of services provided. Autistic adults also noted that it was difficult to find good support workers.</p> |
| Education | <p>School</p> <p>Autistic and non-autistic parents felt that Special Education Needs Coordinators (SENCOs) and resource teachers learning and behaviour (RTLBs) lacked necessary knowledge, training and understanding, or that their knowledge and training was out of date. Non-autistic parents reported that teacher aides didn't understand autism. Professionals and non-autistic parents felt that school staff and Ministry of Education had an outdated, incorrect and deficit-driven understanding of autism, and that this carried through to a lack of knowledge and understanding in classroom teachers and school staff. Classroom teachers were particularly singled out by multiple respondents across groups as having insufficient understanding of autism.</p> <p>Among those who reported positive interactions with their child's school, these were due to school staff or leadership teams with up-to-date training, and in some cases schools specifically investing in training around autism for their staff.</p> <p>Respondents across multiple groups felt that the level of knowledge and understanding at special schools was far greater than mainstream; respondents' feelings towards special schools were almost universally positive, and there was a strong feeling that more special schools and easier access to special schools was necessary as autistic children's needs cannot be met in mainstream schools.</p> |

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| | <p>Tertiary Non-autistic parents felt that tertiary disability support had no understanding of autism.</p> <p>Multiple autistic adults reported having positive experiences in tertiary education, due to the greater level of understanding at university, particularly within disability services. One comment from an autistic adult noted that tertiary staff are uneducated, and another reported being required to write or talk about autism incorrectly to pass their tertiary courses.</p> <p>Childcare Non-autistic parents reported that childcare providers had no training in caring for autistic children</p> |
| Family and friends | Some autistic adults and non-autistic parents felt that friends, family, Whānau, and iwi didn't understand autism, fluctuating needs and capabilities, or how to help; or in some cases were in denial that there were any problems or that the person was autistic at all. Others felt that siblings, immediate family, close friends or their partners were understanding. Respondents from the family and whanau group felt that family were supportive and understanding. |
| Wider community | Respondents across all groups felt that there was not sufficient education or understanding in the wider community, and that people often had a narrow understanding of autism based on limited examples in the media. Autistic adults felt that they were treated as rude, disrespectful, lazy or useless. While non-autistic parents felt that some people in the community were understanding, some also reported that their autistic child had been treated as suspicious by police or retail staff, or their fears that this would be a problem in future. |
| Employment | <p>Autistic adults and non-autistic parents reported that employment services such as Workbridge, did not understand the autistic person or their needs.</p> <p>Respondents across all groups felt that employers had a limited understanding of autism in general. Autistic adults said that their manager did not believe that they were autistic, and one non-autistic parent reported that their child had been fired from multiple jobs due to lack of understanding.</p> <p>Respondents across multiple groups reported their perception that the employment process is designed to screen out autistic applicants.</p> |
| Work and Income New Zealand (WINZ) | Autistic adults reported that Work and Income New Zealand (WINZ) did not understand their needs as autistic people, with one respondent saying that others' experiences had made them too afraid to disclose their autism to Work and Income New Zealand (WINZ) at all. |
| Police | <p>Autistic adults, non-autistic parents, professionals, and family/whanau believed that police were not trained well enough in regards to autism. Professionals felt that police had no understanding of autistic needs. Autistic adults and autistic parents reported that this poor understanding resulted in misinterpretation of autistic body language and behaviour as guilt, mental health crisis, being under the influence, or being combative. Because of this, autistic adults and non-autistic parents felt afraid of the police, having them called during a meltdown, or misinterpreting autistic behaviour. Autistic adults felt that police need better understanding of meltdowns.</p> <p>Some positive experiences with the police were also reported, involving individual police officers showing compassion, understanding, and/or willingness to learn about an autistic person.</p> |
| Justice system | <p>Autistic and non-autistic parents believed that family court staff lacked training, experience and understanding around autism.</p> <p>Several parents felt that their children were misrepresented by their lawyers due to the lawyers' lack of understanding of autism.</p> <p>Autistic people also reported feeling that their stimming, stress behaviour, and/or expression of emotion led to them being misunderstood, misinterpreted, or treated like criminals by court staff. One professional noted that it is difficult for the legal system to understand autistic people, particularly those who do not have a diagnosis.</p> |

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| Oranga Tamariki | Respondents across the non-autistic parent, professional, and family/whānau groups felt that Oranga Tamariki lacked training, experience and understanding around autism. Professionals felt that there were too many instances of Oranga Tamariki trying to remove children because they did not understand the behaviour of autistic parents. However, professionals also believed that, while there was still a long way to go, Oranga Tamariki was improving; one non-autistic parent reported that they had encountered Oranga Tamariki staff with a good understanding of the lives and support needs of people with disabilities, and another reported that Oranga Tamariki's understanding improved over time. |
| Autism is just bad behaviour | Respondents felt that being autistic leads to being labelled as 'difficult' or naughty by family, healthcare, and education professionals instead of recognising differences and struggles. Autistic behaviour such as stimming, meltdowns, or differences in communication was misunderstood and interpreted as bad behaviour by teachers. Respondents across both parent groups reported that school staff interpreted avoiding overwhelm as bunking off class or being lazy, or distress as misbehaving. |
| Terminology | Respondents across the autistic, autistic parent, and non-autistic parent groups encountered health professionals (usually doctors or GPs) using outdated terminology such as 'Asperger's' or functioning labels. |
| Lived experience | <p>Autistic adults felt that mental health professionals did not understand the lived perspective and experience of autism, they didn't know about Applied Behaviour Analysis (ABA), the controversies and potential harm surrounding it, and they did not understand why a diagnosis might be important to an autistic person.</p> <p>Autistic adults felt that professionals only understood if they had lived experience themselves, or if they had an autistic person in their family. They also expressed that other marginalised communities, such as the LGBTIQ+ community, and people with personal experience with autism, neurodivergence, or disability had a better understanding.</p> |
| Masking | <p>Autistic adults felt that there was a lack of understanding of masking from healthcare professionals, psychiatrists, counsellors, mental health professionals, other therapists, employment services, and the workplace in general. They experienced scepticism and questioning from professionals around their diagnosis due to a lack of understanding of masking.</p> <p>Autistic adults reported not being believed when they were in pain or overwhelmed, due to masking. This included health professionals not believing patients who were in pain.</p> <p>Respondents across the autistic, non-autistic parent, and professional groups also mentioned school and legal staff misinterpreting or dismissing autistic children due to a lack of understanding of masking.</p> |
| Diagnosis | <p>Respondents across groups reported that GPs, paediatricians, psychologists, counsellors, and schools did not recognise, or pick up on the signs of autism. They said that autistic people were being seen by multiple healthcare professionals without a diagnosis or referral. One autistic adult commented, <i>"I saw far too many mental health professionals throughout my life for it to be reasonable that it was missed for 15 years"</i>.</p> <p>Autistic adults, autistic parents, and professionals noted that autism is often mistaken for mental health conditions and is misdiagnosed, particularly in females. Autistic adults said that they received a long series of labels and were repeatedly misdiagnosed before the diagnosis of autism was made. Autistic people reported themselves or their child being misdiagnosed with borderline personality disorder, anxiety, psychosis, bipolar disorder, ADHD and PDDNOS. Professionals felt that mental health clinicians prefer to blame anxiety and disordered personality rather than considering autism as a possibility.</p> <p>The few positive comments around diagnosis from autistic adults referred to health professionals picking up on autism or neurodivergence when other professionals hadn't.</p> |

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| <p>Need for support and accommodations</p> | <p>Professionals reported that general practitioners didn't understand autistic needs and accommodations. A non-autistic parent felt that their GP didn't understand their child's need for supports.</p> <p>Autistic adults said that mental health clinicians and their Needs assessments service coordination (NASC) assessor did not know what executive dysfunction was.</p> <p>Multiple respondents across groups reported an assumption from professionals working with autistic people that no obvious, visible signs of distress mean that no accommodation was needed – which combined with the lack of understanding of masking mentioned above meant that autistic people often did not get the support that they needed.</p> |
| <p>Conversation and communication</p> | <p>Autistic adults and autistic parents felt that health professionals, psychiatrists, and general practitioners did not understand communication differences or the need for clear language. Autistic adults said that they had trouble being understood in services or were being misunderstood constantly. An autistic parent said that mental health clinicians were not understanding of the need for more time to process conversation.</p> <p>One autistic adult reported being assigned a support worker who regularly became frustrated with their inability to function and communicate like a non-autistic person, ignored their stimming and distress signals, and generally did not seem to know anything about autistic functioning or communication despite being employed to support autistic people.</p> |
| <p>Augmentative and Alternative Communication (AAC) and non-speaking</p> | <p>Autistic parents reported that professionals including the health sector, police, the wider justice system, and Oranga Tamariki had no understanding of non-speaking autistics or of alternative communication; one autistic parent mentioned that someone using an Augmentative and Alternative Communication (AAC) device was often assumed to have an intellectual disability.</p> |
| <p>Accounting for autism</p> | <p>Autistic adults and professionals felt that very few mental health professionals understood the way autism interacted with mental health, or that mental health professionals didn't know how to adjust treatment for autistic people.</p> <p>Multiple non-autistic parents reported that counsellors did not understand autistic burnout; and one autistic adult said that counsellors did not seem to understand autistic thought processes.</p> <p>Some respondents also identified a lack of awareness in health professionals around autistic experiences, particularly how differences or difficulties with interoception and proprioception impact physical health, pain, and injuries.</p> |
| <p>They'll grow out of it</p> | <p>GPs, dentists, and family believed that autism is a phase that the child would grow out of, or asked if the child was still autistic.</p> |
| <p>Racial bias</p> | <p>Autistic adults believed that there was a lack of training for professionals in recognising autism in non-white people.</p> |
| <p>Blamed on bad parenting</p> | <p>Autistic parents, non-autistic parents, and professionals felt that meltdowns, non-neurotypical behaviour, or other struggles were being blamed on bad parenting. In particular, they felt that this was coming from mental health clinicians, Oranga Tamariki, Special Education Needs Coordinators (SENCOs), school staff, family and the wider community. They also felt that their parenting was questioned when outdated supports didn't work. This was further reinforced by professionals suggesting or requiring parenting courses instead of, or before, providing support for the child. Parents felt judged, and as if they were only being told how to parent, instead of being offered actual support.</p> <p>Autistic parents also reported being treated as stupid or incapable as parents due to their own autism diagnosis and/or their child's, including one parent who was accused of injuring their child who had self-harmed.</p> |

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Stereotyped understandings

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| Autism in females | <p>Respondents reported that services and professionals across all areas of life (such as, GP's, healthcare professionals, mental health clinicians- particularly diagnosing clinicians, teachers, school staff, disability services, employment services, and workplaces) don't understand autism in females. Some believe that girls or women can not be autistic at all. Psychiatrists were among the professionals mentioned as believing that female autism does not exist. This stereotyped belief means that knowledge of autism, particularly in adults or individuals with low support needs, is poor. Professionals don't understand women or girls who mask, and subsequently these individuals 'fall through the cracks'.</p> <p>Commentors felt that generations of women were going undiagnosed, misdiagnosed, or diagnosed very late. Numerous commentors reported that their diagnosis was not picked up for years due to being female or that they were misdiagnosed once or multiple times before receiving their autism diagnosis.</p> |
| Autism in Adults | <p>Commentors felt that knowledge of adult autism, particularly with low support needs, is poor. They felt that mental health professionals had limited, or no knowledge on autism in adults and that diagnosis in adults was therefore not considered.</p> |
| Autistic = less intelligent | <p>Autistic adults, autistic parents, non-autistic parents, and professionals reported that there was the perception that autistic individuals, particularly those who are non-speaking had a learning or intellectual disability. There were also reports of feeling infantilised. They reported that this assumption and treatment was coming from mental health services, disability services, Individualised Funding (IF) hosts, Work and Income New Zealand (WINZ), healthcare professionals, general practitioners, and whānau, among other places which were not specified. Similarly, one respondent reported that education professionals believed that having a higher IQ meant that the individual was less autistic.</p> <p>Respondents felt that services such as Individualised Funding (IF) hosts and Work and Income New Zealand (WINZ), were condescending and "treated clients like idiot". Autistic adults felt that they were treated like a child or not taken seriously. Parents reported their children being talked down to or treated as if they were stupid after receiving an autism diagnosis.</p> |
| Doesn't 'look autistic' | <p>General practitioners, healthcare professionals and mental health clinicians, including psychiatrists and counsellors made comments that autistic patients didn't 'look' or 'seem' autistic, or were sceptical of individuals who were masking. Diagnosing clinicians believed that a person can not be autistic if they make eye contact, show signs of empathy, or are too animated. This was reported across both autistic and parent groups.</p> <p>Autistic adults reported being denied support from the Needs assessments service coordination (NASC) and from Work and Income New Zealand (WINZ) due to masking, not being 'disabled enough', or the needs assessor not wanting to limit independence by granting support. Autistic adults reported being afraid to seek support because they know they seem 'high functioning'. They also reported not being able to get accommodations or support because they didn't 'look autistic'. An autistic adult said that they struggled in mainstream school because they were not autistic enough for the specialist unit. Another said that they masked too well to get support in school.</p> <p>Autistic adults and autistic parents reported being told that they, or their child, did not look or seem autistic.</p> <p>Parents reported their child not being able to access support for mental health or school or losing support when transitioning to primary school due to the child masking their autism. A non-autistic parent said that they felt judged by health</p> |

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| | professionals because their child did not 'look autistic' enough. |
| Autistic = dangerous | Autistic adults felt that they were treated as though they were dangerous after disclosing their autism diagnosis, or when they became stressed. One professional reported that education staff were worried that an autistic child would be violent or harm others unless constantly supervised, with no evidence to support this fear. Other respondents also noted that stimming, lack of eye contact, and use of headphones was viewed as suspicious. |
| Autistic = savant | Non-autistic parents reported that due to stereotypes, there was an expectation that their child would be a savant. |

Acceptance

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| Acceptance of autism | <p>Respondents across all groups reported that autistic people felt judged or afraid of judgement in the community; some were too afraid to go out in public, or minimised interaction with the public as a result. However, some non-autistic parents felt that people in the community were generally accepting.</p> <p>Autistic adults generally did not feel accepted or understood in the community. However, some believed that change is happening because autistic people are more vocal, and that it is 'hard to be afraid of something you see all the time'. Some autistic adults felt that autism and neurodiversity are becoming more accepted in the media and were being promoted as a good thing.</p> <p>Some autistic respondents felt that New Zealand's laws and policies treat autistic people as a burden on society, particularly immigration laws.</p> |
| Autism label is negative | <p>Autistic adults, autistic parents and non-autistic parents reported that mental health professionals did not want to label clients even if they were seeking a diagnosis, were unwilling to diagnose children, or rejected the diagnosis due to viewing it as negative. They, as well as professionals, felt that diagnosis was inaccessible for adults as it was resisted by clinicians.</p> <p>Respondents across the non-autistic parent and professional groups reported that it can be difficult for parents and whānau to come to terms with an autism diagnosis, and that children's diagnoses are sometimes delayed due to the parents' fear of an autism label. Some autistic respondents also reported that their parents or family are in denial, and do not want to believe that a family member is autistic.</p> |
| Being pitied | Autistic and non-autistic parents felt pitied by general practitioners and other health professionals who treated them as damaged or apologised for how hard their life must be. One non-autistic parent felt that their family showed pity for their autistic child. |
| Unwillingness to understand | Non-autistic parents reported a general unwillingness from family, professionals, counsellors, and employers to understand or learn more about autism. |
| Unwillingness to accommodate | Multiple autistic people reported that their family or community are unwilling to provide any accommodations, or are only accepting of autism and autistic people if they do not require any support. One autistic adult said that they have an Augmentative and Alternative Communication (AAC) device, but that their family refuses to engage with them when they use it because they can speak sometimes. |
| Disclosure | Autistic people were told not to, afraid to, or chose not to disclose their diagnosis due to stigma. They felt they had to lie about, or hide being autistic in order to get a job. |
| Expectation to fit-in or mask | Autistic adults, non-autistic parents, and professionals felt that there was an expectation that autistic people should 'fit in' instead of having changes to their environments. Multiple respondents across the two autistic groups reported that they did not feel like they could be themselves in public or the community; and non-autistic parents reported that their children did not feel that they could be themselves in public. |

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| | <p>Respondents across both parent groups reported that their children were expected and pressured to mask from a young age, and that they were punished or shamed for exhibiting non-neurotypical behaviour.</p> <p>One autistic parent reported that as autistic children get older, the community becomes less tolerant towards them. This aligns with the reports from non-autistic parents that their communities are friendly and accepting towards their children, and the reports from autistic adults that they do not feel safe or that they can be themselves in their communities.</p> <p>Multiple respondents reported that autistic people felt the need to mask in the workplace. Some autistic adults said that they had been successful in employment because they are able to mask well, while some non-autistic parents reported that their children had lost jobs or been bullied at work, or that employment services had insisted on placing their children in jobs below their skill level, because of the child's inability to mask. Respondents across all groups said that masking was exhausting and overwhelming, with one autistic parent saying that the pressure to mask destroys autistic children's self-identity.</p> |
| Exclusion and isolation | <p>Non-autistic parents in particular felt alone, isolated or abandoned by family and friends. They felt that no one wanted to talk about autism or the difficulties with their autistic child. <i>"This is a lonely journey where it's in the too hard basket for everyone,"</i> one commentor said. Non-autistic parents also felt that their child did not have any friends or that they were isolated following school exclusion.</p> <p>Respondents across the two autistic groups felt that as children and adults they had been deliberately excluded from friend groups and the community; or that they felt alone, uncared for, or like they did not fit in socially. Professionals reported that they have encountered a fear of autism and autistic people in the community, and that neurotypical people often avoid interacting with autistic people.</p> <p>Autistic adults (from both the autistic and autistic parent groups) frequently reported that most or all of their friends were also neurodivergent. Autistic parents also reported that the only community events with accommodations that allowed them or their children to attend tend to be run by neurodivergent, disabled, or LGBTIQ+ people and groups.</p> |
| Growing acceptance | <p>Professionals reported that parents and families were becoming more accepting, and that children are generally very accepting of autistic peers.</p> <p>Autistic adults said that the current generation of children is more accepting of diversity in general, and that there is a drive towards including autistic people.</p> <p>Respondents across all groups reported that they have encountered individual teachers, school staff, employers, and communities who are accepting of and interested in learning about autism, and that this has been beneficial for them and their children.</p> <p>There were also multiple comments across groups around the positive aspects of autism, including being able to see solutions others can not; bringing insight, beauty, and joy into parents' and family members' lives; and the idea that autism is a superpower, a super-ability, or a gift.</p> |

Overall experience of services

Awareness and information around supports and services

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| Information | <p>Autistic and non-autistic parents said that they did not know whether they were eligible for supports such as benefits, ongoing resourcing scheme (ORS) funding and Individualised Funding (IF). They did not know what they were entitled to, where to find out, or how to access supports and services. Autistic adults and non-autistic parents said that it was hard to find information or services and they did not know who to contact. Multiple respondents said that they had been given incorrect information by Work and Income New Zealand (WINZ), which led to delays in receiving support or support being denied.</p> |
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| | <p>Non-autistic parents said that they knew nothing about Individualised Funding (IF), did not know where to find out, information given to them by Individualised Funding (IF) hosts was not enough or that information provided was incorrect. Professionals felt that it was difficult to find any information on how it works. Autistic adults, autistic parents, non-autistic parents, and professionals reported that even when granted Individualised Funding (IF) or carer support, they did n'o know how to access, use, or spend it. In one case a parent did not realise that had been granted funding under the Individualised Funding (IF) system until it had nearly expired.</p> <p>Some autistic people reported not accessing services because they did not know what being supported by this service would be like; the lack of clear descriptions of services anywhere made them too scary or stressful to access.</p> <p>One autistic parent said that schools often do not apply for ongoing resourcing scheme (ORS) funding if they do not believe it will be granted, leading to the Ministry of Education believing they are meeting the need for funding when in reality there are many children who need ongoing resourcing scheme (ORS) funding but have never applied.</p> |
| Awareness | <p>Many autistic people and their families are unaware of any services. One non-autistic parent commented that you <i>"Can't ask for things you don't know exist"</i>. Autistic adults also said that they weren't aware of any employment services. Autistic parents felt that professionals did not know what other support was available, and non-autistic parents said that they only found out about Individualised Funding (IF) though friends or relatives working in the disability sector. Non-autistic parents were also unaware of any support from Work and Income New Zealand (WINZ) for autistic people.</p> <p>Multiple people responded to questions around the efficacy of supports and services with confusion, as they were not aware that these supports existed. In particular, multiple non-autistic parents reported that they did not know of any transition support for young autistic people moving from school to work; multiple people commented that they did not know that needs assessments service coordination (NASC) or needs assessments existed; and parents in both parent groups reported that professionals often do not know what's available, and so cannot pass the information on to families.</p> |

Waitlists and delays

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| Health and therapy | <p>Supports and services with long wait times include public mental health services, GPs, psychologists, and psychiatrists. These were reported by autistic adults attempting to access services for themselves, and non-autistic parents attempting to access services for their children.</p> <p>One non-autistic parent said that it takes weeks to get an appointment with their GP.</p> <p>Autistic adults noted that it took years to get access to a psychiatrist or psychologist.</p> |
| Diagnosis | <p>Respondents across all groups reported long waitlists for diagnosis across the board. Autistic parents said they waited years for a referral.</p> <p>Multiple respondents said that the delay in getting a diagnosis meant delays in accessing support,. <i>"5 long hard terrible years of failed schooling and no support.t"</i></p> |
| Disability support | <p>Supports and services with long wait times include NASCs, Talklink, Enabling Good Lives (EGL), Individualised Funding (IF) hosts, and access to devices and Augmentative and Alternative Communication (AAC). Long wait lists for Talklink were mentioned by non-autistic parents and professionals; Enabling Good Lives by non-autistic parents; IF hosts across autistic, autistic parent, and non-autistic parent groups; and access to AAC devices by professionals and autistic parents.</p> <p>Long wait lists and wait times for NASCs was mentioned repeatedly throughout the qualitative data, across autistic, autistic parent, professional, and family/whānau groups.</p> |
| Education | <p>The Ministry of Education (MoE) has long waitlists/wait times. This was reported across the two parent groups.</p> |

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| Living and community | <p>Supports and services with long wait times include Work and Income New Zealand (WINZ) (reported across all groups), supported housing (reported by autistic adults), and housing modifications (reported by professionals).</p> <p>Autistic adults mentioned the long wait lists for government-supported housing.</p> |
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Funding

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| Health and therapy | <p>Participants across groups reported that mental healthcare and therapy, including counselling, speech therapy, and occupational therapy, was unavailable due to lack of funding. In some cases this was because the services themselves were underfunded leading to a lack of available clinicians and/or hours, while in others the services were too expensive, leading to those without the necessary funds being denied access.</p> <p>Diagnosis in particular was mentioned across professional, autistic, and autistic parent groups, with respondents saying that their or their child's diagnosis was a financial burden, or that they have not pursued diagnosis because they can not afford it. One respondent commented that <i>"Diagnosis has become a privilege"</i>.</p> |
| Disability support | <p>Autistic adults felt that all support organisations were underfunded.</p> <p>Non-autistic parents felt that carer support rates were too low and that no one wants to care for their child within those rates.</p> <p>Multiple professionals reported that there is a lack of funding to support autistic children who can speak and whose behaviour is not aggressive or disruptive.</p> |
| Education | <p>Professionals, autistic adults, autistic parents and non-autistic parents felt that there was limited funding for schools, particularly teacher aides and Special Education Needs Coordinators (SENCOs). Some schools were having to fund teacher aides themselves as they had no support from the Ministry of Education.</p> <p>Non-autistic parents said that they were struggling financially due to being unable to work while also homeschooling their child.</p> <p>Professionals reported that autistic children without ongoing resourcing scheme (ORS) funding did not get any support, while even those with ongoing resourcing scheme (ORS) funding did not get enough to meet their needs.</p> <p>Non-autistic parents and professionals reported that the lack of funding and low pay for teacher aides resulted in high turnover and lack of consistency for the autistic child, as well as restrictions on attendance for children who were only allowed to attend school with a teacher aide present.</p> <p>Multiple parents expressed a preference for special schools over mainstream education, but reported that the lack of funding for special schools or their own lack of funds meant that their child was forced to attend mainstream school.</p> |
| Living and community | <p>Non-autistic parents reported that transport is unaffordable.</p> |

Lack of supports and options

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| Mental health | <p>Respondents across groups felt that there weren't enough psychologists or psychiatrists, nor clinicians available to diagnose.</p> <p>One autistic adult reported being unable to find any autistic-specific mental health support, and one non-autistic parent felt that there are not enough counsellors trained to work with autistic and/or intellectually disabled young adults.</p> |
| Other therapies | <p>Respondents reported that there are not enough speech and language therapists or occupational therapists.</p> |

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| Disability support | <p>Autistic adults felt that it was hard to find support in general.</p> <p>Autistic and non-autistic parents felt that NASCs were too overwhelmed and dealing with significant staff turnover and a lack of staff. They also felt that not enough support was offered from the needs assessments service coordination (NASC).</p> <p>Autistic adults, autistic parents, and non-autistic parents said that they couldn't find support workers or respite carers to use their funding on, or that there was a lack of suitable support workers and carers. One professional mentioned the particular lack of respite for parents of autistic teenagers.</p> <p>Professionals felt that the approved provider list for safety features is too limited, leading to long wait times. Professionals also reported that increases in autism diagnosis rates mean more pressure on already overbooked services.</p> |
| Culturally responsive services | <p>Non-autistic parents felt that there was a lack of culturally responsive or appropriate services and a lack of resources about Māori approaches to autism.</p> |
| Education | <p>Respondents across groups felt that there was little to no support in school; there were not enough teacher aides; and children without ongoing resourcing scheme (ORS) funding or teacher aide hours were left with no support at all. One parent said, <i>"I believe the education system is failing our kids"</i>; another said, <i>"Primary school was horrific for my son. He will be affected for the rest of his life."</i></p> <p>Multiple respondents felt that even when teacher aides were available they provided insufficient or no support, with one commenter reporting that their child's teacher aide is good but spread too thinly over all the students; and another reporting that the teacher just followed their child around without providing any support.</p> <p>Non-autistic parents felt that Special Education Needs Coordinators (SENCOs) were overworked or too busy to be helpful, and resource teachers learning and behaviour (RTLBs) were helpful but the support only lasted for a limited time. Professionals also reported that resource teachers learning and behaviour (RTLBs) were being asked to do jobs that they were not qualified for due to lack of other options.</p> <p>Respondents across the autistic adult, non-autistic parent, and professional groups reported that there are not enough spaces in special schools, and that autistic children are encouraged or pushed into mainstream schooling with no support.</p> <p>Autistic respondents and non-autistic parents reported a lack of support or accommodations in tertiary education, some dropping out as a result.</p> |
| Transition | <p>Autistic parents, non-autistic parents, and professionals said that there was no support transitioning to adulthood, and autistic parents said that there were gaps in transitioning from child to adult benefits.</p> <p>One autistic adult reported that there was no support in transitioning to adulthood for autistic people with lower support needs; and one non-autistic parent said that all the transitioning support they had been able to find catered for people with intellectual disabilities, with nothing available for other autistic young people.</p> <p>Several non-autistic parents were worried about their children transitioning from intermediate to high school, or reported that this transition had been difficult. Non-autistic parents also reported being concerned about their children's transitions into adulthood and employment.</p> |
| Support across the spectrum | <p>Autistic adults and autistic parents felt that supports are catered towards those with higher support needs, and that "higher functioning" autistics fall through the cracks. They said that there was no support for those who did well in school nor high masking autistic adults.</p> <p>Some respondents in the professional and non-autistic parent groups, however, felt that services were catered towards "high functioning" autistics, and that there were no supports in place for 'severely autistic' people.</p> |
| Adults | <p>Respondents across groups said that there were no services or supports for autistic adults. One autistic adult said, <i>"There is nothing for adults. You're just left to suffer."</i></p> |

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| | <p>Autistic adults and some non-autistic parents felt that supports and services were marketed towards, and focused on parents of autistic children. They also said they had not been able to find occupational therapy for adults as they were all aimed at children. Non-autistic parents felt that there were no supported accommodation options for autistic adults.</p> <p>Respondents across multiple groups reported difficulties in getting adult diagnoses as all services are geared towards children; that the health system is primarily focussed on children and not trained in how to help autistic adults; and that support suddenly disappears when young autistic adults leave school.</p> <p><i>"There is a massive gap for Autistic people and their families post school".</i></p> |
| Living and community | <p>Multiple autistic respondents said public places are inaccessible. <i>"the world is not designed for us."</i> Respondents felt that there were very few, or no low sensory options for trading hours and no accommodations at events.</p> <p>Non-autistic parents felt that there was a lack of support or a lack of appropriate support from Oranga Tamariki.</p> <p>Courts struggle to provide appropriate support. This was identified across all groups.</p> |
| Employment | <p>Multiple respondents across categories reported that they or their children have been consistently unemployed or underemployed.</p> <p>Autistic and non-autistic parents frequently reported that they had lost or left their jobs, or significantly reduced their work hours, in order to care for their autistic children.</p> <p>Respondents across groups felt that there was no support or not enough support for autistic people in the workplace. One professional felt that there are no true options or freedom of choice for autistic people when it comes to employment; and non-autistic parents reported their children having lost jobs due to lack of support.</p> |
| Housing | <p>Non-autistic parents reported autistic adults living with parents due to lack of other options and one professional reported that there are no housing options if parents cannot afford to financially support their adult autistic children. Professionals said that there was not enough housing with safe outdoor areas for autistic children.</p> <p>Autistic people reported that they have limited options around housing, including being unable to find accommodation because they seem 'weird' to potential flatmates or landlords; struggling to afford housing because of a need to live alone; and not having any rights around pets being allowed in rented accommodation as a disability support. Multiple non-autistic parents also reported that their adult autistic children struggle to or cannot afford housing due to the need to live alone. One family member said that their autistic child being loud and having behaviour issues made it difficult for them to find housing.</p> <p>Lack of housing, employment and support options restricts autistic people's freedom of choice.</p> |
| Parents acting on behalf of autistic adult due to lack of support | <p>Respondents, most of whom were autistic adults, reported that they had significant support from their parents, without which they would have no other options.</p> <p>Parents are acting as:</p> <ul style="list-style-type: none"> - Employment support by helping to write CVs, prepare for, and get job interviews. - Agents acting on behalf of, and protecting, the autistic adult in the health, Work and Income New Zealand (WINZ) and housing systems. Autistic adults and non-autistic parents reported that the autistic adult would not have housing without the parent or carer navigating the system. They also reported that the parent or carer needed to protect them from WINZ. - Support workers, attending appointments with the autistic adult and providing support for the autistic adult to live alone - Advocates - Financial support for housing to allow the autistic person to live alone or in a suitable housing arrangement that the autistic person cannot afford. Commentors across both the autistic adults and non-autistic parent groups reported that the autistic person is only able to live alone because of parental financial support. - The safety net as there are no other supports available. |

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| | <p>Parents and carers of autistic adults are having to provide additional support and funding to enable them to live independently when the system fails to do so. This has the potential to be inequitable for those who cannot access this kind of support from a parent or carer.</p> |
| Specific groups | <p>Autistic adults reported that there is no aged care that caters specifically for autistic people, and that many autistic people find existing aged care services inappropriate or traumatic.</p> <p>Respondents across groups also reported several categories for which there is no specific support available, including autistic women; people who are unable to drive; and people who are employed.</p> <p>Multiple respondents reported a lack of support in smaller or regional communities, including places where needs assessments, support organisations like Autism New Zealand and Altogether Autism, parent support groups, and Augmentative and Alternative Communication (AAC) providers are unavailable.</p> |

Accommodations and adjustments

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| Health and therapy | <p>Professionals felt that mental health services were not set up well for autistic people. Autistic adults and non-autistic parents found that healthcare environments were overstimulating and overwhelming and that doctors didn't offer sensory accommodations. They felt that healthcare professionals perceived their needs as difficult and didn't communicate clearly, understand autistic communication, or give autistic patients enough time to process communication.</p> <p>Autistic adults found it difficult or impossible to access doctors or mental health services due to clinics requiring communication and appointment bookings to be done over the phone. They said that healthcare and mental health professionals asked questions that were difficult to interpret, did not give time to process questions or instructions, and did not respond well to clients who were temporarily non-speaking. Health professionals refused to look at pre-written information from clients who were not able to speak during the appointment.</p> <p>One autistic parent reported an interaction with a paediatrician working with their autistic child in which the paediatrician spoke too loudly and quickly, wore overwhelming perfume, and generally behaved inappropriately, to the point where the parent had a meltdown.</p> <p>A few respondents did report positive interactions with professionals in healthcare environments; all of these specified that the staff they interacted with were flexible and willing to accommodate their needs.</p> |
| Disability support | <p>Professionals reported that most disability services are only provided in English, and require a high level of English literacy, making them inaccessible to some families.</p> <p>Autistic adults reported that many support workers require verbal communication instead of communicating over text, which can be inaccessible. One autistic parent said that all the disability services they could access required phone calls, which made them impossible to access.</p> |
| Education | <p>Multiple autistic respondents reported that school was too loud and chaotic for them to cope with full-time, or that they needed low-sensory environments to complete schoolwork or exams, and these were not provided. Respondents across groups felt that schools and school staff are not equipped for children who do not learn well in mainstream environments or those who do not cope well with the National Certificate of Educational Achievement (NCEA) system; Parents reported encountering school staff who could not or would not adapt their teaching style to suit autistic children, with some also reporting schools not allowing or supporting tools like sensory tools, sensory breaks, Augmentative and Alternative Communication (AAC) devices, or supported communication techniques.</p> <p>Multiple parents and professionals reported that their children or children they worked with were unable to cope with the school environment, with professionals in particular</p> |

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| | <p>reporting that there is no place to retreat or escape from stimulation in many schools. One autistic parent commented that “inclusion” just means trapping autistic children in an overwhelming environment.</p> <p>Some non-autistic parents reported that their child’s school was flexible and reduced the pressure on their child; others reported that adaptable teachers, or staff willing to change the school to fit the child helped to meet their child’s needs. A few autistic respondents said that teachers had noticed they were having difficulty and accommodated them, or found ways for them to participate that worked for them. Some professionals felt that there was a lack of structure and routine in schools, which was detrimental to autistic children.</p> <p>Some respondents felt that primary school was more flexible and easier to deal with than secondary. Several autistic respondents reported that university was more accommodating than school; these commenters talked about programmes being adjusted to support them, the experience in general being individualised, and the higher proportion of autistic people in tertiary education (particularly in STEM fields) meaning that staff often had practice working out how to communicate in different ways.</p> |
| Living and community | <p>Several respondents outlined positive steps that their communities have taken towards acceptance and meeting their needs, including sensory-friendly or low-sensory community events; low sensory-sessions at some cinemas; the Hapai Access card and participating places; sunflower lanyards at the airport; relaxed theatre performances; and particularly supermarket sensory hour and autism-friendly COVID vaccination spaces.</p> <p>Others pointed out aspects of the community that are still inaccessible or difficult, including buses being unable to take mobility scooters; police interviewers who are unable to accommodate autistic communication; supermarkets that had sensory hours which have now disappeared; and Kainga Ora being unable to provide housing that is set up for co-occurring disabilities.</p> |
| Employment | <p>Autistic adults reported that their support needs were dismissed or denied by their employers. They said that bright lights and screens in offices were ‘sensory hell’. Some autistic respondents felt that open-plan or hot-desking set-ups were ‘nightmarish’ and that they felt pressured to go back into the office by employers who did not understand the benefits of working from home.</p> <p>However, autistic adults also said that they had supportive co-workers who learned about autism and went out of their way to provide accommodations and support. Some autistic respondents reported that employers had made accommodations for them, including allowing hybrid work to help with sensory overload.</p> |
| Work and Income New Zealand (WINZ) | <p>Autistic respondents reported that Work and Income New Zealand (WINZ) is only accessible via phone call, and that Work and Income New Zealand (WINZ) called them unexpectedly, both of which they found difficult or impossible to manage. They also found the Work and Income New Zealand (WINZ) office environments inaccessible due to the amount of noise and other stimulation. One commenter said that Work and Income New Zealand (WINZ) have “<i>zero understanding of how traumatising their offices are</i>”.</p> <p>Other commenters reported various difficulties with Work and Income New Zealand (WINZ), including the application process being inappropriate for people with disabilities; the lack of access to online applications; communication difficulties meaning that Work and Income New Zealand (WINZ) staff did not understand them and so denied them any support; and requirements for lengthy in-person appointments which made finding childcare difficult or impossible.</p> |
| Justice system | <p>Professionals expressed that the legal system is not accessible for autistic people. Other commenters reported that no accommodations were made for autistic people in arrest or temporary jail situations, and that police interviewers did not take autism into account.</p> |

Processes for accessing support

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| Diagnosis | Autistic adults felt that the diagnosis assessment process was overwhelming, particularly for girls or women. Some did not feel that they had the capacity to |
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| | <p>pursue a diagnosis, having seen how difficult the process was for their children or other people they knew. Professionals felt that separate diagnosis pathways made it difficult for those with co-occurring conditions, and respondents across groups reported general practitioners refusing to refer, or dismissing the client when asking for an autism assessment. Autistic adults also reported being dismissed by mental health professionals and felt that they were roadblocks to diagnosis.</p> |
| Disability support | <p>Participants across all groups felt that disability services were difficult, confusing, or too complicated to navigate, especially when they were not confident that there would be any support at the end. Non-autistic parents and professionals felt that this would be particularly difficult for family/whanau who have cognitive difficulties or mental health problems themselves. Even advocacy services found it difficult to support clients through the process. <i>“The advocacy services are banging their heads against a brick wall”</i>. Parents also noted that some supports were withheld until they had gone through parenting courses, some of which were during work hours, and some supports and services had to be accessed in a particular order.</p> <p>Autistic adults, autistic parents, and non-autistic parents felt that forms to access funding and support were too complicated. Autistic adults also felt that they were unable to complete forms as they were confusing and unclear. Some autistic people reported being unable to access disability supports due to the nature of their disability, while others were only able to access it if they had support from a parent or carer to do so, or had to access support privately using their own funds.</p> |
| NASC | <p>Both autistic and non-autistic parents found it very confusing or difficult, or were struggling to access supports through, or engage with the needs assessments service coordination (NASC). Non-autistic parents noted that the only way to get support is through the needs assessments service coordination (NASC) which is difficult to access, and has a stressful and lengthy process. Autistic adults and professionals felt that the application process was too long and intimidating.</p> <p>Parents found it difficult to access or use carer support, particularly due to the lack of online process and having to complete everything on paper and via post.</p> |
| Individualised funding (IF) | <p>Professionals felt that managing staff and budgets in order to use Individualised Funding (IF) was a huge task or responsibility for autistics and families. This alone is a barrier and disadvantage for those who are unable to navigate setting themselves up as an employer and managing the responsibilities that come with that, while also dealing with the difficulties that allowed them to qualify for the support in the first place.</p> <p>The rules and expectations around Individualised Funding (IF) are unclear and some participants were unable to access funds held by their Individualised Funding (IF) host. Autistic adults, autistic parents, non-autistic parents, and professionals all felt that the process to access Individualised Funding (IF) was too difficult or complex.</p> |
| Devices | <p>Autistic parents and professionals commented on how difficult it was to access Augmentative and Alternative Communication (AAC) devices, with some being repeatedly declined. Professionals felt that there was no clear pathway to get devices or safety measurements in the home.</p> |
| Education | <p>Professionals felt that it was too difficult to get teacher aide support in primary school.</p> <p>Parents and professionals found the ongoing resourcing scheme (ORS) funding process too long and complex and noted that schools will not apply for it if they are not sure they will get it.</p> <p>Non-autistic parents wanted to be able to book time with occupational therapists or speech and language therapists directly instead of having to go through Ministry of Education.</p> <p>One non-autistic parent felt that the process of getting support from a resource teacher learning and behaviour (RTL) was unhelpful because the process restarted every year, so there was no consistency and it was a lot of work to go over the child’s support needs every time.</p> |

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| | Some parents also felt that it was too difficult to get their children into specialist schools, and so they were forced to settle for mainstream education. |
| Work and Income New Zealand (WINZ) | All groups reported finding it difficult, confusing, and exhausting to access support through Work and Income New Zealand (WINZ) or to get onto the correct benefit. Professionals felt that Work and Income New Zealand (WINZ) was only accessible if you had someone to help you navigate the system. Autistic adults struggled to organise all of the required paperwork, and some autistic adults and non-autistic parents felt that Work and Income New Zealand (WINZ) demanded information that was inappropriate and unnecessary. Parents felt that it was difficult to establish what they were eligible for, and one autistic participant pointed out that autism isn't listed as a disability on Work and Income New Zealand (WINZ) forms, making it difficult or impossible for autistic people to get disability-related support. |
| Housing | Autistic adults and professionals found housing services difficult to access, and one professional felt that the application process for housing modifications like safety fences is too complex. |
| Legal | Multiple non-autistic parents felt that there is too much red tape around the welfare guardianship process, and that this is too difficult for something that they feel does not represent any change in how their lives work. |

Advocacy requirements

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| Advocacy required to access support | Autistic adults, autistic parents, and non-autistic parents expressed that constantly advocating for themselves or their child to access support, get their needs met, be taken seriously, and be heard was exhausting, and for some the burnout from this constant advocacy meant that they could no longer advocate for themselves. |
| Diagnosis | Respondents from all groups reported that it took persistent advocacy or self-advocacy to get a diagnosis, sometimes taking years, due to professional reluctance and dismissal. One autistic adult felt that it had been <i>"7 yrs of hell trying to access appropriate services"</i> . Another commented <i>"It's hard to get help when people don't let me speak."</i> |
| Disability support | Respondents across the non-autistic parent, professional, and family/whānau groups reported that it took persistent advocacy to access supports. They felt that if you can't proactively research, reach out to, and fight for support services, you don't get support. <i>"As a parent you have to constantly advocate for your child"</i> <i>"Families are having to tell their story over and over again to multiple people, often without any change in outcome"</i> <i>"I see families at the end of their tethers and no one has listened"</i> |
| Education | Parents reported having to advocate intensely to get any support from the Ministry of Education, or to ensure that their child got into a special school. |
| Not being heard | Respondents across all groups reported not being taken seriously, or feeling dismissed by their GP. Non-autistic parents felt that their concerns were brushed off as 'normal' behaviour. They felt ignored by their needs assessments service coordination (NASC) and felt that Work and Income New Zealand (WINZ) staff didn't listen or were dismissive. Multiple autistic respondents felt that their concerns were dismissed by mental health professionals, and particularly that counsellors didn't or wouldn't listen to them. Autistic respondents also felt that Work and Income New Zealand (WINZ) staff ignored or trivialised their struggles. Commenters also felt that they were ignored or dismissed by Individualised Funding (IF) staff, other professionals, and particularly in the non-autistic parent group, school staff. |
| Not being believed | <i>"People have to fight to be believed"</i> Autistic adults and non-autistic parents reported being disbelieved by health professionals. They reported being told by health and education professionals that they weren't experiencing things that they were, or that it was not as bad as they were |

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| | <p>making it out to be. One person was also accused of making up problems and having factitious disorder. Autistic individuals also reported health professionals not believing they was in pain due to masking, as well as people around them not believing that they were struggling because they mask well.</p> <p>Respondents also reported being disbelieved in regards to their autism diagnosis.</p> <p>Multiple respondents across groups felt that Work and Income New Zealand (WINZ) treated them as if they were trying to 'game the system' or scam their way into benefits they weren't entitled to.</p> |
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Strict eligibility criteria

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| Barriers or requirements | <p>Autistic adults mentioned constantly trying to access support but being turned down. Some were declined assistance or referral to disability services due to having accessed mental health services. Others were refused support from Work and Income New Zealand (WINZ) and employment services for reasons such as masking or not 'looking disabled enough'. One non-autistic parent reported being declined assistance due to their son being 'too intelligent' to need help.</p> <p>One professional commented that they had seen multiple services discharge autistic people based on 'lack of engagement', which unfairly penalises autistic people who do not or cannot engage in a neurotypical way.</p> |
| Individualised funding | <p>Autistic parents felt that Individualised Funding (IF) was being declined despite need. They felt that families with autistic children were being denied Individualised Funding (IF) by NASCs in some areas. Non-autistic parents felt that the criteria for what funding could be used for was overly limited and monitored too strictly, and commenters across the two parent groups reported that funding was unevenly distributed with no apparent reasoning behind why one family received more than another.</p> |
| Therapy | <p>Respondents across both parent groups and the professional group felt that the criteria for access to occupational therapy is too high with some reporting that there is no access to occupational therapy at all for children without ongoing resourcing scheme (ORS) funding.</p> |
| Support in education | <p>Autistic adults and non-autistic parents reported being declined necessary ongoing resourcing scheme (ORS) funding. One parent noted that a Ministry of Education psychologist agreed that the child wouldn't make it in the mainstream classroom, but support was still denied without an alternative solution. Non-autistic parents felt that early intervention, ongoing resourcing scheme (ORS) funding, and support was only available for violent children, or visibly impaired children, with one autistic parent commenting that the only way for them to get support was to exaggerate their child's violent behaviour.</p> <p>Multiple non-autistic parents felt that the ongoing resourcing scheme (ORS) system is inequitable, and commenters across all groups said that many children who need support aren't considered severe enough to qualify for ongoing resourcing scheme (ORS) funding or teacher aide support.</p> |
| Work and Income New Zealand (WINZ) | <p>Parents felt that income thresholds of Work and Income New Zealand (WINZ) were too low, and one autistic adult reported being illegally denied a benefit.</p> |
| Formal diagnostic report | <p>Respondents across groups reported that services such as Work and Income New Zealand (WINZ) and NASCs were inaccessible without a diagnosis, or without the paperwork proving said diagnosis. One autistic parent reported that their District Health Board (DHB) did not provide formal documentation for adult diagnosis, which meant no access to support. Autistic respondents felt that services were gatekept behind formal diagnosis, or that undiagnosed or self-diagnosed autistic people and their families had no access to supports or benefits. This also meant that autistic students struggled in school due to lack of diagnosis.</p> <p>Commenters across the autistic and non-autistic parent groups reported being denied accommodations due to a lack of diagnosis; losing early intervention time because of a delayed diagnosis; and/or their child aging out of disability support services due to a delayed diagnosis.</p> |

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| Support only available at crisis point | Respondents across all groups felt that many supports were only available for those in crisis. Autistic people reported only being able to access government housing or mental health support due to crises, while both autistic and non-autistic parents said that their children were only able to access occupational therapy, diagnoses, or other supports when they were in crisis or suicidal. One autistic commenter reported accessing support while in crisis, then being discharged as soon as the crisis was over with nothing in place to prevent the next one, leading to a repeating cycle. |
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Coordination and consistency

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| Overall | Respondents across groups felt that there was no coordination between any services. <i>"It's like you have all these agencies working against each other rather than collaborating together"</i> . <i>"Coordination between the services is terrible and no one can agree on who does what"</i> . One professional believed that the system incentivised clinicians to get rid of patients by passing them off to a different service. |
| Disability vs mental health | Autistic adults, non-autistic parents, and professionals felt that there was no coordination between mental health and disability services (including NASCs). Some were refused support from the mental health services because they viewed autism as a disability problem, while others were refused disability support due to having accessed mental health services. |
| Health and education | Non-autistic parents and professionals felt that there was no coordination between the Ministries of Health and Education. |
| Coordination and consistency within disability sector | <p>Autistic parents reported that different NASCS don't coordinate or communicate with each other. Both autistic and non-autistic parents reported that the level and quality of support depends on individual needs assessments service coordination (NASC) assessors and that there is no consistency around how much support or funding each person qualifies for, leading to unfair funding allocations and difficulty planning or budgeting because needs assessments are inconsistent over time.</p> <p>One non-autistic parent said that different funding levels come down to how hard parents can push for their child to get more funding, with some comments from the professional group agreeing that funding and services go to the parents who can advocate the loudest.</p> <p>Non-autistic parents reported being contacted by multiple different agencies immediately following their child's diagnosis, and being unable to keep track of or remember who to contact about which issue; they also reported having to repeat their stories over and over to different services.</p> <p>Moving between regions, schools, and services presented problems with commenters across groups reporting gaps and inconsistency in supports when they or their children moved regions or changed schools.</p> |
| Every consumer has the right have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer. | <p>Autistic respondents felt that the few supports that exist for autistic adults tend to be harmful. One autistic parent said that they avoid all supports because of the harm they have seen them cause to other autistic people and one non-autistic parent felt that anyone they encountered who had a qualification but no lived experience did more harm than good. <i>"I see so much damage caused by well meaning health, education and care professionals"</i></p> <p>Healthcare Autistic respondents reported serious neglect by health professionals due to not understanding autistic communication; medical notes recording incorrect information; healthcare causing significant harm to their wellbeing; children being inappropriately restrained by medical staff; and bad experiences with medical professionals leading to them avoiding healthcare entirely. Both autistic adults and non-autistic parents specifically reported bad experiences with dentists.</p> <p>Care facilities Autistic adults felt that care facilities for older people were inappropriate, abusive, and traumatic for autistics, and one autistic commenter reported experiencing abuse in state care.</p> |

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| | <p>Mental health services Respondents across all groups felt that mental health professionals were providing inappropriate or harmful treatment. One autistic respondent felt that dealing with the public mental health services was traumatic; another said that a psychiatrist made things worse; and another felt that standard mental health approaches cause more harm than good for autistic patients. Parents felt that mental health services worsened anxiety in their child, and that psychologists/psychiatrists were damaging. They reported receiving inappropriate or harmful recommendations from mental health services, counsellors, and the District Health Board (DHB). These included being told to send their child to behavioural college, to avoid their child's special interest, and to force the autistic child out of their comfort zone. Non-autistic parents also reported being advised by other parents to stay away from public mental health services.</p> <p>Diagnosis Non-autistic parents found the diagnostic process and lack of post diagnosis support to be traumatic.</p> <p>Other therapies Autistic adults were disappointed that occupational therapy was poor in quality, and applied behaviour analysis (ABA) style in approaches and techniques. One autistic adult said that all children's therapy that they received was rooted in Applied Behaviour Analysis (ABA) or related ideals, and a non-autistic parent said that finding support that was not Applied Behaviour Analysis-based (ABA-based) was difficult because different wording was used to hide this. One autistic adult said that the support for autistic children they know is there, but it is all geared towards making the children more 'normal'.</p> <p>Disability support Parents felt that dealing with support systems had a negative impact on their mental health. One autistic parent said that the mental health impact of dealing with the disability support system, meant that they could no longer work full time with another autistic adult reporting that their negative experiences with support services have led to them avoiding supports altogether. Non-autistic parents reported finding it inappropriate that they were asked to talk about their child's struggles or difficulties in front of child.</p> <p>Employment services One autistic adult felt that employment services seemed fixated on retail or other jobs which are unsuitable for most autistics.</p> |
| <p>Every consumer has the right to co-operation among providers to ensure quality and continuity of services.</p> | <p>Autistic and non-autistic parents reported that high staff turnover, and frequent changes to support workers, doctors and needs assessments service coordination (NASC) staff, and co-ordinators disrupted continuity and consistency of services for autistic people and their families. Autistic respondents also said that support workers often did not turn up.</p> <p>Respondents from both parent groups reported their children's enrolment in school or tertiary education being pre-emptively blocked, or being informed that the institution cannot support neurodivergent students.</p> |

Wellbeing and mental health

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| <p>Abuse</p> | <p>One autistic parent reported that abuse is common for autistic people with one professional feeling that abuse or neglect of autistic children is common.</p> |
| <p>Harmful environments and strategies</p> | <p>Education Autistic parents feel that the education system is not set up for neurodiversity. Autistic adults, non-autistic parents, and professionals feel that modern learning environments, or open learning classrooms are inappropriate and harmful for autistic individuals. <i>"Open classrooms... are generally a nightmare for autistic children. Even the basic property design is not geared for full inclusion of needs"</i></p> <p>Professionals felt that teachers were using inappropriate interventions and strategies. And non-autistic parents reported Special Education Needs Coordinators (SENCOs), RTLB, and school staff using Applied behaviour analysis (ABA)-style</p> |

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| | <p>techniques, which included preventing and suppressing stimming, and encouraging and rewarding masking and behaving neurotypically. Autistic adults, autistic parents, and non-autistic parents also reported punishment for autistic behaviour.</p> <p>Some commenters reported more severe incidents, such as a child being denied food by school staff.</p> <p>Ministry of Education (MoE) Non-autistic parents felt that Ministry of Education (MoE) protected schools that were discriminating against, harming, or abusing autistic children. Respondents across parent and professionals groups reported Ministry of Education (MoE) staff using harmful techniques or interventions that made the situation worse.</p> <p>Police Autistic people feel that police react inappropriately to autistics expressing nervousness or not behaving in an expected, neurotypical way.</p> |
| <p>Impact on mental health</p> | <p>Autistic people reported mental health issues due to masking. <i>“If we are not safe to be ourselves, our needs cannot be met”.</i></p> <p>Multiple commenters across the non-autistic and professional groups reported that parents are burnt out and overwhelmed from trying to get support for themselves and their children, and from supporting other parents going through the same thing. Non-autistic parents and professionals also reported negative effects on parents’ mental health due to autistic children’s behaviour. One professional reported seeing multiple parents and teachers burnt out by supporting children with no information or resources due to the children not being diagnosed yet.</p> <p>Education Parents felt that dealing with the education system had a negative impact on their mental health.</p> <p>Autistic parents reported that school had long-term negative impacts on their children, particularly on the children’s self-esteem.</p> <p>One autistic adult reported negative psychological effects from being expected to listen to their lecturers’ negative and outdated views on autism, and having to write incorrectly about autism in order to pass tertiary courses.</p> <p>Employment Non-autistic parents feel that job interviews are traumatic</p> <p>Autistic adults reported being burnt out at work.</p> <p>One autistic parent reported low self-esteem due to lack of income, because their child requires too much support for them to be able to work and they cannot access financial support.</p> <p>Work and Income New Zealand (WINZ) Autistic people, non-autistic parents, and professionals felt that Work and Income New Zealand (WINZ) needing to be repeatedly told that the person is still autistic is stressful and unnecessary. <i>“This process brings the WINZ trauma back every year”.</i></p> <p>Both autistic and non-autistic parents reported that Work and Income New Zealand (WINZ) negatively impacted their mental health, particularly around the pressure to work when their children need extra care, with one parent saying <i>“The process with WINZ staff was so traumatic for me... I did not apply for the Child Disability Allowance for my second (ASD diagnosed) child.”</i></p> |
| <p>Safety and intimidation</p> | <p>Non-autistic parents reported that school leadership, and teachers made their children feel unsafe with one autistic parent reporting being threatened and intimidated by school staff, and another saying that Oranga Tamariki forced their child to return to an unsafe school environment. Multiple autistic parents reported feeling threatened or intimidated by Oranga Tamariki staff. They also felt that it was too hard, or unsafe to go out into the community.</p> |

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| <p>Physical harm</p> | <p>Education Multiple parents reported that their children have been physically assaulted and/or restrained by school staff. Multiple parents also reported that their children have been locked in rooms, in bathrooms, or outside alone by school staff.</p> <p>Living and community Autistic parents reported that their children have been physically threatened or restrained by professionals in the community, including supermarket staff and police.</p> <p>Lack of recourse Multiple parents reported that they had no recourse following their children being assaulted in school, including serious physical assaults causing lasting harm. Parents felt that the schools were not held accountable for the harm caused to their children.</p> <p>Autistic adults reported courts refusing to press charges after their child was assaulted; being the victim of crimes that were never dealt with and believing this is due to their autism; and lack of recourse in the justice system following being assaulted by support staff.</p> <p>Unsafe to disclose Many autistic commenters felt that it was safer not to tell anyone that they're autistic, with several commenting that disclosing their diagnosis or not masking comes with significant personal and professional risks.</p> |
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Exclusion from mainstream schooling

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| <p>Illegal or unfair exclusion</p> | <p>Non-autistic parents reported their child being stood-down or excluded illegally, or being excluded for responding or retaliating to bullying. Professionals reported children being given “Kiwi stand-downs” – parents being asked to remove their child or reduce their school hours without any official process being followed.</p> |
| <p>Punishment</p> | <p>Non-autistic parents reported stand-downs as punishment for their child’s meltdowns or other autistic behaviours, or exclusion for autistic behaviour or difficulties prior to diagnosis. Several parents said that their children had been expelled multiple times, and one referred to a constant battle against stand-downs and expulsions.</p> |
| <p>Lack of support</p> | <p>Autistic parents, non-autistic parents, and professionals reported children being excluded due to lack of support and waitlists for safety equipment. They reported education staff pushing to exclude the child instead of support them, exclusion being seen as the easiest options, or only being allowed in school for limited hours.</p> |
| <p>School trips or afterschool activities</p> | <p>Non-autistic parents and professionals reported autistic children being banned from, or asked not to attend school trips and activities, as well as being excluded from after-school activities, or excluded from any trips and activities that parents cannot attend.</p> |
| <p>Homeschooling</p> | <p>Respondents across groups reported that autistic child were being homeschooled due to mainstream or primary school not working or meeting their needs. Some parents felt that they were forced to homeschool after trying multiple schools, or due to not qualifying for ongoing resourcing scheme (ORS) funding. Others were homeschooling due to social difficulties or bullying at school. Both autistic and non-autistic parents were homeschooling due to their child’s anxiety or mental health. However, respondents from both groups also reported being unable to homeschool due to it not being financially feasible.</p> |

Bullying and discrimination

Bullying

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| <p>Overall</p> | <p>Many autistic commenters reported being bullied, and one said that they don’t know any autistic people who haven’t been bullied.</p> |
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| | Autistic parents felt that it is still seen as acceptable to pick on people for being 'weird/different.' |
| Health professionals | Autistic parents reported being bullied by health professionals with one saying that a doctor made fun of autistic communication. |
| Support workers | Autistic adults reported being bullied by support workers. |
| Schools | <p>Respondents across all groups reported themselves or their whānau being bullied in school, including being insulted, and laughed at by teachers and school staff. They reported that the school took no action against the child's bullies, or that the child was punished by school staff for being bullied or responding to it. Autistic parents reported that their children were bullied by teachers or other school staff and non-autistic parents reported that they had moved schools or moved to special schools due to bullying concerns.</p> <p>Two non-autistic parents said that their child had been bullied in school, but that the school had responded well and proactively.</p> |
| Public | Respondents across groups reported bullying and harassment in public, including being scolded by strangers; having abuse yelled at them; being mocked or ridiculed for having meltdowns; racist abuse including vandalism of their home; and their child being bullied or verbally abused for having a meltdown in public. |
| Workplace | Multiple commenters across all groups reported that they or their children are bullied in the workplace. |
| WINZ | Multiple commenters across groups reported that they or their children had been bullied by Work and Income New Zealand (WINZ) staff. |

Discrimination

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| School | Autistic and non-autistic parents reported discrimination in schools. Non-autistic parents also reported children being excluded from afterschool activities, entirely based on diagnosis. |
| Employment | <p>Autistic adults, autistic parents, non-autistic parents and professionals reported discrimination or ableism in the workplace or recruitment processes. Some felt that job interviews were specifically designed to screen autistic people out. One non-autistic parent said, "<i>Autistic people should not have to hide who they are in order to obtain employment</i>". Non-autistic parents felt that there were limited options for autistic people who were unable to act neurotypical, and that employers didn't want to take the 'risk' of hiring an autistic person.</p> <p>Some participants reported being fired from their jobs or denied employment after disclosure or discovery of diagnosis. Others felt that no one really wants to interview or employ autistic people.</p> <p>One autistic person reported being denied promotions due to their autism diagnosis; another said that inequality and discrimination in their workplace exacerbated a health condition and led to them leaving the job.</p> |
| Immigration | <p>Respondents across groups felt that diagnosis affecting immigration was inequitable and discriminatory.</p> <p>One autistic parent felt it was particularly unacceptable that autistic trans people fleeing persecution are unable to immigrate to New Zealand because of discrimination against autism in immigration law.</p> |

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

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| Enforceability | Autistic adults feel that the guideline is generally a good and valuable resource. However, autistic adults, non-autistic parents, and professionals felt that the guidelines can not do anything because they are not enforceable. |
| Implementation | <p>Respondents across groups noted that there needs to be funding, guidance, and further work to make sure the guidelines are implemented. Non-autistic parents felt that getting people to read or engage with the large, wordy guideline was a struggle.</p> <p>Non-autistic parents feel that Ministry of Education (MoE) and Ministry of Health do not follow the guidelines, but they need to.</p> <p>Professionals commented that better communication about the Guideline is needed for those who are expected to implement it; and that some people do not take it seriously because it is not enforceable.</p> |
| Problematic elements | Some individual commenters felt that elements of the Guideline are problematic: one autistic adult was 'annoyed' that Applied Behaviour Analysis (ABA) is still mentioned; one autistic parent said that the use of 'ASD' is out of date; one professional felt that the psychometrics section relies on out-of-date research; and one non-autistic parent said that therapy is barely mentioned in the Guideline, which they found 'odd' as this was what helped their daughter the most. |
| Clearer obligations and recommendations | <p>Commenters had several recommendations for the Guideline: more standardised language (e.g. defined meanings for "should", "need to", etc.); stronger wording against cognitive behavioural therapy for autistic people; clearer obligations for professionals; and more access to the Guideline for families and the wider community.</p> <p>Some commenters also questioned whether the Guideline's development was autistic-led, and whether there was any Māori or Pasifika consultation.</p> |

Neurodivergence, autism specific, and general disability approaches

Autism and neurodivergence

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| <p>In favour of autism specific approach</p> | <p>Respondents from the professional group and both parent groups commented that 'neurodivergent' is too general a term to communicate anything about someone's needs. Autistic people have unique needs and significant differences to other conditions so they shouldn't be lumped together.</p> <p>Some respondents across the autistic parent and professional groups believed that neurodiversity terminology increases stigma against autism. It is used as a euphemism or more palatable way to identify as autistic. It should not be used interchangeably with 'autistic'</p> <p>One non-autistic parent believed that a neurodivergence approach is useful for educating the wider population, but an autism specific approach is needed to meet individual needs.</p> <p>Non-autistic parents reported that there is already a huge range of needs and differences across the autism spectrum, having a neurodivergent approach would be too wide and mean that no one gets looked after; and that any approach would need individually tailored approaches rather than broad strokes.</p> <p>Non-autistic parents also believed that a neurodivergence approach will leave autistic people out. Generalising across neurodivergence misses the key communication component and removes communication support.</p> <p>Autistic adults want/need an autism specific approach to be included within an neurodivergence approach.</p> <p>One professional believed that the neurodivergence movement has been beneficial for autistic teenagers and adults who are able to articulate their views, but harmful for the families of young autistic children, and that it doesn't include young children or autistic people with high support needs.</p> |
| <p>In favour of neurodivergent approach</p> | <p>Step away from putting neurodivergent people in boxes/recognise that everyone had different needs. This enables us to prioritise needs first and labels second. A neurodivergent approach is the opposite of 'one size fits all' and reduces the danger of suggesting that all autistic people have the same needs. Need to promote inclusion of diversity but without buzzwords - neurodiversity is the opposite of one size fits all.</p> <p>Neurodivergence approach is more inclusive and includes those who don't have a formal diagnosis.</p> <p>Autism overlaps with other conditions such as ADHD, which makes a neurodivergent approach or category helpful. Many autistic people have co-occurring conditions so a wider umbrella makes sense.</p> <p>Some commenters felt that neurodivergence as a concept may be more relatable or easier to grasp for the general population than information about many separate conditions; one professional said that neurodivergence training for professionals gets you more awareness of more people than autism training.</p> <p>Other commenters felt that a neurodivergence approach would mean strength in numbers and the ability to join together collectively instead of fighting other disability groups for funding.</p> |

Future autism support

Overall support needs

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| <p>Understanding and acceptance</p> | <p>Autistic adults feel that understanding the benefits of diversity in general will lead to greater inclusion of autistic people. They were against trying to make autistic people more neurotypical. However, they also felt that forced acceptance wouldn't work. One person said that they want a system that celebrated everyone's differences.</p> <p>Autistic parents feel that services need to honour autistic people's special interests, talents and unique way of thinking. One person said that professionals should honour the positives as well as the struggles whilst others felt that we need to promote more autistic people's achievements, celebrate autistic people's differences and contributions; and work towards an autism pride movement.</p> <p>Non-autistic parents feel that the legal system is a particularly important place to get autism understanding right, because of the potential for hugely significant repercussions on someone's life.</p> <p>Family and whānau feel that everyone should adopt Autism NZ's positive narrative and attitude towards autism.</p> <p>One autistic commenter cautioned against overdoing awareness promotion, saying that change management does not work if you are 'always in people's faces'.</p> |
| <p>Representation</p> | <p>Autistic adults would like more media representation as they feel that this would be helpful. They feel that there needs to be exposure to real autistic people and movement away from Rain Man.</p> |
| <p>Lived experience</p> | <p>Autistic people and non-autistic parents feel that neurotypicals do not understand autistic people and that they need more neurodivergent health and educational professionals. Autistic people feel that too much help or support comes from neurotypicals and there needs to be more autistic-led support. <i>"What matters most is that ND people define our own support". "Too often those who 'represent' us are not autistic and it's beneficial to nobody".</i></p> <p>Autistic people commenters felt that the education, health, and policy systems need autistic people working within them, and that the Autism Guideline should be lived experience-led. Non-autistic parents felt that more professionals with autistic children are needed, as those who don't have autistic children themselves cannot understand.</p> |
| <p>Social vs medical model</p> | <p>Respondents across groups were in favour of moving away from medical approaches to autism and more towards a social model of disability. Parents were against the use of a deficit-based model. One professional said that the medical model requires whānau to talk up their child's deficits, which is not a mana-enhancing approach.</p> |
| <p>Culturally appropriate supports</p> | <p>Autistic people feel that culturally appropriate care is important and that non-Pakeha cultures need to be understood so that autistic people of any culture can be supported. They feel that there is value in looking at how different cultures view autism and that Te Ao Māori approach to autism is kinder/more supportive and should be listened to by Pakeha institutions.</p> <p>Some non-autistic parents and professionals feel that Māori have their own approach to autism that works for Māori and should not be superseded by a mainstream approach, while others expressed being against race-based policies. One person felt that including different strategies around ethnicity is likely to get autism put in the 'too hard' basket and no progress will be made.</p> |
| <p>Marginalised communities</p> | <p>Autistic people feel that new approaches need to consider the ways in which autistic people are impacted by other marginalised identities such as ethnicity and gender diversity.</p> |
| <p>Against cures</p> | <p>Autistic adults, autistic parents, and professionals are against anything that focuses on eradicating autistic people, eugenics, or curing autism, including</p> |

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| | research. |
| Stop viewing autism/neurodivergence as a disability | Multiple commenters across the autistic adult, autistic parent, and family/whānau groups expressed a desire to stop thinking of autism or neurodivergence as a disability, and or the idea that calling autism a disability is harmful. |
| Protect autistic people from harm in services and supports | Some parents felt that policy should be aiming to improve things for all neurodivergent people, not just autistic people. One autistic parent felt that any future initiatives needed to be careful not to shoehorn autistic people into harmful supports or systems with one professional said that any strategy must be able to be individualised. |

Further education required

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| Gender | Autistic people want more awareness and recognition around the different presentation of autism in girls, women, and non-binary individuals. |
| Guideline | Non-autistic parents want training on the guidelines for General practitioners and teachers. |
| Healthcare | <p>Autistic adults feel that training on autism should be required for GPs. They felt that GPs should be required to do training on how to provide appropriate care for autistic people, and that health professionals need more education and awareness around autism-specific issues like masking and autistic catatonia.</p> <p>Non-autistic parents feel that emergency services need more training in autism, and professionals feel that training around autism should be compulsory for nurses.</p> <p>Commenters also felt that specific sectors of healthcare including nurses, paediatricians, Ministry of Health staff, and Plunket's Well Child staff needed more autism education.</p> |
| Therapy | Professionals feel that more speech language therapists (SLTs) need to be trained on Augmentative and Alternative Communication (AAC). |
| Education | <p>Autistic parents, non-autistic parents, and professionals feel that there should be more training and professional development on autism, for teachers and teacher aides. Autistic people feel that teachers should be educated on autism presentation in different groups of people, and principals need autism training as they set the tone for school.</p> <p>One family/whānau member believed that the Way to Play program should be available in schools; and one non-autistic parent wanted specific training for sexuality/relationships educators in teaching autistic teenagers.</p> |
| Professionals | Autism education should be a compulsory part of training for anyone working with the public. |
| General public | <p>Autistic adults and professionals said that there needs to be more public information and education to pull people's understanding away from stereotypes. Non-autistic parents feel that there needs to be increasing awareness and understanding of autism as diagnosis rates are increasing. Parents said that there needs to be early education about neurodiversity for children so that it is normalised.</p> <p>Professionals also felt that parents need more training and education around autism.</p> |
| Employment | Parents expressed a need for courses to help businesses and employers see the value in hiring neurodivergent people. |
| Work and Income New Zealand (WINZ) | Respondents across all groups said that Work and Income New Zealand (WINZ) needs more education around autism |
| Oranga Tamariki | Professionals and parents said that Oranga Tamariki need more training on autism including how it contributes to and impacts parenting. |

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| Police | Respondents across groups feel that police need more training and understanding on autism, meltdowns, and how to resolve situations with autistic people. |
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Areas to address in future approaches

Improving healthcare and disability support

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| Healthcare | One non-autistic parent said that healthcare services need a private space to wait for appointments with one professional suggesting a health service specifically for autistic or neurodivergent people. |
| Diagnosis | Commenters over both autistic groups felt that autistic girls should be diagnosed earlier. Autistic adults feel that self-diagnosis should be as valid as formal diagnosis. |
| Mental health services | Non- autistic parents indicated need access to counselling for parents/carers. One professional commenter wanted regular reviews of children’s wellbeing attached to any funding for families |
| Advocacy | Autistic adults, non-autistic parents, and professionals said that they need more advocacy services, more autism advocates, or more funding so that advocacy services can be more effective. Non-autistic parents wanted advocates to help them navigate services following their child’s diagnosis, and to help autistic people within the justice system. |
| Coordination | Non-autistic parents and professionals felt that services should be sorted by one person, or that there should be a centralised database. |
| Access to healthcare, therapy, and disability support | Non-autistic parents feel that access to therapy and disability supports should be a human right. |
| Enabling Good Lives (EGL) | Commenters across groups are in support of putting an Enabling Good Lives (EGL) approach in place across services and regions, and feel that this will be positive. |
| Assessing needs | Autistic commenters felt that needs assessments should be assessing what people actually need, rather than whether they are eligible for existing services; and that people need to be trusted to know their own needs. |
| Whole life | Non-autistic parents feel that autistic adults are vulnerable and should have ongoing, one-on-one support to ensure that they are living in a safe environment and are cared for appropriately. One professional suggested a system to ensure that individuals are supported throughout their lives; and one family/whānau member wanted a whole of life approach for autism that includes aging. |
| Augmentative and Alternative Communication (AAC) | Autistic adults felt that funding for Augmentative and Alternative Communication (AAC) devices needs to come with funding and support for implementing Augmentative and Alternative Communication (AAC) use with whānau and support staff; and that any future approaches should not prioritise any one form of communication over others. |
| Behavioural therapy | Autistic adults, autistic parents, non-autistic parents, and professionals are against Applied Behaviour Analysis (ABA), behavioural therapy, punitive approaches, or anything that aims to suppress autistic behaviour such as stimming, or aims to make autistic people more ‘normal’ or more neurotypical. Autistic and non-autistic parents particularly mentioned being against Positive Behavioural Interventions and Supports (PBIS) and Positive Behaviour for Learning (PB4L). One said that far too often autistic kids are being shamed and written up in systems like PB4L for their disabilities. Autistic parents are against the use of reward and punishment based systems that are aimed at compliance. Some non-autistic parents feel that Applied Behaviour Analysis (ABA) should be banned, while others want access to it, and increased funding to make it affordable. |

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| | Non-autistic parents and one professional were the only ones to express a desire for Applied Behaviour Analysis (ABA). |
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Improving education

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| Overall | Multiple non-autistic parents commented that children have a right to education, which is currently not being met for autistic children. |
| Teacher aides | Parents feel that every class should have a permanent, full-time teacher aide. |
| Special schools | Autistic parents and professionals expressed a need for access to alternative education or more support and capacity for special schools. |
| Smaller schools or class sizes | Autistic adults feel that there is a need for smaller schools to reduce overload from too many children being around at lunchtimes etc. They, as well as non-autistic parents, and professionals said that class sizes need to be smaller. |
| Sex and consent education | Non-autistic parents identified this as a gap in their teenagers' education, commenting that they wanted an autism-specific programme in one case, and in another more emphasis on teaching informed consent in addition to when and how to report sexual abuse given autistic teenagers' higher susceptibility to abuse. |

Improving living and community

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| Social and support groups | Commenters across groups identified a need for more support groups and social groups for autistic people, including groups for older autistic adults. |
| Training/courses for autistic people | Autistic parents felt that autistic children need to learn resilience and how to cope with bullying and bullies from an early age. One non-autistic parent wanted training for autistic adults to learn how to 'cope' in society; some professionals identified a need for parenting skills classes and resources to help parents transition to their autistic child being a teenager. |
| Employment | Respondents in the non-autistic parent group feel that there needs to be more investment in finding employment for autistic people. |
| Housing | Autistic adults feel that there should be quiet accessible housing options for autistic people. Non-autistic parents feel that affordable, safe housing is the biggest issue for the autistic community, and that there need to be supported living options for autistic people without intellectual or learning disabilities. One non-autistic parent wanted support for disabled people to own their homes; another suggested a system of supported apartments or villages for autistic adults with varying support needs. |

Improving research

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| Against research on the causes of autism | Autistic adults indicated they are against genetic research or research into the causes of autism. |
| Other research | Autistic commenters wanted more research with input from autistic people; more research into how mental illness affects autistic brains vs. neurotypical ones; and research into how to better train professionals to identify autism in girls and women. |

Improving government and legislation

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| Legislation | <p>Several autistic adults felt that if there are not legal requirements, most people will not do anything; others felt that legislation is not helpful, or that legislation makes people reluctant or resentful about learning rather than willing and open.</p> <p>Respondents across groups want enforceable accessibility legislation.</p> <p>Autistic parents feel that autistic identity should be protected in the Human Rights Act.</p> <p>Multiple autistic parents suggested changing the taxation system to redistribute funding from big corporations to health and education.</p> |
| Accountability | Multiple commenters across groups said that any legislation needed to include accountability to stakeholders and to the wider autism community. |
| Immigration | Autistic adults want to get rid of residency and immigration rules that see autism as a burden. Family and whanau feel that immigration rules place enormous stress on families who fear getting a diagnosis because they will be deported. |
| Autism commissioner/minister | Autistic people feel that there should only be an autism Minister, advisor, or commissioner if they are autistic or neurodivergent themselves. |
| Whaikaha should step in | Autistic parents feel that disabled people should be removed from Work and Income New Zealand 's (WINZ's) database and supported by Whaikaha instead. One autistic parent felt that the education system needs more oversight and suggested that Whaikaha take this on; one professional felt that it needs to someone's specific role to ensure that any new approach actually happens, and suggested Whaikaha for this. |

People to include in future development

Important voices

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| Prioritise autistic voices | <p>"Nothing about us without us" was a sentiment shared by respondents across all groups. They felt that no decisions should be made without input from autistic people. They believe that autistic voices need to be the loudest and have the final say, and autistic people need to lead future changes.</p> <p>Autistic adults said that future strategies or legislation, etc. needs to be written by autistic people. It is important that parents and professionals aren't placed at the forefront of any new approaches. They also felt that non-autistic people should not be involved in producing policies or supports. <i>"You can't speak on our behalf and we aren't incapable of directing this work ourselves". "Autistic adults are the only adults with any right to speak on behalf of autistic people".</i></p> <p>Non-autistic parents indicated that strategies will only be helpful if they prioritise autistic voices. Professionals feel that anything that is not led and supported by autistic people shouldn't be included in new policies.</p> <p>With regard to language: autistic people across both autistic groups used language like "most important voices"; "only people who should be listened to"; "autistic-led"; and "deference to autistic voices". By contrast, the non-autistic parent and professional groups used language like "working with autistic voices"; "be open to autistic voices"; "autistic people should be consulted"; and "listen to autistic people and their families". The autistic groups felt strongly that autistic people should be the only or the most important voices and lead any future approach; while the majority of the non-autistic comments agreed that autistic people should have a voice, this was</p> |
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| | overwhelmingly in a consulting role, in concert with families' voices, or working with the non-autistic people who are leading the initiative. |
| Avoid tokensim | Autistic parents want to include a variety of autistic voices, not just one token person, and one autistic adult said that services that only get the opinion of one specific autistic person are not helpful. |
| Consider the spectrum | Some comments across groups pointed out the need to balance the voices of autistic people with lower support needs who are more able to advocate for themselves with the voices of those with higher support needs who may not be able to make themselves as visible, particularly non-speaking autistic people. |
| Include Māori and Pasifika autistic individuals | Autistic adults feel that Māori and Pasifika autistic people are under-represented and should be more represented in decision making. |
| Honour Te Tiriti | Autistic adults reported that there is an obligation under Te Tiriti to include Māori people/groups in any future policy initiatives. |
| Other ethnicities | Professionals feel that different ethnicities (specifically Asian, Māori, Pasifika) should be involved in deciding policy, while some non-autistic parents were against race-based groups being involved in deciding policy. |
| Include the LGBTIQA+ community | Autistic people feel that it is very important to include the LGBTIQA+ community in policy decisions due to much higher likelihood of autistic people being gay or trans. One autistic person felt that autistic gender non-conforming people should be considered in policy decisions, because of the significant overlap between the autistic and gender non-conforming populations. |
| Include parents | <p>Non-autistic parents feel that parent-led involvement is important and that parents of autistic children need to be consulted.</p> <p>Some non-autistic parents felt that parents are the main group that should be involved or consulted; or that parents understand the issues that impact autistic people more than any other segment of the community.</p> <p>Some parents also commented that any approaches needed to include the voices of very young children's families, and those of whānau who are responsible for older autistic adults.</p> |
| Include family and people who live or work with autistic people | Professionals feel that anyone who works with autistic people, or who will be delivering a service needs to be involved. |
| Include women | Some autistic adults commented that autistic women are undervalued and that female autistic voices and/or groups that represent autistic women should be included in future initiatives. |
| Who not to include | One non-autistic parent wanted to specifically exclude researchers involved in behavioural interventions; another non-autistic parent wanted to exclude autistic people; and one professional wanted to exclude professionals who do not work directly with autistic people. |

Māori and Pacific Peoples

Note: These ideas are integrated throughout the main report.

Comments from Māori and Pasifika respondents have been analysed as part of the wider data set. The Pasifika group was small, skewed heavily towards non-autistic parents, and essentially agreed with the wider group with no particular topics that came through more strongly than in the overall data.

There was a different approach to autism and to disability in general evident in some comments within the Māori group; some respondents were against referring to autism as a disability at all, some wanted to promote autistic people's achievements and awareness of the positive aspects of autism, and some specified that they followed a strengths-based rather than deficit-based approach. One respondent recommended changing the narrative around autism from helping people who cannot function or cannot do certain things, to empowering people who can achieve things.

The Māori group had multiple respondents who reported incidents of bullying or abuse directed towards themselves or their children. This was a strong theme in the qualitative data overall, but particularly strong within the Māori group, with most of the severe incidents reported coming from within this subset.

Several respondents within the Māori group felt that the New Zealand government denies equitable treatment and rights to autistic people, and that government policies are discriminatory and create systemic issues for autistic people. Some commenters felt that the law treats autism and autistic people as a burden on society, while others felt that policies around disability and autism were uninformed and therefore unhelpful. One commenter said that gatekeeping of disability services disproportionately impacts more vulnerable groups.

There were several comments around disability services and government ministries having names in Te Reo; all of the comments that were against this practice came from the Māori group. One commenter felt that having non-English names for services was confusing and a barrier to access for autistic people; another referred to giving services named in Te Reo as 'bullying'; others did not provide the reasoning behind their beliefs.

Themes not included in the main report

Standard of care

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| <p>Lack of communication</p> | <p>Respondents reported a lack of communication across the board, including from GP's and Ministry of Health, making it difficult for anyone to access supports and services.</p> <p>Participants, particularly autistic adults and non-autistic parents found that there was no communication from Individualised Funding (IF) hosts and that it took multiple contacts or complaints to finish the funding process.</p> <p>Respondents reported no communication or action from Whaikaha since it was established, with others having had no communication or response from Autism NZ or NASCs.</p> <p>Commentors reported funding stopping due to admin error, forms being sent to the wrong email address, and having to chase up services for their assessments to be processed.</p> <p>Respondents reported having to redo assessments or diagnosis due to paperwork or system errors.</p> |
| <p>Services are difficult or upsetting to deal with</p> | <p>Respondents from the autistic parent, non-autistic parent, and professional groups reported that Ministry of Education (MoE) early intervention teachers and/or teams were difficult to deal with.</p> <p>Autistic adults and autistic parents report having bad experiences with their GP. These experiences were bad enough that some respondents would not attend appointments with their GP, and others had anxiety over interacting with a new GP.</p> <p>All groups felt that Work and Income New Zealand (WINZ) was too difficult to deal with, reporting Work and Income New Zealand (WINZ) staff to be cold and uncaring to parents struggling with a recent diagnosis: <i>"I have stopped eating for lack of money rather than go back to WINZ"</i>. A commenter reported having to complain to the Accident Compensation Corporation (ACC) to get anything done, with another feeling attacked for asking for help.</p> |

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| Manner of approach | <p>Several non-autistic parents reported being treated like helicopter parents, or as if they are being overbearing or oversensitive when trying to get support for their children. One professional said <i>“They are treated as neurotic parents instead of as experts on their child”</i>.</p> <p>Across all groups, commenters reported that various services including employment support, needs assessments service coordination (NASC), health professionals, and school staff were rude, dismissive, or patronising.</p> <p>Multiple non-autistic parents did have positive interactions with police, reporting that individual police officers were kind, patient, and supportive. Non-autistic parents also generally had positive interactions with Enabling Good Lives (EGL), and multiple comments across all groups praised individual teachers for their compassion.</p> <p>Autistic adults, autistic parents, non-autistic parents, and professionals felt that Work and Income New Zealand (WINZ) staff asked for or insisted on being provided inappropriate or private information.</p> |
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New Zealand is behind other countries

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| Overall | <p>Autistic adults feel that NZ is behind on neurodivergent rights compared to the rest of the world.</p> <p>One autistic parent reported that they have left New Zealand because of how bad it is for autistic people; one non-autistic parent reported being able to get a diagnosis quickly overseas after long wait times in New Zealand. One recent immigrant felt strongly that they would have been worse off growing up in New Zealand.</p> |
| United Kingdom | <p>Both autistic groups reported having a much better experience in the United Kingdom (UK). They noted things that contributed to this, such as acceptance, advocacy, mandatory learning and disability training, employment programs, an autism framework, and recognition of autism in schools. One person said, “if you come to New Zealand you’re going back to the past”.</p> |
| Australia | <p>Non-autistic parents said that New Zealand should move to a Medicare model like Australia; that New Zealand’s disability system is under-resourced and ill-equipped compared to Australia’s; and that we are generally decades behind Australia.</p> |
| Other countries | <p>One autistic parent commented that Canada have great health policies and processes that New Zealand should emulate; one family member said that Israel’s early intervention practices were better, particularly as they take place before children turn two; and one non-autistic parent believed that Applied Behaviour Analysis (ABA) has now been classified as child abuse in a number of US states, and that New Zealand should follow suit.</p> |

Appendix C

Demographic Characteristics

Table 1.

Universal demographic characteristics for autistic adults (n = 217), non-autistic parents/caregivers (n = 461), autistic parent/caregiver (n = 79), professionals (n = 242), and family/whānau (n = 43).

| Demographic characteristic | All n (%) | autistic adults n (%) | Non-autistic parent/ caregiver n (%) | Autistic parent/ caregiver n (%) | Professionals n (%) | Family/whānau n (%) |
|---|--------------|--------------------------|--|--|------------------------|------------------------|
| All identities/roles*n | | | | | | |
| Autistic (self-diagnosed) | 119 (11.42%) | 54 (24.88%) | 0 (0%) | 54 (68.35%) | 11 (4.55%) | 0 (0%) |
| Autistic (formally diagnosed) | 188 (18.04%) | 163 (75.12%) | 0 (0%) | 25 (31.65%) | 0 (0%) | 0 (0%) |
| Parent or caregiver | 594 (57.01%) | 34 (15.67%) | 461 (100%) | 79 (100%) | 18 (7.44%) | 2 (4.63%) |
| Family/whānau | 169 (16.22%) | 46 (21.2%) | 35 (7.59%) | 20 (25.32%) | 25 (10.33%) | 43 (100%) |
| Professional | 346 (33.21%) | 24 (11.06%) | 68 (14.75%) | 11 (13.92%) | 236 (97.52%) | 7 (16.28%) |
| Researcher/policy maker | 30 (2.88%) | 7 (3.23%) | 6 (1.3%) | 3 (3.8%) | 12 (4.96%) | 2 (4.65%) |
| Gender | | | | | | |
| Female | 855 (82.05%) | 124 (57.14%) | 416 (90.24%) | 67 (84.81%) | 213 (88.02%) | 35 (81.4%) |
| Male | 137 (13.15%) | 54 (24.88%) | 38 (8.24%) | 10 (12.66%) | 28 (11.57%) | 7 (16.28%) |
| Non-binary | 37 (3.55%) | 35 (16.13%) | 0 (0%) | 1 (1.27%) | 1 (0.41%) | 0 (0%) |
| Prefer not to say | 13 (1.25%) | 3 (1.38%) | 7 (1.52%) | 1 (1.27%) | 1 (0.41%) | 1 (2.33%) |
| Other | 9 (0.86%) | 8 (3.69%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (2.33%) |
| Age group | | | | | | |
| 18-24 | 69 (6.62%) | 59 (27.19%) | 0 (0%) | 0 (0%) | 8 (3.31%) | 2 (4.65%) |
| 25-34 | 179 (17.18%) | 67 (30.88%) | 50 (10.85%) | 10 (12.66%) | 44 (18.18%) | 8 (18.6%) |
| 35-44 | 312 (29.94%) | 47 (21.66%) | 167 (36.23%) | 37 (46.84%) | 49 (20.25%) | 12 (27.91%) |
| 45-54 | 244 (23.42%) | 18 (8.29%) | 137 (29.72%) | 25 (31.65%) | 59 (24.38%) | 5 (11.63%) |
| 55-64 | 121 (11.61%) | 12 (5.53%) | 52 (11.28%) | 3 (3.8%) | 49 (20.25%) | 5 (11.63%) |
| 65+ | 37 (3.55%) | 8 (3.69%) | 12 (2.6%) | 2 (2.53%) | 10 (4.13%) | 5 (11.63%) |
| Prefer not to say | 80 (7.68%) | 6 (2.76%) | 43 (9.33%) | 2 (2.53%) | 23 (9.5%) | 6 (13.95%) |
| Ethnicity** | | | | | | |
| Pākehā/New Zealand European/other European | 885 (84.93%) | 193 (88.94%) | 386 (83.73%) | 69 (87.34%) | 204 (84.3%) | 33 (76.74%) |
| Māori | 121 (11.61%) | 26 (11.98%) | 60 (13.02%) | 9 (11.39%) | 14 (5.79%) | 12 (27.91%) |
| Pacific Peoples | 40 (3.84%) | 4 (1.84%) | 24 (5.21%) | 3 (3.8%) | 8 (3.31%) | 1 (2.33%) |

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|-------------------|------------|-----------|------------|-----------|-----------|-----------|
| Chinese | 25 (2.4%) | 6 (2.76%) | 13 (2.82%) | 1 (1.27%) | 3 (1.24%) | 2 (4.65%) |
| Indian | 19 (1.82%) | 3 (1.38%) | 9 (1.95%) | 0 (0%) | 7 (2.89%) | 0 (0%) |
| South African | 11 (1.06%) | 3 (1.38%) | 0 (0%) | 0 (0%) | 8 (3.31%) | 0 (0%) |
| British | 13 (1.25%) | 3 (1.38%) | 3 (0.65%) | 4 (5.06%) | 3 (1.24%) | 0 (0%) |
| Other Asian | 19 (1.82%) | 2 (0.92%) | 10 (2.17%) | 1 (1.27%) | 5 (2.07%) | 1 (2.33%) |
| Prefer not to say | 24 (2.3%) | 5 (2.3%) | 7 (1.52%) | 2 (2.53%) | 8 (3.31%) | 2 (4.65%) |
| Other | 10 (0.96%) | 2 (0.92%) | 7 (1.52%) | 0 (0%) | 0 (0%) | 1 (2.33) |

*Participants were able to select all identities and roles that applied to them, this means that percentages exceed 100%.

**Participants were able to select all ethnicities that applied to them, this means that percentages exceed 100%.

Table 2.
Age of diagnosis for autistic children and autistic adults across all roles/identities.

| Demographic characteristic | All | Autistic (self) | Autistic- (formally | Non-autistic parent/ | Autistic parent/ | Professional | Family/ whānau | Prefer not to say | Not applicable |
|--|---------|-----------------|---------------------|----------------------|------------------|--------------|----------------|-------------------|----------------|
| | (years) | (years) | (years) | (years) | (years) | (years) | (years) | n | n |
| Adult age of diagnosis/self-diagnosis | 30.37 | 28.96 | 25.97 | - | 39.62 | 43.88 | - | 24 | 484 |
| Child age of diagnosis | 7.3 | 12.43 | 10.95 | 6.71 | 7.43 | 10.45 | 22 | 22 | 201 |
| Age of all reported autistic diagnosis | 14.94 | 26.85 | 24.32 | 6.89 | 22.97 | 23.18 | 22 | 46 | 685 |

Note: This table include all participants who were autistic or who had an autistic child regardless of what they selected for primary identity. The number of not applicable responses varies due to the way in which the questions were structured.

Table 3.
Professional roles (n = 345).

| Role | All n (%) |
|--|--------------|
| Profession | |
| Speech language therapist/occupational therapist | 41 (11.88%) |
| Psychologist/psychiatrist | 37 (10.72%) |
| Other health and mental health care providers* | 32 (9.28%) |
| Behavioural therapist/early intervention | 11 (3.19%) |
| Paediatrician/doctor | 9 (2.61%) |
| Disability services** | 43 (12.46%) |
| Education professional*** | 128 (37.1%) |
| Prefer not to say | 26 (7.54%) |
| Other | 26 (7.54%) |

Note: Professionals were able to have multiple roles.

*Nurse, physiotherapist, counsellor, autism assessment practitioner, mental health support workers and other health practitioners

** Disability services, case managers, coordinators, autism services, support workers, social workers, employment services

*** Teachers, Teacher aides, principals, SENCOs, RTLB, ECE manager, educational psychologist, educational support worker, learning assistant, learning support coordinator, lecturer.

Appendix D

Findings for All Participants

Table 1
Understanding and acceptance of all supports across all respondents (n = 1042), autistic adults (n = 217), non-autistic parents (n = 461), autistic parents (n = 79), family/whānau (n = 43), and professionals (n = 242).

| Understanding and acceptance | Very bad (%) | | | | | | Bad (%) | | | | | | Neutral (%) | | | | | | Good (%) | | | | | | Very good (%) | | | | | | Unsure/not relevant (%) | | | | | |
|--|--------------|-----------|-----|----|---|---|-----------|-----------|-----------|-----------|-----------|-----------|-------------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|---------------|----|-----------|----|-----------|-----------|-------------------------|----|-----|----|----|----|
| | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P |
| Health and therapy | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| General practitioners | 7 | 14 | 6 | 10 | 7 | 2 | 22 | 28 | 21 | 28 | 14 | 20 | 30 | 27 | 30 | 29 | 33 | 32 | 24 | 20 | 28 | 20 | 33 | 21 | 9 | 6 | 13 | 11 | 5 | 5 | 7 | 6 | 2 | 1 | 9 | 19 |
| Other health clinicians | 6 | 12 | 4 | 9 | 7 | 2 | 23 | 28 | 22 | 32 | 16 | 18 | 33 | 31 | 32 | 32 | 37 | 34 | 24 | 14 | 29 | 25 | 23 | 23 | 7 | 4 | 10 | 3 | 12 | 7 | 7 | 11 | 3 | 0 | 5 | 15 |
| Mental health clinicians | 6 | 12 | 5 | 10 | 5 | 2 | 18 | 31 | 13 | 20 | 14 | 13 | 23 | 21 | 25 | 35 | 21 | 16 | 27 | 20 | 25 | 20 | 33 | 39 | 15 | 10 | 16 | 6 | 12 | 19 | 12 | 6 | 16 | 8 | 16 | 11 |
| Other therapists | 2 | 6 | 2 | 3 | 2 | 0 | 7 | 9 | 6 | 13 | 5 | 7 | 19 | 22 | 21 | 18 | 30 | 12 | 28 | 17 | 30 | 29 | 28 | 35 | 24 | 5 | 27 | 18 | 21 | 39 | 19 | 42 | 14 | 20 | 14 | 7 |
| Disability support services | 5 | 9 | 5 | 6 | 2 | 3 | 11 | 12 | 13 | 11 | 14 | 6 | 22 | 22 | 21 | 20 | 23 | 24 | 26 | 15 | 27 | 35 | 30 | 32 | 17 | 11 | 18 | 8 | 19 | 22 | 18 | 31 | 16 | 19 | 12 | 12 |
| NASC | 5 | 6 | 5 | 9 | 5 | 3 | 12 | 12 | 13 | 9 | 12 | 10 | 20 | 19 | 22 | 24 | 23 | 17 | 23 | 12 | 25 | 27 | 19 | 30 | 15 | 5 | 19 | 15 | 26 | 15 | 24 | 46 | 16 | 16 | 16 | 25 |
| IF hosts/providers | 4 | 6 | 4 | 5 | 7 | 2 | 10 | 9 | 10 | 6 | 5 | 12 | 18 | 14 | 20 | 22 | 16 | 19 | 13 | 9 | 15 | 8 | 28 | 12 | 9 | 5 | 12 | 5 | 12 | 8 | 46 | 57 | 39 | 54 | 33 | 48 |
| ACC | 6 | 13 | 4 | 6 | 2 | 5 | 10 | 12 | 9 | 10 | 9 | 12 | 16 | 14 | 13 | 16 | 12 | 22 | 5 | 6 | 3 | 0 | 19 | 5 | 2 | 3 | 2 | 3 | 7 | 1 | 61 | 52 | 69 | 65 | 51 | 54 |
| Community | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Family/whānau | 6 | 13 | 5 | 10 | 2 | 2 | 21 | 19 | 25 | 25 | 19 | 14 | 23 | 23 | 23 | 25 | 14 | 26 | 34 | 32 | 31 | 25 | 47 | 43 | 14 | 12 | 16 | 13 | 16 | 12 | 1 | 1 | 0 | 1 | 2 | 4 |
| Friends/peers | 3 | 3 | 4 | 4 | 7 | 2 | 18 | 13 | 22 | 27 | 23 | 13 | 28 | 18 | 32 | 34 | 14 | 31 | 34 | 44 | 29 | 22 | 37 | 39 | 13 | 18 | 12 | 11 | 12 | 11 | 3 | 4 | 1 | 3 | 7 | 4 |
| Colleagues | 5 | 9 | 4 | 6 | 5 | 1 | 15 | 18 | 17 | 15 | 14 | 10 | 23 | 23 | 26 | 30 | 16 | 17 | 25 | 16 | 27 | 24 | 26 | 31 | 15 | 8 | 12 | 8 | 12 | 33 | 16 | 26 | 15 | 16 | 28 | 7 |
| General community | 11 | 13 | 13 | 20 | 7 | 3 | 42 | 41 | 41 | 52 | 37 | 42 | 30 | 26 | 30 | 22 | 26 | 36 | 12 | 10 | 12 | 5 | 12 | 14 | 2 | 3 | 2 | 0 | 12 | 2 | 3 | 7 | 1 | 1 | 7 | 3 |
| Police | 7 | 16 | 5 | 5 | 2 | 4 | 15 | 15 | 12 | 19 | 19 | 18 | 20 | 14 | 18 | 18 | 16 | 32 | 9 | 9 | 10 | 10 | 14 | 8 | 4 | 6 | 2 | 5 | 9 | 3 | 45 | 40 | 53 | 43 | 40 | 36 |
| Employers/managers | 9 | 18 | 6 | 16 | 7 | 3 | 21 | 21 | 18 | 25 | 14 | 26 | 24 | 22 | 22 | 30 | 23 | 29 | 13 | 14 | 14 | 8 | 14 | 12 | 7 | 4 | 8 | 9 | 9 | 7 | 26 | 22 | 33 | 11 | 33 | 21 |
| Employment support services | 7 | 11 | 5 | 13 | 7 | 3 | 15 | 18 | 16 | 15 | 12 | 14 | 18 | 14 | 13 | 15 | 14 | 31 | 10 | 10 | 6 | 8 | 14 | 16 | 3 | 3 | 3 | 1 | 7 | 5 | 47 | 44 | 57 | 48 | 47 | 31 |
| Teachers | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Pre-school | 7 | 8 | 10 | 9 | 0 | 3 | 18 | 14 | 19 | 30 | 9 | 18 | 21 | 19 | 21 | 20 | 28 | 20 | 21 | 7 | 24 | 13 | 30 | 28 | 11 | 2 | 15 | 16 | 12 | 10 | 22 | 50 | 11 | 11 | 21 | 21 |
| Primary | 11 | 15 | 12 | 19 | 5 | 3 | 23 | 23 | 23 | 37 | 16 | 20 | 18 | 15 | 20 | 20 | 19 | 19 | 20 | 14 | 19 | 9 | 26 | 30 | 12 | 1 | 16 | 9 | 12 | 14 | 16 | 32 | 10 | 6 | 23 | 15 |
| Secondary | 11 | 20 | 9 | 15 | 9 | 6 | 19 | 24 | 15 | 13 | 16 | 24 | 15 | 17 | 12 | 18 | 12 | 19 | 14 | 10 | 14 | 10 | 21 | 18 | 5 | 4 | 6 | 5 | 7 | 3 | 36 | 26 | 43 | 39 | 35 | 30 |
| Tertiary | 4 | 9 | 3 | 4 | 2 | 2 | 10 | 18 | 5 | 14 | 5 | 14 | 12 | 19 | 5 | 8 | 9 | 21 | 10 | 19 | 5 | 4 | 21 | 12 | 4 | 6 | 3 | 3 | 7 | 3 | 60 | 29 | 80 | 68 | 56 | 47 |
| Teacher aides/education support | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Pre-school | 3 | 3 | 4 | 4 | 2 | 2 | 8 | 5 | 11 | 5 | 2 | 9 | 16 | 9 | 16 | 22 | 14 | 19 | 20 | 7 | 19 | 14 | 35 | 32 | 12 | 3 | 15 | 13 | 16 | 14 | 40 | 73 | 34 | 43 | 30 | 23 |
| Primary | 5 | 4 | 7 | 8 | 2 | 1 | 10 | 7 | 10 | 18 | 19 | 11 | 16 | 12 | 17 | 22 | 19 | 17 | 23 | 11 | 23 | 18 | 26 | 33 | 13 | 3 | 17 | 8 | 9 | 18 | 32 | 63 | 26 | 28 | 26 | 20 |
| Secondary | 5 | 6 | 5 | 5 | 5 | 3 | 8 | 7 | 7 | 8 | 14 | 10 | 13 | 12 | 12 | 15 | 7 | 17 | 15 | 11 | 13 | 8 | 28 | 21 | 7 | 3 | 7 | 5 | 7 | 10 | 53 | 62 | 56 | 59 | 40 | 39 |
| Specialist support at school | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Pre-school | 4 | 2 | 7 | 6 | 2 | 2 | 8 | 2 | 12 | 10 | 2 | 7 | 14 | 12 | 14 | 16 | 19 | 15 | 17 | 6 | 15 | 13 | 33 | 28 | 13 | 3 | 15 | 11 | 14 | 21 | 44 | 75 | 38 | 43 | 30 | 28 |
| Primary | 6 | 4 | 10 | 11 | 2 | 2 | 12 | 6 | 17 | 20 | 12 | 7 | 15 | 12 | 16 | 14 | 14 | 16 | 20 | 9 | 19 | 19 | 19 | 31 | 18 | 4 | 20 | 14 | 23 | 27 | 29 | 66 | 19 | 22 | 30 | 18 |
| Secondary | 5 | 5 | 6 | 6 | 5 | 4 | 9 | 8 | 10 | 8 | 12 | 7 | 12 | 10 | 11 | 11 | 7 | 16 | 16 | 11 | 15 | 14 | 21 | 23 | 9 | 5 | 8 | 5 | 12 | 15 | 49 | 61 | 51 | 56 | 44 | 34 |
| Tertiary | 2 | 3 | 2 | 1 | 5 | 1 | 4 | 6 | 3 | 5 | 2 | 5 | 9 | 11 | 6 | 6 | 9 | 16 | 9 | 13 | 4 | 4 | 14 | 14 | 5 | 6 | 3 | 1 | 9 | 7 | 71 | 62 | 82 | 82 | 60 | 57 |
| School leadership | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |

| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
|-----------------|----|-----------|----|----|---|---|-----------|-----------|-----------|-----------|----|-----------|-----------|-----------|-----------|-----------|-----------|-----------|----|----|-----------|----|-----------|-----------|----|---|----|----|----|----|----|----|----|----|----|----|--|--|
| Pre-school | 7 | 6 | 9 | 8 | 5 | 5 | 12 | 9 | 13 | 16 | 5 | 11 | 17 | 9 | 16 | 23 | 19 | 22 | 15 | 5 | 16 | 11 | 26 | 21 | 10 | 2 | 14 | 14 | 7 | 11 | 39 | 69 | 32 | 28 | 40 | 30 | | |
| Primary | 11 | 10 | 15 | 20 | 5 | 5 | 18 | 14 | 18 | 30 | 12 | 17 | 18 | 12 | 19 | 20 | 23 | 19 | 17 | 11 | 16 | 11 | 20 | 24 | 12 | 4 | 15 | 6 | 12 | 15 | 24 | 51 | 16 | 11 | 28 | 20 | | |
| Secondary | 9 | 10 | 10 | 8 | 7 | 6 | 14 | 18 | 11 | 10 | 12 | 17 | 15 | 14 | 12 | 18 | 12 | 23 | 11 | 7 | 12 | 13 | 19 | 12 | 6 | 4 | 7 | 4 | 9 | 5 | 45 | 47 | 48 | 48 | 42 | 37 | | |
| Tertiary | 4 | 6 | 3 | 3 | 5 | 2 | 7 | 12 | 2 | 6 | 7 | 10 | 11 | 16 | 6 | 6 | 9 | 18 | 6 | 8 | 4 | 3 | 19 | 7 | 3 | 5 | 2 | 1 | 2 | 2 | 70 | 53 | 83 | 81 | 58 | 61 | | |
| Other contexts | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Legal | 7 | 12 | 6 | 10 | 2 | 5 | 17 | 16 | 14 | 13 | 12 | 27 | 12 | 11 | 10 | 9 | 16 | 17 | 5 | 6 | 4 | 3 | 12 | 6 | 2 | 4 | 2 | 0 | 7 | 0 | 57 | 52 | 64 | 66 | 51 | 45 | | |
| WINZ | 13 | 24 | 12 | 18 | 5 | 5 | 22 | 20 | 19 | 27 | 26 | 26 | 18 | 12 | 17 | 24 | 28 | 21 | 10 | 10 | 14 | 3 | 16 | 5 | 3 | 2 | 4 | 1 | 2 | 1 | 34 | 32 | 34 | 28 | 23 | 41 | | |
| Oranga Tamariki | 7 | 11 | 6 | 8 | 5 | 5 | 11 | 7 | 10 | 8 | 5 | 18 | 12 | 8 | 7 | 9 | 23 | 24 | 6 | 6 | 3 | 1 | 9 | 14 | 2 | 1 | 2 | 0 | 7 | 1 | 62 | 67 | 72 | 75 | 51 | 38 | | |

Note: A = autistic adult; NAP. = non-autistic parent; AP. = autistic parent; F = family/whānau; P = professionals. Bold font indicates the most frequent response(s) for each area and participant group, excluding unsure/not relevant.

Table 2.

Experience of all supports across all respondents (n = 1042), autistic adults (n = 217), non-autistic parents (n = 461), autistic parents (n = 79), family/whānau (n = 43), and professionals (n = 242).

| Overall experience | Very bad (%) | | | | | | Bad (%) | | | | | | Neutral (%) | | | | | | Good (%) | | | | | | Very good (%) | | | | | | Unsure/not relevant (%) | | | | | |
|---|--------------|----|-----|----|----|----|---------|----|-----|----|----|----|-------------|----|-----|----|----|----|----------|----|-----|----|----|----|---------------|----|-----|----|----|---|-------------------------|----|-----|----|----|----|
| | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P |
| Health and therapy | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Early identification of autism | 20 | 21 | 22 | 35 | 14 | 12 | 20 | 12 | 19 | 22 | 28 | 25 | 13 | 9 | 12 | 11 | 19 | 17 | 14 | 7 | 14 | 8 | 21 | 23 | 11 | 2 | 15 | 13 | 7 | 9 | 22 | 49 | 17 | 11 | 12 | 14 |
| Assessment for children | 23 | 17 | 28 | 41 | 19 | 15 | 27 | 19 | 25 | 28 | 35 | 38 | 15 | 12 | 16 | 10 | 5 | 18 | 15 | 7 | 18 | 13 | 19 | 16 | 7 | 4 | 8 | 8 | 14 | 5 | 13 | 40 | 5 | 1 | 9 | 8 |
| Assessment for adult | 29 | 44 | 20 | 63 | 9 | 27 | 15 | 18 | 9 | 19 | 16 | 23 | 8 | 14 | 4 | 1 | 14 | 14 | 5 | 10 | 3 | 3 | 21 | 3 | 1 | 3 | 1 | 0 | 2 | 1 | 41 | 11 | 64 | 14 | 37 | 32 |
| Access to mental health services | 32 | 38 | 30 | 49 | 21 | 26 | 28 | 27 | 23 | 28 | 21 | 40 | 13 | 16 | 11 | 9 | 9 | 15 | 6 | 8 | 5 | 4 | 14 | 5 | 2 | 2 | 2 | 0 | 7 | 0 | 19 | 9 | 28 | 10 | 28 | 13 |
| Access to suitable mental health services | 35 | 46 | 32 | 49 | 21 | 30 | 25 | 22 | 23 | 24 | 16 | 35 | 12 | 12 | 11 | 13 | 9 | 15 | 6 | 8 | 5 | 3 | 19 | 6 | 2 | 2 | 3 | 0 | 7 | 0 | 19 | 10 | 27 | 11 | 28 | 13 |
| Healthcare services | 18 | 25 | 19 | 22 | 12 | 10 | 26 | 25 | 24 | 33 | 21 | 28 | 22 | 18 | 22 | 18 | 30 | 26 | 10 | 9 | 12 | 6 | 12 | 10 | 3 | 2 | 4 | 0 | 9 | 2 | 20 | 20 | 19 | 22 | 16 | 24 |
| Therapy and support for children | 18 | 7 | 23 | 29 | 9 | 14 | 22 | 8 | 23 | 30 | 14 | 30 | 16 | 13 | 17 | 10 | 19 | 19 | 17 | 12 | 16 | 10 | 35 | 24 | 6 | 1 | 8 | 8 | 12 | 7 | 20 | 58 | 12 | 13 | 12 | 6 |
| Therapy and support for adults | 22 | 29 | 16 | 44 | 12 | 20 | 13 | 14 | 9 | 13 | 9 | 22 | 9 | 12 | 7 | 4 | 19 | 12 | 5 | 8 | 3 | 1 | 14 | 7 | 3 | 3 | 3 | 0 | 7 | 2 | 48 | 33 | 63 | 38 | 40 | 37 |
| Disability supports and services | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Assistance and safety devices | 12 | 10 | 15 | 10 | 9 | 10 | 19 | 6 | 18 | 20 | 21 | 31 | 17 | 12 | 15 | 20 | 23 | 21 | 7 | 6 | 5 | 3 | 21 | 11 | 3 | 3 | 3 | 1 | 2 | 3 | 42 | 62 | 43 | 46 | 23 | 24 |
| NASC | 10 | 9 | 10 | 14 | 12 | 7 | 17 | 12 | 17 | 19 | 19 | 20 | 22 | 17 | 25 | 23 | 21 | 21 | 22 | 10 | 25 | 22 | 26 | 26 | 7 | 6 | 9 | 8 | 7 | 4 | 23 | 46 | 14 | 15 | 16 | 23 |
| Disability support services | 13 | 8 | 16 | 20 | 12 | 9 | 21 | 13 | 21 | 22 | 16 | 29 | 22 | 17 | 20 | 24 | 21 | 29 | 18 | 12 | 20 | 9 | 23 | 19 | 6 | 5 | 7 | 6 | 9 | 3 | 21 | 45 | 16 | 19 | 19 | 11 |
| IF hosts/providers | 12 | 11 | 14 | 14 | 9 | 9 | 20 | 13 | 19 | 22 | 16 | 30 | 20 | 12 | 19 | 28 | 21 | 24 | 14 | 10 | 16 | 3 | 28 | 13 | 5 | 4 | 7 | 3 | 7 | 2 | 30 | 49 | 25 | 32 | 19 | 22 |
| Coordination of services | 23 | 23 | 24 | 35 | 16 | 17 | 27 | 19 | 26 | 25 | 26 | 37 | 14 | 10 | 14 | 16 | 12 | 19 | 8 | 10 | 6 | 3 | 21 | 9 | 2 | 2 | 2 | 0 | 5 | 2 | 26 | 36 | 27 | 20 | 21 | 15 |
| Advocacy | 11 | 11 | 14 | 16 | 12 | 5 | 17 | 16 | 20 | 10 | 19 | 17 | 20 | 21 | 17 | 19 | 12 | 25 | 13 | 11 | 10 | 6 | 28 | 21 | 5 | 5 | 3 | 8 | 7 | 5 | 34 | 37 | 36 | 41 | 23 | 27 |
| Education | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Support in classroom (primary/int.) | 18 | 16 | 23 | 32 | 9 | 8 | 21 | 17 | 22 | 22 | 23 | 25 | 20 | 14 | 21 | 19 | 19 | 23 | 16 | 8 | 15 | 15 | 21 | 23 | 6 | 3 | 9 | 1 | 7 | 6 | 19 | 43 | 11 | 11 | 21 | 15 |
| Support outside classroom (primary/int.) | 19 | 16 | 23 | 34 | 5 | 12 | 22 | 18 | 22 | 18 | 19 | 28 | 19 | 12 | 22 | 19 | 21 | 18 | 12 | 7 | 12 | 16 | 16 | 16 | 5 | 3 | 6 | 0 | 14 | 4 | 23 | 45 | 15 | 13 | 26 | 22 |
| Support in classroom (sec.) | 14 | 17 | 14 | 14 | 9 | 12 | 16 | 17 | 13 | 14 | 14 | 22 | 15 | 15 | 12 | 14 | 16 | 19 | 10 | 10 | 10 | 4 | 16 | 9 | 4 | 3 | 5 | 5 | 2 | 2 | 42 | 39 | 46 | 49 | 42 | 36 |
| Support outside classroom (sec.) | 14 | 18 | 13 | 18 | 7 | 12 | 14 | 15 | 12 | 13 | 12 | 19 | 13 | 12 | 12 | 10 | 12 | 17 | 8 | 8 | 8 | 4 | 26 | 6 | 4 | 3 | 4 | 4 | 7 | 2 | 47 | 43 | 50 | 52 | 37 | 44 |
| Support in tertiary | 6 | 12 | 4 | 10 | 5 | 3 | 8 | 12 | 4 | 4 | 5 | 14 | 10 | 16 | 6 | 5 | 5 | 14 | 9 | 20 | 4 | 3 | 21 | 8 | 3 | 6 | 3 | 1 | 5 | 1 | 65 | 34 | 80 | 77 | 60 | 60 |
| Living and community | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Acc. in community | 14 | 18 | 14 | 22 | 12 | 9 | 27 | 30 | 25 | 30 | 16 | 31 | 21 | 13 | 24 | 28 | 16 | 21 | 9 | 12 | 7 | 6 | 28 | 9 | 2 | 3 | 2 | 0 | 2 | 1 | 26 | 24 | 28 | 14 | 26 | 30 |
| WINZ | 15 | 24 | 13 | 30 | 12 | 5 | 17 | 19 | 17 | 15 | 14 | 14 | 18 | 12 | 21 | 19 | 9 | 21 | 16 | 12 | 18 | 13 | 30 | 16 | 5 | 5 | 8 | 3 | 9 | 1 | 28 | 29 | 23 | 20 | 19 | 43 |
| Transition to adulthood | 13 | 22 | 11 | 19 | 9 | 7 | 19 | 23 | 13 | 15 | 16 | 30 | 13 | 12 | 11 | 10 | 16 | 19 | 5 | 7 | 3 | 1 | 12 | 7 | 1 | 2 | 1 | 0 | 7 | 1 | 48 | 34 | 61 | 54 | 40 | 36 |
| Employment | 15 | 25 | 13 | 18 | 9 | 10 | 21 | 25 | 13 | 24 | 19 | 32 | 12 | 19 | 8 | 10 | 7 | 17 | 4 | 7 | 2 | 4 | 21 | 3 | 2 | 2 | 2 | 0 | 5 | 1 | 47 | 22 | 64 | 44 | 40 | 38 |
| Employment support services | 8 | 16 | 8 | 8 | 5 | 4 | 10 | 14 | 6 | 9 | 19 | 14 | 12 | 13 | 7 | 13 | 5 | 21 | 6 | 9 | 3 | 5 | 9 | 8 | 2 | 2 | 1 | 1 | 12 | 2 | 62 | 46 | 76 | 65 | 51 | 50 |
| Housing | 18 | 29 | 15 | 15 | 16 | 14 | 17 | 19 | 9 | 16 | 12 | 30 | 7 | 9 | 5 | 3 | 5 | 11 | 2 | 3 | 1 | 1 | 19 | 1 | 1 | 3 | 1 | 1 | 0 | 1 | 55 | 36 | 70 | 63 | 49 | 43 |
| Legal | 10 | 14 | 8 | 10 | 7 | 11 | 13 | 15 | 8 | 13 | 2 | 20 | 9 | 6 | 7 | 8 | 7 | 16 | 3 | 7 | 2 | 1 | 16 | 2 | 1 | 2 | 1 | 1 | 7 | 1 | 64 | 55 | 75 | 67 | 60 | 50 |

Note: AA = autistic adult; NAP = non-autistic parent; AP = autistic parent; F = family/whānau; P = professionals. Bold font indicates the most frequent response(s) for each area and participant group, excluding unsure/not relevant.

Table 3.

Rates of whether participants have experienced bullying and harassment themselves or know someone who has across all respondents (n = 1042), autistic adults (n = 217), non-autistic parents (n = 461), autistic parents (n = 79), Family/whānau (n = 43), and professionals (n = 242).

| | Myself (%) | | | | | | Someone I know (%) | | | | | | No (%) | | | | | |
|---|------------|----|-----|----|---|---|--------------------|----|-----|----|----|----|--------|----|-----|----|----|----|
| | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P |
| Experienced bullying, harassment, or hate crime | 20 | 76 | N/A | 56 | 5 | 1 | 71 | 51 | 79 | 82 | 72 | 71 | 20 | 11 | 21 | 9 | 30 | 29 |
| Experienced discrimination | 17 | 65 | N/A | 39 | 7 | 1 | 70 | 46 | 75 | 77 | 72 | 81 | 21 | 19 | 25 | 14 | 21 | 20 |

Note: A = autistic adult; NAP. = non-autistic parent; AP. = autistic parent; F = Family/whānau; P = professionals; Autistic participants were able to select whether they had personally experienced bullying and harassment and whether they know someone who had experienced these things, as such total percentages exceed 100.

Table 4.

Agreement with whether autistic people's needs are being met in their daily lives across all respondents (n = 1042), autistic adults (n = 217), non-autistic parents (n = 461), autistic parents (n = 79), family/whānau (n = 43), and professionals (n = 242).

| | Strongly disagree (%) | | | | | | Disagree (%) | | | | | | Neutral (%) | | | | | | Agree (%) | | | | | | Strongly agree (%) | | | | | | Unsure/not relevant (%) | | | | | |
|--|-----------------------|----|-----|-----------|---|----|--------------|-----------|-----------|----|-----------|-----------|-------------|----|-----|----|----|----|-----------|----|-----|----|----|---|--------------------|----|-----|----|---|---|-------------------------|----|-----|----|---|---|
| | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P |
| Autistic people's needs are being met in their daily lives | 27 | 35 | 30 | 46 | 9 | 12 | 43 | 36 | 40 | 39 | 42 | 56 | 18 | 13 | 19 | 14 | 21 | 19 | 7 | 8 | 7 | 0 | 19 | 9 | 2 | 3 | 2 | 1 | 2 | 1 | 3 | 4 | 3 | 0 | 7 | 3 |

Note: AA = autistic adult; NAP. = non-autistic parent; AP. = autistic parent; F = family/whānau; P = professionals. Bold font indicates the most frequent response for each area and participant group, excluding unsure/not relevant.

Table 5.

Satisfaction with the Country's effort to address issues and disadvantages across all respondents (n = 1042), autistic adults (n = 217), non-autistic parents (n = 461), autistic parents (n = 79), family/whānau (n = 43), and professionals (n = 242).

| | Very dissatisfied (%) | | | | | | Dissatisfied (%) | | | | | | Neutral (%) | | | | | | Satisfied (%) | | | | | | Very satisfied (%) | | | | | | Unsure/not relevant (%) | | | | | |
|---|-----------------------|-----------|-----|----|----|----|------------------|----|-----------|-----------|-----------|-----------|-------------|----|-----|----|----|----|---------------|----|-----|----|----|---|--------------------|----|-----|----|---|---|-------------------------|----|-----|----|---|---|
| | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P |
| Country's efforts to address issues and disadvantages | 30 | 36 | 34 | 39 | 16 | 17 | 43 | 35 | 40 | 42 | 42 | 57 | 17 | 15 | 18 | 11 | 12 | 19 | 7 | 8 | 6 | 4 | 19 | 6 | 1 | 1 | 1 | 0 | 9 | 0 | 2 | 5 | 1 | 4 | 2 | 2 |

Note: AA = autistic adult; NAP. = non-autistic parent; AP. = autistic parent; F = family/whānau; P = professionals. Bold font indicates the most frequent response for each area and participant group excluding unsure/not relevant.

Table 9.

Helpfulness of approaches for supporting the implementation of the Guideline across all respondents who were at least somewhat aware of the current edition (n = 288), including autistic adults (n = 67), non-autistic parents (n = 84), autistic parents (n = 15), family/whānau (n = 14), and professionals (n = 108).

| What would help implementation | Very unhelpful (%) | | | | | | Unhelpful (%) | | | | | | Neutral (%) | | | | | | Helpful (%) | | | | | | Very helpful (%) | | | | | | Unsure/not relevant (%) | | | | | |
|--|--------------------|----|-----|----|---|---|---------------|----|-----|----|---|---|-------------|----|-----|----|---|----|-------------|-----------|-----------|-----------|-----------|-----------|------------------|-----------|-----------|-----------|-----------|-----------|-------------------------|----|-----|----|---|---|
| | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P |
| Face to face engagement | 1 | 0 | 1 | 7 | 0 | 2 | 2 | 3 | 1 | 13 | 0 | 0 | 9 | 10 | 10 | 7 | 0 | 8 | 40 | 51 | 35 | 40 | 71 | 34 | 41 | 30 | 43 | 13 | 29 | 51 | 7 | 6 | 11 | 20 | 0 | 5 |
| Video summaries | 1 | 1 | 1 | 7 | 0 | 1 | 4 | 3 | 5 | 7 | 7 | 4 | 13 | 13 | 14 | 13 | 0 | 13 | 43 | 40 | 43 | 27 | 64 | 44 | 32 | 34 | 29 | 27 | 29 | 33 | 7 | 7 | 8 | 20 | 0 | 5 |
| Simple resources | 1 | 0 | 2 | 7 | 0 | 1 | 2 | 1 | 2 | 13 | 0 | 0 | 7 | 7 | 10 | 7 | 0 | 6 | 34 | 36 | 32 | 27 | 71 | 31 | 51 | 49 | 49 | 40 | 29 | 57 | 5 | 6 | 5 | 7 | 0 | 4 |
| Tertiary training for prof. in autism sector | 1 | 0 | 0 | 13 | 0 | 2 | 1 | 0 | 1 | 0 | 0 | 1 | 4 | 3 | 5 | 7 | 7 | 3 | 24 | 34 | 25 | 33 | 36 | 13 | 63 | 55 | 61 | 33 | 57 | 73 | 8 | 7 | 8 | 13 | 0 | 8 |
| Ongoing PD for prof. in autism sector | 1 | 0 | 0 | 7 | 0 | 2 | 1 | 0 | 0 | 7 | 7 | 0 | 4 | 7 | 5 | 7 | 7 | 1 | 22 | 31 | 21 | 27 | 43 | 13 | 66 | 55 | 68 | 47 | 43 | 78 | 6 | 6 | 6 | 7 | 0 | 6 |
| Tertiary training for prof. in gen public | 2 | 1 | 1 | 13 | 0 | 2 | 0 | 0 | 0 | 7 | 0 | 0 | 5 | 4 | 5 | 0 | 7 | 5 | 19 | 25 | 21 | 20 | 43 | 11 | 67 | 61 | 67 | 47 | 50 | 77 | 6 | 7 | 6 | 13 | 0 | 6 |
| Ongoing PD for prof. in gen public | 1 | 0 | 0 | 7 | 0 | 2 | 1 | 0 | 0 | 13 | 0 | 0 | 3 | 6 | 1 | 7 | 0 | 3 | 22 | 22 | 30 | 27 | 43 | 12 | 68 | 64 | 64 | 47 | 57 | 78 | 5 | 7 | 5 | 0 | 0 | 6 |

Note: AA = autistic adult; NAP = non-autistic parent; AP = autistic parent; F = family/whānau; P = professionals. Bold font indicates the most frequent response for each area and participant group, excluding unsure/not relevant.

Table 10

Helpfulness of neurodivergence, autism specific, and general disability approaches and potential future supports across all respondents (n = 1042), autistic adults (n = 217), non-autistic parents (n = 461), autistic parents (n = 79), family/whānau (n = 43), and professionals (n = 242).

| | Very unhelpful (%) | | | | | | Unhelpful (%) | | | | | | Neutral (%) | | | | | | Helpful (%) | | | | | | Very helpful (%) | | | | | | Unsure/not relevant (%) | | | | | |
|---|--------------------|-----------|-----|----|----|----|---------------|-----------|-----------|-----------|----|----|-------------|----|-----|----|-----------|-----------|-------------|----|-----|----|----|----|------------------|-----------|-----------|-----------|-----------|-----------|-------------------------|----|-----|----|----|----|
| | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P |
| Approaches | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| The current general disability approach | 12 | 12 | 15 | 16 | 9 | 8 | 26 | 27 | 27 | 33 | 14 | 25 | 25 | 23 | 24 | 24 | 30 | 28 | 17 | 15 | 16 | 10 | 21 | 21 | 7 | 6 | 7 | 5 | 14 | 7 | 12 | 17 | 12 | 11 | 12 | 10 |
| An autism specific approach | 2 | 1 | 2 | 1 | 7 | 0 | 3 | 2 | 4 | 4 | 2 | 2 | 10 | 7 | 10 | 6 | 26 | 10 | 34 | 36 | 32 | 33 | 21 | 37 | 45 | 46 | 44 | 49 | 37 | 45 | 6 | 7 | 7 | 6 | 7 | 5 |
| A neurodivergence approach | 3 | 3 | 3 | 4 | 7 | 1 | 3 | 2 | 5 | 3 | 5 | 2 | 9 | 6 | 11 | 8 | 16 | 6 | 25 | 29 | 26 | 15 | 16 | 25 | 53 | 53 | 48 | 66 | 44 | 61 | 6 | 7 | 7 | 5 | 12 | 5 |
| Future autism supports | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Neurodiversity inclusion advisors | 2 | 1 | 3 | 0 | 9 | 2 | 2 | 3 | 2 | 5 | 5 | 1 | 8 | 9 | 6 | 9 | 9 | 10 | 32 | 31 | 31 | 30 | 33 | 35 | 52 | 51 | 54 | 49 | 40 | 51 | 4 | 6 | 5 | 6 | 5 | 2 |
| Autism or neurodivergence commissioner | 3 | 1 | 2 | 0 | 14 | 3 | 3 | 4 | 2 | 1 | 7 | 5 | 11 | 6 | 12 | 15 | 9 | 15 | 31 | 34 | 30 | 20 | 30 | 36 | 47 | 50 | 49 | 58 | 35 | 39 | 4 | 6 | 5 | 5 | 5 | 2 |
| Autism or neurodivergence strategy | 2 | 1 | 2 | 1 | 5 | 1 | 2 | 2 | 1 | 1 | 5 | 2 | 7 | 6 | 7 | 10 | 14 | 8 | 30 | 33 | 29 | 19 | 35 | 32 | 56 | 53 | 58 | 65 | 37 | 56 | 3 | 4 | 3 | 4 | 5 | 1 |
| Legislation | 2 | 1 | 2 | 1 | 7 | 2 | 3 | 3 | 2 | 1 | 7 | 6 | 11 | 8 | 9 | 6 | 14 | 17 | 30 | 33 | 30 | 33 | 28 | 28 | 48 | 49 | 50 | 52 | 35 | 44 | 6 | 6 | 6 | 6 | 9 | 3 |
| Advocacy | 1 | 0 | 2 | 1 | 7 | 0 | 1 | 0 | 1 | 1 | 0 | 2 | 6 | 6 | 6 | 5 | 5 | 5 | 24 | 23 | 24 | 19 | 33 | 26 | 63 | 65 | 63 | 71 | 51 | 63 | 5 | 7 | 4 | 3 | 5 | 3 |
| Continuing our current approach | 22 | 28 | 22 | 29 | 7 | 19 | 26 | 22 | 27 | 33 | 19 | 27 | 26 | 21 | 24 | 22 | 30 | 34 | 8 | 6 | 8 | 0 | 23 | 10 | 6 | 7 | 6 | 3 | 14 | 5 | 12 | 16 | 13 | 14 | 7 | 6 |

Note: AA = autistic adult; NAP = non-autistic parent; AP = autistic parent; F = family/whānau; P = professionals. Bold font indicates the most frequent response for each area and participant group, excluding unsure/not relevant.

Table 11.
Important areas to address in future approaches to autism across all respondents (n = 1042), autistic adults (n = 217), non-autistic parents (n = 461), autistic parents (n = 79), family/whānau (n = 43), and professionals (n = 242).

| | Very unimportant (%) | | | | | | Unimportant (%) | | | | | | Somewhat unimportant (%) | | | | | | Neutral (%) | | | | | | Somewhat important (%) | | | | | | Important (%) | | | | | | Very important (%) | | | | | |
|--|----------------------|----|-----|----|---|---|-----------------|----|-----|----|---|---|--------------------------|----|-----|----|---|---|-------------|----|-----|----|---|---|------------------------|----|-----|----|---|---|---------------|----|-----|----|----|----|--------------------|-----------|-----------|-----------|-----------|-----------|
| | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P |
| Understanding and acceptance of autism in society | 2 | 3 | 3 | 4 | 0 | 1 | 0 | 0 | 0 | 1 | 0 | 0 | 1 | 3 | 0 | 3 | 2 | 0 | 3 | 5 | 2 | 1 | 7 | 1 | 5 | 6 | 5 | 3 | 5 | 5 | 19 | 17 | 18 | 11 | 12 | 25 | 70 | 65 | 72 | 77 | 74 | 69 |
| Early identification of autism | 2 | 2 | 3 | 1 | 0 | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 1 | 3 | 1 | 0 | 0 | 0 | 2 | 6 | 2 | 3 | 2 | 1 | 7 | 12 | 5 | 13 | 5 | 6 | 17 | 19 | 13 | 18 | 26 | 19 | 70 | 55 | 77 | 66 | 67 | 74 |
| Access to assessment and diagnosis | 2 | 2 | 2 | 1 | 0 | 1 | 0 | 0 | 0 | 3 | 0 | 0 | 1 | 3 | 1 | 0 | 2 | 0 | 1 | 4 | 1 | 0 | 0 | 1 | 3 | 5 | 2 | 3 | 5 | 2 | 12 | 12 | 10 | 10 | 19 | 14 | 81 | 72 | 84 | 84 | 74 | 82 |
| Access to therapy and support | 2 | 2 | 2 | 1 | 0 | 1 | 0 | 1 | 0 | 0 | 2 | 0 | 1 | 1 | 0 | 1 | 2 | 0 | 1 | 4 | 1 | 0 | 0 | 1 | 1 | 4 | 0 | 3 | 0 | 1 | 11 | 14 | 8 | 13 | 16 | 10 | 83 | 73 | 87 | 82 | 79 | 87 |
| Education inclusion/outcomes | 2 | 2 | 2 | 1 | 0 | 1 | 0 | 1 | 0 | 1 | 0 | 0 | 1 | 1 | 0 | 1 | 2 | 0 | 1 | 2 | 1 | 1 | 2 | 0 | 3 | 4 | 3 | 3 | 5 | 3 | 13 | 22 | 9 | 6 | 19 | 15 | 78 | 66 | 82 | 85 | 72 | 80 |
| Employment inclusion/outcomes | 1 | 2 | 2 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 2 | 0 | 2 | 5 | 1 | 3 | 0 | 0 | 4 | 6 | 3 | 0 | 7 | 3 | 17 | 16 | 14 | 18 | 16 | 24 | 72 | 67 | 75 | 76 | 70 | 71 |
| Transition into adulthood | 2 | 2 | 2 | 1 | 2 | 0 | 1 | 1 | 0 | 1 | 2 | 0 | 1 | 2 | 1 | 0 | 2 | 0 | 1 | 5 | 1 | 0 | 0 | 1 | 3 | 4 | 3 | 1 | 0 | 2 | 16 | 21 | 12 | 15 | 16 | 21 | 73 | 61 | 77 | 80 | 74 | 74 |
| Choice and control with living and housing | 1 | 2 | 2 | 1 | 0 | 0 | 1 | 2 | 0 | 1 | 0 | 0 | 0 | 1 | 0 | 1 | 2 | 0 | 2 | 5 | 1 | 0 | 0 | 1 | 6 | 6 | 6 | 8 | 0 | 6 | 19 | 17 | 17 | 19 | 21 | 25 | 66 | 65 | 67 | 67 | 72 | 65 |
| Health and care services | 2 | 2 | 2 | 1 | 0 | 0 | 1 | 1 | 1 | 1 | 0 | 0 | 1 | 1 | 0 | 0 | 5 | 0 | 1 | 3 | 1 | 0 | 2 | 1 | 4 | 6 | 3 | 4 | 5 | 3 | 17 | 17 | 15 | 15 | 12 | 21 | 74 | 69 | 77 | 77 | 76 | 73 |
| Mental health services and outcomes | 2 | 2 | 2 | 1 | 2 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 1 | 1 | 0 | 1 | 2 | 0 | 1 | 2 | 1 | 0 | 2 | 1 | 2 | 6 | 1 | 1 | 2 | 1 | 12 | 11 | 11 | 9 | 14 | 13 | 81 | 76 | 81 | 86 | 74 | 84 |
| Training for professionals within the autism sector and general public | 2 | 2 | 2 | 1 | 2 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 1 | 2 | 0 | 1 | 2 | 0 | 1 | 3 | 0 | 0 | 2 | 1 | 3 | 5 | 2 | 3 | 2 | 3 | 14 | 15 | 12 | 11 | 23 | 16 | 79 | 71 | 82 | 84 | 67 | 80 |
| Coordination and cooperation between types of services | 2 | 2 | 2 | 1 | 0 | 1 | 0 | 0 | 0 | 1 | 2 | 0 | 1 | 2 | 1 | 0 | 2 | 0 | 2 | 2 | 2 | 0 | 2 | 1 | 3 | 6 | 2 | 4 | 2 | 2 | 15 | 20 | 15 | 8 | 19 | 13 | 76 | 67 | 76 | 85 | 72 | 82 |
| Support within the legal and criminal justice system | 1 | 1 | 2 | 1 | 0 | 0 | 1 | 1 | 1 | 1 | 0 | 0 | 1 | 2 | 0 | 0 | 2 | 0 | 2 | 3 | 1 | 3 | 0 | 1 | 5 | 7 | 4 | 3 | 7 | 4 | 20 | 24 | 17 | 19 | 23 | 22 | 65 | 57 | 67 | 68 | 63 | 69 |
| Advocacy services | 2 | 1 | 2 | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 2 | 0 | 1 | 2 | 1 | 0 | 2 | 0 | 2 | 2 | 2 | 4 | 0 | 1 | 4 | 8 | 2 | 6 | 9 | 2 | 19 | 18 | 16 | 19 | 14 | 24 | 71 | 65 | 74 | 68 | 70 | 71 |
| Building the right support in the community | 2 | 2 | 2 | 1 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 1 | 1 | 0 | 0 | 2 | 0 | 2 | 6 | 1 | 1 | 2 | 1 | 4 | 7 | 3 | 3 | 2 | 4 | 19 | 18 | 17 | 20 | 26 | 22 | 70 | 63 | 73 | 72 | 67 | 70 |

Note: A = autistic adult; NAP. = non-autistic parent; AP. = autistic parent; F = family/whānau; P = professionals. Bold font indicates the most frequent response for each area and participant group. Unsure/not relevant responses are not shown in this table but ranged from 0-9% across participants and within each participant group.

Table 12.
Rating for important people/groups to include in future approaches across all respondents (n = 1042), autistic adults (n = 217), non-autistic parents (n = 461), autistic parents (n = 79), family/whānau (n = 43), and professionals (n = 242).

| | Very unimportant (%) | | | | | | Unimportant (%) | | | | | | Somewhat unimportant (%) | | | | | | Neutral (%) | | | | | | Somewhat important (%) | | | | | | Important (%) | | | | | | Very important (%) | | | | | |
|--------------------------|----------------------|----|-----|----|---|---|-----------------|----|-----|----|---|---|--------------------------|----|-----|----|---|---|-------------|----|-----|----|---|---|------------------------|-----------|-----|----|----|----|---------------|-----------|-----|-----------|----|----|--------------------|-----------|-----------|-----------|-----------|-----------|
| | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P | All | AA | NAP | AP | F | P |
| Autistic | 1 | 2 | 1 | 3 | 0 | 0 | 1 | 0 | 1 | 1 | 0 | 0 | 1 | 1 | 0 | 1 | 0 | 0 | 1 | 2 | 1 | 1 | 5 | 1 | 4 | 4 | 4 | 4 | 12 | 3 | 13 | 9 | 15 | 8 | 14 | 13 | 78 | 80 | 75 | 82 | 70 | 82 |
| Parents/family | 1 | 1 | 1 | 3 | 0 | 0 | 1 | 1 | 0 | 0 | 2 | 0 | 2 | 6 | 1 | 0 | 0 | 0 | 2 | 6 | 1 | 3 | 2 | 1 | 7 | 24 | 3 | 6 | 0 | 3 | 19 | 30 | 15 | 22 | 21 | 17 | 67 | 31 | 77 | 67 | 72 | 78 |
| Educators | 1 | 1 | 1 | 3 | 0 | 0 | 1 | 2 | 0 | 1 | 0 | 0 | 2 | 5 | 1 | 1 | 5 | 1 | 5 | 11 | 4 | 9 | 0 | 1 | 15 | 29 | 12 | 19 | 12 | 9 | 29 | 28 | 28 | 29 | 28 | 30 | 46 | 24 | 51 | 37 | 56 | 58 |
| Mental health clinicians | 1 | 1 | 2 | 3 | 0 | 0 | 1 | 2 | 0 | 1 | 2 | 0 | 2 | 4 | 1 | 0 | 5 | 1 | 5 | 10 | 4 | 8 | 0 | 0 | 13 | 22 | 12 | 15 | 9 | 7 | 29 | 32 | 27 | 35 | 21 | 29 | 48 | 28 | 52 | 38 | 60 | 61 |
| Health prof. | 1 | 1 | 2 | 3 | 0 | 0 | 1 | 3 | 0 | 1 | 2 | 0 | 2 | 4 | 1 | 1 | 5 | 0 | 5 | 12 | 3 | 9 | 0 | 2 | 15 | 24 | 14 | 16 | 12 | 8 | 30 | 30 | 29 | 33 | 21 | 32 | 45 | 26 | 49 | 37 | 60 | 56 |
| Disability support | 2 | 2 | 2 | 4 | 2 | 0 | 1 | 2 | 0 | 1 | 0 | 0 | 1 | 3 | 0 | 0 | 2 | 0 | 3 | 5 | 2 | 1 | 5 | 1 | 11 | 18 | 8 | 23 | 7 | 5 | 29 | 37 | 25 | 29 | 16 | 33 | 53 | 31 | 61 | 41 | 67 | 60 |
| Academics | 1 | 1 | 2 | 3 | 0 | 1 | 1 | 2 | 1 | 1 | 0 | 0 | 3 | 5 | 2 | 3 | 5 | 2 | 6 | 9 | 6 | 4 | 5 | 4 | 17 | 20 | 16 | 24 | 12 | 14 | 33 | 35 | 31 | 33 | 23 | 36 | 37 | 25 | 40 | 33 | 51 | 43 |
| Autism advocacy group | 1 | 0 | 2 | 3 | 0 | 0 | 1 | 2 | 1 | 0 | 5 | 0 | 1 | 2 | 1 | 0 | 0 | 0 | 3 | 3 | 2 | 9 | 2 | 1 | 8 | 12 | 8 | 10 | 7 | 7 | 23 | 29 | 21 | 25 | 19 | 22 | 61 | 49 | 64 | 52 | 67 | 69 |
| Allied health prof. | 1 | 1 | 1 | 4 | 0 | 0 | 1 | 2 | 0 | 3 | 0 | 0 | 1 | 2 | 1 | 0 | 2 | 0 | 3 | 8 | 2 | 4 | 5 | 0 | 12 | 23 | 8 | 15 | 9 | 7 | 31 | 34 | 30 | 39 | 19 | 29 | 50 | 29 | 55 | 34 | 65 | 63 |
| Māori | 1 | 0 | 2 | 3 | 0 | 0 | 1 | 0 | 1 | 3 | 2 | 0 | 2 | 3 | 2 | 0 | 0 | 0 | 5 | 5 | 8 | 5 | 7 | 1 | 7 | 6 | 8 | 9 | 12 | 4 | 26 | 27 | 29 | 22 | 16 | 24 | 54 | 55 | 46 | 57 | 56 | 69 |
| Pacifika | 1 | 0 | 2 | 3 | 0 | 0 | 1 | 1 | 1 | 3 | 2 | 0 | 2 | 1 | 3 | 0 | 2 | 0 | 6 | 5 | 8 | 6 | 9 | 1 | 6 | 5 | 7 | 10 | 7 | 5 | 28 | 31 | 29 | 24 | 16 | 26 | 53 | 52 | 45 | 52 | 56 | 68 |
| Other ethnicities | 1 | 0 | 2 | 3 | 0 | 0 | 1 | 0 | 1 | 4 | 0 | 0 | 2 | 3 | 2 | 0 | 5 | 0 | 7 | 6 | 10 | 5 | 7 | 2 | 8 | 7 | 8 | 10 | 9 | 7 | 27 | 28 | 29 | 24 | 14 | 26 | 51 | 51 | 43 | 52 | 58 | 64 |

Note: A = autistic; NAP = non-autistic parent; AP = autistic parent; F = family/whānau; P = professionals. Bold font indicates the most frequent response for each area and participant group. Unsure/not relevant responses are not shown in this table, but all were ≤ 7% across all participants and within each participant group.

Appendix E

Primary Identity Analyses

Table 1
Results of Kruskal Wallis analyses for the relationship between understanding and acceptance of autism in health and therapy and primary identity.

| Health and therapy | n | Kruskall Wallis | Post-hoc pairwise comparisons |
|---|-----|--|---|
| General practitioners (GP) | 969 | H (4) = 26.913, p < 0.001 | -autistic adults rated the understanding and acceptance of GPS significantly <u>lower</u> than professionals (adj. p = 0.030) and non-autistic parents (adj. p <.001). |
| Other Health clinicians (e.g., other doctors/nurses/medical professionals) | 965 | H (4) = 39.800, p < 0.001 | -autistic adults rated the understanding and acceptance of other health clinicians significantly <u>lower</u> than non-autistic parents (adj. p < 0.001), family/whānau (adj. p = 0.048) and professionals (Ad. P <.001). -autistic parents rated the understanding and acceptance of other health clinicians significantly <u>lower</u> than non-autistic parents (adj. p = 0.048) |
| Mental health clinicians (e.g., psychologists, psychiatrists, counsellors, mental health nurses etc.) | 916 | H (4) = 60.998, p < 0.001 | -autistic adults rated the understanding and acceptance of mental health clinicians significantly <u>lower</u> than non-autistic parents (adj. p <0.001) and professionals (adj. p <.001). -autistic parents rated the understanding and acceptance of mental health clinicians significantly <u>lower</u> than non-autistic parents (adj. p = 0.008) and professionals (adj. p <.001). |
| Other therapists (e.g. Occupational therapists, speech and language therapists) | 846 | H (4) = 80.828, p < 0.001 | -autistic adults rated the understanding and acceptance of other therapists significantly <u>lower</u> than autistic parents (adj. p = 0.036), non-autistic parents (adj. p <0.001), and professionals (adj. p <.001). -autistic parents rated the understanding and acceptance of other therapists significantly <u>lower</u> than professionals (adj. p = 0.002). -Non-autistic parents rated the understanding and acceptance of other therapists <u>lower</u> than professionals (adj. p = 0.010) |
| Disability support services (e.g. support workers, carer support, respite, etc.) | 853 | H (4) = 26.777, p < 0.001 | -autistic adults rated the understanding and acceptance of disability support services significantly <u>lower</u> than non-autistic parents (adj. p = 0.015), and professionals (adj. p <.001). |
| NASC (needs assessment and service coordination) | 789 | H (4) = 23.153, adj. p < 0.001 | -autistic adults rated the understanding and acceptance of NASC significantly <u>lower</u> than non-autistic parents (adj. p <.001), family/whānau (adj. p = 0.046) and professionals (adj. p <.001). |
| Individualised funding hosts/providers (e.g. Manawanui, Geneva Healthcare, Mycare, etc.) | 566 | H (4) = 12.284, p = 0.016 | -No difference between primary identity group/roles |
| ACC | 407 | H (4) = 14.007, adj. p = 0.120 | -No difference between primary identity group/roles |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 2

Results of Kruskal Wallis analyses for relationship between understanding and acceptance of autism in the community and primary identity.

| Community | n | Kruskall Wallis | Post-hoc pairwise comparisons |
|-----------------------------|------|-------------------------------------|---|
| Family/wider whānau | 1027 | H (4) = 18.303, p = 0.001 | - autistic parents rated the understanding and acceptance of the family/whānau significantly <u>lower</u> than professionals (adj. p = 0.033) -autistic adults rated the understanding and acceptance of the family/whānau significantly <u>lower</u> than professionals (adj. p = 0.006). |
| Friends/peers | 1016 | H (4) = 31.583, p < 0.001 | - autistic parents rated the understanding and acceptance of friends/peers significantly <u>lower</u> than autistic adults (adj. p <0.001). -Non-autistic parents rated the understanding and acceptance of friends/peers significantly <u>lower</u> than autistic adults (adj. p <0.001) and professionals (adj. p = 0.048). |
| Colleagues | 874 | H (4) = 78.722, p < 0.001 | -autistic adults rated the understanding and acceptance of colleagues significantly <u>lower</u> than non-autistic parents (adj. p = 0.023) and professionals (adj. p < 0.001). -autistic parents rated the understanding and acceptance of colleagues significantly <u>lower</u> than professionals (adj. p < 0.001). -Non autistic parents rated the understanding and acceptance of colleagues significantly <u>lower</u> than professionals (adj. p < 0.001) |
| The general community | 1008 | H (4) = 27.437, p < 0.001 | -autistic parents rated the understanding and acceptance of the general community significantly <u>lower</u> than professionals (adj. p < 0.001), non-autistic parents (adj. p = 0.013), and family/whānau (adj. p < 0.006). -autistic adults rated the understanding and acceptance of the general community significantly <u>lower</u> than professionals (adj. p = 0.047). -Non-autistic parents rated the understanding and acceptance of the general community significantly <u>lower</u> than professionals (adj. p = 0.037). |
| Police | 575 | H (4) = 9.099, p = 0.059 | - No significant differences between primary identity group/roles. |
| Employers/managers | 770 | H (4) = 19.161, p < 0.001 | -autistic adults rated the understanding and acceptance of employers/managers significantly <u>lower</u> than non-autistic parents (adj. p = 0.001) and professionals (adj. p = 0.047). |
| Employment support services | 549 | H (4) = 27.918, p < 0.001 | - autistic parents rated the understanding and acceptance of employment support services significantly <u>lower</u> than professionals (adj. p = 0.004). -autistic adults rated the understanding and acceptance of employment support services significantly <u>lower</u> than professionals (adj. p < 0.001). -Non-autistic parents rated the understanding and acceptance of employment support services significantly <u>lower</u> than professionals (adj. p < 0.001). |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 3.

Results of Kruskal Wallis analyses for relationship between understanding and acceptance of autism in education and primary identity.

| Education | n | Kruskall Wallis | Post-hoc pairwise comparisons |
|--|-----|---|--|
| Teachers - Pre-school | 813 | H (4) = 30.578 p < 0.001 | autistic adults rated the understanding and acceptance of the preschool teachers significantly <u>lower</u> than family/whānau (adj. p = 0.001), non-autistic parents (adj. p < 0.001), and professionals (adj. p < 0.001). |
| Teachers - Primary | 875 | H (4) = 59.533, p < 0.001 | -autistic adults rated the understanding and acceptance of the primary teachers significantly <u>lower</u> than family/whānau (adj. p = 0.005), non-autistic parents (adj. p < 0.001), and professionals (adj. p < 0.001). -autistic parents rated the understanding and acceptance of the primary teachers significantly <u>lower</u> than family/whānau (adj. p = 0.016), non-autistic parents (adj. p = 0.004), and professionals (adj. p < 0.001). -Non-autistic parents also rated the understanding and acceptance of primary teachers significantly <u>lower</u> than professionals (adj. p = 0.019). |
| Teachers - Secondary | 667 | H (4) = 20.742, p < 0.001 | -autistic adults rated the understanding and acceptance of the primary teachers significantly <u>lower</u> than non-autistic parents (adj. p = 0.001) and professionals (adj. p = 0.002). |
| Teachers - Tertiary | 418 | H (4) = 9.165, p = 0.057 | - No significant differences between primary identity group/roles. |
| Education support workers - Pre-school | 621 | H (4) = 13.095, p = 0.011 | - No significant differences between primary identity group/roles. |
| Teacher aides - Primary | 705 | H (4) = 28.291, p < 0.001 | -autistic adults rated the understanding and acceptance of primary school teacher aides significantly <u>lower</u> than professionals (adj. p < 0.001) and non-autistic parents (adj. p = 0.015). -autistic parents rated the understanding and acceptance of primary school teacher aides significantly <u>lower</u> than professionals (adj. p = 0.001) and non-autistic parents (adj. p = 0.037). |
| Teacher aides - Secondary | 489 | H (4) = 8.305, p = 0.081 | - No significant differences between primary identity group/roles. |
| Specialist support - Pre-school | 280 | H (4) = 8.362, p = 0.079 | - No significant differences between primary identity group/roles. |
| Specialist support -Primary | 739 | H (4) = 42.443, p < 0.001 | -autistic adults rated the understanding and acceptance of primary school specialist support significantly <u>lower</u> than professionals (adj. p < 0.001). -autistic parents rated the understanding and acceptance of primary school specialist support significantly <u>lower</u> than professionals (adj. p < 0.001). -Non-autistic parents rated the understanding and acceptance of primary school specialist support significantly <u>lower</u> than professionals (adj. p < 0.001). |
| Specialist support - Secondary | 530 | H (4) = 15.303, p = 0.004 | -autistic adults rated the understanding and acceptance of secondary school specialist support significantly <u>lower</u> than professionals (adj. p < 0.001). -Non-autistic parents rated the understanding and acceptance of secondary school specialist support significantly <u>lower</u> than professionals (adj. p = 0.013) |
| Specialist support - Tertiary | 299 | H (4) = 4.963, p = 0.291 | - No significant differences between primary identity group/roles. |
| Leadership - Pre-school | 631 | H (4) = 15.711, p = 0.003 | -autistic adults rated the understanding and acceptance of pre-primary leadership significantly <u>lower</u> than professionals (adj. p = 0.007) and non-autistic parents (adj. p = 0.007). |
| Leadership - Primary | 788 | H (4) = 34.100, p < 0.001 | -autistic parents rated the understanding and acceptance of primary leadership significantly <u>lower</u> than family/whānau (adj. p = 0.022), non-autistic parents, (adj. p = 0.020) and professionals (adj. p < 0.001). |

| | | | |
|------------------------|-----|-----------------------------|--|
| | | | -autistic adults rated the understanding and acceptance of primary leadership significantly <u>lower</u> than professionals (adj. p < 0.001). -Non-autistic parents rated the understanding and acceptance of primary leadership significantly <u>lower</u> than professionals (adj. p = 0.014) |
| Leadership - Secondary | 571 | H (4) = 8.138, p = 0.087 | - No significant differences between primary identity group/roles. |
| Leadership - Tertiary | 309 | H (4) = 3.568, p = 0.468 | - No significant differences between primary identity group/roles. |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 4.

Results of Kruskal Wallis analyses for relationship between understanding and acceptance of autism in other contexts and primary identity.

| Other contexts | n | Kruskall Wallis | Post-hoc pairwise comparisons |
|--|-----|---|--|
| Legal system/courts/ judges/lawyers | 452 | H (4) = 12.571, p = 0.014 | - No significant differences between primary identity group/roles. |
| Work and Income New Zealand (WINZ) | 685 | H (4) = 23.819, p < 0.001 | -autistic adults rated the rated the understanding and acceptance of autism at WINZ significantly <u>lower</u> than non-autistic parents (adj. p < 0.001) and family/whānau (adj. p = 0.027). |
| Oranga Tamariki | 393 | H (4) = 18.822, p < 0.001 | -autistic parents rated the understanding and acceptance of autism at Oranga Tamariki significantly <u>lower</u> than family/whānau (adj p = 0.032). -autistic adults rated the understanding and acceptance of autism at Oranga Tamariki significantly <u>lower</u> than family/whānau (adj p = 0.041) |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 5.

Results of Kruskal Wallis analyses for relationship between overall experience with health and therapy and primary identity.

| Health and therapy | n | Kruskal Wallis | Post-hoc pairwise comparisons |
|--|-----|-------------------------------------|--|
| Early identification | 810 | H (4) = 26.681, p < 0.001 | -autistic adults rated the overall experience with early identification significantly <u>lower</u> than non-autistic parents (adj. p = 0.002) and professionals (adj. p < 0.001). -autistic parents rated their overall experience with early identification significantly <u>lower</u> than professionals (adj. p = 0.012). |
| Access to autism assessment and diagnosis for children | 909 | H (4) = 9.301, p = 0.054 | - No significant differences between primary identity group/roles. |
| Access to autism assessment and diagnosis for adults | 617 | H (4) = 43.893, p < 0.001 | -autistic parents rated the overall experience with access to autism assessment and diagnosis for adults significantly <u>lower</u> than non-autistic parents (adj. p = 0.038), professionals (adj. p < 0.001), family/whānau (adj. p < 0.001), and autistic adults (adj. p < 0.001) -Non-autistic parents rated the overall experience with access to autism assessment and diagnosis for adults significantly <u>lower</u> than family/whānau (adj. p < 0.001). -autistic adults rated the overall experience with access to autism assessment and diagnosis for adults significantly <u>lower</u> than family/whānau (adj. p = 0.001). -Professionals the overall experience with access to autism assessment and diagnosis for adults significantly <u>lower</u> than family/whānau (adj. p = 0.005). |
| Access to public mental health services for autistic adults | 840 | H (4) = 16.112, p = 0.003 | -autistic parents rated the overall experience with access to public mental health services significantly <u>lower</u> than professionals (adj. p = 0.008) and family/whānau (adj. p = 0.007). |
| Access/availability of mental health services tailored to autistic people's unique experiences and needs | 844 | H (4) = 18.282, p = 0.001 | -autistic parents rated the overall experience with tailored mental health services significantly <u>lower</u> than family/whānau (adj. p = 0.003) -autistic adults rated the overall experience with tailored mental health services significantly <u>lower</u> than family/whānau (adj. p = 0.011) |
| Health care services (for physical health) suitable for autistic people | 829 | H (4) = 19.565, p < 0.001 | -autistic parents rated the overall experience with health care services significantly <u>lower</u> than professionals (adj. p = 0.040) and family/whānau (adj. p = 0.031). -autistic adults rated the overall experience with health care services significantly <u>lower</u> than professionals (adj. p = 0.015) and family/whānau (adj. p = 0.036). |
| Therapy and support for autistic children | 829 | H (4) = 25.014, p < 0.001 | -autistic parents rated the overall experience of therapy and support for autistic children significantly <u>lower</u> than professionals (adj p = 0.011), autistic adults (adj. p = 0.047), and family/whānau (adj. p < 0.001). -Non autistic parents rated the overall experience with therapy and support for autistic children significantly <u>lower</u> than family/whānau (adj., p < 0.005). |
| Therapy and support for autistic adults | 544 | H (4) = 33.626, p < 0.001 | -autistic parents rated the overall experience with therapy and support for autistic adults significantly <u>lower</u> than autistic adults (adj. p = 0.001), non-autistic parents (adj. p = 0.001), professionals, (adj. p < 0.001) and family/whānau (adj. p < 0.001). -autistic adults rated the overall experience with therapy and support for autistic adults significantly <u>lower</u> than family/whānau (adj. p = 0.22). -Non-autistic parents rated the overall experience with therapy and support for autistic adults significantly <u>lower</u> than family/whānau (adj. p = 0.21). |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 6.

Results of Kruskal Wallis analyses for relationship between overall experience with disability supports and services, and primary identity.

| Disability supports and services | n | Kruskall Wallis | Post-hoc pairwise comparisons |
|---|-----|----------------------------------|---|
| Access to assistance and safety devices, such as communication (AAC) devices or safety fences | 605 | H (4) = 10.892, p = 0.028 | - No significant differences between primary identity group/roles. |
| Needs Assessment and service coordination (NASC) | 803 | H (4) = 4.467, p = 0.335 | - No significant differences between primary identity group/roles. |
| Disability support services | 822 | H (4) = 5.889, p = 0.208 | - No significant differences between primary identity group/roles. |
| Accessibility of Individualised funding providers/hosts | 734 | H (4) = 11.070, p = 0.026 | - No significant differences between primary identity group/roles. |
| Coordination of different services responsible for supporting autistic people with different challenges | 776 | H (4) = 18.252, p = 0.001 | -autistic parents rated the experience of coordination of services significantly <u>lower</u> than professionals (adj. p = 0.007) and family/whānau (adj. p = 0.011). |
| Advocacy services | 687 | H (4) = 25.471, p < 0.001 | -Non-autistic parents rated the experience of advocacy services significantly <u>lower</u> than professionals (adj. p < 0.001). |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 7.

Results of Kruskal Wallis analyses for relationship between overall experience with education and primary identity.

| Education | n | Kruskall Wallis | Post-hoc pairwise comparisons |
|--|-----|-------------------------------------|---|
| Support and adjustments in the classroom in primary/intermediate education | 843 | H (4) = 28.039, p < 0.001 | -autistic parents rated the overall experience with support and adjustments in the primary/intermediate classroom significantly <u>lower</u> than professionals (p < 0.001). -autistic adults rated the overall experience with support and adjustments in the primary/intermediate classroom significantly <u>lower</u> than professionals (p < 0.001). -Non-autistic parents rated the overall experience with support and adjustments in the primary/intermediate classroom significantly <u>lower</u> than professionals (p = 0.007). |
| Support and adjustments outside the classroom, such as on field trips, in primary/intermediate education | 800 | H (4) = 20.391, p < 0.001 | -autistic parents rated the overall experience with support and adjustments outside the primary/intermediate classroom significantly <u>lower</u> than family/whānau (adj. p = 0.001). -autistic adults rated the overall experience with support and adjustments outside the primary/intermediate classroom significantly <u>lower</u> than family/whānau (adj. p = 0.004). -Non-autistic parents rated the overall experience with support and adjustments outside the primary/intermediate classroom significantly <u>lower</u> than family/whānau (adj. p = 0.013). |
| Support and adjustments in the classroom in secondary education | 602 | H (4) = 2.924, p = 0.571 | - No significant differences between primary identity group/roles. |
| Support and adjustments outside the classroom, such as on field trips in secondary education | 554 | H (4) = 14.202, p = 0.007 | -autistic parents rated the overall experience with support and adjustments outside the secondary classroom significantly <u>lower</u> than family/whānau (adj. p = 0.011). -autistic adults rated the overall experience with support and adjustments outside the secondary classroom significantly <u>lower</u> than family/whānau (adj. p = 0.007). -Professionals rated the overall experience with support and adjustments outside the secondary classroom significantly <u>lower</u> than family/whānau (adj. p = 0.031). |
| Support and adjustments in tertiary education | 369 | H (4) = 11.382, p = 0.023 | - No significant differences between primary identity group/roles. |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 8.

Results of Kruskal Wallis analyses for relationship between overall experience with living and community, and primary identity.

| Living and community | n | Kruskall Wallis | Post-hoc pairwise comparisons |
|--|-----|---|--|
| Accommodations for autistic people in community services, events, and facilities | 766 | H (4) = 10.277, p = 0.36 | - No significant differences between primary identity group/roles. |
| Accessibility of WINZ and income tested benefits | 747 | H (4) = 31.095, p < 0.001 | -autistic parents rated the overall experience of WINZ significantly <u>lower</u> than non-autistic parents (adj. p = 0.004), professionals (adj. p = 0.006), and family/whānau (adj. p = 0.026). -autistic adults rated the overall experience of WINZ significantly <u>lower</u> than non-autistic parents (adj. p < 0.001), professionals (adj. p = 0.002), and family/whānau (adj. p = 0.036). |
| Transition to adulthood | 539 | H (4) = 23.299, p < 0.001 | - autistic parents rated the overall experience of transition to adulthood significantly <u>lower</u> than professionals (adj. p = 0.008) and family/whānau (adj. p = 0.007). -autistic adults rated the overall experience of transition to adulthood significantly <u>lower</u> professionals (adj. p = 0.013) and family/whānau (adj. p = 0.036). |
| Employment for autistic people | 556 | H (4) = 14.707 p = 0.005 | -autistic parents rated the overall experience of employment significantly <u>lower</u> than family/whānau (adj. p = 0.029). -Non-autistic parents rated the overall experience of employment significantly <u>lower</u> than family/whānau (adj. p = 0.009). |
| Employment support services | 399 | H (4) = 16.705, p = 0.002 | -Non-autistic parents rated the overall experience of employment support services significantly <u>lower</u> than professionals (adj. p = 0.008). -autistic parents rated the overall experience of employment support services significantly <u>lower</u> than professionals (adj. p = 0.028). |
| Affordable housing options | 466 | H (4) = 10.923, p = 0.027 | - No significant differences between primary identity group/roles. |
| Legal and criminal justice system | 377 | H (4) = 13.262, p = 0.010 | -autistic parents rated the overall experience with the legal and criminal justice system <u>lower</u> than family/whānau (adj. p = 0.016). -Non-autistic parents rated the overall experience with the legal and criminal justice system <u>lower</u> than family/whānau (adj. p = 0.004). -autistic adults rated the overall experience with the legal and criminal justice system <u>lower</u> than family/whānau (adj. p = 0.011). -Professionals rated the overall experience with the legal and criminal justice system <u>lower</u> than family/whānau (adj. p = 0.011). |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 9.

Results of Chi Square analyses for primary identity and bullying, harassment and hate crime.

| Bullying, harassment, and hate crime | Chi-square | n | Explanation |
|---|--|------|--|
| An autistic person/people I know have experience bully, harassment or hate crime. | $\chi^2(4) = 61.996, p < 0.001$ | 1042 | -autistic adults were significantly more likely to know someone who had experienced bullying than autistic parents, non-autistic parents, and professionals. |

Note: significance of primary analyses set at $p \leq 0.01$, adjusted p for all analyses post-hoc analyses ≤ 0.05 . Significant results are presented in bold.

Table 10.
Results of Chi Square analyses for primary identity and discrimination.

| Discrimination | Chi-square | n | Explanation |
|--|--|------|---|
| I know an autistic person/people who has/have experienced discrimination as a result of being autistic | $\chi^2(4) = 61.996, p < 0.001$ | 1042 | -autistic adults were significantly more likely to know someone who had experienced discrimination than autistic parents, non-autistic parents, family/whānau and professionals (all other primary identity group/roles). |

Note: significance of primary analyses set at $p \leq 0.01$, adjusted p for all analyses post-hoc analyses ≤ 0.05 . Significant results are presented in bold.

Table 11.
Results of Kruskal Wallis analyses for relationship between perception of autistic people's needs being met and primary identity.

| Needs met | n | Kruskall Wallis | Post-hoc pairwise comparisons |
|---|------|-----------------------------|--|
| Autistic people's needs are being met in their daily lives. | 1010 | H (4) = 42.132, $p < 0.001$ | -autistic parents rated autistic people's needs being met <u>lower</u> than non-autistic parents (adj. $p = 0.026$), professionals (adj. $p < 0.001$), and family/whānau (adj. $p < 0.001$). -autistic adults rated autistic people's needs being met <u>lower</u> than professionals (adj. $p = 0.001$) and family/whānau (adj. $p = 0.003$). -Non autistic parents rated autistic people's needs being met <u>lower</u> than professionals (adj. $p = 0.003$), and family/whānau (adj. $p = 0.008$) |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 12
Results of Kruskal Wallis analyses for relationship between satisfaction with the country's efforts to address issues and disadvantages for autistic people and primary identity.

| Satisfaction with country's efforts | n | Kruskall Wallis | Post-hoc pairwise comparisons |
|--|------|-----------------------------|---|
| Satisfaction with the country's efforts to address issues and disadvantages for autistic people in Aotearoa New Zealand? | 1018 | H (4) = 24.201, $p < 0.001$ | -autistic parents rated their satisfaction with the countries efforts to address issues and disadvantages for autistic people significantly <u>lower</u> than professionals (adj. $p = 0.011$), and family/whānau (adj. $p = 0.001$). -autistic adults whānau rated their satisfaction with the countries efforts to address issues and disadvantages for autistic people significantly <u>lower</u> than family/whānau (adj. $p = 0.008$). -Non-autistic parents whānau rated their satisfaction with the countries efforts to address issues and disadvantages for autistic people significantly <u>lower</u> than family/whānau (adj. $p = 0.013$) |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 13.
Results of Chi Square analyses for primary identity and awareness of the Guideline.

| Awareness of Guideline | Chi-square | n | Explanation |
|--|---------------------------------|------|---|
| Awareness of any edition of the Guideline since it was first published in 2008 | $\chi^2(4) = 74.584, p < 0.001$ | 1043 | autistic adults, autistic parents, and non-autistic parents were less aware of any edition of the guideline than professionals. |
| Knowledge of what is included in the current (third) edition of the Guideline* | $\chi^2(4) = 59.407, p < 0.001$ | 1043 | autistic adults, autistic parents, and non-autistic parents were less aware of the current guideline than professionals. autistic adults were more aware of the guideline than autistic parents. |

Note: significance of primary analyses set at $p \leq 0.01$, adjusted p for all analyses post-hoc analyses ≤ 0.05 . Significant results are presented in bold.

Table 14.
Results of Kruskal Wallis analyses for relationship between satisfaction with content and implementation of the current Guideline, and primary identity.

| Satisfaction with Guideline | n | Kruskal Wallis | Post-hoc pairwise comparisons |
|--|-----|---------------------------|--|
| Satisfaction with recommendations and good practice points | 239 | $H(2) = 9.861, p = 0.007$ | -Autistic people (adults/parents) rated their satisfaction with the recommendations and good practice points significantly <u>lower</u> than non-autistic parents (adj. $p = 0.005$). |
| Satisfaction with implementation | 225 | $H(2) = 0.148, p = 0.929$ | - No significant differences between primary identity group/roles. |

Note: significance of primary analyses set at $p \leq 0.01$, adjusted p for all analyses post-hoc analyses ≤ 0.05 . Significant results are presented in bold.

Due to the small number of autistic parents ($n = 10$) and family/whānau members ($n = 14$) who were at least somewhat aware of the current edition of the Guideline, autistic parents have been combined with autistic adults, and family/whānau members have been removed

Table 15.

Results of Kruskal Wallis analyses for relationship between perceived helpfulness of strategies for supporting implementation of the Guideline, and primary identity.

| Helpfulness of strategies to support implementation | n | Kruskall Wallis | Post-hoc pairwise comparisons |
|---|-----|-------------------------------------|--|
| Face to face engagement | 253 | H (2) = 9.903, p = 0.007 | -Autistic people (adults/parents) rated the helpfulness of face-to-face engagement significantly <u>lower</u> than professionals (adj. p = 0.006). |
| Video summaries of key recommendations | 254 | H (2) = 0.490, p = 0.783 | - No significant differences between primary identity group/roles. |
| Simple resources and handbooks | 261 | H (2) = 2.718, p = 0.257 | - No significant differences between primary identity group/roles. |
| Tertiary training for professionals and clinicians working in the autism sector | 251 | H (2) = 9.926, p = 0.007 | -Autistic people (adults/parents) rated the helpfulness of tertiary training for autism professionals significantly <u>lower</u> than professionals (adj. p = 0.006). |
| Ongoing professional development for professionals and clinicians working in the autism sector | 257 | H (2) = 14.882, p < 0.001 | -Autistic people (adults/parents) rated the helpfulness of ongoing professional development for autism professionals significantly <u>lower</u> than professionals (adj. p < 0.001). |
| Tertiary training for professionals and clinicians working in the general public | 256 | H (2) = 6.278, p = 0.043 | - No significant differences between primary identity group/roles. |
| Ongoing professional development for professionals and clinicians working in the general public | 259 | H (2) = 7.716, p = 0.021 | - No significant differences between primary identity group/roles. |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold. Due to the small number of autistic parents ($n = 8$) and family/whānau members ($n = 14$) who were at least somewhat aware of the current edition of the Guideline, autistic parents have been combined with autistic adults, and family/whānau members have been removed.

Table 16.

Results of Kruskal Wallis analyses for relationship between perceived helpfulness of different approaches for supporting autistic people, and primary identity.

| Helpfulness of approaches | n | Kruskall Wallis | Post-hoc pairwise comparisons |
|---|-----|-------------------------------------|---|
| The current general disability approach | 921 | H (4) = 17.321, p = 0.002 | -autistic parents rated the current disability approach significantly <u>lower</u> than professionals (adj. p = 0.025) and family/whānau (adj. p = 0.025) |
| An autism specific approach | 975 | H (4) = 7.014, p = 0.135 | - No significant differences between primary identity group/roles. |
| A neurodivergence approach | 975 | H (4) = 21.643, p < 0.001 | -Non autistic parents rated the neurodivergence approach significantly <u>lower</u> than professionals (adj. p = 0.001) |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 17.

Results of Kruskal Wallis analyses for relationships between perceived helpfulness of additional approaches to supporting autistic people, and primary identity.

| Helpfulness of additional approaches | n | Kruskal Wallis | Post-hoc pairwise comparisons |
|--|------|---|--|
| Autism/neurodiversity inclusion advisors | 997 | H (4) = 6.159, p = 0.188 | - No significant differences between primary identity group/roles. |
| An autism or neurodivergence commissioner or a minister | 996 | H (4) = 21.466, p < 0.001 | -Family/whānau rated an autism or neurodivergence commissioner or minister significantly <u>lower</u> than autistic adults (adj. p = 0.050) and autistic parents (p = 0.028). -Professionals rated the helpfulness of an autism or neurodivergence commissioner or minister significantly <u>lower</u> than non-autistic parents (adj. p = 0.025), autistic parents (adj. p = 0.023), and autistic adults (adj. p = 0.014). |
| A nationwide autism or neurodivergence strategy. | 1013 | H (4) = 10.664, p = 0.031 | - No significant differences between primary identity group/roles. |
| Autism/neurodivergence legislation or legal requirements | 984 | H (4) = 14.237, p = 0.007 | - While the overall model was significant, there was no significant differences between primary identity group/roles in the post-hoc tests. |
| Advocacy services | 995 | H (4) = 5.654, p = 0.226 | - No significant differences between primary identity group/roles. |
| Continuing with our current approach | 918 | H (4) = 30.771, p < 0.001 | -autistic parents rated the helpfulness of continuing with our current approach significantly <u>lower</u> than professionals (adj. p = 0.007) and family/whānau (adj. p < 0.001). -autistic adults rated the helpfulness of continuing with our current approach significantly <u>lower</u> than family/whānau (adj. p < 0.001). -Non-autistic parents the helpfulness of continuing with our current approach significantly <u>lower</u> than family/whānau (adj. p < 0.001). -autistic parents rated the helpfulness of continuing with our current approach significantly <u>lower</u> than family/whānau (adj. p = 0.014). |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 18.
Results of Kruskal Wallis analyses for relationship between areas of importance and primary identity.

| Perceived importance of addressing | n | Kruskall Wallis | Post-hoc pairwise comparisons |
|--|------|---|--|
| Understanding and acceptance of autism in society | 918 | H (4) = 5.321, p = 0.251 | - No significant differences between primary identity group/roles. |
| Early identification of autism | 1037 | H (4) = 38.726, p < 0.001 | -autistic adults rated the importance of early identification significantly <u>lower</u> than non-autistic parents (adj. p < 0.001) and professionals (adj. p < 0.001) |
| Access to assessment and diagnosis | 1036 | H (4) = 13.665, p = 0.008 | - autistic adults rated the importance of access to assessment and diagnosis <u>lower</u> than non-autistic parents (adj. p = 0.005). |
| Access to therapy and support | 1037 | H (4) = 24.416, p < 0.001 | -autistic adults rated the importance of access to therapy and support <u>lower</u> than non-autistic parents (adj. p < 0.001) and professionals (adj. p < 0.001) |
| Education inclusion/outcomes | 1027 | H (4) = 23.623, p < 0.001 | -autistic adults rated the importance of education/inclusion <u>lower</u> than autistic parents (adj. p = 0.014), non-autistic parents (adj. p < 0.001) and professionals (adj. p = 0.008) |
| Employment inclusion/outcomes | 1008 | H (4) = 9.365, p = 0.053 | - No significant differences between primary identity group/roles. |
| Transition into adulthood | 1005 | H (4) = 23.708, p < 0.001 | -autistic adults rated the importance of transition to adulthood <u>lower</u> than autistic parents (adj. p = 0.018), non-autistic parents (adj. p < 0.001) and professionals (adj. p = 0.022) |
| Choice and control with living and housing | 998 | H (4) = 3.754, p = 0.440 | - No significant differences between primary identity group/roles. |
| Health and care services | 1031 | H (4) = 5.984, p = 0.200 | - No significant differences between primary identity group/roles. |
| Mental health services and mental health outcomes | 1028 | H (4) = 7.318, p = 0.120 | - No significant differences between primary identity group/roles. |
| Training for professionals within the autism sector and general public | 1034 | H (4) = 16.067, p = 0.003 | -autistic adults rated the importance of training for professionals in the autism sector significantly <u>lower</u> than non-autistic parents (adj. p = 0.007) |
| Coordination and cooperation between types of services | 1027 | H (4) = 19.868, p < 0.001 | -autistic adults rated the importance of coordination significantly <u>lower</u> than professionals (adj. p = 0.001) and autistic parents (adj. p = 0.013). |
| Support within the legal and criminal justice system | 980 | H (4) = 14.788, p = 0.005 | -autistic adults rated the importance of support within the legal and criminal justice system <u>lower</u> than professionals (adj. p = 0.022) and non-autistic parents (adj. p = 0.003). |
| Advocacy services | 1020 | H (4) = 6.592, p = 0.159 | - No significant differences between primary identity group/roles. |
| Building the right support in the community | 1023 | H (4) = 9.425, p = 0.051 | - No significant differences between primary identity group/roles. |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 19.

Results of Kruskal Wallis analyses for relationship between important groups to include in decision making and primary identity.

| Perceived importance of addressing | n | Kruskall Wallis | Post-hoc pairwise comparisons |
|--|------|--|---|
| Autistic people | 1033 | H (4) = 7.180, p = 0.127 | - No significant differences between primary identity group/roles. |
| Parents/family of autistic people | 1034 | H (4) = 189.499, p < 0.001 | -autistic adults rated the importance of including parents/family significantly <u>lower</u> than autistic parents (adj. p < 0.001), non-autistic parents (adj. p < 0.001), family/whānau (adj. p < 0.001), and professionals (adj. p < 0.001). |
| Educators | 1030 | H (4) = 98.050, p < 0.001 | -autistic adults rated the importance of including educators significantly <u>lower</u> than non-autistic parents (adj. p < 0.001), family/whānau (adj. p < 0.001), professionals (adj. p < 0.001). -autistic parents rated the importance of including educators significantly <u>lower</u> than non-autistic parents (adj. p = 0.042) and professionals (adj. p < 0.001). |
| Mental health clinicians | 1026 | H (4) = 81.396, p < 0.001 | -autistic adults rated the importance of including mental health clinicians significantly <u>lower</u> than non-autistic parents (adj. p < 0.001), family/whānau (adj. p < 0.001), professionals (adj. p < 0.001). -autistic parents rated the importance of including mental health clinicians significantly <u>lower</u> than professionals (adj. p = 0.001). |
| Health Professionals | 1029 | H (4) = 80.481, p < 0.001 | -autistic adults rated the importance of including health professionals significantly <u>lower</u> than non-autistic parents (adj. p < 0.001), family/whānau (adj. p < 0.001), professionals (adj. p < 0.001). -autistic parents rated the importance of including health professionals significantly <u>lower</u> than professionals (adj. p = 0.002). |
| Disability support providers | 1027 | H (4) = 80.655, p < 0.001 | -autistic adults rated the importance of including health professionals significantly <u>lower</u> than non-autistic parents (adj. p = 0.001), family/whānau (adj. p < 0.001), professionals (adj. p < 0.001). -autistic parents rated the importance of including health professionals significantly <u>lower</u> than professionals (adj. p = 0.001) and non-autistic parents (adj. p = 0.001). |
| Academics/researchers | 1018 | H (4) = 28.571, p < 0.001 | -autistic adults rated the importance of including academics/researchers significantly <u>lower</u> than non-autistic parents (adj. p = 0.001), family/whānau (adj. p = 0.013), and professionals (adj. p < 0.001). |
| Autism advocacy groups | 1028 | H (4) = 26.095, p < 0.001 | -autistic adults rated the importance of including advocacy groups significantly <u>lower</u> than non-autistic parents (adj. p = 0.002) and professionals (adj. p < 0.001). -autistic parents rated the importance of including health professionals significantly <u>lower</u> than professionals (adj. p = 0.023). |
| Allied health professionals | 1027 | H (4) = 95.189, p < 0.001 | -autistic adults rated the importance of including health professionals significantly <u>lower</u> than non-autistic parents (adj. p = 0.001), family/whānau (adj. p < 0.001), professionals (adj. p < 0.001). -autistic parents rated the importance of including health professionals significantly <u>lower</u> than professionals (adj. p < 0.001), non-autistic parents (adj. p = 0.003), and family/whānau (adj. p = 0.029). |
| Māori people/groups with a connection to autism | 1008 | H (4) = 41.650, p < 0.001 | -Non-autistic parents rated the importance of including Māori significantly <u>lower</u> than professionals (adj. p < 0.001). -autistic adults rated the importance of including Māori significantly <u>lower</u> than professionals (adj. p = 0.021). |
| Pacific people/groups with a connection to autism | 1006 | H (4) = 39.485, p < 0.001 | -Non-autistic parents rated the importance of including Pacific Peoples significantly <u>lower</u> than professionals (adj. p < 0.001) -autistic parents rated the importance of including Pacific Peoples significantly <u>lower</u> than professionals (adj. p = 0.031) -autistic adults rated the importance of including Pacific Peoples significantly <u>lower</u> than professionals (adj. p = 0.020) |
| Other ethnicities/groups with a connection to autism | 1003 | H (4) = 31.171, p < 0.001 | -Non-autistic parents rated the importance of including other ethnicities <u>lower</u> than professionals (adj. p < 0.001). |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Appendix F

Ethnicity Analyses

Table 1.

Results of Mann-Whitney U tests for relationship between understanding and acceptance of autism in health and therapy and Māori, Pacific and Asian ethnicities.

| Health and therapy | n | Mann-Whitney U | Description of effect |
|---|-----|---|---|
| General practitioners (GP) | 949 | -Māori: $z = -2.506$, $p = 0.012$ -Pacific: $z = 1.441$, $p = 0.149$ -Asian: $z = 0.140$, $p = 0.889$ | -No difference for ethnicity |
| Other Health clinicians (e.g., other doctors/nurses/medical professionals) | 945 | -Māori: $z = -0.874$, $p = 0.382$ -Pacific: $z = 1.500$, $p = 0.134$ -Asian: $z = 1.762$, $p = 0.078$ | -No difference for ethnicity |
| Mental health clinicians (e.g., psychologists, psychiatrists, counsellors, mental health nurses etc.) | 897 | -Māori: $z = -1.019$, $p = 0.308$ -Pacific: $z = -0.250$, $p = 0.803$ -Asian: $z = 1.578$, $p = 0.115$ | -No difference for ethnicity |
| Other therapists (e.g. Occupational therapists, speech and language therapists) | 829 | -Māori: $z = -0.389$, $p = 0.697$ -Pacific: $z = 1.525$, $p = 0.127$ -Asian: $z = 0.338$, $p = 0.735$ | -No difference for ethnicity |
| Disability support services (e.g. support workers, carer support, respite, etc.) | 832 | -Māori: $z = 0.189$, $p = 0.850$ -Pacific: $z = 0.495$, $p = 0.621$ -Asian: $z = 1.295$, $p = 0.195$ | -No difference for ethnicity |
| NASC (needs assessment and service coordination) | 769 | -Māori: $z = 0.885$, $p = 0.376$ -Pacific: $z = -2.157$, $p = 0.031$ -Asian: $z = -0.379$, $p = 0.704$ | -No difference for ethnicity |
| Individualised funding hosts/providers (e.g. Manawanui, Geneva Healthcare, Mycare, etc.) | 552 | -Māori: $z = -0.447$, $p = 0.655$ -Pacific: $z = -0.438$, $p = 0.662$ -Asian: $z = -0.135$, $p = 0.892$ | -No difference for ethnicity |
| ACC | 397 | -Māori: $z = -2.332$, $p = 0.020$ -Pacific: $z = -0.607$, $p = 0.544$ -Asian: $z = 2.960$, $p = 0.003$ | -Asians rated the understanding and acceptance of AAC <u>higher</u> than non-Asians |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 2.

Results of Mann-Whitney U tests for relationship between understanding and acceptance of autism in the community and ethnicity.

| Community | n | Mann-Whitney U | Direction ethnicity |
|-----------------------------|------|--|------------------------------|
| Family/wider whānau | 1007 | -Māori: $z = -1.723$, $p = 0.085$ -Pacific: $z = -0.778$, $p = 0.473$ -Asian: $z = -1.157$, $p = 0.247$ | -No difference for ethnicity |
| Friends/peers | 997 | -Māori: $z = -0.447$, $p = 0.655$ -Pacific: $z = -0.561$, $p = 0.575$ -Asian: $z = -1.266$, $p = 0.205$ | -No difference for ethnicity |
| Colleagues | 858 | -Māori: $z = -1.362$, $p = 0.173$ -Pacific: $z = 0.145$, $p = 0.885$ -Asian: $z = -0.246$, $p = 0.806$ | -No difference for ethnicity |
| The general community | 990 | -Māori: $z = -1.002$, $p = 0.316$ -Pacific: $z = -0.671$, $p = 0.502$ -Asian: $z = 1.262$, $p = 0.207$ | -No difference for ethnicity |
| Police | 556 | -Māori: $z = -1.248$, $p = 0.212$ -Pacific: $z = -0.359$, $p = 0.720$ -Asian: $z = -0.280$, $p = 0.780$ | -No difference for ethnicity |
| Employers/managers | 757 | -Māori: $z = -0.317$, $p = 0.751$ -Pacific: $z = 1.563$, $p = 0.118$ -Asian: $z = -0.261$, $p = 0.794$ | -No difference for ethnicity |
| Employment support services | 537 | Māori: $z = -0.913$, $p = 0.361$ -Pacific: $z = 0.954$, $p = 0.340$ -Asian: $z = -0.669$, $p = 0.503$ | -No difference for ethnicity |

Note: significance of primary analyses set at $p \leq 0.01$.

Table 3.*Results of Mann Whitney U analyses for relationship between understanding and acceptance of autism in education and ethnicity.*

| Education | n | Mann Whitney U | Direction of effect |
|--|-----|--|------------------------------|
| Teachers - Pre-school | 357 | -Māori: z = 0.587, p = 0.557 -Pacific: z = 1.244, p = 0.214 -Asian: z = -1.151, p = 0.250 | -No difference for ethnicity |
| Teachers - Primary | 858 | Māori: z = 0.165, p = 0.869 -Pacific: z = 1.991, p = 0.046 -Asian: z = 0.687, p = 0.492 | -No difference for ethnicity |
| Teachers - Secondary | 649 | Māori: z = -1.493, p = 0.135 -Pacific: z = -0.522, p = 0.602 -Asian: z = 0.436, p = 0.663 | -No difference for ethnicity |
| Teachers - Tertiary | 407 | Māori: z = -0.221, p = 0.825 -Pacific: z = -1.340, p = 0.180 -Asian: z = 1.617, p = 0.106 | -No difference for ethnicity |
| Education support workers - Pre-school | 608 | Māori: z = 1.619, p = 0.105 -Pacific: z = -0.775, p = 0.438 -Asian: z = -1.407, p = 0.159 | -No difference for ethnicity |
| Teacher aides - Primary | 689 | Māori: z = -0.897, p = 0.370 -Pacific: z = 0.915, p = 0.360 -Asian: z = -0.991, p = 0.322 | -No difference for ethnicity |
| Teacher aides - Secondary | 474 | -Māori: z = -1.433, p = 0.152 -Pacific: z = -0.886, p = 0.376 -Asian: z = 0.211, p = 0.833 | -No difference for ethnicity |
| Specialist support - Pre-school | 271 | Māori: z = 0.004, p = 0.997 -Pacific: z = -0.687, p = 0.492 -Asian: z = 0.541, p = 0.588 | -No difference for ethnicity |
| Specialist support -Primary | 723 | Māori: z = 0.403, p = 0.687 -Pacific: z = 2.017, p = 0.044 -Asian: z = 0.401, p = 0.689 | -No difference for ethnicity |
| Specialist support - Secondary | 515 | Māori: z = -0.102, p = 0.919 -Pacific: z = -0.615, p = 0.539 -Asian: z = 0.462, p = 0.644 | -No difference for ethnicity |
| Specialist support - Tertiary | 292 | Māori: z = -1.741, p = 0.082 -Pacific: z = -0.048, p = 0.962 -Asian: z = -0.145, p = 0.885 | -No difference for ethnicity |
| Leadership - Pre-school | 617 | -Māori: z = 0.365, p = 0.715 -Pacific: z = 1.724, p = 0.085 -Asian: z = -0.667, p = 0.505 | -No difference for ethnicity |
| Leadership - Primary | 771 | Māori: z = -0.711, p = 0.477 -Pacific: z = 2.161, p = 0.031 -Asian: z = 0.141, p = 0.888 | -No difference for ethnicity |
| Leadership - Secondary | 555 | Māori: z = -0.576, p = 0.564 -Pacific: z = 0.565, p = 0.572 -Asian: z = 0.226, p = 0.226 | -No difference for ethnicity |
| Leadership - Tertiary | 301 | Māori: z = 0.050, p = 0.960 -Pacific: z = -0.550, p = 0.583 -Asian: z = 1.339, p = 0.181 | -No difference for ethnicity |

Note: significance of primary analyses set at $p \leq 0.01$.

Table 4.

Results of Mann Whitney U analyses for relationship between understanding and acceptance of autism in other contexts and ethnicity.

| Other contexts | n | Mann Whitney U | Description effect |
|--|-----|--|---|
| Legal system/courts/ judges/lawyers | 443 | -Māori: $z = -1.767$, $p = 0.077$ -Pacific: $z = 0.117$, $p = 0.907$ -Asian: $z = -1.028$, $p = 0.303$ | -No difference for ethnicity |
| Work and Income New Zealand (WINZ) | 671 | -Māori: $z = -1.139$, $p = 0.255$ -Pacific: $z = 0.367$, $p = 0.713$ -Asian: $z = 1.512$, $p = 0.131$ | -No difference for ethnicity |
| Oranga Tamariki | 385 | -Māori: $z = -2.750$, $p = 0.006$ -Pacific: $z = 0.003$, $p = 0.998$ -Asian: $z = 0.821$, $p = 0.411$ | -Māori rated the understanding and acceptance of Oranga Tamariki <u>lower</u> than non-Māori. |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 5.

Results of Mann Whitney U analyses for relationship between overall experience with health and therapy and ethnicity.

| Health and therapy | n | Mann Whitney U | Direction of effect |
|--|-----|--|--|
| Early identification | 794 | -Māori: $z = 0.701$, $p = 0.483$ -Pacific: $z = 1.841$, $p = 0.066$ -Asian: $z = 0.951$, $p = 0.341$ | -No difference for ethnicity |
| Access to autism assessment and diagnosis for children | 891 | Māori: $z = -0.456$, $p = 0.648$ -Pacific: $z = 1.869$, $p = 0.062$ -Asian: $z = 0.973$, $p = 0.330$ | -No difference for ethnicity |
| Access to autism assessment and diagnosis for adults | 602 | Māori: $z = -2.099$, $p = 0.036$ -Pacific: $z = 0.807$, $p = 0.420$ -Asian: $z = 2.493$, $p = 0.013$ | -No difference for ethnicity |
| Access to public mental health services for autistic adults | 819 | Māori: $z = -0.954$, $p = 0.340$ -Pacific: $z = 0.073$, $p = 0.942$ -Asian: $z = 1.664$, $p = 0.096$ | -No difference for ethnicity |
| Access/availability of mental health services tailored to autistic people's unique experiences and needs | 823 | Māori: $z = -0.958$, $p = 0.338$ -Pacific: $z = 0.659$, $p = 0.510$ -Asian: $z = 2.355$, $p = 0.019$ | -No difference for ethnicity |
| Health care services (for physical health) suitable for autistic people | 808 | Māori: $z = -1.980$, $p = 0.048$ -Pacific: $z = 0.832$, $p = 0.405$ -Asian: $z = 0.363$, $p = 0.717$ | -No difference for ethnicity |
| Therapy and support for autistic children | 810 | -Māori: $z = 1.219$, $p = 0.223$ -Pacific: $z = 1.155$, $p = 0.248$ -Asian: $z = 0.916$, $p = 0.360$ | -No difference for ethnicity |
| Therapy and support for autistic adults | 527 | -Māori: $z = -0.363$, $p = 0.716$ -Pacific: $z = 1.524$, $p = 0.128$ -Asian: $z = 2.910$, $p = 0.004$ | Asians rated their overall experience with health and therapy <u>higher</u> than non-Asians. |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 6.

Results of Mann Whitney U analyses for relationship between overall experience with disability supports and services, and ethnicity.

| Disability supports and services | n | Mann Whitney U | Direction of effect |
|---|-----|--|------------------------------|
| Access to assistance and safety devices, such as communication (AAC) devices or safety fences | 592 | -Māori: z = -0.059, p = 0.953 -Pacific: z = 1.264, p = 0.206 -Asian: z = 0.919, p = 0.358 | -No difference for ethnicity |
| Needs Assessment and service coordination (NASC) | 782 | -Māori: z = -1.471, p = 0.0141 -Pacific: z = -1.113, p = 0.266 -Asian: z = -0.531, p = 0.595 | -No difference for ethnicity |
| Disability support services | 802 | -Māori: z = -0.759, p = 0.448 -Pacific: z = 2.077, p = 0.038 -Asian: z = 0.611, p = 0.541 | -No difference for ethnicity |
| Accessibility of Individualised funding providers/hosts | 716 | -Māori: z = -1.642, p = 0.100 -Pacific: z = 0.299, p = 0.765 -Asian: z = 0.497, p = 0.619 | -No difference for ethnicity |
| Coordination of different services responsible for supporting autistic people with different challenges | 759 | Māori: z = -0.394, p = 0.694 -Pacific: z = 1.158, p = 0.247 -Asian: z = 1.626, p = 0.104 | -No difference for ethnicity |
| Advocacy services | 670 | Māori: z = 0.307, p = 0.759 -Pacific: z = 0.0643, p = 0.520 -Asian: z = -0.277 p = 0.781 | -No difference for ethnicity |

Note: significance of primary analyses set at $p \leq 0.01$.

Table 7.

Results of Mann Whitney U analyses for relationship between overall experience with education and ethnicity.

| Education | n | Mann Whitney U | Direction of effect |
|--|-----|---|------------------------------|
| Support and adjustments in the classroom in primary/intermediate education | 824 | -Māori: z = -1.063, p = 0.759 -Pacific: z = 1.618, p = 0.106 -Asian: z = 1.523, p = 0.128 | -No difference for ethnicity |
| Support and adjustments outside the classroom, such as on field trips, in primary/intermediate education | 782 | Māori: z = -1.259, p = 0.288 -Pacific: z = 1.607, p = 0.108 -Asian: z = 1.718, p = 0.086 | -No difference for ethnicity |
| Support and adjustments in the classroom in secondary education | 586 | Māori: z = -0.658, p = 0.208 -Pacific: z = 1.118, p = 0.264 -Asian: z = 0.428, p = 0.669 | -No difference for ethnicity |
| Support and adjustments outside the classroom, such as on field trips in secondary education | 539 | Māori: z = -0.593, p = 0.510 -Pacific: z = 1.566, p = 0.117 -Asian: z = 0.711, p = 0.477 | -No difference for ethnicity |
| Support and adjustments in tertiary education | 362 | -Māori: z = -2.124, p = 0.034 -Pacific: z = -0.075, p = 0.940 -Asian: z = -0.153, p = 0.878 | -No difference for ethnicity |

Note: significance of primary analyses set at $p \leq 0.01$.

Table 8.

Results of Mann Whitney U analyses for relationship between overall experience with living and community, and ethnicity.

| Living and community | n | Mann Whitney U | Direction of effect |
|--|-----|---|------------------------------|
| Accommodations for autistic people in community services, events, and facilities | 754 | -Māori: $z = -1.270$, $p = 0.204$ -Pacific: $z = 0.865$, $p = 0.387$ -Asian: $z = 1.130$, $p = 0.258$ | -No difference for ethnicity |
| Accessibility of WINZ and income tested benefits | 731 | Māori: $z = -1.514$, $p = 0.130$ -Pacific: $z = -0.337$, $p = 0.736$ -Asian: $z = 1.036$, $p = 0.300$ | -No difference for ethnicity |
| Transition to adulthood | 527 | -Māori: $z = -0.049$, $p = 0.961$ -Pacific: $z = 0.983$, $p = 0.326$ -Asian: $z = 1.338$, $p = 0.181$ | -No difference for ethnicity |
| Employment for autistic people | 546 | -Māori: $z = 1.139$, $p = 0.255$ -Pacific: $z = 1.128$, $p = 0.259$ -Asian: $z = 1.218$, $p = 0.223$ | -No difference for ethnicity |
| Employment support services | 391 | -Māori: $z = -1.159$, $p = 0.247$ -Pacific: $z = 0.668$, $p = 0.504$ -Asian: $z = -0.356$, $p = 0.722$ | -No difference for ethnicity |
| Affordable housing options | 456 | -Māori: $z = -0.417$, $p = 0.676$ -Pacific: $z = 1.118$, $p = 0.263$ -Asian: $z = 0.489$, $p = 0.825$ | -No difference for ethnicity |
| Legal and criminal justice system | 369 | -Māori: $z = -1.350$, $p = 0.177$ -Pacific: $z = 1.821$, $p = 0.069$ -Asian: $z = -1.349$, $p = 0.177$ | -No difference for ethnicity |

Note: significance of primary analyses set at $p \leq 0.01$.

Table 9.

Results of Chi Square analyses for ethnicity and bullying, harassment and hate crime.

| Bullying, harassment, and hate crime | Chi Square | n | Explanation |
|---|--|------|---|
| As an autistic person I have experienced bullying, harassment or hate crime. | -Māori: $\chi^2(1) = 0.008$, $p = 0.929$ -Pasifika: $\chi^2(1) = 3.116$, $p = 0.078$ -Asian: $\chi^2(1) = 0.241$, $p = 0.624$ | 1020 | -No significant differences for ethnicity |
| An autistic person/people I know has/have experience bully, harassment or hate crime. | -Māori: $\chi^2(1) = 2.161$, $p = 0.124$ -Pasifika: $\chi^2(1) = 1.580$, $p = 0.209$ -Asian: $\chi^2(1) = 1.399$, $p = 0.237$ | 1020 | -No significant differences for ethnicity |

Note: significance of primary analyses set at $p \leq 0.01$.

Table 10.
Results of Chi Square for ethnicity and discrimination.

| Discrimination | Chi Square | n | Explanation |
|--|---|------|---|
| I (an autistic person) have experienced discrimination as a result of being autistic | -Māori: $\chi^2(1) = 0.262, p = 0.609$ -Pasifika: $\chi^2(1) = 0.161, p = 0.688$ -Asian: $\chi^2(1) = 0.073, p = 0.782$ | 1020 | -No significant differences for ethnicity |
| I know an autistic person/people who has/have experienced discrimination as a result of being autistic | -Māori: $\chi^2(1) = 1.098, p = 0.295$ -Pasifika: $\chi^2(1) = 0.002, p = 0.967$ -Asian: $\chi^2(1) = 0.024, p = 0.877$ | 1020 | -No significant differences for ethnicity |

Note: significance of primary analyses set at $p \leq 0.01$.

Table 11.
Results of Mann Whitney U analyses for relationship between perception of autistic people's needs being met and ethnicity.

| Needs met | n | Mann Whitney U | Direction of effect |
|---|-----|---|------------------------------|
| Autistic people's needs are being met in their daily lives. | 989 | -Māori: $z = -0.660, p = 0.509$ -Pacific: $z = 0.642, p = 0.521$ -Asian: $z = 0.513, p = 0.608$ | -No difference for ethnicity |

Note: significance of primary analyses set at $p \leq 0.01$.

Table 12.
Results of Mann Whitney U analyses for relationship between satisfaction with the country's efforts to address issues and disadvantages for autistic people and ethnicity.

| Satisfaction with country's efforts | n | Mann Whitney U | Direction of effect |
|---|-----|--|------------------------------|
| Satisfaction with the country's efforts to address issues and disadvantages for autistic people in Aotearoa New Zealand | 997 | -Māori: $z = -1.879, p = 0.060$ -Pacific: $z = 0.913, p = 0.361$ -Asian: $z = -1.131, p = 0.258$ | -No difference for ethnicity |

Note: significance of primary analyses set at $p \leq 0.01$.

Table 13.
Results of Chi Square for ethnicity and awareness of the Guideline.

| Awareness of Guideline | Chi Square | n | Explanation |
|---|---|------|---|
| Awareness of any edition of the Guideline since it was first published in 2008* | -Māori: $\chi^2(1) = 9.003, p = 0.003$ -Pasifika: $\chi^2(1) = 1.308, p = 0.253$ -Asian: $\chi^2(1) = 0.332, p = 0.564$ | 1020 | -Māori were less aware of any edition of the guideline than non-Māori |
| Knowledge of what is included in the current (third) edition of the Guideline | -Māori: $\chi^2(1) = 3.178, p = 0.075$ -Pasifika: $\chi^2(1) = 0.533, p = 0.465$ -Asian: $\chi^2(1) = 0.436, p = 0.509$ | 1020 | -No difference for ethnicity |

Note: significance of primary analyses set at $p \leq 0.01$. *Awareness of most/all and some recommendations was combined.

Table 14.

Results of Mann Whitney U analyses for relationship between satisfaction with content and implementation of the current Guideline, and ethnicity.

| Satisfaction with Guideline | n | Mann Whitney U | Direction of effect |
|--|-----|--|------------------------------|
| Satisfaction with recommendations and good practice points | 245 | -Māori: z = -1.272, p = 0.203 -Pacific: z = -0.926, p = 0.355 -Asian: z = 0.673, p = 0.501 | -No difference for ethnicity |
| Satisfaction with implementation | 231 | -Māori: z = -0.589, p = 0.556 -Pacific: z = -1.904, p = 0.057 -Asian: z = 0.440, p = 0.501 | -No difference for ethnicity |

Note: significance of primary analyses set at $p \leq 0.01$.

Table 15.

Results of Mann Whitney U analyses for relationship between perceived helpfulness of strategies for supporting implementation of the Guideline, and ethnicity.

| Helpfulness of strategies to support implementation | n | Mann Whitney U | Direction of effect |
|---|-----|--|------------------------------|
| Face to face engagement | 259 | -Māori: z = 0.005, p = 0.996 -Pacific: z = -1.134, p = 0.257 -Asian: z = 0.953, p = 0.341 | -No difference for ethnicity |
| Video summaries of key recommendations | 260 | -Māori: z = 1.446, p = 0.148 -Pacific: z = 0.870, p = 0.384 -Asian: z = -1.055, p = 0.292 | -No difference for ethnicity |
| Simple resources and handbooks | 267 | -Māori: z = -0.577, p = 0.564 -Pacific: z = 1.192, p = 0.233 -Asian: z = 1.261, p = 0.207 | -No difference for ethnicity |
| Tertiary training for professionals and clinicians working in the autism sector | 257 | -Māori: z = -2.304, p = 0.021 -Pacific: z = 0.859, p = 0.390 -Asian: z = 1.361, p = 0.173 | -No difference for ethnicity |
| Ongoing professional development for professionals and clinicians working in the autism sector | 263 | -Māori: z = -0.921, p = 0.357 -Pacific: z = 1.198, p = 0.231 -Asian: z = 1.019, p = 0.308 | -No difference for ethnicity |
| Tertiary training for professionals and clinicians working in the general public | 262 | -Māori: z = -1.230, p = 0.219 -Pacific: z = 1.241, p = 0.215 -Asian: z = 1.234, p = 0.217 | -No difference for ethnicity |
| Ongoing professional development for professionals and clinicians working in the general public | 265 | -Māori: z = -0.575, p = 0.567 -Pacific: z = -0.031, p = 0.975 -Asian: z = 1.682, p = 0.093 | -No difference for ethnicity |

Note: significance of primary analyses set at $p \leq 0.01$.

Table 16.

Results of Mann Whitney U analyses for relationship between perceived helpfulness of different approaches for supporting autistic people, and ethnicity.

| Helpfulness of approaches | n | Mann Whitney U | Direction of effect |
|---|-----|--|--|
| The current general disability approach | 893 | -Māori: z = -0.657, p = 0.511 -Pacific: z = 2.174, p = 0.030 -Asian: z = 2.652, p = 0.008 | -Asians rated the helpfulness of the current disability approach <u>higher</u> than non-Asians |
| An autism specific approach | 956 | Māori: z = -0.578, p = 0.563 -Pacific: z = -0.136, p = 0.892 -Asian: z = -1.511, p = 0.131 | -No difference for ethnicity |
| A neurodivergence approach | 955 | Māori: z = -1.591, p = 0.112 -Pacific: z = -1.891, p = 0.059 -Asian: z = -1.077, p = 0.283 | -No difference for ethnicity |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 17.

Results of Mann Whitney U analyses for relationships between perceived helpfulness of additional approaches to supporting autistic people, and ethnicity.

| Helpfulness of additional approaches | n | Mann Whitney U | Direction of effect |
|--|-----|---|---|
| Autism/neurodiversity inclusion advisors | 975 | -Māori: z = 1.366, p = 0.172 -Pacific: z = 1.404, p = 0.160 -Asian: z = -0.739, p = 0.460 | -No difference for ethnicity |
| An autism or neurodivergence commissioner or a minister | 974 | Māori: z = 0.168, p = 0.867 -Pacific: z = 1.848, p = 0.065 -Asian: z = -0.341, p = 0.733 | -No difference for ethnicity |
| A nationwide autism or neurodivergence strategy. | 991 | Māori: z = 0.079, p = 0.937 -Pacific: z = 1.227, p = 0.220 -Asian: z = -0.902, p = 0.367 | -No difference for ethnicity |
| Autism/neurodivergence legislation or legal requirements | 962 | Māori: z = -0.074, p = 0.941 -Pacific: z = 1.500, p = 0.134 -Asian: z = -0.057, p = 0.954 | -No difference for ethnicity |
| Advocacy services | 973 | Māori: z = -0.246, p = 0.806 -Pacific: z = 0.243, p = 0.808 -Asian: z = -0.996, p = 0.319 | -No difference for ethnicity |
| Continuing with our current approach | 899 | Māori: z = -0.063, p = 0.950 -Pacific: z = 2.713, p = 0.007 -Asian: z = 3.480, p < 0.001 | Pacific Peoples and Asians rated continuing with our current approach <u>higher</u> than non-Pacific peoples and non-Asians |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Table 18.*Results of Mann Whitney U analyses for relationship between areas of importance and ethnicity.*

| Perceived importance of addressing | n | Mann Whitney U | Direction of effect |
|--|------|---|------------------------------|
| Understanding and acceptance of autism in society | 1014 | -Māori: z = 0.520, p = 0.603 -Pacific: z = 1.336, p = 0.182 -Asian: z = -0.403, p = 0.687 | -No difference for ethnicity |
| Early identification of autism | 1014 | -Māori: z = 0.698, p = 0.485 -Pacific: z = 0.740, p = 0.459 -Asian: z = 0.280, p = 0.780 | -No difference for ethnicity |
| Access to assessment and diagnosis | 1013 | -Māori: z = -0.805, p = 0.421 -Pacific: z = 0.101, p = 0.919 -Asian: z = -0.732, p = 0.464 | -No difference for ethnicity |
| Access to therapy and support | 1014 | -Māori: z = 0.206, p = 0.837 -Pacific: z = 0.386, p = 0.713 -Asian: z = -1.072, p = 0.284 | -No difference for ethnicity |
| Education inclusion/outcomes | 1004 | -Māori: z = -0.211, p = 0.833 -Pacific: z = 1.484, p = 0.138 -Asian: z = -0.116, p = 0.907 | -No difference for ethnicity |
| Employment inclusion/outcomes | 987 | -Māori: z = -0.477, p = 0.633 -Pacific: z = 1.794, p = 0.073 -Asian: z = -1.484, p = 0.138 | -No difference for ethnicity |
| Transition into adulthood | 983 | -Māori: z = -0.468, p = 0.640 -Pacific: z = 1.598, p = 0.110 -Asian: z = -0.015, p = 0.988 | -No difference for ethnicity |
| Choice and control with living and housing | 976 | -Māori: z = 0.880, p = 0.379 -Pacific: z = 1.723, p = 0.085 -Asian: z = -0.515, p = 0.607 | -No difference for ethnicity |
| Health and care services | 1008 | -Māori: z = 0.735, p = 0.462 -Pacific: z = 2.337, p = 0.019 -Asian: z = -0.599, p = 0.549 | -No difference for ethnicity |
| Mental health services and mental health outcomes | 1005 | -Māori: z = -0.158, p = 0.875 -Pacific: z = -0.909, p = 0.364 -Asian: z = -0.224, p = 0.822 | -No difference for ethnicity |
| Training for professionals within the autism sector and general public | 1011 | -Māori: z = 0.741, p = 0.458 -Pacific: z = 1.225, p = 0.221 -Asian: z = 0.193, p = 0.847 | -No difference for ethnicity |
| Coordination and cooperation between types of services | 1004 | -Māori: z = 0.653, p = 0.514 -Pacific: z = 0.661, p = 0.508 -Asian: z = -0.069, p = 0.945 | -No difference for ethnicity |
| Support within the legal and criminal justice system | 961 | -Māori: z = 0.363, p = 0.716 -Pacific: z = 1.313, p = 0.189 -Asian: z = -1.165, p = 0.244 | -No difference for ethnicity |
| Advocacy services | 998 | -Māori: z = 0.577, p = 0.564 -Pacific: z = 1.587, p = 0.113 -Asian: z = 0.413, p = 0.679 | -No difference for ethnicity |
| Building the right support in the community | 1000 | -Māori: z = -0.010, p = 0.992 -Pacific: z = 1.888, p = 0.059 -Asian: z = 0.541, p = 0.589 | -No difference for ethnicity |

Note: significance of primary analyses set at $p \leq 0.01$

Table 19.*Results of Mann Whitney U analyses for relationship between important groups to include in decision making and ethnicity.*

| Groups to include | n | Mann Whitney U | Direction of effect |
|--|------|--|--|
| Autistic people | 1010 | -Māori: z = -1.330, p = 0.184 -Pacific: z = -0.791, p = 0.429 -Asian: z = 0.607, p = 0.544 | -No difference for ethnicity |
| Parents/family of autistic people | 1011 | Māori: z = -0.293, p = 0.769 -Pacific: z = 0.964, p = 0.335 -Asian: z = -0.468, p = 0.640 | -No difference for ethnicity |
| Educators | 1007 | Māori: z = -1.200, p = 0.230 -Pacific: z = 1.188, p = 0.235 -Asian: z = 1.717, p = 0.086 | -No difference for ethnicity |
| Mental health clinicians | 1003 | Māori: z = -0.195, p = 0.846 -Pacific: z = 1.244, p = 0.213 -Asian: z = 1.567, p = 0.117 | -No difference for ethnicity |
| Health Professionals | 1006 | -Māori: z = -0.650, p = 0.516 -Pacific: z = 1.690, p = 0.091 -Asian: z = 1.181, p = 0.238 | -No difference for ethnicity |
| Disability support providers | 1004 | Māori: z = 0.311, p = 0.756 -Pacific: z = 1.900, p = 0.057 -Asian: z = 0.492, p = 0.623 | -No difference for ethnicity |
| Academics/researchers | 995 | -Māori: z = -0.917, p = 0.359 -Pacific: z = 2.207, p = 0.027 -Asian: z = 1.857, p = 0.063 | -No difference for ethnicity |
| Autism advocacy groups | 1005 | -Māori: z = 0.586, p = 0.558 -Pacific: z = 1.640, p = 0.101 -Asian: z = -1.137, p = 0.255 | -No difference for ethnicity |
| Allied health professionals (e.g. speech language therapist, occupational therapist) | 1004 | -Māori: z = -0.291, p = 0.771 -Pacific: z = 2.276, p = 0.023 -Asian: z = 0.622, p = 0.534 | -No difference for ethnicity |
| Māori people/groups with a connection to autism | 985 | -Māori: z = 2.756, p = 0.006 -Pacific: z = 2.947, p = 0.003 -Asian: z = 0.802, p = 0.422 | Māori and Pacific Peoples rated the importance of including Māori <u>higher</u> than non-Māori and non-Pacific people. |
| Pacific people/groups with a connection to autism | 983 | -Māori: z = 2.610, p = 0.009 -Pacific: z = 2.915, p = 0.004 -Asian: z = 0.775, p = 0.438 | Māori and Pacific Peoples rated the importance of including Pacific People <u>higher</u> than non-Māori and non-Pacific people |
| Other ethnicities/groups with a connection to autism | 980 | -Māori: z = 2.073, p = 0.038 -Pacific: z = 3.558, p < 0.001 -Asian: z = 1.436, p = 0.151 | Pacific Peoples rated the importance of including other ethnicities groups <u>higher</u> than non-Pacific people. |

Note: significance of primary analyses set at $p \leq 0.01$. Significant results are presented in bold.

Appendix G

Within Subjects Analyses

Table 1.
Results of Wilcoxin analyses comparing participant satisfaction with the Guideline recommendations and good practice points with the implementation of the Guideline.

| Wilcoxin Signed Ranks Test | n | Explanation |
|----------------------------|-----|--|
| Z = -10.236, p < 0.001 | 233 | -Participants were more satisfied with the Guideline recommendations and good practice points than the Guideline implementation. |

Note: significance of primary analyses set at $p \leq 0.01$.

Table 2.
Results of Friedman's analyses comparing perceived helpfulness of different approaches to supporting guideline implementation.

| Friedman's Two-Way Analysis of Variance | n | Pairwise post-hoc comparisons |
|---|-----|---|
| $\chi^2(6) = 267.107$, p < 0.001 | 248 | <p>-Videos were perceived to be less helpful than resources and handbooks (adj. p < 0.001), tertiary training for the clinicians working in the general public (adj. p < 0.001), tertiary training for the autism sector (adj. p < 0.001), ongoing professional development for the clinicians working in general public (adj. p < 0.001), and ongoing professional development for the autism sector (adj. p < 0.001). Note: Lower than all but face-to-face engagement.</p> <p>-Face-to-face engagement was rated lower than tertiary training for clinicians working in the general public (adj. p < 0.001), tertiary training for the autism sector (adj. p < 0.001), ongoing professional development for clinicians working in the general public (adj. p < 0.001), ongoing professional development for clinicians working in the autism sector (adj. p < 0.001). Note: lower than all tertiary training and professional development.</p> <p>-Resources and handbooks were rated lower than tertiary training for clinicians working in the general public (adj. p = 0.005), ongoing professional development for clinicians working in the general public (adj. p = 0.031), and ongoing professional development for clinicians working in the autism sector (adj. p = 0.030). Note: lower than all professional development and general tertiary training.</p> |

Note: significance of primary analyses set at $p \leq 0.01$. Adj. = Adjusted

Table 3.
Results of Friedman's analyses comparing the perceived effectiveness of different overarching approaches to support (disability, autism-specific, and neurodivergence approach).

| Friedman's Two Way Analysis of Variance | n | Pairwise post-hoc comparisons |
|---|-----|--|
| $\chi^2(2) = 861.333,$ $p < 0.001$ | 880 | <p style="text-align: center;">-</p> <ul style="list-style-type: none"> -The disability approach was perceived to be significantly less effective than both the neurodivergence approach (adj. $p < 0.001$) and the autism specific approach (adj. $p < 0.001$). -There was no significant difference between the neurodivergence approach and the autism specific approach. |

Note: significance of primary analyses set at $p \leq 0.01$. Adj. = Adjusted

Table 4.
Results of Friedman's analyses comparing perceived helpfulness of different future approaches to support.

| Friedman's Two Way Analysis of Variance | n | Pairwise post-hoc comparisons |
|---|-----|---|
| $\chi^2(5) = 1928.394,$ $p < 0.001$ | 856 | <p style="text-align: center;">-</p> <ul style="list-style-type: none"> -Continuing with the current approach was perceived to be significantly less helpful than a commissioner or minister (adj. $p < 0.001$), legislation or legal requirements (adj. $p < 0.001$), inclusion advisors (adj. $p < 0.001$), nationwide strategy (adj. $p < 0.001$), and advocacy (adj. $p < 0.001$). Note: Lower than all other approaches. -A commissioner or minister was significantly less helpful than nationwide strategy (adj. $p < 0.001$) and advocacy (adj. $p < 0.001$). -Legislation or legal requirements were significantly less helpful than nationwide strategy (adj. $p = 0.008$) and advocacy (adj. $p < 0.001$). -Inclusion advisors were significantly less helpful than advocacy (adj. $p = 0.006$). |

Note: significance of primary analyses set at $p \leq 0.01$. Adj. = Adjusted

Table 5.*Results of Friedman's analyses comparing areas of importance to address in Aotearoa New Zealand's future approach.*

| Friedman's Two Way Analysis of Variance | n | Pairwise post-hoc comparisons |
|---|-----|--|
| $\chi^2(14) = 317.151,$ $p < 0.001$ | 923 | <p style="text-align: center;">-</p> <p>-Early identification was rated significantly less important than training for professionals (adj. $p = 0.008$), education inclusion/outcomes (adj. $p = 0.005$), access to assessment and diagnosis (adj. $p = 0.001$), mental health (adj. $p < 0.001$), and access to therapy and support (adj. $p < 0.001$).</p> <p>-Housing was rated significantly less important than training for professionals (adj. $p = 0.008$), education inclusion/outcomes (adj. $p = 0.006$), access to assessment and diagnosis (adj. $p = 0.001$), mental health (adj. $p < 0.001$), and access to therapy and support (adj. $p < 0.001$).</p> <p>-Support with the legal and criminal justice system was rated significantly less important than training for professionals (adj. $p = 0.037$), education inclusion/outcomes (adj. $p = 0.026$), access to assessment and diagnosis (adj. $p = 0.003$), mental health (adj. $p < 0.001$), and access to therapy and support (adj. $p < 0.001$).</p> <p>Note: Early identification, housing, and support with the legal and criminal justice system all rated lower than the same areas.</p> <p>-Understanding and acceptance of autism in society was rated significantly lower than access to assessment and diagnosis (adj. $p = 0.035$), mental health (adj. $p = 0.003$), and access to therapy and support (adj. $p < 0.001$).</p> <p>-Building the right support in the community was rated significantly lower than mental health (adj. $p = 0.006$), and access to therapy and support (adj. $p < 0.001$).</p> <p>-Advocacy services were rated significantly lower than mental health (adj. $p = 0.033$), and access to therapy and support (adj. $p = 0.001$).</p> <p>Note: Building the right support in the community and advocacy services both rated significantly lower than mental health and access to therapy and support.</p> |

Note: significance of primary analyses set at $p \leq 0.01$. Adj. = Adjusted

Table 6.

Results of Friedman's analyses comparing the importance of including various groups in the decision making and development of any future approach.

| Friedman's Two Way Analysis of Variance | n | Pairwise post-hoc comparisons |
|---|-----|---|
| $\chi^2(14) = 888.457, p < 0.001$ | 979 | <p>-The importance of including academics/researchers was rated significantly lower than health professionals (adj. $p < 0.001$), educators (adj. $p < 0.001$), mental health professionals (adj. $p < 0.001$), other ethnicities (adj. $p < 0.001$), allied health professionals (adj. $p < 0.001$), Pacific people/groups (adj. $p < 0.001$), disability support providers (adj. $p < 0.001$), Māori people/groups (adj. $p < 0.001$), autism advocacy groups (adj. $p < 0.001$), parents/family (adj. $p < 0.001$), and autistic people (adj. $p < 0.001$). Note: Including academics/researchers was lower than all other groups.</p> <p>-The importance of including health professionals was rated significantly lower than including Pacific people/groups (adj. $p = 0.002$), disability support providers (adj. $p < 0.001$), Māori people/groups (adj. $p < 0.001$), autism advocacy groups (adj. $p < 0.001$), parents/family (adj. $p < 0.001$), and autistic people (adj. $p < 0.001$). -The importance of including educators was rated lower than including Pacific people/groups (adj. $p = 0.016$), disability support providers (adj. $p = 0.006$), Māori people/groups (adj. $p = 0.002$), autism advocacy groups (adj. $p < 0.001$), parents/family (adj. $p < 0.001$), and autistic people (adj. $p < 0.001$). Note: Health professionals and educators were rated lower than the same groups.</p> <p>-The importance of including mental health professionals was rated significantly lower than including autism advocacy groups (adj. $p < 0.001$), parents/family (adj. $p < 0.001$), and autistic people (adj. $p < 0.001$). -The importance of including other ethnicities was rated significantly lower than including autism advocacy groups (adj. $p < 0.001$), parents/family (adj. $p < 0.001$), and autistic people (adj. $p < 0.001$). -The importance of including allied health professionals was rated significantly lower than including autism advocacy groups (adj. $p = 0.001$), parents/family (adj. $p < 0.001$), and autistic people (adj. $p < 0.001$). -Note: mental health professionals, other ethnicities, and allied health professionals were all rated lower than autism advocacy groups, parents/family, and autistic people.</p> <p>-The importance of including Pacific people/groups was rated significantly lower than including parents/family (adj. $p < 0.001$), and autistic people (adj. $p < 0.001$). -The importance of including disability support providers was rated significantly lower than including parents/family (adj. $p < 0.001$), and autistic people (adj. $p < 0.001$). -The importance of including Māori people/groups was rated significantly lower than including parents/family (adj. $p < 0.001$), and autistic people (adj. $p < 0.001$). -The importance of including advocacy groups was rated significantly lower than including parents/family (adj. $p < 0.001$), and autistic people (adj. $p < 0.001$). Note: Pacific people/groups, disability support providers, Māori people/groups, and advocacy groups were all rated lower than parents/family and autistic people.</p> <p>-The importance including parents/family was rated significantly lower than the importance of including autistic people (adj. $p = 0.001$).</p> |

Note: The importance of including autistic people was rated higher than the importance of including all other groups.

Appendix H

Rankings of the helpfulness and importance of future approaches to support.

Table 1.
Rankings for the relative helpfulness of different approaches to Guideline implementation across groups and for each primary identity group/role.

| All | | | Autistic adults | | | Non-autistic parents | | | Autistic parents | | | Professionals | | | Family/ Whānau | | |
|---------------------------|-------|-------|--------------------------------|-------|-------|--------------------------------|-------|-------|--------------------------------|-------|-------|--------------------------------|-------|-------|--------------------------------|-------|-------|
| | % VH | %VH+H | | % VH | %VH+H | | % VH | %VH+H | | % VH | %VH+H | | % VH | %VH+H | | % VH | %VH+H |
| Ongoing training general | 68.06 | 89.94 | Ongoing training general | 64.18 | 86.57 | Ongoing training general | 64.29 | 94.05 | Ongoing PD autism | 46.67 | 73.34 | Ongoing PD autism | 77.78 | 90.74 | Ongoing training general | 57.14 | 100 |
| Ongoing PD autism | 66.32 | 88.2 | Tertiary training general | 61.19 | 86.56 | Ongoing PD autism | 67.86 | 89.29 | Ongoing training general | 46.67 | 73.34 | Ongoing training general | 77.78 | 89.82 | Tertiary training – autism sec | 57.14 | 92.85 |
| Tertiary training general | 67.36 | 86.9 | Tertiary training – autism sec | 55.22 | 89.55 | Tertiary training general | 66.67 | 88.1 | Tertiary training general | 46.67 | 66.67 | Tertiary training general | 76.85 | 87.96 | Tertiary training general | 50 | 92.86 |
| Tertiary training autism | 62.50 | 86.11 | Ongoing PD autism | 55.22 | 86.56 | Tertiary training – autism sec | 60.71 | 85.71 | Resources | 40 | 66.67 | Tertiary training – autism sec | 73.15 | 86.11 | Resources | 28.57 | 100 |
| Resources | 50.69 | 85.07 | Resources | 49.25 | 85.07 | Resources | 48.81 | 80.95 | Tertiary training – autism sec | 33.33 | 66.66 | Resources | 57.41 | 88.89 | Face-to-face engagement | 28.57 | 100 |
| Face-to-face engagement | 40.63 | 80.91 | Face-to-face engagement | 29.85 | 80.6 | Face-to-face engagement | 42.86 | 77.38 | Video summaries | 26.67 | 53.34 | Face-to-face engagement | 50.93 | 85.19 | Ongoing PD autism | 42.86 | 85.72 |
| Video summaries | 31.6 | 74.66 | Video summaries | 34.33 | 74.63 | Video summaries | 28.57 | 71.43 | Face-to-face engagement | 13.33 | 43.33 | Video summaries | 33.33 | 77.77 | Video summaries | 28.57 | 92.86 |

Note: VH = Very helpful, H = helpful. The different options were placed in order of highest to lowest importance based on the “VH+H” column, unless the difference between the percentage of responses for these two options was less than that for the “VH” column alone.

Table 2.
Rankings for the relative helpfulness of autism specific, neurodivergence, and general disability approaches across groups and for each primary identity group/role.

| All | | | autistic adults | | | Non-autistic parents | | | autistic parents | | | Professionals | | | Family/Whānau | | |
|--------------------|-------|-------|--------------------|-------|-------|----------------------|-------|-------|--------------------|-------|-------|--------------------|-------|-------|-----------------|-------|-------|
| | % VH | %VH+H | | % VH | %VH+H | | % VH | %VH+H | | % VH | %VH+H | | % VH | %VH+H | | % VH | %VH+H |
| Neurodivergence | 53.31 | 78.62 | Neurodivergence | 53.46 | 82.49 | Neurodivergence | 47.72 | 74.18 | Neurodivergence | 65.82 | 81.01 | Neurodivergence | 61.16 | 85.95 | Neurodivergence | 44.19 | 60.47 |
| Autism specific | 45.16 | 78.81 | Autism specific | 46.08 | 82.49 | Autism specific | 44.47 | 76.57 | Autism specific | 49.37 | 82.28 | Autism specific | 45.45 | 82.23 | Autism specific | 37.21 | 58.14 |
| General disability | 7.19 | 23.78 | General disability | 6.45 | 21.2 | General disability | 6.94 | 22.56 | General disability | 5.06 | 15.19 | General disability | 7.44 | 28.93 | Neurodivergence | 44.19 | 60.47 |

Note: VH = Very helpful, H = helpful. The different options were placed in order of highest to lowest importance based on the “VH+H” column, unless the difference between the percentage of responses for these two options was less than that for the “VH” column alone.

Table 3.

Rankings for the relative helpfulness of different future approaches to support across groups and for each primary identity group/role.

| All | Autistic adults | | Non-autistic parents | | Autistic parents | | Professionals | | Family/Whānau | | | | | | | | |
|-----------------------------------|-----------------|-------|-----------------------------------|-------|------------------|-----------------------------------|---------------|-------|-----------------------------------|-------|-------|-----------------------------------|-------|-------|-----------------------------------|-------|-------|
| | % VH | %VH+H | % VH | %VH+H | % VH | %VH+H | % VH | %VH+H | % VH | %VH+H | | | | | | | |
| Advocacy | 63.37 | 87.63 | Advocacy | 64.52 | 87.1 | Advocacy | 62.69 | 86.99 | Advocacy | 70.89 | 89.88 | Advocacy | 63.22 | 89.25 | Inclusion advisors | 39.53 | 72.09 |
| Nationwide strategy | 56.18 | 86.28 | Nationwide strategy | 53.46 | 86.64 | Nationwide strategy | 57.92 | 87.2 | Nationwide strategy | 64.56 | 83.55 | Nationwide strategy | 55.79 | 88.02 | Commissioner or minister | 34.88 | 65.11 |
| Inclusion advisors | 51.68 | 83.61 | Commissioner or minister | 49.77 | 83.41 | Inclusion advisors | 54.01 | 84.81 | Legislation or legal requirements | 51.90 | 84.81 | Inclusion advisors | 50.83 | 85.95 | Nationwide strategy | 37.21 | 72.09 |
| Legislation or legal requirements | 47.94 | 78.26 | Inclusion advisors | 50.69 | 82.03 | Legislation or legal requirements | 49.89 | 80.04 | Commissioner or minister | 58.23 | 78.48 | Legislation or legal requirements | 44.21 | 72.31 | Legislation or legal requirements | 34.88 | 62.79 |
| Commissioner or minister | 46.98 | 78.43 | Legislation or legal requirements | 48.85 | 81.57 | Commissioner or minister | 48.81 | 79.19 | Inclusion advisors | 49.37 | 79.75 | Commissioner or minister | 39.26 | 74.8 | Advocacy | 51.16 | 83.72 |
| Continuing with current approach | 5.85 | 14 | Continuing with current approach | 7.37 | 13.82 | Continuing with current approach | 5.64 | 13.67 | Continuing with current approach | 2.53 | 2.53 | Continuing with current approach | 4.55 | 14.47 | Continuing with current approach | 13.95 | 37.21 |

Note: VH = Very helpful, H = Helpful. The different options were placed in order of highest to lowest importance based on the “VH+H” column, unless the difference between the percentage of responses for these two options was less than that for the “VH” column alone.

Table 4.

Rankings for the relative importance of areas to address in Aotearoa New Zealand’s future approach across groups and for each primary identity group/role.

| All | autistic adults | | | Non-autistic parents | | | autistic parents | | | Professionals | | | Family/whānau | | | | | | | | | | |
|---|-----------------|-------|----------|---|-------|----------|------------------|---|----------|---------------|-------|---|---------------|-------|----------|---|-------|-------|-------|---|-------|-------|-------|
| | % VI | %VI+I | %VI+I+SI | % VI | %VI+I | %VI+I+SI | % VI | %VI+I | %VI+I+SI | % VI | %VI+I | %VI+I+SI | % VI | %VI+I | %VI+I+SI | | | | | | | | |
| Access to therapy | 83.51 | 94.06 | 95.40 | Mental health outcomes | 76.04 | 87.10 | 92.63 | Access to therapy | 87.20 | 95.44 | 95.87 | Mental health outcomes | 86.08 | 94.94 | 96.21 | Access to therapy | 87.19 | 97.11 | 97.94 | Access to therapy | 79.07 | 95.35 | 95.35 |
| Mental health outcomes | 81.02 | 92.53 | 94.64 | Access to therapy | 72.81 | 87.10 | 90.79 | Access to assessment and diagnosis | 83.95 | 94.15 | 95.67 | Training for professionals | 83.54 | 94.93 | 97.46 | Mental health outcomes | 84.30 | 97.11 | 97.94 | Access to assessment and diagnosis | 74.42 | 93.02 | 97.67 |
| Access to assessment and diagnosis | 80.63 | 92.42 | 95.10 | Training for professionals | 71.43 | 86.18 | 91.25 | Training for professionals | 81.78 | 93.71 | 95.66 | Access to therapy | 82.28 | 94.94 | 97.47 | Access to assessment and diagnosis | 81.82 | 95.87 | 98.35 | Choice and control (living and housing) | 72.09 | 93.02 | 93.02 |
| Training for professionals | 78.72 | 92.53 | 95.41 | Access to assessment and diagnosis | 72.35 | 84.33 | 89.40 | Education outcomes | 82.43 | 91.76 | 94.36 | Coordination between services | 84.81 | 92.40 | 96.20 | Coordination between services | 82.23 | 95.04 | 97.52 | Health and care | 76.74 | 88.37 | 93.02 |
| Education outcomes | 78.14 | 91.47 | 94.54 | Health and care | 68.66 | 85.25 | 91.70 | Mental health outcomes | 81.34 | 92.62 | 93.92 | Access to assessment and diagnosis | 83.54 | 93.67 | 96.20 | Training for professionals | 79.75 | 95.45 | 98.34 | Early identification | 67.44 | 93.02 | 97.67 |
| Coordination between services | 75.93 | 91.08 | 94.24 | Coordination between services | 66.82 | 86.64 | 92.17 | Health and care | 76.57 | 91.75 | 95.00 | Education outcomes | 84.81 | 91.14 | 93.67 | Education outcomes | 79.75 | 94.63 | 97.94 | Building the right support | 67.44 | 93.02 | 95.35 |
| Health and care | 74.21 | 90.80 | 94.83 | Education outcomes | 65.90 | 87.56 | 91.25 | Early identification | 76.57 | 89.37 | 94.36 | Transition to adulthood | 79.75 | 94.94 | 96.21 | Transition to adulthood | 73.55 | 94.62 | 97.10 | Transition to adulthood | 74.42 | 90.70 | 90.70 |
| Transition to adulthood | 73.06 | 89.26 | 91.94 | Employment outcomes | 67.28 | 82.95 | 88.94 | Coordination between services | 75.70 | 90.88 | 93.27 | Health and care | 77.22 | 92.41 | 96.21 | Health and care | 73.14 | 93.80 | 97.11 | Education outcomes | 72.09 | 90.69 | 95.34 |
| Employment outcomes | 72.29 | 89.36 | 93.00 | Advocacy services | 64.98 | 83.41 | 91.24 | Transition to adulthood | 77.22 | 89.15 | 91.75 | Employment outcomes | 75.95 | 93.67 | 93.67 | Employment outcomes | 71.07 | 95.45 | 98.34 | Coordination between services | 72.09 | 90.69 | 93.02 |
| Advocacy services | 70.66 | 89.16 | 93.00 | Understanding and acceptance | 65.44 | 82.49 | 88.48 | Building the right support | 72.89 | 90.03 | 93.28 | Understanding and acceptance | 77.22 | 88.61 | 91.14 | Early identification | 73.55 | 92.56 | 98.35 | Mental health outcomes | 74.42 | 88.37 | 90.70 |
| Understanding and acceptance | 70.28 | 88.78 | 93.48 | Choice and control (living and housing) | 65.44 | 82.03 | 88.02 | Advocacy services | 73.75 | 89.59 | 91.76 | Building the right support | 72.15 | 92.40 | 94.93 | Advocacy services | 70.66 | 95.04 | 96.69 | Understanding and acceptance | 74.42 | 86.05 | 90.70 |
| Early identification | 70.18 | 86.67 | 93.86 | Transition to adulthood | 60.83 | 81.11 | 85.26 | Understanding and acceptance | 71.80 | 89.59 | 94.15 | Advocacy services | 68.35 | 87.34 | 93.67 | Building the right support | 70.25 | 92.56 | 96.28 | Training for professionals | 67.44 | 90.70 | 93.03 |
| Building the right support | 69.89 | 88.87 | 92.90 | Building the right support | 62.67 | 80.18 | 87.09 | Employment outcomes | 74.84 | 88.72 | 91.97 | Support within the justice system | 68.35 | 87.34 | 89.87 | Understanding and acceptance | 68.60 | 93.39 | 97.94 | Employment outcomes | 69.77 | 86.05 | 93.03 |
| Choice and control (living and housing) | 66.44 | 85.71 | 91.46 | Support within the justice system | 56.68 | 81.10 | 88.47 | Choice and control (living and housing) | 67.03 | 84.38 | 90.24 | Choice and control (living and housing) | 67.09 | 86.08 | 93.67 | Support within the justice system | 69.01 | 90.91 | 95.04 | Advocacy services | 69.77 | 83.72 | 93.02 |
| Support within the justice system | 65.10 | 85.04 | 89.64 | Early identification | 54.84 | 74.19 | 86.17 | Support within the justice system | 66.59 | 83.29 | 86.98 | Early identification | 65.82 | 83.54 | 96.20 | Choice and control (living and housing) | 64.88 | 90.09 | 95.88 | Support within the justice system | 62.79 | 86.05 | 93.03 |

Note. VI = Very important, I = important, SI = somewhat important. The different options were placed in order of highest to lowest importance based on the “VI+I” column, unless the difference between the percentage of responses for these two options was less than that for the “VI” column alone, or the percentage was less than both the “VI” column and the “VI + I + SI” column.

Table 4.

Rankings for the relative importance of including various groups in the decision making and development of any future approaches, across groups and for each primary identity group/role.

| | All | | | autistic adults | | | Non-autistic parents | | | autistic parents | | | Family/whānau | | | | | | |
|----------------------|-------|-------|----------|----------------------|-------|-------|----------------------|----------------------|-------|------------------|----------|----------------------|---------------|-------|----------|----------------------|-------|-------|-------|
| | % VI | %VI+I | %VI+I+SI | | % VI | %VI+I | %VI+I+SI | | % VI | %VI+I | %VI+I+SI | | % VI | %VI+I | %VI+I+SI | | | | |
| Autistic people | 80.18 | 88.94 | 93.09 | Parents | 77.44 | 92.62 | 95.87 | Autistic people | 82.28 | 89.87 | 93.67 | Autistic people | 82.16 | 95.02 | 97.92 | Parents | 72.09 | 93.02 | 93.02 |
| Māori | 54.84 | 81.57 | 87.56 | Autistic people | 75.7 | 91.1 | 95.22 | Parents | 67.09 | 88.61 | 94.94 | Parents | 78.01 | 94.61 | 97.51 | Autistic people | 69.77 | 83.72 | 95.35 |
| Pacific Peoples | 52.07 | 83.41 | 88.48 | Autism advocacy | 64.43 | 85.47 | 93.06 | Māori | 56.96 | 78.48 | 87.34 | Māori | 69.29 | 93.77 | 97.92 | Autism advocacy | 67.44 | 86.04 | 93.02 |
| Autism advocacy | 49.31 | 78.8 | 90.32 | Disability support | 60.74 | 85.25 | 93.28 | Autism advocacy | 51.9 | 77.22 | 87.35 | Pacific Peoples | 68.05 | 93.36 | 97.92 | Disability support | 67.44 | 83.72 | 90.7 |
| Other ethnicities | 50.69 | 78.34 | 85.25 | Allied health | 54.88 | 84.6 | 93.06 | Pacific Peoples | 51.9 | 75.95 | 86.08 | Autism advocacy | 68.88 | 90.87 | 97.51 | Allied health | 65.12 | 83.72 | 93.02 |
| Disability support | 30.88 | 68.21 | 86.64 | Mental health | 52.28 | 78.96 | 90.46 | Other ethnicities | 51.9 | 75.95 | 86.08 | Allied health | 63.07 | 91.7 | 98.34 | Health professionals | 60.47 | 81.4 | 93.03 |
| Parents | 30.88 | 60.83 | 84.33 | Educators | 50.98 | 79.4 | 91.55 | Disability support | 40.51 | 69.62 | 92.4 | Other ethnicities | 63.49 | 90.05 | 97.1 | Educators | 55.81 | 83.72 | 95.35 |
| Allied health | 28.57 | 62.21 | 85.25 | Health professionals | 48.59 | 77.44 | 91.76 | Mental health | 37.97 | 73.41 | 88.6 | Disability support | 59.75 | 92.53 | 97.51 | Mental health | 60.47 | 81.4 | 90.7 |
| Mental health | 28.11 | 59.91 | 81.57 | Māori | 45.77 | 74.4 | 82.86 | Allied health | 34.18 | 73.42 | 88.61 | Mental health | 61 | 90.05 | 97.52 | Other ethnicities | 58.14 | 72.09 | 81.39 |
| Academics | 25.35 | 60.83 | 80.65 | Pacific Peoples | 44.9 | 74.18 | 81.12 | Health professionals | 36.71 | 69.62 | 86.08 | Educators | 57.68 | 87.97 | 97.1 | Māori | 55.81 | 72.09 | 83.72 |
| Health professionals | 25.81 | 55.76 | 79.26 | Other ethnicities | 43.38 | 72.23 | 80.47 | Educators | 36.71 | 65.82 | 84.81 | Health professionals | 55.6 | 87.97 | 96.27 | Pacific Peoples | 55.81 | 72.09 | 79.07 |
| Educators | 24.42 | 52.07 | 80.64 | Academics | 39.7 | 71.15 | 86.77 | Academics | 32.91 | 65.82 | 89.87 | Academics | 42.74 | 78.42 | 92.11 | Academics | 51.16 | 74.42 | 86.05 |

Note. VI = Very important, I = important, SI = somewhat important. The different options were placed in order of highest to lowest importance based on the “VI+I” column, unless the difference between the percentage of responses for these two options was less than that for the “VI” column alone, or the percentage was less than both the “VI” column and the “VI + I + SI” column. Beige coloured cells indicate no difference in ratings between adjacent rows.

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



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