

# Autistic co-led autism research priorities for Aotearoa New Zealand:

**A partnership with Autistic people, families and  
whānau, service and support providers, and  
researchers**

December 2022

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**DOI:** <https://dx.doi.org/10.26021/13952>

**Suggested citation:** Emerson, L.M., Monk, R., van der Meer, L., & McLay, L. (2022). Autistic co-led autism research priorities for Aotearoa New Zealand: A partnership with Autistic people, families and whānau, service and support providers, and researchers. Christchurch: Te Whare Wānanga o Waitaha | University of Canterbury.

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### **Note on language**

Within this report, Autistic-preferred terminology is used, except where participants have been quoted directly.

## **Acknowledgments**

We would like to thank all members of the Autistic Advisory Group and Partnership Advisory Group for their contributions throughout this project. These advisory groups were essential in informing the design of the research, dissemination to the community, and interpretation of the findings. Some members of the advisory groups are named below. Some members have asked to remain unnamed. We offer our sincere thanks to all members.

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Dr Hannah Waddington, Te Herenga Waka | Victoria University of Wellington  
Dr Hiran Thabrew, The University of Auckland

Thank you to Mel Tainui and Trisha Toreka Lealiifano-Mariota for their cultural guidance and support in the facilitation of the focus groups.

Thank you to A/Prof Dean Sutherland, Melissa Lim and Jessica Heaton for their contributions to the analysis of the data.

A special thank you to Chanelle Moriah for their contribution to editing and creating visuals for this community report, and creating the Autistic Partnership logo.

We also offer many thanks to the Autistic people, families and wh•nau, practitioners, and researchers who took part in each stage of the project, and contributed their valuable time, ideas, energy and passion. This collective knowledge and experience forms the backbone of this project, this report, and the future of autism research in Aotearoa.

This project was funded by a Health Research Council Activation Grant (Ref. 20/1237) and a College of Education, Health and Human Development Collaboration and Capacity Enhancing Grant (2021).

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## **Introduction**

A wealth of research demonstrates that the health and wellbeing needs of Autistic individuals are far less likely to be met than those of non-autistic individuals<sup>1</sup>. Autism research needs to be responsive to the needs of Autistic individuals to ensure it translates into meaningful real-world change.

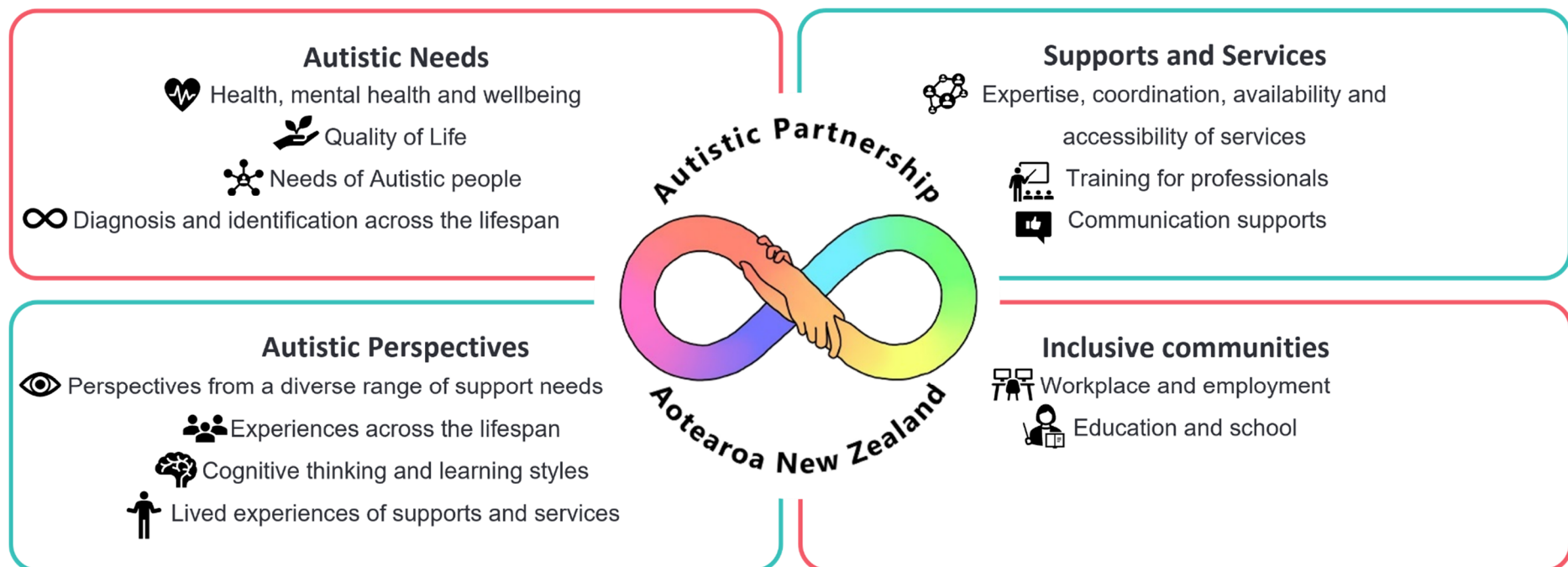
Currently, there are no existing priorities or strategy for autism research in Aotearoa New Zealand. Given the unique social and cultural context of Aotearoa New Zealand and the centralised health, disability, and education systems, it is essential to establish a set of national priorities for autism research.

We set out to work in partnership with the Autistic and autism communities, to co-produce autism research priorities for Aotearoa New Zealand.

**The intended outcome of this work is that the established relationships and priorities will support future research that is informed by, and of direct benefit to, the Autistic community. In doing so, we hope to overcome barriers to knowledge translation in autism research.**

**In this report, we outline the methods that we followed to establish the autism research priorities for Aotearoa New Zealand.**

## Autistic co-led autism research priorities for Aotearoa New Zealand



## Our methods

### A partnership approach

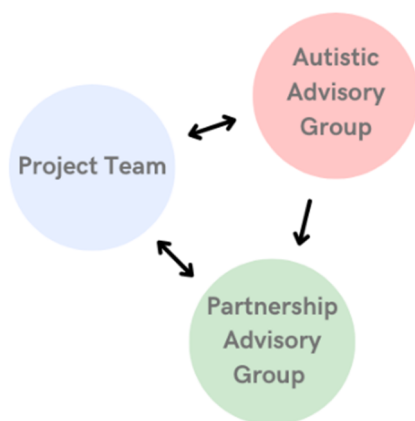
*We set out to work in partnership with people from the Autistic and autism communities in Aotearoa New Zealand.*

The project team included non-Autistic and Autistic researchers. As part of this project, we established two advisory groups: The **Autistic Advisory Group (AAG)** consisted of Autistic adults from the community, and the **Partnership Advisory Group (PAG)** consisted of representatives from the AAG, as well as parents/carers, practitioners from education, health and disability sectors, autism organisations, and researchers.

These advisory groups informed the design of the community consultation activities (focus groups; survey), interpretation of the resulting data, and subsequent research priorities.

Figure 1 depicts how the project team worked in partnership with the advisory groups and how the AAG informed the PAG in the discussion of research design and analysis of findings.

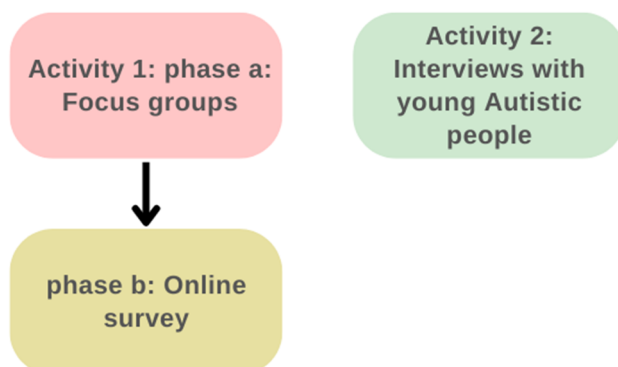
*Figure 1. Relationship between project team and advisory groups*



### Community consultation activities (data collection)

In 2021, we gathered the opinions of people in the Autistic and autism communities through three community consultation activities. Figure 2 depicts these three consultation activities.

*Figure 2. Community consultation activities*

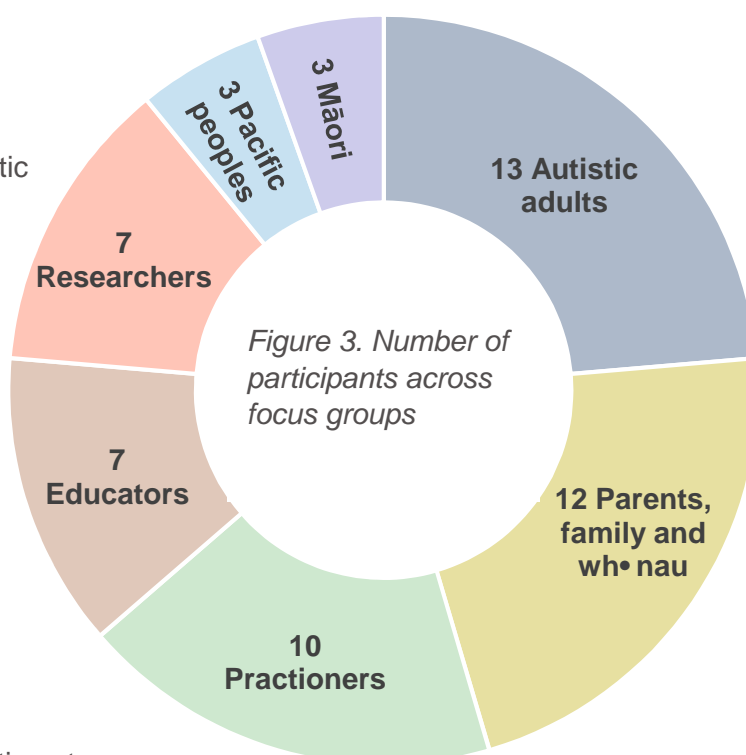


## Community Consultation Activity 1

### Phase a: Focus groups

In a series of focus groups, we held discussions with people from the Autistic and autism communities about what they believed future autism research in Aotearoa New Zealand should focus on.

There were seven participant groups: Autistic adults, parents, family and whānau, researchers, Māori, practitioners, Pacific peoples, and educators. Figure 3 shows the number of people who took part across these groups.



Each group was asked two open questions to prompt this discussion:

- 1. What questions do you think future research should help us to answer about autism?**
- 2. How can research enable Autistic people to lead the life they would like to live?**

The focus groups were held on Zoom, so that people from across Aotearoa New Zealand could take part. Both verbal and written communication was supported.

After these discussions were analysed by researchers in our team, we invited feedback from all participants on the emerging themes and integrated this into the final analysis. The focus group themes were reported to the AAG and PAG, who provided feedback on the analysis and interpretation. The advisory groups then used the themes to determine key categories for autism research for phase b; an online survey.



## **Phase b: Online survey**

The online survey was designed to gather the views of adults (18 years +) living in Aotearoa New Zealand, who were Autistic individuals, parents, carers, family and whānau, professionals or researchers. Alternative forms of the survey were available on request (e.g., paper; translations).

The survey presented people with a list of 32 potential autism research topics (see Appendix A for list of topics), grouped into four broad research areas: Needs and Supports; Inclusive Communities; Aotearoa Autism Research; Autistic Experience. Individuals were asked to rate the importance of each topic to them (5-point Likert scale). Figure 4 shows an example of the survey question.

*Figure 4. Example of survey question*

### **Autistic experience.**

The topics on this page are focused on research that would improve our understanding of the experiences of Autistic people.

						
	Not Important	Slightly Important	Moderately Important	Important	Very Important	Prefer not to answer / Don't know
Autistic peoples lived experiences of supports and services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

A report that summarised the data from the online survey was reviewed and discussed by the AAG and PAG. The importance ratings for the research topics from the online survey informed the autism research priorities presented in this report.

## **Community consultation activity 2: Interviews with Autistic youth**

We also aimed to gather the perspectives of Autistic youth aged 8 – 18 years. Young people were given a choice of being interviewed (in-person or Zoom) individually, in a focus group, or via a questionnaire (emailed). The interview questions were the same across all choices.

After introductions, and being provided with a definition of research, Autistic youth were asked the following main questions:

- 1. What questions do you think future research should help us to answer about autism?***
- 2. How can research help you (and other young Autistic people) to lead the life you would like to live?***
- 3. How can research help you to reach your own goals in life? When you think about this question, you might want to think about what kind of changes could have a big impact for you in your life.***

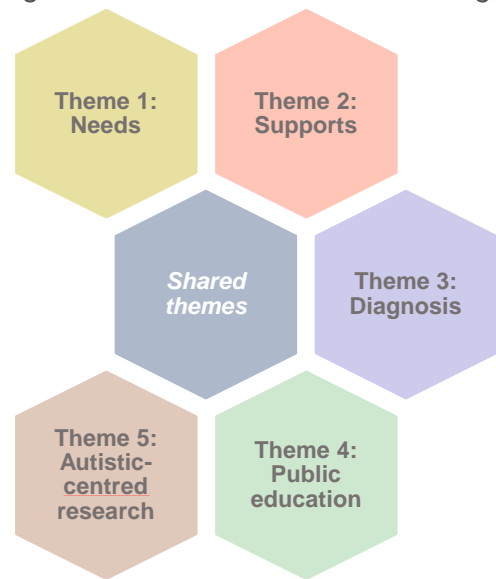
## Findings from the community consultation

### Focus groups themes

Two researchers coded the data from the focus groups by grouping similar opinions within a common theme. Together the researchers identified the key themes that emerged from the data. Each participant group was analysed separately. A third researcher reviewed the themes across each participant group and summarised the themes across all groups.

Shared themes across participant groups are shown in Figure 5 and summarised in the following section. After this summary, additional themes that emerged from a particular participant group(s) are described.

*Figure 5. Shared themes from focus groups*



## Shared themes

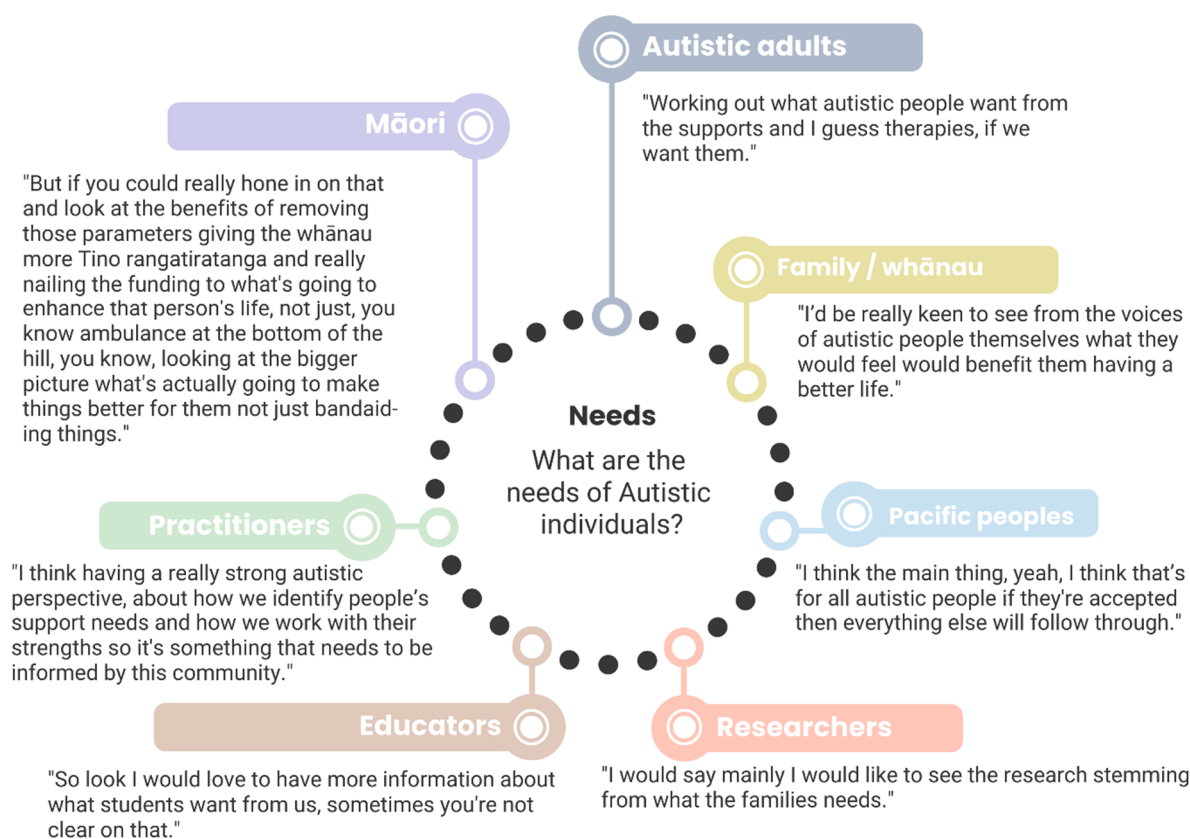
### Shared theme 1. Needs

#### *What are the needs of Autistic people in Aotearoa New Zealand?*

This theme represented the view that research should establish an understanding of the needs and preferences of Autistic people. Across all focus groups there was an echoing of the view that the Autistic perspective should be central to developing an understanding of needs of Autistic people in Aotearoa NZ.

Figure 6 shows an infographic that represents the perspectives from each participant group through the use of quotes from participants.

*Figure 6. Theme from Autistic adults group, common across all focus groups: Needs*



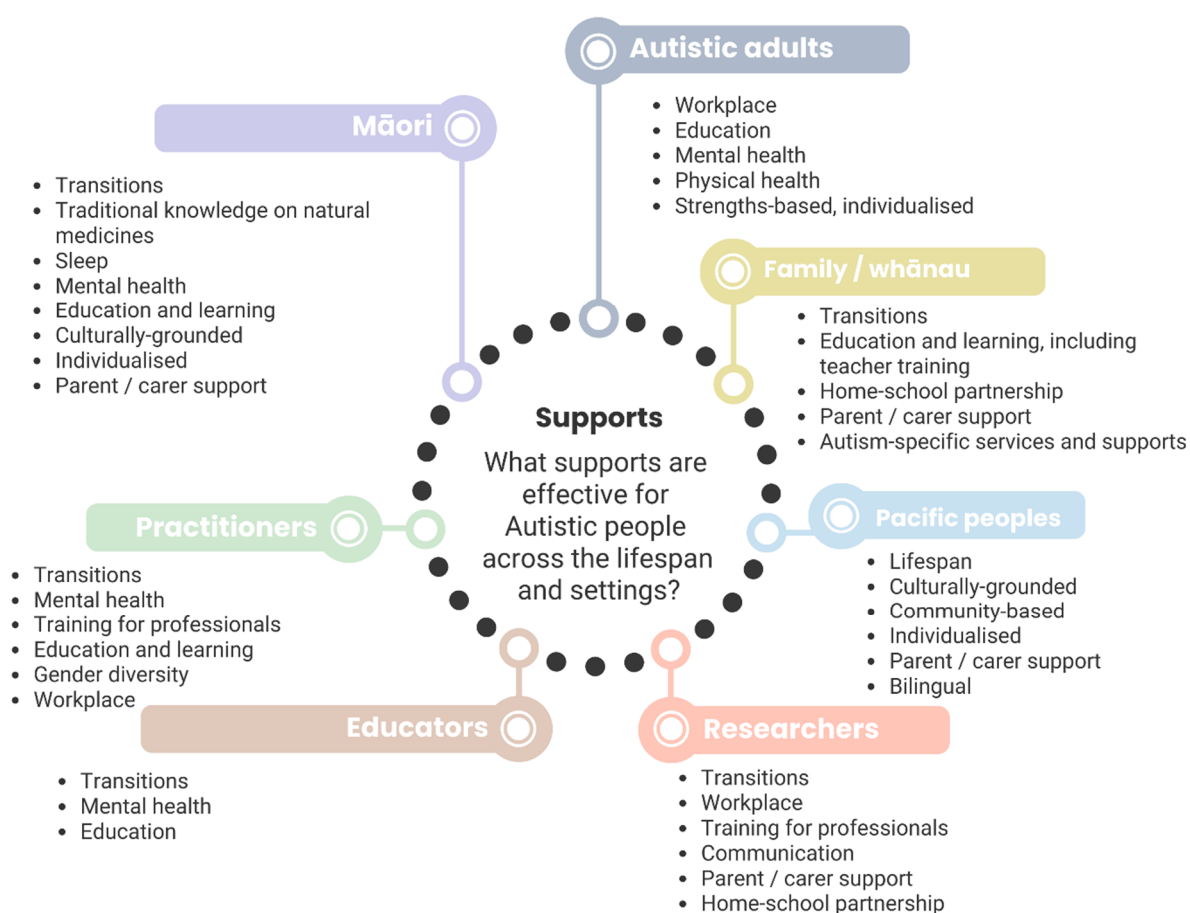
## Shared theme 2. Supports

***What supports are beneficial for Autistic people across the lifespan and in different settings?***

This theme represented an overarching question about what supports are beneficial for Autistic people across different situations and environments, including education, the workplace and times of transition. Mostly, this was related to the idea of developing appropriate and relevant supports that are strengths-based, autism-specific, and culturally-grounded. Support for parents / carers emerged as a theme across multiple groups, as well as training for professionals in supporting roles (see Figure 2).

Figure 7 shows an infographic that represents the perspectives from each participant group by highlighting the sub-themes that emerged from the data that relate to effective supports.

*Figure 7. Theme from Autistic adults group, shared across all focus groups: Supports*



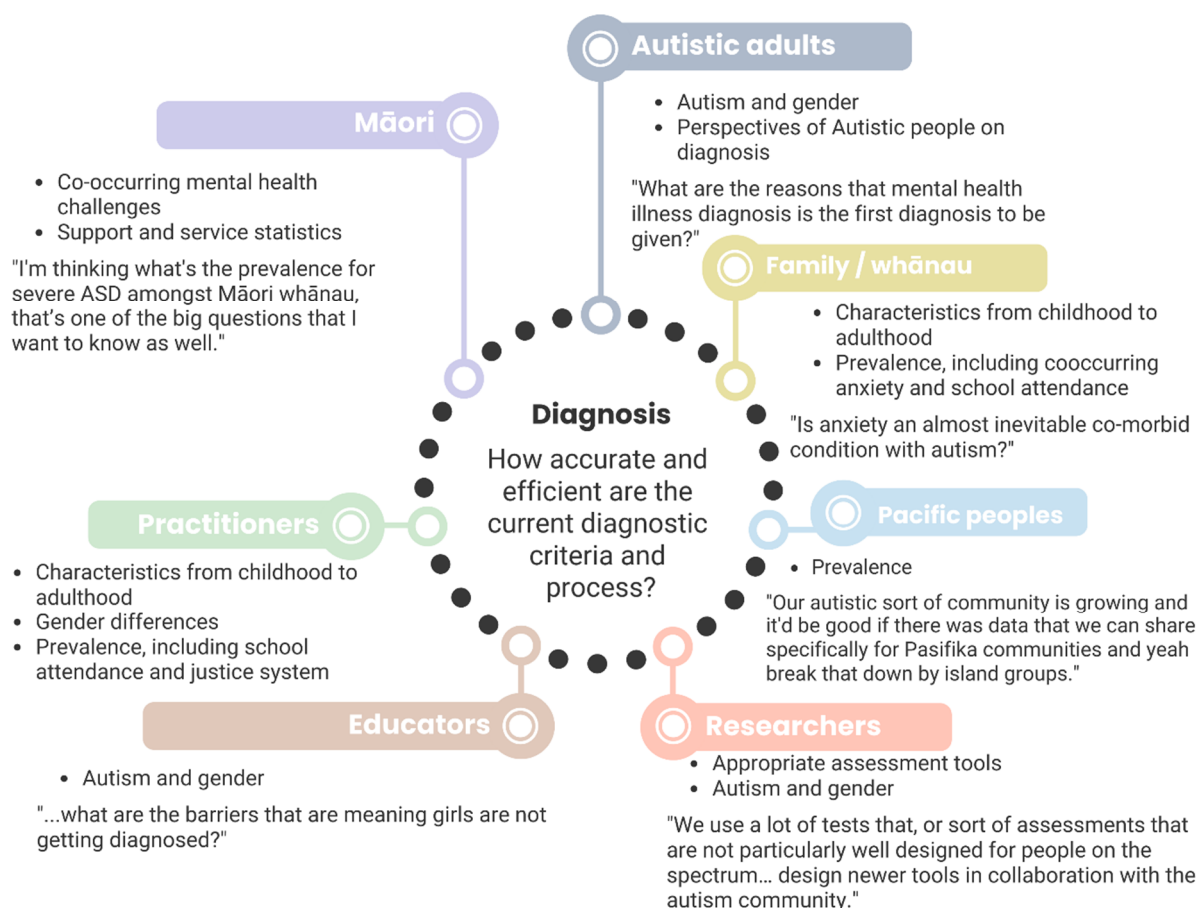
### Shared theme 3. Diagnosis

#### How accurate and efficient are the current autism diagnostic criteria and process?

This theme represented different questions around the area of diagnosis, including criteria, differences across the lifespan and genders, and appropriate processes for diagnosis. Multiple groups highlighted the need for research on understanding differences, or diversity, in characteristics of autism. Research on prevalence of autism was highlighted by multiple groups, including prevalence among children who do not attend school, and among those in the justice system. Incidence of co-occurring mental health conditions emerged across multiple groups. Researchers highlighted the need to improve assessment tools and ensure that they appropriate and accessible for all Autistic people.

Figure 8 shows an infographic that represents the perspectives from each participant group, highlighting sub-themes in each group that relate to diagnosis, and participant quotes.

Figure 8. Theme from Autistic adults group, shared across all focus groups: Diagnosis



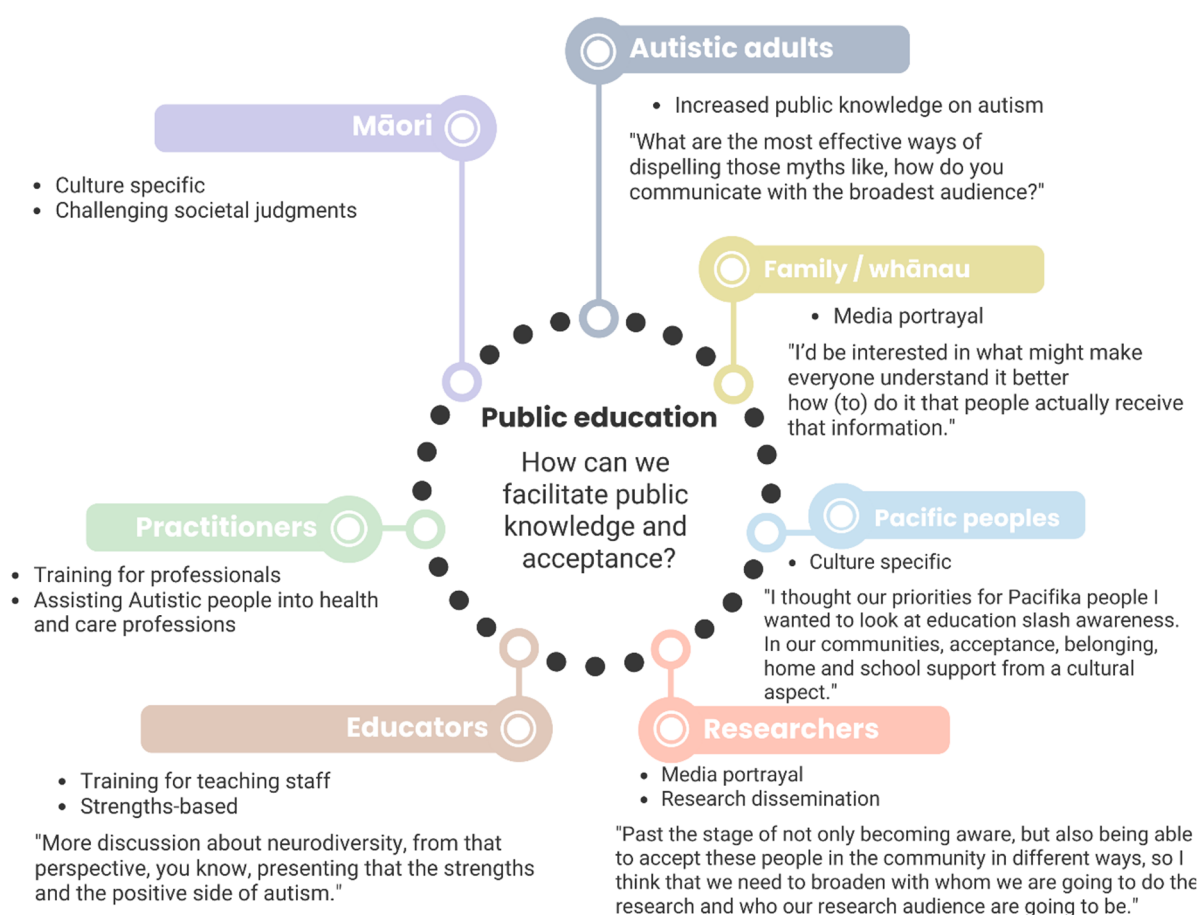
## Shared theme 4. Public Education

### *How can research facilitate public knowledge and acceptance?*

This theme represented the need to develop effective means of improving public knowledge and acceptance around autism. Sub-themes across different participant groups highlighted that public education should include knowledge from different cultures, and challenge inaccurate stereotypes perpetuated in the media. The idea of inclusivity emerged in different participant group sub-themes. The practitioner group highlighted that research should determine how we can support Autistic people into careers that involve supporting other Autistic people and communities. The researcher group highlighted that research dissemination needs to include communication back to the community.

Figure 9 shows an infographic that represents the perspectives from each participant group, highlighting sub-themes in each group that relate to public education, and participant quotes.

Figure 9. Theme from Autistic adults group, shared across all focus groups: Public education



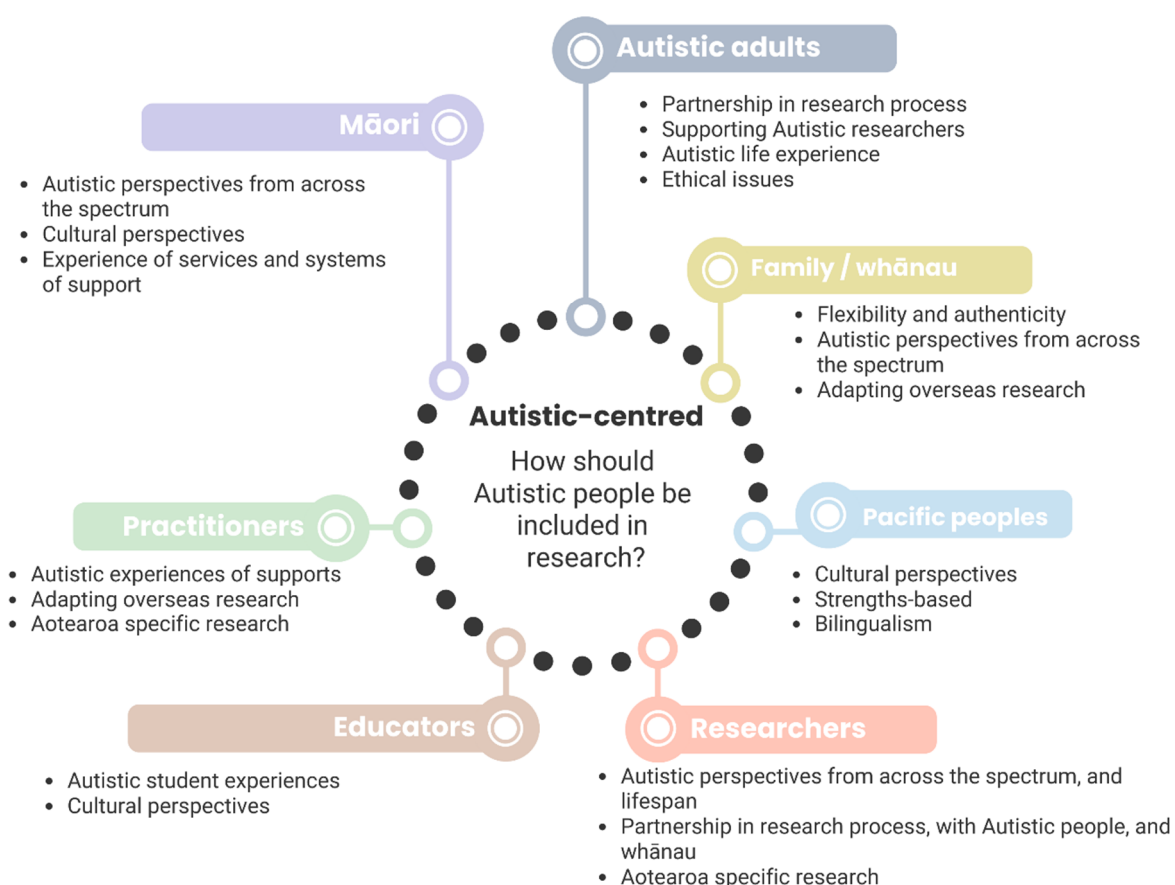
## Shared theme 5. Autistic-centred research

### How can Autistic people be included in research?

This theme represented the view that the Autistic perspective needs to be central through autism research. Within this theme, three key ideas emerged. The first idea was that autism research processes should be inclusive of Autistic people, including authentic partnership in research. The second idea was that autism research should be centred on understanding the experiences of Autistic people, including experiences from across the spectrum, of supports and education. Multiple groups highlighted the need for research on cultural perspectives and Aotearoa specific research. The third idea was that Autistic people should be supported to be involved in autism research as both co-researchers and as lead researchers.

Figure 10 shows an infographic that represents the perspectives from each participant group by highlighting the sub-themes that relate to Autistic-centred research.

Figure 10. Theme from Autistic adults group, shared across all focus groups: Autistic-centred





## Additional themes

### Quality of life

The quality of life of Autistic people was mentioned in multiple focus groups in the context of developing supports and understanding the experiences of Autistic people. Quality of life emerged as a theme from the Autistic adults group. This theme highlighted the need for research that looks at the current quality of life of Autistic people, and how it compares to the non-Autistic people.

#### Autistic adults:

***“The research should note there is a difference in quality of life between NZ Autistics and non-Autistics. The research needs to be fully inclusive of Māori and non-Māori in NZ.”***

### Translation and implementation

A theme related to the translation of research into real-world change emerged from the practitioner and researcher focus groups. This theme highlighted two key aspects of autism research. First, that autism research should be relevant to the daily lives of Autistic people. Second, that action is needed to bridge the research to practice gap so that it benefits the Autistic community.

#### Practitioners:

***“Please can we do research that is actually leading to something that is going to give some practical direction as well? Because there is lots of money spent on research everywhere, but the research to practice gap is still massive in autism.”***

#### Researchers

***“Looking at how our research can really apply to people's everyday lives and make things easier for them and improve their quality of life.”***

***“We want to go back to who is that benefiting, is it benefiting like the scientific world who understand better, But does that have any impact on their life of the Autistic people?”***

### Culturally specific research

The intersection between culture and autism was discussed in multiple focus groups.

#### **Educators:**

Cultural perspectives of autism emerged as a theme, which highlighted the need to understand how to support people who are from cultures that may not recognise autism.

#### **Practitioners and researchers:**

The idea of culture was also captured within the themes of Aotearoa NZ specific research and adapting overseas research.

#### **Māori and Pacific peoples:**

Culturally grounded research was highlighted across each of the themes that emerged from the Māori focus group and the Pacific peoples focus group.

Within the Māori focus group, the discussion highlighted the importance of incorporating Te Ao Māori into autism research – including knowledge of natural medicines, engaging in the community, tikanga, culturally-grounded and relevant education and support systems. In addition, the idea of research by Māori for Māori was highlighted.

***“I don't know what it's going to do to him and his body and his biology, but this is what I want to be able to give them I don't want to give him pharmaceutical Toxins or poisons I want to give him rongo• and there's also another plant that's native to Aotearoa that my auntie was telling me about and it's got...it helps with sleep and I'm thinking... why aren't we looking into our own natural rongo• as well.”***

Within the Pacific peoples focus group, the discussion of culture and autism included questions about bilingualism, what strengths culture may offer and how cultural practices can be inclusive of Autistic people.

***“I definitely think there could be a lot more research into, you know, how does, yeah, culture coexist with autism, what are some of the strengths of Pasifika culture, more generally, in terms of, you know, commonality and our family ties, extended.”***

### **Strengths-based approach**

The idea of applying a strengths-based model to autism research cut across many of the themes that emerged from multiple focus groups. This included the application of a strengths-based approach to understanding autism, to autism supports and education, to public education and to autism research itself.

#### **Autistic adults:**

***“I think the most useful point for Aotearoa is to be looking at autism, from the point of strengths and looking at how we encourage and foster all people's strengths and abilities and I think, personally I think it's time to break free from the deficit approach”***

## **Research ethics and partnership**

Within the Autistic adults group, there was rich discussion about preferences against particular autism research. This included:

- Cure related research
- Behaviour management related research

The discussion within the Autistic adults group raised concerns around the ethics of some approaches and procedures and indicated that the inclusion of Autistic people as partners in research should be central to future autism research. A partnership approach to including Autistic people in research should extend to the design of studies (including selection of appropriate outcomes), ethical decision-making, and funding decisions for autism research. Furthermore, Autistic people should be supported to be researchers, both as lead researchers and as co-researchers.

Other related suggestions included:

- Autistic ethics and oversight group on autism research
- Research to evaluate autism guidelines and diagnosis from an Autistic perspective
- Research about the Autistic experience conducted by Autistic researchers

***“We need to fund action research around what is working and how things are progressing and draw attention to the areas that are successful. We need cross agency participatory research guided by Autistic practitioners and individuals with autism leading the research in collaborative processes. Publicise the successes, share the innovative plans that Autistic individuals identified as beneficial.”***

## Youth data

Eleven youth aged 8 – 18 years (M = 11 years) took part in the interview. Figures 11 and 12 display the gender and ethnicity of the youth.

Figure 11. Gender of youth (frequency, percentage).

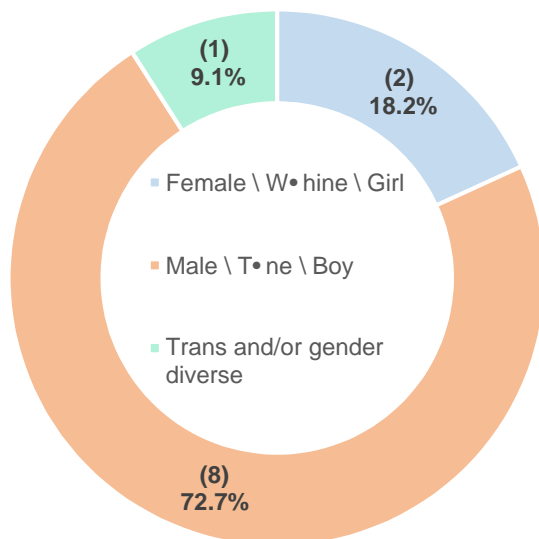
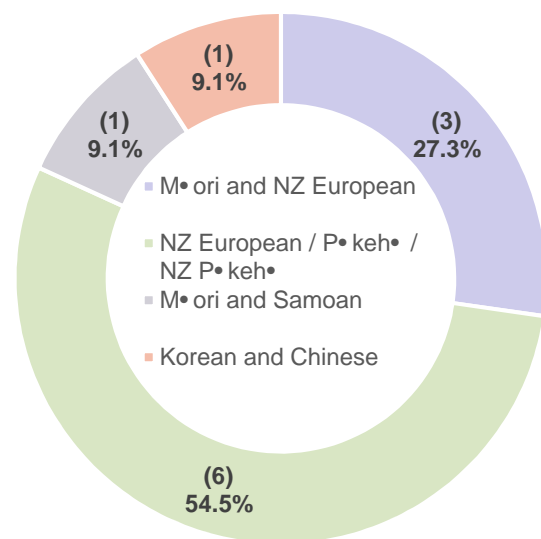


Figure 12. Ethnicity of youth (frequency, percentage).



## Analysis of young person interview data

Data collected from youth (through interviews and questionnaires) were analysed by three researchers. A summary of the initial themes was sent to all participating youth for their feedback, which was incorporated into the final analysis.

## Themes from youth

Five main themes were determined, with subthemes in each. Figure 13 shows the five main themes. Many of these themes corresponded with topics from the community survey priorities. These themes were compared with the top ten priority topics from each group in the survey data. The endorsement of the autism research priorities by youth is indicated in the results (see Table 1).

There were also some unique ideas relating to understanding autism, and what it is like to be Autistic.

### Autistic experience

*Research that explores what it is like to be Autistic.*

- **Life experience**
- **Impact of autism** – the strengths and challenges
- **Understanding Autistic self**

### Needs of Autistic people

*Research that explores the needs of Autistic people and supports that are effective and designed for Autistic individuals.*

- **Learning needs and styles of young Autistic people**
- **Mental health and wellbeing**
- **Training for professionals**
- **Improved access to services**
- **Skill improvement and development**
- **Early supports**
- **Inclusive schools and community environments**
- **Parental understanding**
- **Supporting self-advocacy**
- **Financial supports**
- **Transitions from childhood to adulthood**

### Diagnosis and identification

*Research that explores the accuracy and efficiency of current diagnostic criteria and process.*

- **Diagnostic process and accessibility** – including increasing awareness in clinicians, professional training and resources for diagnosis
- **Improved identification of autism in under-represented populations** - including females, gender diverse, different ages, different cultures

### Understanding autism

*Research that grows our knowledge about autism.*

- **Risk factors for autism**
- **Neurological differences in Autistic people**
- **Prevalence**

### Public education

*Research about how we can facilitate public knowledge and acceptance of autism.*

- **Increased acceptance and understanding of autism**
- **Access to resources**
- **Impact of autism research**
- **Dissemination of research back to the community**

Figure 13. Themes from youth data



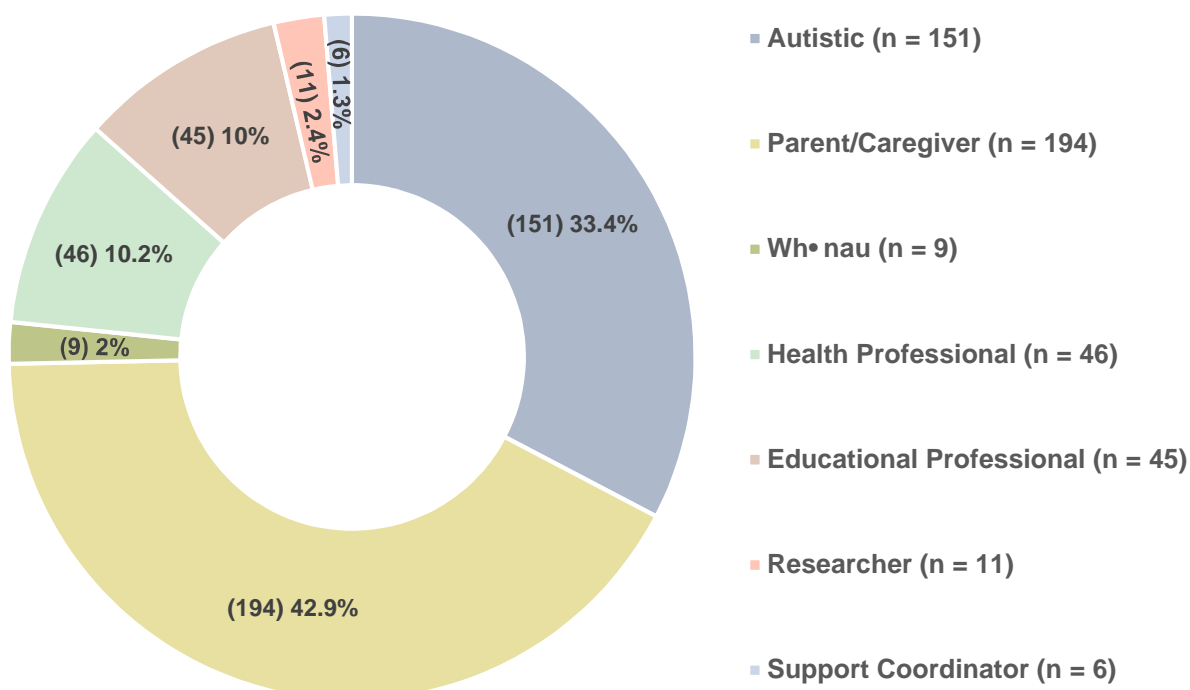
## Online survey

A total of 450 people completed the survey.

### Primary interest in autism research

Figure 15 displays a breakdown of the primary interest in autism research of all participants who completed the survey. The largest group identified their primary interest as a parent / carer of an Autistic person (42.9%), followed by Autistic person (33.4%). A small number of people selected 'not listed' (n = 6), and indicated that their primary interest was both as an Autistic person and a parent /carer; they were included in both groups when analysing the data. Participants who selected 'Not listed' and provided further information (n = 12) were grouped into a relevant category below based on the information they provided (e.g., Psychologist in Ministry of Education – Healthcare professional). Those who indicated they were a sibling, spouse or extended family member of an Autistic person were grouped into whānau (n = 9).

Figure 15. Primary interest in autism research.



Some participants selected 'Not Listed' and described their primary interest as applying to more than one group (e.g. Autistic parents), so they are included in multiple relevant groups.

Participants also indicated if they had a secondary interest in autism research (see Appendix B). Of particular note, Autistic people identified multiple interests across each of the other categories. The most commonly selected secondary interest of those who selected Autistic people as their primary interest was whānau of an Autistic person, followed by parent/carer, health professional, researcher, a disability / support worker, or educational professional. Furthermore, there were people who identified their secondary interest as an Autistic person and their primary interest as a parent/carer, health professional, or education professional.

Figures 16 to 18 display the characteristics (age, ethnicity, gender) of the survey respondents.

*Figure 16. Age distribution of the full sample, and subgroups by primary interest in autism research (frequency; percentage)*

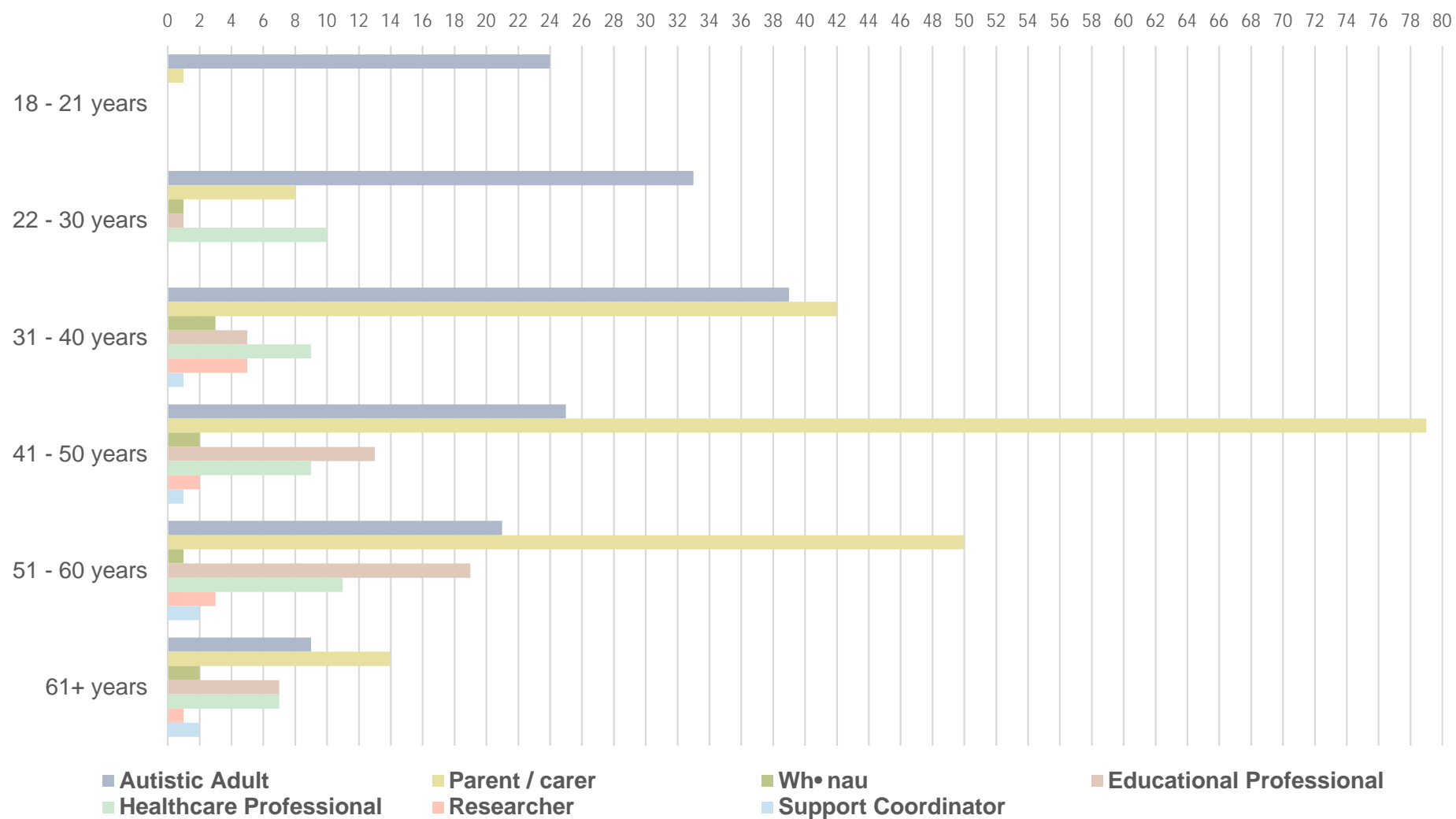
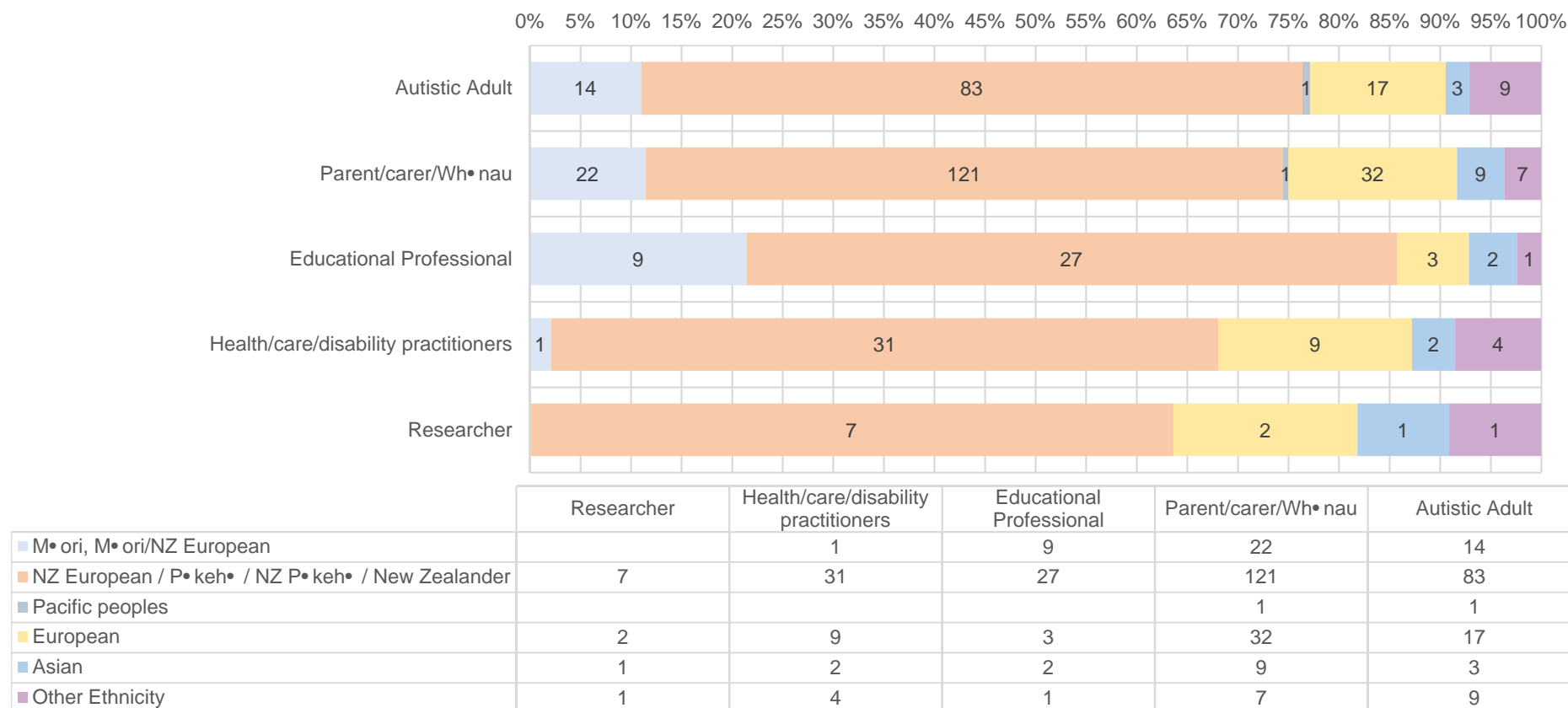


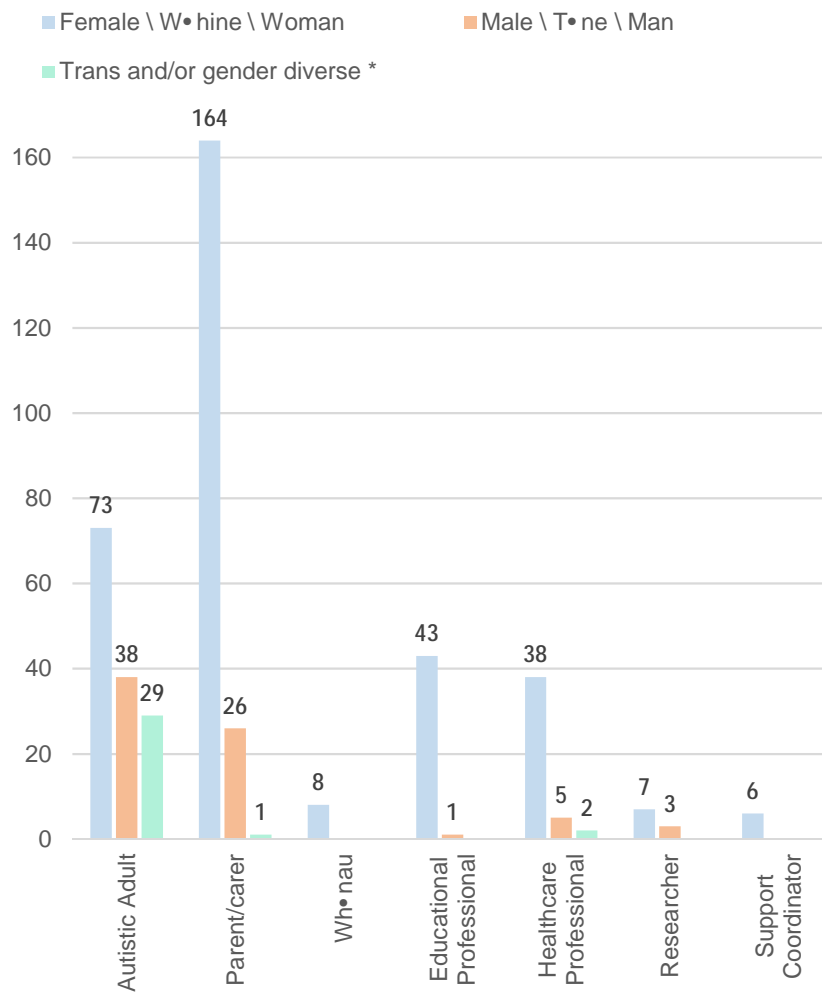
Figure 17. Ethnicity of participants by primary interest in autism research (frequency, percentage). Please note 38 individuals did not answer this question.



Note: Pacific Peoples includes Pasifika and Samoan. European includes British, Dutch and Scottish. Asian includes Chinese, Japanese, Korean, Indian, Sri Lankan and Filipino. Other ethnicity includes North American (n = 8), African (n = 2), Australian (n = 5), White (n = 7). Number of individuals who elected not to disclose their ethnicity = 39.



Figure 18. Gender of participants by primary interest in autism research (frequency). Please note 18 individuals did not answer this question.



\*See Appendix C for a breakdown of gender diverse participants across primary interest groups.

## Analysis of survey data

The survey data were analysed by group – determined by the self-selected primary interest in autism research. Due to the small number of people who selected that their primary interest was whānau, their data were combined with the parent / carer group. Similarly, data from the support coordinator group were combined with the healthcare professionals, to form a healthcare and disability professionals group.

To inform community autism research priorities, we used the importance ratings from the survey data across each group. First, we considered the ratings of all the topics by group (please refer to the Appendix for a breakdown). Second, we summed the 'important' and 'very important' ratings as an indication of 'endorsement' of the research topic. We then reviewed the top 10 topics from each group. To inform the autism research priorities, we included all top 10 topics from the Autistic group. The top 10 topics from other groups were included in the priorities if they met the following criteria:

- Endorsement of the topic by the Autistic adult group was ≥ 90%; and
- The topic was also in the top 10 for at least two other groups in the survey

There were a total of 20 topics that fell within the top 10 of at least one group. Thirteen of those topics met the above criteria.

## Endorsed topics from survey data

Table 1 shows the top 13 topics from each group across the survey, endorsement percentages and young person endorsements.

Key:	Meets criteria for inclusion in final set of priorities	100% endorsed	95-99.9% endorsed	90-94.9% endorsed	80-89.9% endorsed	< 80% endorsed
Youth endorsed						

Table 1. Top 13 topics by group, percentage endorsement (important + very important).

Research topic	Autistic	Whānau	Educator	Healthcare	Researcher	Youth endorsement
Health, mental health and wellbeing of Autistic people	97.4	99.5	100	98.1	81.8	•
Needs of Autistic people in Aotearoa	94.7	98.5	97.8	98.1	90.9	•
Quality of life of Autistic people in Aotearoa	94.7	99.0	100	96.2	90.9	
Expertise, coordination, availability and accessibility of services across the lifespan	92.7	95.5	97.8	96.2	90.9	•
Perspectives from Autistic people with a diverse range of support needs	92.7	95.5	100	98.1	100	
Training for professionals	92.7	97.5	100	90.4	81.1	•
Experiences across the lifespan	92.7	93.1	97.8	96.2	72.7	•
Diagnosis and identification across the lifespan	92.7	87.6	91.3	84.6	81.8	•
Workplace/employment	92.1	94.6	100	98.1	90.9	
Education/school	92.1	98.0	100	98.1	90.9	•
Autistic peoples lived experiences of supports and services	92.1	94.6	97.8	100	90.9	
Cognitive thinking and learning styles of Autistic individuals	90.7	95.0	97.8	100	72.7	•
Communication supports	90.1	94.1	97.8	98.1	100	
Transition from child to adult support services	88.7	94.6	100	96.2	90.9	
Transitions between life stages	88.1	93.1	100	92.3	90.9	•
Supporting skills development from childhood into adulthood	82.1	97.0	97.8	98.1	90.9	•
Diagnosis processes in Aotearoa	85.4	90.6	89.1	94.2	72.7	
Family and carer support	68.9	97.5	97.8	100	90.9	
Culturally-grounded supports	65.6	63.9	91.3	88.5	100	
Culturally-grounded education	62.9	61.9	96.7	86.5	100	

## **Priorities of M•ori**

The survey data of those people who identified as M•ori were included in the previous analysis and were also considered separately. The endorsement across all research topics can be seen in Table 2.

Many of the research topics were highly endorsed by M•ori survey respondents. The 16 topics that received highest endorsement (>90%) are highlighted in Table 2. Four research topics received an endorsement >95% by M•ori, but had not met criteria for inclusion in the highlighted priorities from the full sample:

**1. Supporting Autistic people in their choice of living and housing**

**2. Transitions from child to adult support services**

**3. Access to justice for Autistic people**

**4. Sensory experiences and supports**

Table 2. Top ten research topics by Māori, percentage endorsement (important + very important).

Key:	100% endorsed	95-99.9% endorsed	90-94.9% endorsed	80-89.9% endorsed	< 80% endorsed
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Research topic	%
Education/school	100
Needs of Autistic people in Aotearoa	100
Health, mental health and wellbeing of Autistic people	97.7
Supporting Autistic people in their choice of living and housing	97.7
Transition from child to adult support services	95.5
Expertise, coordination, availability and accessibility of services across the lifespan	95.5
Access to justice for Autistic people	95.5
Quality of life of Autistic people in Aotearoa	95.5
Sensory experiences and supports	95.5
Training for professionals	93.2
Workplace/employment	93.2
Supporting skills development from childhood into adulthood	93.2
Accessible built environment for Autistic people	93.2
Autistic peoples lived experiences of supports and services	93.2
Experiences across the lifespan	93.2
Cognitive, thinking and learning styles of Autistic individuals	93.2

## Overall priorities

From the community consultation activities, 13 autism research priorities emerged. Below is a description of the **13 emerging community autism research priorities**, clustered within **four main research areas**.

### Determining the needs of Autistic people

This research area is focused on establishing the needs of Autistic people. Four topics emerged as priorities in this research area.

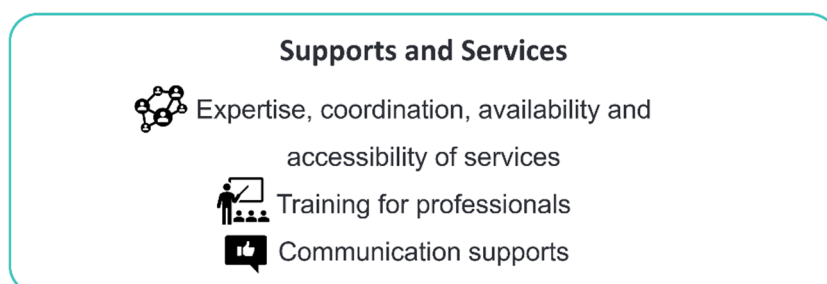
There was a clear call for understanding the health, mental health and wellbeing needs of Autistic people. Two topics were specific to the population in Aotearoa New Zealand: Quality of Life of Autistic people in Aotearoa New Zealand; Needs of Autistic people in Aotearoa New Zealand.



Three of these topics also emerged as priorities Autistic youth (Health, mental health and wellbeing; Needs of Autistic people in Aotearoa New Zealand; Diagnosis and identification). Two of these topics were 100% endorsed by Māori survey respondents (Needs of Autistic people in Aotearoa New Zealand; Quality of life of Autistic people in Aotearoa New Zealand).

### Design, development, and implementation of effective supports and services

This research area is focused on the improvement of available supports for Autistic people. Three topics emerged as priorities in this research area.



Two of these also emerged as priorities for young Autistic people (Expertise, coordination, availability and accessibility of services; Training for professionals). Two of these topics were 100% endorsed by Māori survey respondents (Expertise, coordination, availability and accessibility of services; Training for professionals).





## Understanding the perspectives and experiences of Autistic people

This research area is focused on the Autistic experience and developing a better understanding of life from the point of view of Autistic people. Four topics emerged as priorities in this research area.

There was a clear call for understanding the breadth of experience within the Autistic community, including differences in support needs and a lifespan perspective.

Two of these also emerged as priorities for young Autistic people (Experiences across the lifespan; Cognitive thinking and learning styles).

### Autistic Perspectives



-  Perspectives from a diverse range of support needs
-  Experiences across the lifespan
-  Cognitive thinking and learning styles
-  Lived experiences of supports and services

## Creating communities that are inclusive of Autistic people

This research area is focused on how we (society) can improve our structures and environments to be inclusive of Autistic people. Two topics emerged as priorities in this research area.

One of these topics also emerged as a priority for young Autistic people (Education and school). Both of these topics were also 100% endorsed by M•ori survey respondents.

### Inclusive communities

-  Workplace and employment
-  Education and school

## Discussion

The findings from this project provide the first autism research priorities for Aotearoa New Zealand. Thirteen priorities for autism research emerged, with very high endorsement from Autistic people and across the broader autism community. Many other topics were also rated as important, which indicates the need for increased research and translation of research into services and supports for Autistic people.

As well as areas of priority for autism research, our findings also indicate areas of research that Autistic people expressed strong preferences against: Cure-related research and behaviour management research. These findings from the focus groups with Autistic adults highlighted ethical concerns about such research.

Partnership and involvement of Autistic people in autism research is pivotal to ethical and relevant autism research. In this project, we used a participatory approach, to ensure that

these research priorities have been determined primarily determined by Autistic individuals, and inclusive of the perspectives of people from the wider autism community.

A important strength of this project was the proportion of Autistic people who took part in the community consultation activities. Of the 450 people who completed the survey, 39% identified as Autistic (either primary or secondary interest). This proportion of Autistic people is substantially greater than other previous international autism research priority-setting projects. For example, in a similar UK study 8.5% of the survey respondents identified as Autistic<sup>2</sup>, and only 4% in a European study across 11 countries<sup>3</sup>.

In addition, we included the perspectives of youth, which has not been considered in previous priority-setting in other countries.

The people who took part had broad and varied interests in autism research. Autistic people also identified as parents / carers, researchers, whānau, health and educational professionals. Those in the wider autism community also identified multiple interests in autism research. This evidences that the emerging priorities are a good representation of the views of the Autistic community, alongside those in the wider autism community.

This report presents the main autism research priorities as indicated by our diverse sample of survey respondents from the Autistic and autism communities. Future analyses of this data could include the examination of differences between sub-groups within this sample, including a comparison of the priorities of Autistic parents and non-Autistic parents, and a comparison of the priorities of Autistic people by their secondary interest in autism research.

## **The future of autism research in Aotearoa New Zealand**

Our intention is that these findings will inform future funding decisions and future research directions in Aotearoa New Zealand, so they align with the priorities of the Autistic and autism communities. The translation of these priorities into action in the research community is essential to advance our knowledge and supports for Autistic people in Aotearoa New Zealand in a way that centralises the preferences and needs identified by the community.

Another intention from the project team is to influence the research design of future autism research in Aotearoa New Zealand. We strongly encourage autism researchers to follow a similar participatory approach, such that Autistic people are involved and engaged throughout the research process, from initial design through to dissemination. Action by individual researchers is important and necessary, but not sufficient<sup>4</sup>.

To create and sustain real change to the future of autism research in Aotearoa New Zealand, action is needed by organisations and funders that support autism research. These priorities should be central to the design and funding of future autism research. Research organisations are responsible for providing the required resourcing and support to their researchers to engage in meaningful and authentic partnerships with the community. Autistic partnership in autism research can then progress to become the standard not the exception. We join the call of our international peers, and the Autistic and autism communities, for a fundamental change in how autism research is conducted<sup>5</sup>.



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- <sup>4</sup>den Houting, J., Higgins, J., Isaacs, K., Mahony, J., & Pellicano, E. (2022). From ivory tower to inclusion: Stakeholders' experiences of community engagement in Australian autism research. *Frontiers in psychology*, 13, 876990. <https://doi.org/10.3389/fpsyg.2022.876990>
- <sup>5</sup>Pellicano, E., & den Houting, J. (2022). Annual research review: Shifting from 'normal science' to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*, 63(4), 381-396. <https://doi.org/10.1111/jcpp.13534>

## **Appendix A**

### **Autism research topics included in the survey**

#### ***Needs and supports:***

- Diagnosis and identification across the lifespan
- Health, mental health and wellbeing of Autistic people
- Family and carer support
- Traditional medicines
- Transition from child to adult support services
- Training for professionals
- Expertise, coordination, availability and accessibility across the lifespan
- Culturally-grounded support

#### ***Inclusive communities:***

- Education/school
- Workplace/employment
- Culturally-grounded education
- Transitions between life stages
- Cultural traditions and practices
- Supporting skills development from childhood into adulthood
- Access to justice for Autistic people
- Accessible built environment for Autistic people
- Supporting Autistic people in their choice of living and housing

#### ***Aotearoa autism research***

- Number of Autistic people in Aotearoa
- Diagnosis processes in Aotearoa
- Quality of life of Autistic people in Aotearoa
- Needs of Autistic people in Aotearoa
- Use and adaption of overseas autism research in Aotearoa
- Māori understandings of autism
- Number of Autistic Māori
- Māori support services

#### ***Autistic experience***

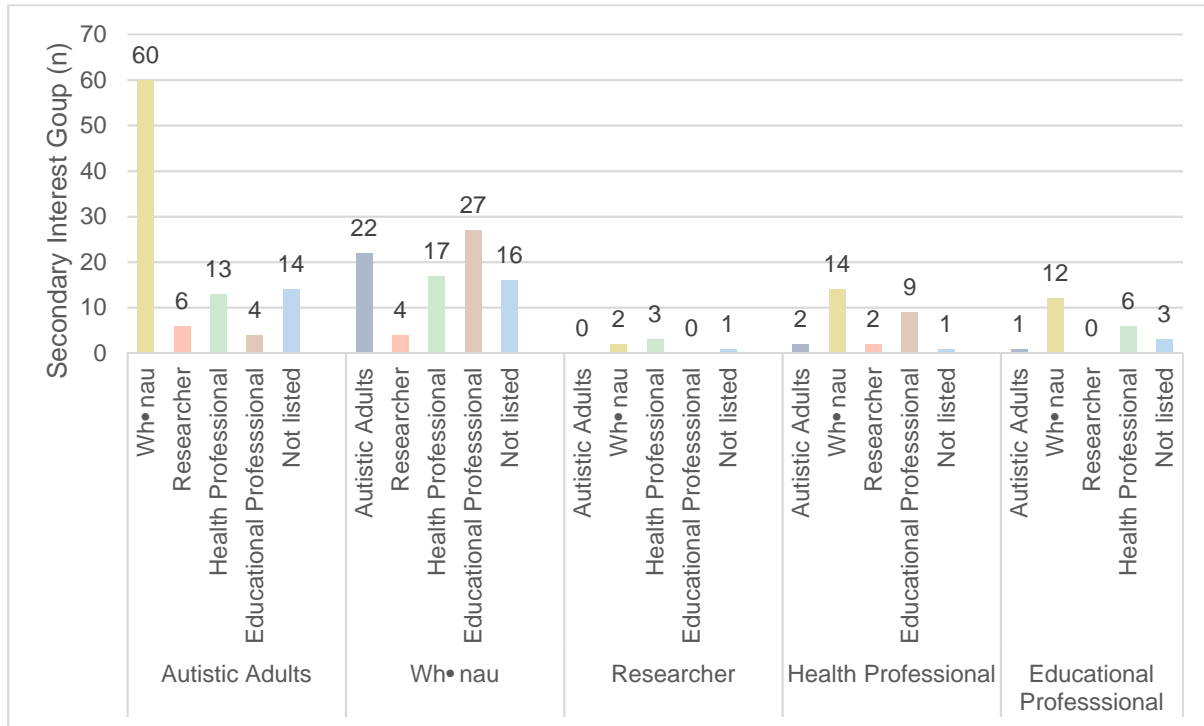
- Autistic people lived experiences of support and services
- Perspectives from Autistic people with a diverse range of support needs
- Gender diversity and inclusivity
- Experience across the lifespan

- Communication supports
- Sensory experiences and supports
- Cognitive, thinking and learning styles of Autistic individuals

## Appendix B

### Survey respondents' secondary interest in autism research by primary interest group

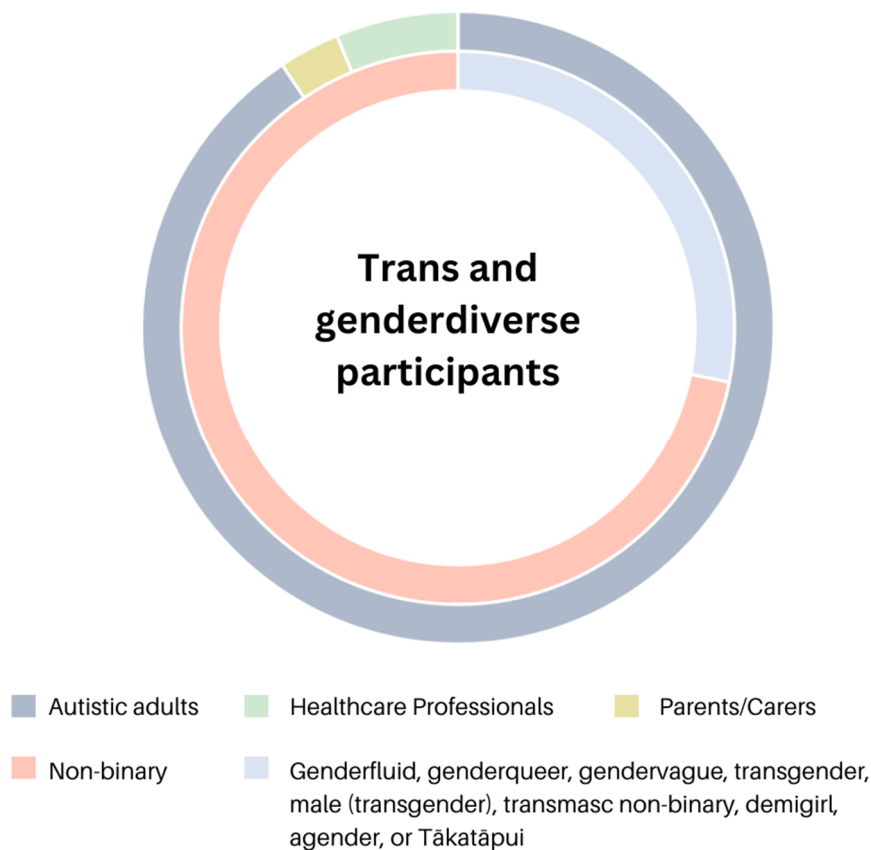
Figure 20. Secondary interests by primary interest group



## Appendix C

### Gender diversity across primary interest groups

*Breakdown of gender diversity by primary interest group for the online survey*



32 participants identified with trans and/or gender diverse identities. 29 Autistic participants identified with trans\* and/or gender diverse identities, including 20 non-binary participants with the remaining participants identifying as genderfluid, genderqueer, gendervague, transgender, male (transgender), transmasculine non-binary, demigirl, agender, or T•kat•pui. 1 parent/carer and 2 health professionals identified as non-binary.