



AutismCRC

The autism diagnostic process in New Zealand

FINAL REPORT

Dr Larah van der Meer

Dr Kiah Evans

January 2021



THE UNIVERSITY OF
WESTERN
AUSTRALIA



Curtin University



Australian Government
Department of Industry, Science,
Energy and Resources

Business
Cooperative Research
Centres Program

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Project number: 1.058RU

ISBN: 978-1-922365-17-0

Citation: van der Meer, L. & Evans, K. (2021). The autism diagnostic process in New Zealand: Final Report. Brisbane. Autism CRC.

Copies of this report can be downloaded from the Autism CRC website autismcrc.com.au.

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Acknowledgements

The authors acknowledge the financial support of the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centre Program. Staff and non-staff in kind were provided by Autism CRC participants, in particular Autism New Zealand and the University of Western Australia (Telethon Kids Institute), and organisations named in the contributors lists in the appendices. With thanks to the Autism New Zealand Expert Panel, Autism New Zealand Consumer Panel, INSIGHT Research, as well as the autistic adults, caregivers of children on the autism spectrum, clinicians, researchers and other professionals who provided feedback in development of the survey. Thank you to the autistic adults, caregivers of children on the autism spectrum and clinicians who shared their experiences with the autism diagnostic process in New Zealand during the workshops and surveys. Other investigators are also acknowledged as contributing throughout the research process, including Dane Dougan, Dr Matthew Eggleston, Dr Lauren Taylor, Dr Hiran Thabrew, Dr Hannah Waddington and Professor Andrew Whitehouse. Finally, we are grateful for project administration provided by the Autism New Zealand team (including Amanda August and Kirsty Herapath) and research assistance from Telethon Kids Institute (Maryam Boutrus and Sasha Johnston). We hope these contributions will lead to earlier, consistent and quality diagnosis and supports in the future.

The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

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A note on terminology

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

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

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Executive Summary

Introduction/Background

Current prevalence estimates suggest 1 in 59 people are on the autism spectrum [1], which equates to approximately 82,000 New Zealanders meeting the diagnostic criteria for autism. Autism diagnosis is complex because it relies on clinical judgement, in a context of variability in autism characteristics and considerable behavioural overlap with other developmental disorders [2]. New Zealand children are not diagnosed until six years of age on average [3, 4], even though autism can often be reliably diagnosed at a much younger age [5]. Delays in diagnosis leads to many children not receiving support until school age, missing the crucial period for effective early intervention [6]. In addition, with no formal diagnostic pathway in the public system for adults [7], there are likely to be further barriers in accessing a diagnosis and supports for adults.

The New Zealand Autism Spectrum Disorder Guideline (the Guideline is a joint initiative by the Ministries of Health and Education) was first published in 2008, with a second edition released in 2016 [7]. It is updated annually on specific topics by the Living Guideline Group. The Guideline provides recommendations for best practice in the diagnosis, initial assessment and ongoing supports for people on the autism spectrum. Whilst the Guideline recommends an integrated and synthesised approach to the diagnosis of autism, there is not currently a consistent and resourced pathway for coordinated and publicly funded diagnostic services in New Zealand.

This project subsequently aimed to:

1. Explore autism diagnostic practices in New Zealand, including disparities between individuals being assessed and variations across regions of New Zealand.
2. Explore how autistic individuals and their families in New Zealand experience the autism diagnostic process and their suggestions for improving future service delivery.
3. Lay the foundation for key policy reforms related to autism in New Zealand.

Research Design and Methods

This project was undertaken in two phases with ethics approval from the New Zealand Ethics Committee (Reference number 2018_28). The first phase involved three workshops held across New Zealand and the second phase involved three national online surveys.

Workshops were held in Auckland, Hamilton and Wellington in October 2018. The workshops were attended by 17 professionals involved in autism assessment and/or post-diagnostic support services, including medical professionals, allied health professionals, service providers and a researcher. The workshops centred around two key objectives: (1) discussing local experiences of the autism assessment process and implementation of national guideline recommendations; and (2) suggestions regarding the national online survey content, recruitment and administration. Workshops were audio recorded and summarised by a member of the research team, prior to undergoing thematic analysis.

The online surveys were administered during August 2019 and were completed by 70 autistic adults, 458 caregivers and 112 clinicians. The autistic adult and caregiver surveys contained 32 closed and open-ended questions focused on experiences and satisfaction during the three phases of the autism assessment process: (1) First queries and help sought; (2) Autism diagnosis; and (3) Post-diagnostic support. The clinician survey contained 29 closed and open-ended questions that addressed: (1) diagnostic services, (2) implementation of the Guideline, (3) the diagnostic process, (4) post-diagnostic support, and (5) training and cultural issues. Quantitative data analysis involved descriptions (frequency, mean, standard deviation, median and/or range), correlations (Spearman's rho correlation coefficient) and comparisons (Pearson's chi-square test, one-way analysis of variance, Fisher's exact test of independence, Mann-Whitney U test and/or Kruskal-Wallis H test). Qualitative data analysis involved an interactive process by multiple researchers to identify themes and sub-themes using the template analysis approach.

Findings

The findings from this project are presented in a series of appendices in their original format:

- **Appendix A** is a research report published by Autism New Zealand titled “Autism/Takiwātanga: The pathway to diagnosis and supports in New Zealand.” This research report has been written with the New Zealand autism community, government and Living Guideline Group as the intended audience. The findings in this research report describe key insights and recommendations during three phases: (1) the pathway to diagnosis; (2) the diagnostic process; and (3) supports during and after diagnosis. Considerations for autism within the wider system are also outlined.
- **Appendix B** is a journal manuscript titled “The autism diagnostic process in New Zealand: A cross-sectional survey of satisfaction amongst autistic adults.” The findings in this journal manuscript explore the key drivers of satisfaction during the identification, diagnostic

assessment and post-diagnostic support stages of the autism diagnostic process. These drivers are discussed in relation to international guidelines and research findings, with recommendations to key stakeholders involved in the autism diagnostic process.

- **Appendix C** is the precursor to a journal manuscript and/or conference presentation “Strategies for improving satisfaction with the autism diagnostic process in New Zealand – An autistic adult perspective”. Eight strategies suggested by adults to improving satisfaction will be described. These are: ‘be aware of the signs of autism’, ‘a much clearer and more streamlined path to diagnosis’, ‘easier access and cost less’, ‘health professionals who are experienced and aware of the complexities of autism’, ‘clearer guidelines for the assessment of adults’, ‘be neurodiversity friendly’, ‘more support needs to be offered post-diagnosis’ and ‘wrap around support is vital’.
- **Appendix D** is the precursor to a journal manuscript and/or conference presentation titled “The autism diagnostic process in New Zealand: A call for action from caregivers.” This journal manuscript will report findings that emerged from quantitative and qualitative survey responses provided by caregivers during the online survey. Seven themes calling on professionals involved in the autism assessment process to act will be described, including ‘Notice’, ‘Listen’, ‘Investigate’, ‘Explain’, ‘Help’, ‘Coordinate’ and ‘Expediate’. Four themes were a call to action for peak bodies and government departments to ‘Guide’, ‘Include’, ‘Provide’ and ‘Train’.
- **Appendix E** is a journal manuscript titled “The clinical landscape of autism diagnosis in New Zealand.” The findings in this journal manuscript outline current diagnostic processes, including variability and adherences to Guideline recommendations. The manuscript concludes with a discussion of diagnostic practices, with a focus on settings, standardised assessments, diagnosis in adolescents and adults, post-diagnostic supports and early identification of autism. Implications for research and clinical practice are discussed.
- **Appendix F** is a summary of the themes that emerged from qualitative responses provided by clinicians during the online survey. These themes focus on effective approaches, clinical training needs, service gaps and suggested improvements.

- **Appendix G** is a summary of the themes that emerged from the workshops, including aspects of the autism diagnostic process that are working well and areas for improvement. The findings also include suggestions for the online survey content, recruitment and administration.
- **Appendix H** is the autistic adult and caregiver survey.
- **Appendix I** is the clinician survey.

Limitations

There are a number of limitations that need to be considered when interpreting the findings from this project. Firstly, a convenience sampling approach was adopted for the workshops and online surveys, hence the participants are unlikely to be representative of all autistic adults, caregivers and clinicians within the New Zealand autism community. It is reasonable to assume that autistic adults, caregivers and clinicians may have been more likely to participate in this project if they had more positive or negative perspectives to share. It is also possible that some individuals were unaware of the project or chose not to participate due to limited internet access, lower literacy and cultural or linguistic diversity. Secondly, the retrospective and cross-sectional design of the project prevented real-time experiences and causal relationships being explored.

Implications for Research and Practice

Implications for Researchers

This project has added to the body of knowledge about the autism diagnostic process in New Zealand, from the perspectives of autistic adults, caregivers and clinicians. When the research findings are considered in the context of the broader research literature, it is apparent that the experiences within the New Zealand population studied are comparable to experiences reported internationally. Areas for future research include evaluating the implementation of recommended changes to the autism diagnostic process, such as awareness campaigns, formal screening systems, resources articulating / servicing a clear diagnostic pathway, coordination services and provision of post-diagnostic supports to meet unmet needs.

Implications for Autistic Adults and Caregivers

This project has given a voice to autistic adults and caregivers regarding their experiences, unmet needs and suggestions for improving the autism diagnostic process in New Zealand in the future. Some of the key resources of autistic adults and caregivers that emerged during this research was their ability to advocate when empowered to do so (either through facing adversity or due to supportive professionals) and the multitude of benefits provided by belonging to an autism community. There is an opportunity to facilitate the continued growth of these resources through co-producing a revised and expanded autism diagnostic process.

Implications for Professionals involved in the Autism Diagnostic Process

This project has highlighted areas in which the autism diagnostic process has been successfully implemented in New Zealand, along with inconsistencies and unmet needs. Autistic adults, caregivers and clinicians have made valuable and informed recommendations for addressing these challenges in the future. Educational, health and other professionals are encouraged to consider how these recommendations may be adopted within their workplaces to continuously improve their service delivery to autistic individuals and caregivers.

Implications for Government Ministries

This project has collected and compiled evidence to inform future revisions of the Guideline through the existing Living Guideline Group, along with a series of recommendations for additional resources and activities to enhance implementation of the Guideline across all regions, settings and sectors involved in the autism diagnostic process in New Zealand.

Key Recommendations

1. Form an inter-ministry, inter-disciplinary, cross-sector, and consumer-oriented national steering committee to lead New Zealand's strategic and long-term approach to autism identification, diagnostic assessment and post-diagnostic supports. This steering committee should utilise a hub and spoke model, where it is supported by local stakeholder groups.
2. Increase awareness of autism among the general public (including parents), educators and clinicians. This should focus on providing education and training about signs and symptoms of autism (across the lifespan and for all genders), implementing Guideline recommendations for the autism diagnostic process (from the time of initial concerns until

supports are in place), and effective supports for individuals on the autism spectrum and their families.

3. Develop and appropriately resource a clear pathway within the public sector that includes robust developmental surveillance and screening practices, equitable access to Developmental Services / ASD Coordinators, effective referral processes for initial assessments, specialist autism services and tertiary centres (as required), and linkage to required supports. This pathway should be person-centred, strengths-based, collaborative and informed by a comprehensive needs assessment.
4. Further investigate, and translate into practice, potential strategies that would promote the implementation of Guideline recommendations into standard practice across all regions, settings and populations across New Zealand. These strategies should be evaluated and revised over time.

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Appendix A – Autism/Takiwātanga: The Pathway to Diagnosis and Supports in New Zealand

Autism/Takiwātanga: The Pathway to Diagnosis and Supports in New Zealand

January 2021



Foreword

We are excited to be sharing this report on the pathway to autism diagnosis and supports in New Zealand with you. Autism New Zealand is passionate about empowering people on the autism spectrum to make informed choices and take action – “every step together”. We do this by providing information, support, and education on autism for individuals, their family and whānau, caregivers, and professionals.

This report is important for autistic people, and those who work with them alike, because we understand that diagnosis is a critical point that can have long term impacts on an individual’s life as well as for their family and whānau. Diagnosis can help an individual to understand and explain themselves or their child, and it is often seen as an important step towards accessing necessary supports. However, we also understand that providing an accurate and timely diagnosis can be a challenging clinical task. Anecdotally, we have often heard from people that obtaining a diagnosis through the public system involves lengthy waitlists, that costs for diagnosis in private practice are prohibitively high, and that there is variability in assessment processes from individual to individual across the country. Many have said the pathway to pursue a diagnosis is often unclear and stressful. As a result, diagnosis occurs too late and many children miss the window for early intervention which is known to support best outcomes. Further, a lack of post-diagnostic supports across the lifespan is commonly reported, or when supports are available these are typically fragmented and inadequate.

Autism New Zealand believes that a clearly articulated and well-delivered journey is needed for people on the autism spectrum – from suspecting and finding out about autism, to getting an initial consultation with a health professional, navigating the diagnostic pathway, adjusting to the diagnosis, and gaining appropriate supports and services. Importantly, this journey needs to start with timely, consistent and quality diagnosis.

We also know that there are many excellent clinicians who are passionate about working with people on the autism spectrum and doing their best to provide best-practice diagnosis and supports, but are not always supported by enough system leadership, funds or resources to effectively deliver what they are trying to achieve. The New Zealand Autism Spectrum Disorder Guideline (the Guideline) also acknowledges that there is current inconsistent and inequitable access to diagnostic assessment. Furthermore, while the Guideline was developed to assist informed decision-making, the autism community commonly report a vast disparity between recommendations made in the Guideline and the service that is experienced.

An understanding of this need, and the current project, was developed through significant engagement with the autism community. Likewise, instead of relying on anecdotal evidence, Autism New Zealand sought to lead a project aimed at formally investigating the existing autism diagnostic and post-diagnostic supports landscape, and uptake of the Guideline. Autism New Zealand became an Essential Participant of the Co-Operative Research Centre for Living with Autism Spectrum Disorders (Autism CRC) in 2017. The Autism CRC provided funding for the project, which involved collaboration between Autism New Zealand, the University of Auckland, Canterbury District Health Board, Victoria University of Wellington, as well as researchers from the University of Western Australia (Telethon Kids Institute) who have completed a similar project in Australia.

A series of in-depth questionnaires were completed by 458 parents of children diagnosed with autism, 70 adults diagnosed with autism and 112 clinicians engaged in diagnosing and managing autism. Results supported previous anecdotal evidence, with respondents reporting variation in the way autism is diagnosed and gaps in the supports people receive. Results

strongly support the need for the formation of a national steering committee, with a wide range of stakeholders, including autistic adults and parents/families and whānau of people on the autism spectrum. This committee is needed to make system-wide improvements for autism within New Zealand, including implementation of the following key recommendations:

- Earlier identification of autism and clarity in the diagnostic pathway.
- Supporting uptake of the Guideline to ensure timeliness, consistency and accuracy in the diagnostic process.
- Equitable access to person-centred, strengths-based, and collaborative supports.

These recommendations align with Government initiated system reviews across health and education, including The Health and Disability System Review, Well Child Tamariki Ora Review, and the Learning Support Action Plan. We hope that outcomes from this project will be acknowledged and adequately supported and funded by the Government to ensure specific needs of the autism community are incorporated in implementation of these reviews. Autism New Zealand will actively work with the Government and other key stakeholders to ensure recommendations from this project are implemented.

Dane Dougan
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- Marty Flavall, Think Differently Solutions
- Simon Monks, Simon Monks and Associates



Citation: Autism New Zealand. (2020). Autism/Takiwātanga: The pathway to diagnosis and supports in New Zealand. Wellington: Author.

Acknowledgements

The authors acknowledge the financial support of the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centre Program. Staff and non-staff in kind were provided by Autism CRC participants, Autism New Zealand, and organisations named in the contributors list.

With thanks to the Autism New Zealand Expert Panel, Autism New Zealand Consumer Panel, INSIGHT Research, as well as parents of children on the autism spectrum, autistic adults, clinicians, and researchers who provided feedback in development of the survey.

Thank you to the parents of children on the autism spectrum, autistic adults and clinicians who shared their experiences with the autism diagnostic process in New Zealand, leading to the development of these recommendations that we hope will lead to earlier consistent, quality diagnosis and supports.

The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.



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A note on terminology

This project acknowledges that there is no single term preferred by all people on the autism spectrum and other stakeholders to refer to autism/takiwātanga. Many people (particularly adults) in the autism/takiwātanga community prefer to use identity-first language to refer to themselves as being autistic. Some prefer to describe themselves as being on the autism spectrum, or as having autism. Reflecting common preferences and for consistency, this report will use the terms: *autistic person* or *person on the autism spectrum*. The term *diagnosed with autism* will be used when referring to a person's formal diagnosis. Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

The term *family and whānau* is used throughout this report to reflect that whānau cannot be directly translated as family. It is based on genealogy/whakapapa and includes physical, emotional, and spiritual dimensions. The structure of whānau can vary from immediate family to much broader collectives.

To simply and clearly differentiate the diagnostic process for each stakeholder group, the following terms are used throughout this report:

1. **Children:** responses provided by parents/caregivers about *children* diagnosed with autism will be referred to as *children*. Furthermore, most respondents from the questionnaire for parents/caregivers of children diagnosed with autism were parents (97%) compared to caregivers (3%). Therefore, the term *parents* will be used.
2. **Adults:** responses provided by people diagnosed with autism during adulthood will be referred to as *adults*.
3. **Clinicians:** responses provided by allied health and medical professionals involved in the diagnosis of autism will be referred to as *clinicians*.

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Executive Summary

This report describes the pathway to autism/takiwātanga diagnosis and supports in New Zealand, from the perspectives of parents of children on the autism spectrum, autistic adults and clinicians. This includes evaluating implementation of the New Zealand Autism Spectrum Disorder Guideline (the Guideline) recommendations and identifying opportunities for improving best practice in the diagnosis and supports for New Zealand individuals on the autism spectrum and their family and whānau.

The Guideline was created over a decade ago by the Ministries of Health and Education to provide evidence-based good practice in the identification, diagnosis, and ongoing supports for people on the autism spectrum. Whilst good levels of awareness and use of the Guideline across New Zealand are common, anecdotal reports from the autism community suggest there are some differences between what is recommended in the Guideline and the service that is experienced. As a result, Autism New Zealand sought to lead a project aimed at systematically investigating the existing autism diagnostic landscape and uptake of the Guideline.

Who participated?

A total of 458 parents of children diagnosed with autism and 70 adults diagnosed with autism completed an in-depth questionnaire exploring their experiences of, and satisfaction with, the autism diagnostic process. In addition, 112 clinicians completed a questionnaire exploring the autism diagnostic process in both public and private settings.

What did we find out about the diagnostic process?

Findings from this project highlight areas that are working relatively well, such as reasonable satisfaction with the diagnostic process overall and with the manner of professionals, both in terms of disclosing the diagnosis and sensitivity to cultural needs. The findings also support anecdotal concerns in terms of there being variation in the way autism is diagnosed and dissatisfaction with supports people receive.

Identification and initial help

Autism is not being identified early enough

For most respondents it was the parent that first had queries about a possible autism diagnosis for their child and adults themselves typically first had queries about their own diagnosis. For children this wasn't until an average age of 4.5 years, indicating they are not being identified early enough. As a result, there is an opportunity to improve early identification so that more children can access effective early intervention.

The diagnostic pathway is unclear

When help was sought, most parents received a diagnosis or commenced the diagnostic pathway, however nearly a quarter of parents were guided down paths that delayed the eventual autism diagnosis by being told there was "no problem" or told to come back if there was no improvement. Consequently, less than half of parents were satisfied with the initial help they received. Promisingly, two-thirds of adults said a diagnostic process was initiated when they initially sought help and nearly two-thirds of adults were satisfied with the initial help they received. Despite this, most parents and adults said the diagnostic pathway was unclear, suggesting work can be done to develop clear diagnostic pathways for both children and adults.

The diagnostic process

The diagnostic process varies

Clinicians indicated good awareness of the Guideline, however implementation of some recommendations was variable. Public and private diagnostic assessments were performed differently, with the public system following the Guideline more closely. Children were typically diagnosed in the public system through a comprehensive multidisciplinary approach. However, adults were clearly underserved by the public system, with most being diagnosed in private practice by a sole practitioner. Few respondents pursued a second opinion for the diagnosis. However, results indicated complexities in diagnosis for females and parents of boys were more satisfied with the diagnostic process than parents of girls. These findings suggest the need for continual training and professional development in the complexities of autism diagnosis, a finding supported by clinicians.

The diagnostic process can take a long time

On average, children were not diagnosed until 6.4 years of age (with the average age of diagnosis for girls somewhat higher than for boys). This was associated with a 1.9-year gap from initial queries until diagnosis. This can particularly impact outcomes for young children, where research consistently demonstrates early diagnosis (less than two years) is reliable and supports access to early intervention, significantly improving outcomes. Diagnosis in the public system is especially characterised by delay and poor experience. The slow process is likely due to demands for service being too high for the available resources to conduct multidisciplinary assessments, and this is likely to have implications on health outcomes.

Differences in satisfaction with the diagnostic process

While there were regional differences in wait times to obtain a diagnosis and in overall satisfaction with the diagnostic process, these lacked obvious geographical patterns. Despite incurring cost, diagnosis within the private setting was perceived as significantly more satisfactory for both children and adults. This satisfaction was linked to greater satisfaction with initial help, the manner of the professional disclosing the diagnosis, involvement of fewer professionals and shorter wait times to receive a diagnosis. These findings suggest co-design of the diagnostic process to ensure a consultative and strengths-based approach is taken.

Supports during and after diagnosis

Dissatisfaction with supports

Across parents and adults, only about a quarter were satisfied with post-diagnostic supports and very few indicated post-diagnostic supports were well coordinated or timely. These results indicated services are not meeting expectations or needs, with common experiences suggesting lack of supports and a sense they had to 'deal with it themselves'. Less than half of parents reported their children accessed the Developmental Services/ASD Coordinator indicating work is needed to facilitate understanding of and access to this service.

Not enough cultural supports

While cultural supports were not required for almost half of Māori and Pacific respondents, results indicated substantial unmet cultural needs for the remainder of Māori and Pacific peoples, with a need for better access to cultural supports. Promisingly, age of diagnosis was slightly younger for Māori and Pacific compared to NZ European children, suggesting early access to autism assessment and more opportunity for better outcomes.

Widespread range of support needs

Notable gaps and dissatisfaction included counselling to adjust to the diagnosis, early intervention, learning support, and vocational support. While adults indicated dissatisfaction with

the disability allowance and needs assessment service coordination, parents indicated some of the highest levels of satisfaction with these services for their children. Given the long-term impact of post-diagnostic supports in assisting people on the autism spectrum to reach their full potential and participate in society, there is urgency to make substantial improvements in these areas.

What can we do to support improvement?

The challenge is to achieve high-quality diagnosis and supports that are accessible, evidence-based, timely, culturally appropriate, and person-centred, across the health and disability, education, and social systems. This report concludes with a set of recommendations to improve the pathway to diagnosis and supports. Implementation of the recommendations arising from this project will not be possible without support, resources, and funding from the Government.

Considerations for autism within the wider system

There is a pressing need to develop a long-term approach for autism in New Zealand that focuses on continuous improvement through:

1. Formation of an inter-ministry, inter-disciplinary, cross-sector, and consumer-oriented national steering committee who can lead New Zealand's strategic and long-term approach to autism using a hub and spoke model. This could be usefully supplemented by local stakeholder groups.

Identification and initial help

To support timely identification of autism and clarity in the diagnostic pathway, we propose:

2. Increasing public awareness of autism, including early signs of autism.
3. Providing continually available and up-to-date evidence-informed training for primary health clinicians and education professionals on the early signs of autism to enable earlier identification.
4. Developing and promoting clear and explicit national autism diagnostic pathways for children and adults within the public system.

The diagnostic process

To support timeliness, consistency and accuracy in autism diagnosis, we propose:

5. Updating the Guideline to revise and add recommendations, including further guidance to determine when a full multidisciplinary team assessment is required or whether an abbreviated assessment with 1-2 clinicians is sufficient.
6. System-level implementation of existing Guideline recommendations, including exploring establishment of specialist autism services and a network of tertiary centres to support complex diagnoses.
7. Promoting understanding and consistent clinical uptake of the Guideline recommendations.
8. Providing continually available and up-to-date evidence-informed specialist autism training for clinicians involved in the diagnosis of children and adults.

Supports during and after diagnosis

To support access, coordination, and satisfaction with post-diagnostic supports, we propose:

9. Development of a formal pathway for supports that is person-centred, strengths-based, and collaborative. This should include earlier provision of supports informed by a comprehensive needs assessment.

10. Analysis of how to improve understanding of and access to the Developmental Services/ASD Coordinator, including consideration for extension of this service to adults.
11. Providing continually available and up-to-date evidence-informed professional development and training for clinicians on effective supports for individuals on the autism spectrum.
12. Ensuring timely access to effective early intervention.
13. Improved access to support services where there is a high unmet need.

Section 1 -

Context/background

Diagnosing Autism in New Zealand

Autism is a neurodevelopmental condition that affects cognitive, sensory, and social processing, changing the way people see the world and interact with others [1]. Current prevalence estimates suggest 1 in 59 people are on the autism spectrum [2]. Taking the country's current population [3], this would suggest approximately 82,000 New Zealanders meet the diagnostic criteria for autism.

The diagnosis of autism relies on clinical judgement because there is no objective test for diagnosis and diagnosis is based on the overall presentation of the person. The variability in autism characteristics and the considerable behavioural overlap with other developmental disorders can make autism diagnosis complex [4]. For these reasons, it is possibly not surprising that New Zealand children are not diagnosed until six years of age on average [5, 6], even though autism can often be reliably diagnosed from 14 months of age [7].

A complicating factor is that there is no consistent referral and assessment pathway for publicly funded specialist diagnostic services in New Zealand, despite this being a key recommendation of The New Zealand Autism Spectrum Disorder Guideline (the Guideline). This leads to confusion amongst individuals, parents and clinicians about what to do when a person is identified as showing signs of autism [8]. Furthermore, publicly funded health support services sometimes require a diagnosis to be accessed [9]. As a result, most children are not being identified and receiving support until school age, missing the crucial period for effective early intervention, known to support developmental and long-term health and quality of life outcomes [10]. In addition, with no formal diagnostic pathway in the public system for adults [8], there are likely to be further barriers in accessing a diagnosis and supports for adults.

The New Zealand Autism Spectrum Disorder Guideline

The Guideline, a joint initiative by the Ministries of Health and Education was first published in 2008, with a second edition released in 2016 [8]. The Guideline provides evidence-based information for people on the autism spectrum, their family and whānau, as well as health, disability, education and social service professionals and agencies. It includes information about good practice that is evidence-based and aims to improve the health, educational and social outcomes for people on the autism spectrum.

The Guideline was developed in consultation with key stakeholders, including autistic adults, parents/families and whānau of people on the autism spectrum, clinical bodies and services, representation across the Health and Education sectors, as well as Māori and Pacific advisors. It is updated annually on specific topics by the Living Guideline Group. The Guideline provides recommendations for best practice in the diagnosis, initial assessment and ongoing supports for people on the autism spectrum.

The Guideline recommends an integrated and synthesised approach to the diagnosis of autism. This is achieved through an interactive group process, that is robust and accurate, whilst also reducing repetition and redundancy (see Appendix I for key recommendations). The Guideline recommends that individuals are initially assessed by a multidisciplinary specialist assessment

team where possible. This team should include two or three members from the following professions: paediatricians, psychiatrists, clinical or educational psychologists, speech-language therapists and occupational therapists. The assessment should be comprehensive, including a developmental and family history, along with a standardised autism assessment interview. Intellectual, adaptive, and cognitive skills associated with autism should be considered. The evaluation of mental health, behaviour, needs and strengths, as well as a medical evaluation, should be included. Observation should occur in a range of environments.

The Guideline indicates that good post-diagnostic supports include helping individuals and their families and whānau with (a) understanding autism and how it affects an individual's life, (b) access to good quality autism information, (c) finding out about financial entitlements (if any), (d) identifying services for specific autism support, (e) networking with other people on the autism spectrum, and (f) obtaining counselling from appropriately skilled clinicians.

Purpose of this Report

Perspectives of parents of children diagnosed with autism and adults diagnosed with autism in New Zealand are needed so that the future of autism assessment and support evolves through active and meaningful co-design between providers and recipients of autism diagnosis. Perspectives of clinicians involved in the diagnosis of autism in New Zealand are also needed to understand the service delivery context more completely. Given implementation of clinical guidelines can be inconsistent [11], research such as the current project, is needed to evaluate the current autism diagnostic process.

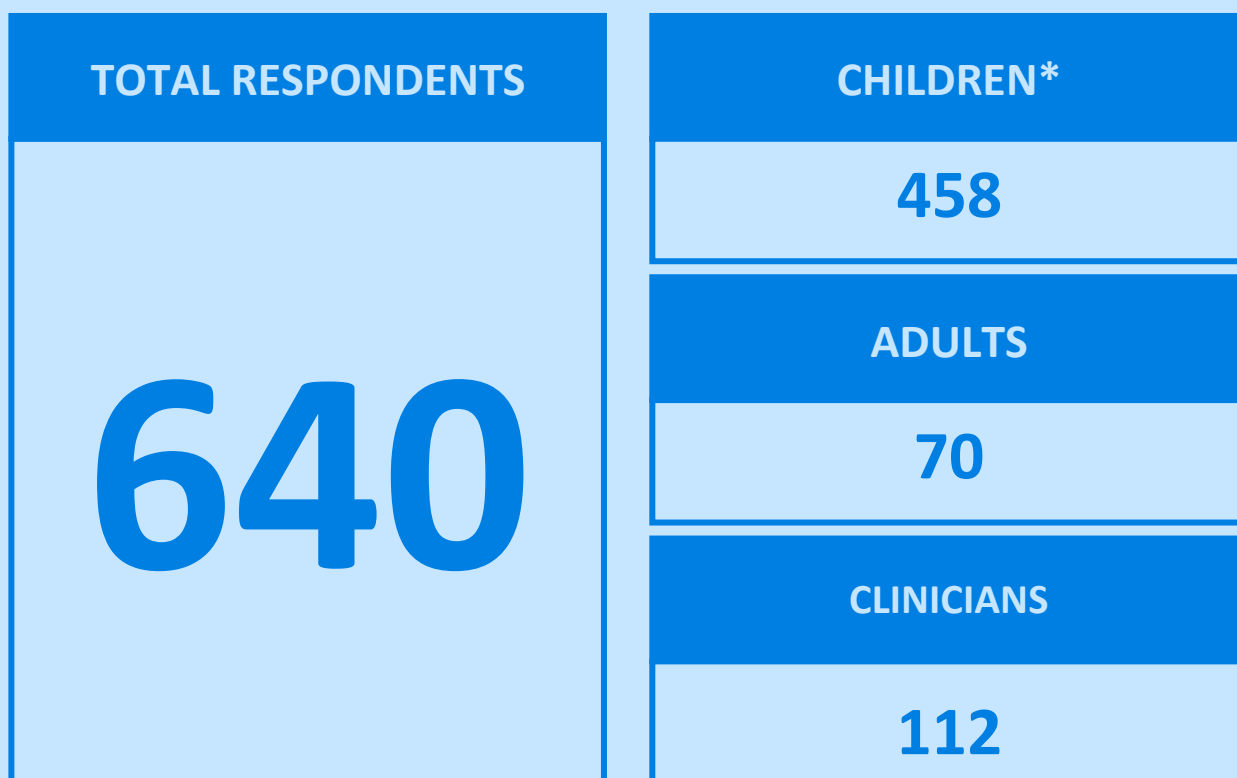
This project aimed to gain an understanding of the current autism/takiwātanga diagnostic process and supports as well as evaluate the implementation of recommendations from the Guideline. Our key objectives were to:

1. Provide actual data (quantitative and qualitative) about the timeliness, consistency, quality, and satisfaction with the autism diagnostic process and supports in New Zealand in reference to the Guideline recommendations; and
2. Inform recommendations for improving best practice in the future diagnosis and support of New Zealand individuals on the autism spectrum.

Research Approach

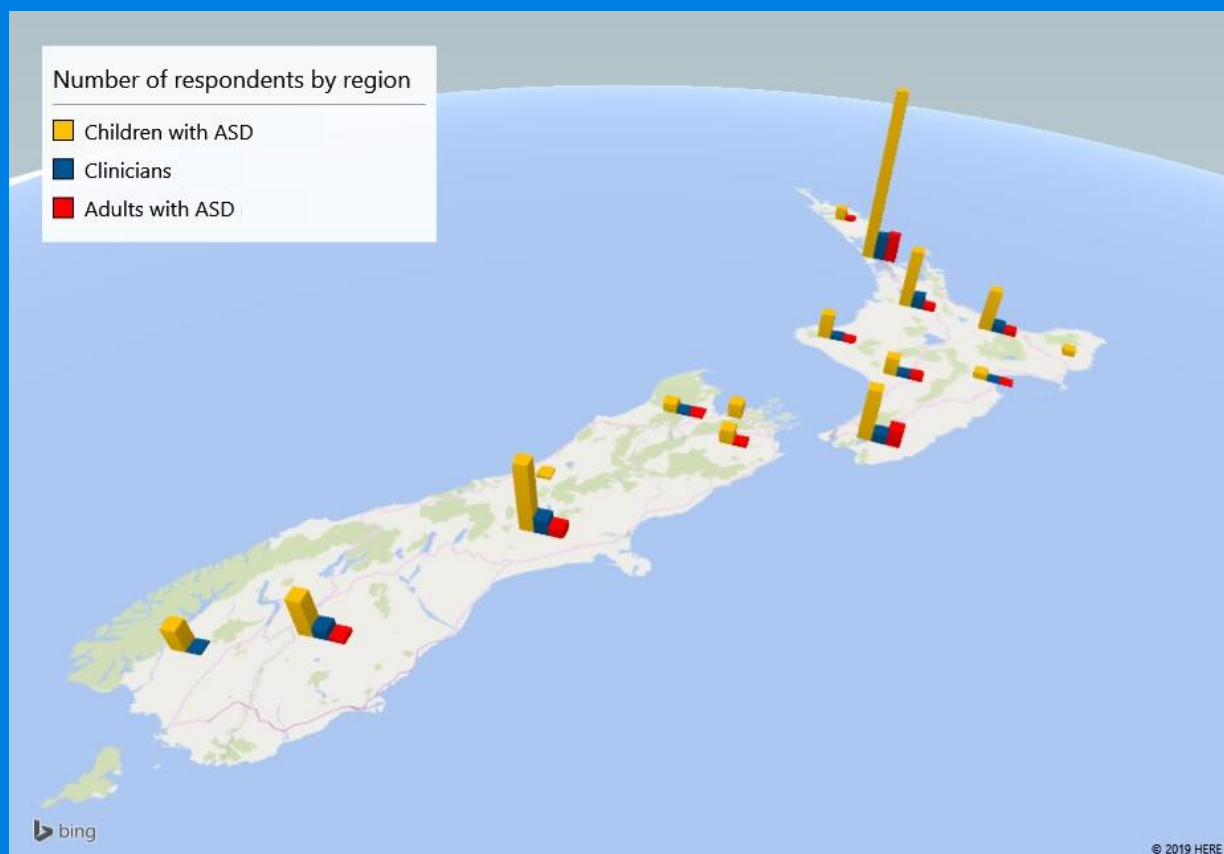
Parents of children diagnosed with autism and adults diagnosed with autism were invited to participate in a questionnaire exploring their experiences of, and satisfaction with, the autism diagnostic process. Clinicians were also invited to participate in a questionnaire exploring the autism diagnostic process in both public and private sectors. All questions were optional, participants did not have to respond to questions they did not feel comfortable answering. This resulted in different numbers of responses for different questions. Data were analysed based on the number of responses recorded for each question. Furthermore, some questions allowed for multiple response options to be selected. In these cases, percentages were calculated out of the number of people who responded to the question rather than the total number of responses for that question. In these cases, totals may equal more than 100.

Section 2 – Who responded?



*97% of responses regarding children were completed by parents; 3% were completed by caregivers

Figure 1. New Zealand regions represented across questionnaire respondents



Key findings and insights

- Across the three questionnaires all 17 geographic regions of New Zealand were represented.
- Over three-quarters of children were male, while about two-thirds of adults were female.
- For children, responses were representative of New Zealand's population for Māori, NZ European, and Pacific peoples, but were under-represented for Asian and other ethnicities. The number of adult Māori and Pacific people who responded were underrepresented.
- Most clinicians completed the questionnaire based on their work in the public system.
- Most clinicians were Psychologists, Psychiatrists or Paediatricians.
- Almost all clinician respondents were trained in autism diagnosis and assessment, just over half were trained in administration of standardised assessment interviews, as per the Guideline. This may contribute to variance in assessment and diagnostic processes.

Responses were mostly representative

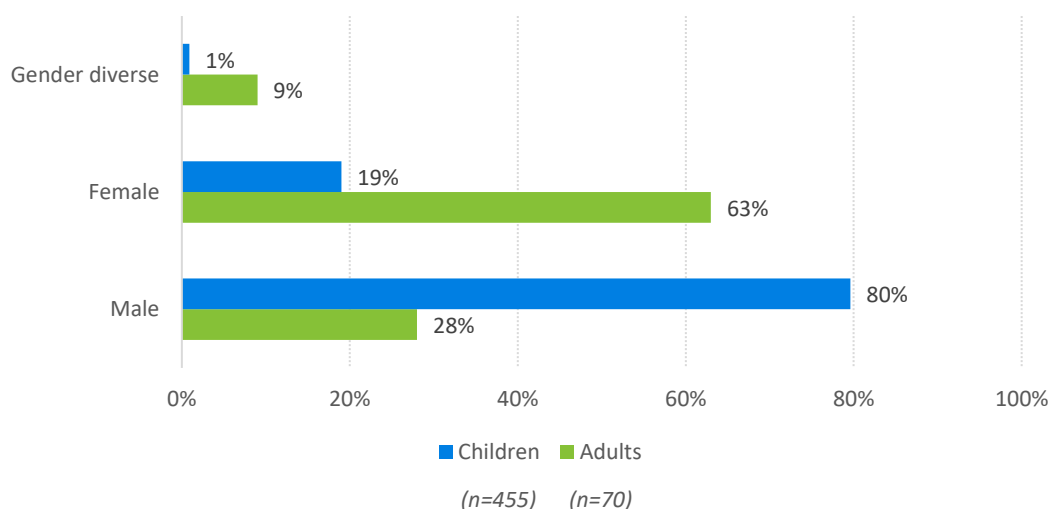
Region

All 17 surveyed regions were represented in responses for children. There were 12 regions represented for adults, and 11 regions for clinicians. There were responses for all three questionnaires across the most populated regions. Nearly a third (30%) of clinicians did not indicate the region in which they diagnose autism, which prevented analysis of regional differences in the diagnostic process.

Gender

For children, responses were consistent with the common ratio of 4:1 males to females diagnosed with autism, where 80% were male [2]. In adults however, 63% percent of respondents were female, which is not representative of adults on the autism spectrum in New Zealand. This may be because females are more likely to complete surveys than males [12]. There was a higher prevalence of gender diverse adults compared to the general population, consistent with research indicating an overlap between autism and gender diversity [13].

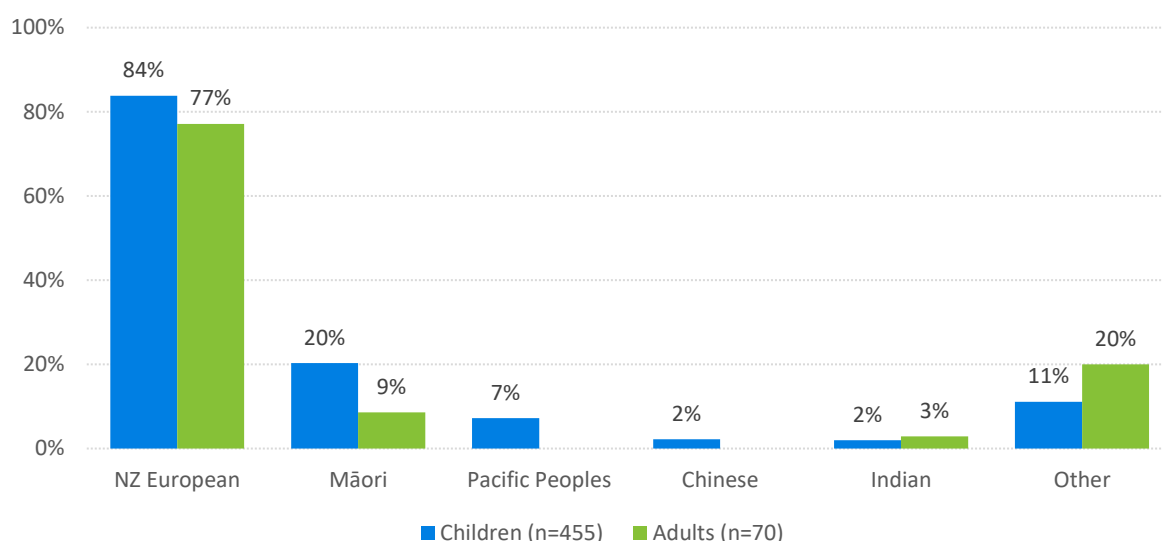
Figure 2. Gender of children and adults diagnosed with autism



Ethnicity

Twenty one percent of all children and adult responses identified with more than one ethnicity. Relative to New Zealand's 2013 census data [14], there was a slightly higher representation for Māori children, but lower for Māori adults. It was representative for Pacific children, but there were no responses for Pacific adults. Both children and adults of NZ European ethnicity were representative, however both children and adults of Asian ethnicity were underrepresented.

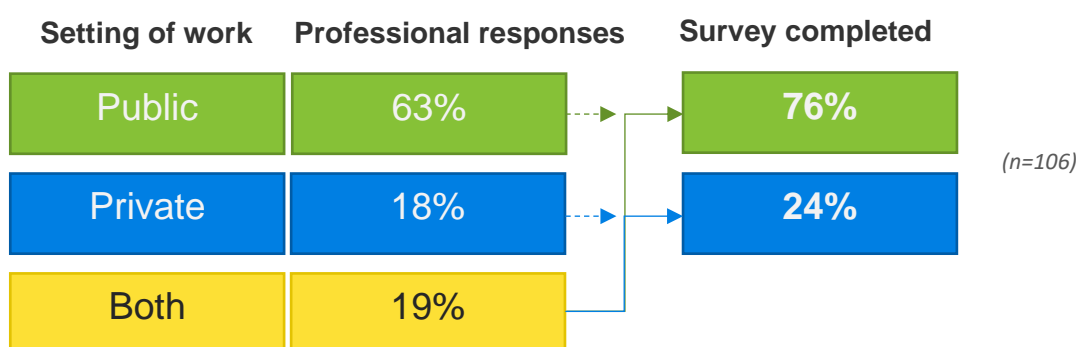
Figure 3. Ethnicity of children and adults diagnosed with autism



Most clinicians worked in the public setting

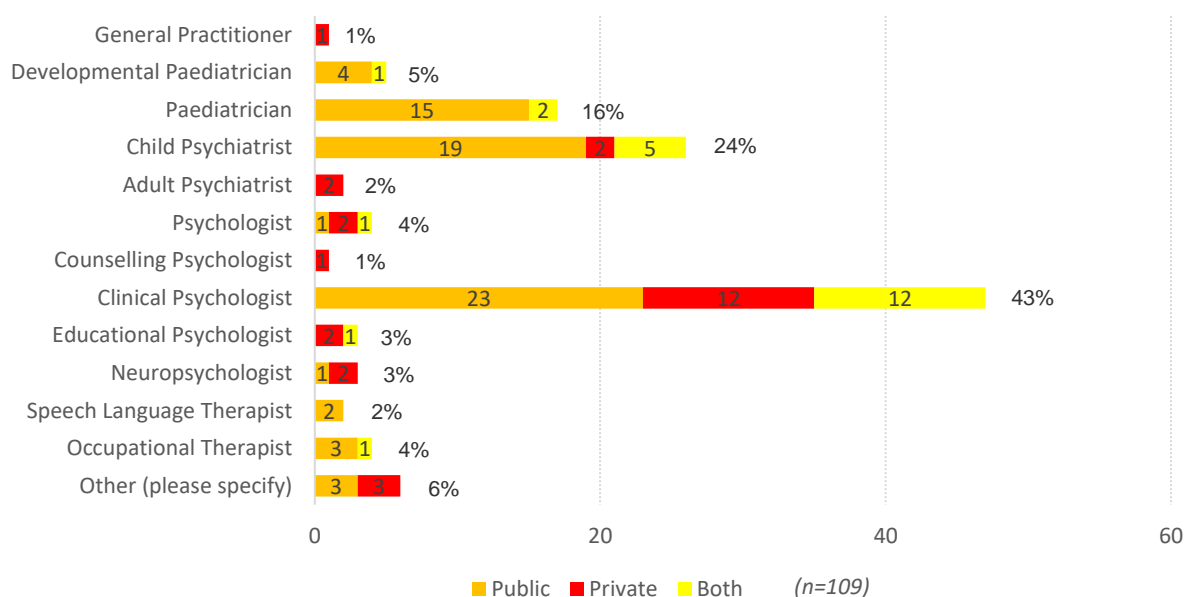
Most clinicians worked in the public setting, but some indicated they practiced in both public and private settings. Clinicians chose which service setting they would respond for, and about three quarters completed the questionnaire based on their work in the public sector.

Figure 4. Diagnostic setting in which clinicians practice



Most clinicians who responded were across three types of professions: Psychologists, Psychiatrists, and Paediatricians. Over half of the respondents were Psychologists but there were fewer Paediatrician responses than previous research has indicated are involved in the diagnostic process [5]. The total proportion of responses across General Practitioners, Speech Language Therapists, Occupational Therapists and other clinicians (13%) is not representative of who parents and clinicians report are involved in multidisciplinary diagnostic assessments (see figure 13). This may mean that results are not representative of diverse clinician perspectives.

Figure 5. Professional discipline of clinicians across public and private settings



Paediatricians, Psychiatrists, Speech Language Therapists and Occupational Therapists typically worked in the public system, while Psychologists were relatively more likely to work in private practice, or both public and private settings.

Nearly all (95%) clinicians indicated they had received training in autism diagnostic assessments, most commonly including observation of experienced clinicians (77%), case discussions (77%), and postgraduate training (71%). The Guideline also recommends education and training of local clinicians in the administration of standardised autism assessment interviews and schedules, for which 58% of respondents indicated they had received such training. This suggests a need for further training in specific assessment tools. For clinicians who indicated what sort of training they would like to access, training in diagnostic assessment tools, subtleties in differential diagnosis and complex presentation, diagnosing adults and females, and cultural competence specific to autism were most commonly cited.

Section 3 - The pathway to diagnosis

Identification and initial help

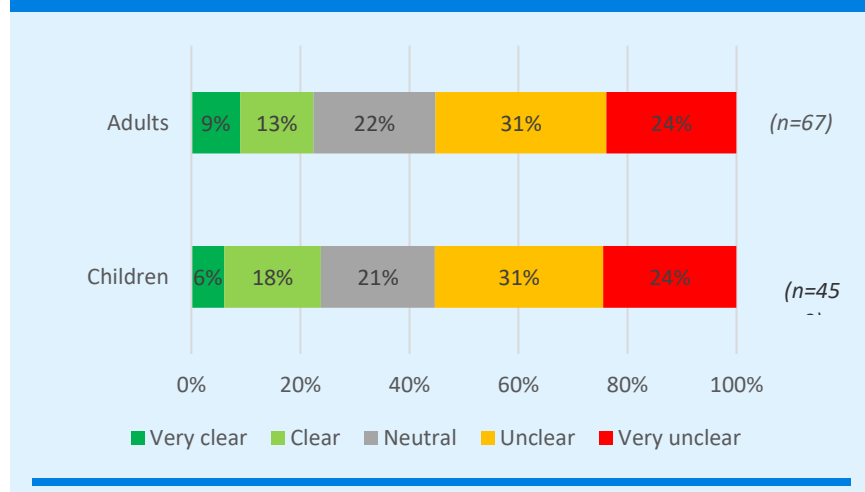
Key findings and insights

- On average, parents usually first had queries about their child having a possible autism diagnosis at 4.5 years of age. Typically, adults themselves first had queries that they might have autism at age 34 years.
- For most parents and adults, the pathway to diagnosis was unclear.
- Information regarding the diagnostic pathway was primarily sought from health professionals, with nearly half of all parents going to a General Practitioner first. This suggests that pathway analysis and improvement initiatives should consider the important role of General Practitioners in identifying and initiating onward referrals at the right time.
- There was little involvement from Well Child/Tamariki Ora (Plunket) at this early stage, suggesting early identification of autism in these settings is not occurring consistently.
- Regardless of who they saw first, nearly a quarter of parents were guided down paths that delayed the eventual autism diagnosis by being advised there was “no problem” or told to come back if there was no improvement. This may indicate that early identification lacks accuracy and/or urgency to undertake a full diagnostic assessment.
- Less than half of parents were satisfied with the initial help they received.
- For two-thirds of adults a diagnosis was made when they initially sought help indicating a rapid process for obtaining an autism diagnosis. In addition, nearly two-thirds of adults were satisfied with the initial help they received.

The diagnostic pathway is unclear

For children, it was usually the parents themselves (65%) who first had queries about their child being on the autism spectrum. On average, this occurred when the child was 4.5 years of age (median: 3.5 years). Most adults had the first queries about a possible autism diagnosis themselves (66%) at about the age of 34 (average). However, the pathway to pursue a diagnosis was mostly unclear (see figure 6). Commonly, health professionals advised about the pathway to pursue a diagnosis. For children, early

Figure 6. Clarity of diagnostic pathway

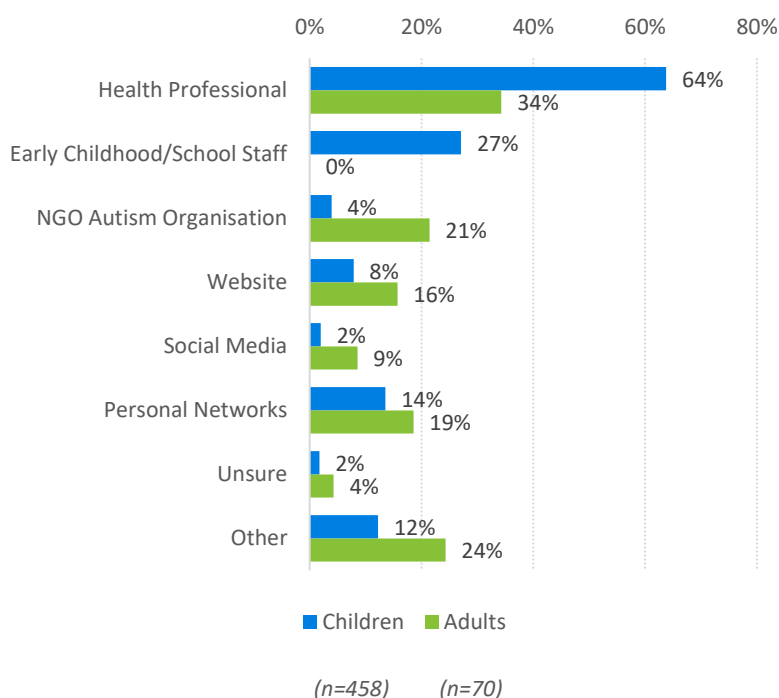


childhood/school staff were regularly involved, while for adults there were a wide range of sources (see figure 7).

Children commonly saw a General Practitioner (48%) or Paediatrician (36%) when a diagnosis was initially sought. Adults typically saw a Psychologist (47%), General Practitioner (39%), or Psychiatrist (26%) when they first sought a diagnosis. This indicates that for both children and adults, General Practitioners currently play a key role as first health contact, and are frequently involved in providing initial information, advice and referrals regarding the diagnostic pathway.

Well Child/Tamariki Ora (Plunket) however, were only seen by 14% of all children at this first point of contact. Given the Well Child/Tamariki Ora programme is a free service offered to all children from birth to five years, this indicates a missed opportunity for early identification and intervention and work needs to be done to support these professionals in the early identification of autism.

Figure 7. Finding out about the pathway to pursue a diagnosis

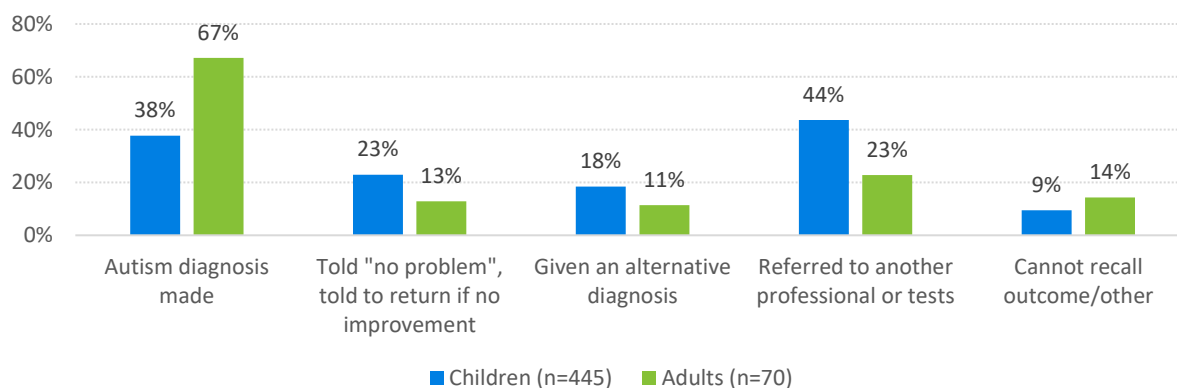


Uncertainty and delay during initial help

Just over half (53%) of children were referred on to another professional or for more tests. Nearly a quarter of children were either advised there was “no problem” or told to return if there was no improvement. This suggests uncertainty or inaccuracy in the diagnosis and a wait and see approach which may delay access to supports that require a diagnosis.

“GP referred me first to someone who couldn't diagnose me, who then went on to give me two contacts of people who could.”
– Adult

Figure 8. Outcome of initial help sought from professionals



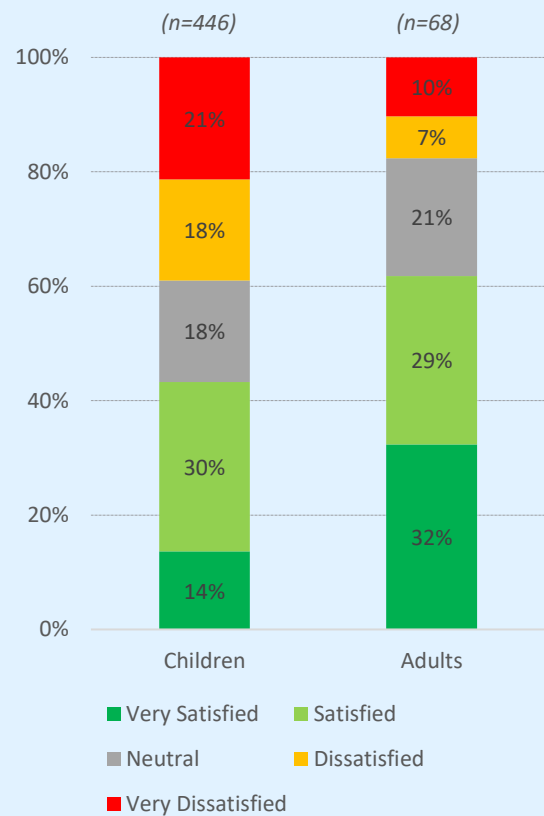
Adults were more satisfied with initial help

Only 44% of parents were satisfied with the initial help they received for their child, whereas nearly two-thirds of adults (61%) indicated they were satisfied. The primary reasons for their dissatisfaction were feeling that: (1) their concerns had been “dismissed”; (2) health and education professionals had “missed” signs of autism due to a lack of “awareness” and screening procedures; and (3) the process to reach an initial appointment for the diagnostic assessment was “too long” and required families “to jump through hoops”. Higher satisfaction for adults may reflect that they had shorter wait times in private practice, fewer “wait and see” approaches when seeking initial help, or that they were more likely to be seen by an autism diagnostician.

Most adults who went to a Psychologist or a Psychiatrist were diagnosed as a result of the initial help sought from professionals.

“[The] GP gave the “he’ll grow out of it” answer. I went back a week later not happy with that, and the next GP was incredible and put through an urgent referral.” - Parent

Figure 9. Overall satisfaction with initial help



The diagnostic process

Key findings and insights

- Referral from a professional was the main reason children and adults were diagnosed in either public or private settings. This probably reflects that there are few private diagnosticians for children and extremely few public diagnostic options for adults.
- Most children were diagnosed in the public sector through a multidisciplinary approach (including Paediatricians, Psychiatrists, Psychologists, Speech Language Therapists, and Occupational Therapists), while most adults were diagnosed in private practice by a sole practitioner (typically Psychiatrists or Psychologists). These results indicate adults are underserved by the public system and contrasts with the Guideline recommendation that a multidisciplinary assessment should be undertaken for adults.
- There were significant differences in assessment processes between public and private settings. For example, a multidisciplinary approach and the use of standardised assessment tools, including autism-specific tools were more commonly used in the public system. These results indicate the assessment process in the public system more closely adheres to the Guideline recommendations.
- Few respondents pursued a second opinion for the diagnosis. For both children and adults this was typically because they were not initially given an autism diagnosis or given an alternative diagnosis they did not agree with.
- Gender disparities were evident across children and adults. Boys were diagnosed at a younger age on average and parents of boys were more satisfied with the diagnostic process overall. Qualitative data from adults indicated clinicians need to be more aware of autism presentation in females and that assessment tools may be less appropriate for females, meaning many females may be “slipping through the cracks”.
- Although the Guideline provides recommendations for differential diagnosis and co-morbidities, there were a range of reasons clinicians deferred a diagnosis or gave a diagnosis when the individual did not meet full diagnostic criteria. These results suggest ongoing variability and ambiguity when clinical features are atypical or complex.
- In the public system, over a third of children had to wait 7 months or more for an initial diagnostic assessment appointment.
- The total time from being placed on a waitlist for the initial appointment to the actual diagnosis was 10.9 months on average. This is likely to be due to difficulties meeting demand and variable multidisciplinary processes, particularly within the public system. This is likely to have an impact on health outcomes.
- The private diagnostic process was faster for adults, compared to children, with most adults receiving an initial diagnostic assessment appointment within 3 months. The total time from being placed on a waitlist for the initial appointment to the actual diagnosis was 4.8 months on average.
- On average, children were not diagnosed until 6.4 years of age (median 5.5 years), which demonstrates a 1.9-year gap from initial queries until diagnosis. Consequently, this indicates that children are not being identified early enough, the autism diagnostic process takes too long and, as a result, too many children miss the opportunity for effective early intervention.
- Lower average age of diagnosis for Māori and Pacific children compared to NZ European children indicate earlier access, which contrasts with common inequities in accessing healthcare for Māori and Pacific.
- Nearly all clinicians reported they were aware of the Guideline with just over half indicating they follow the Guideline closely, further indicating variability in diagnostic processes. These results suggest work may be needed to ensure clarity within the Guideline, particularly for clinicians working in private practice.

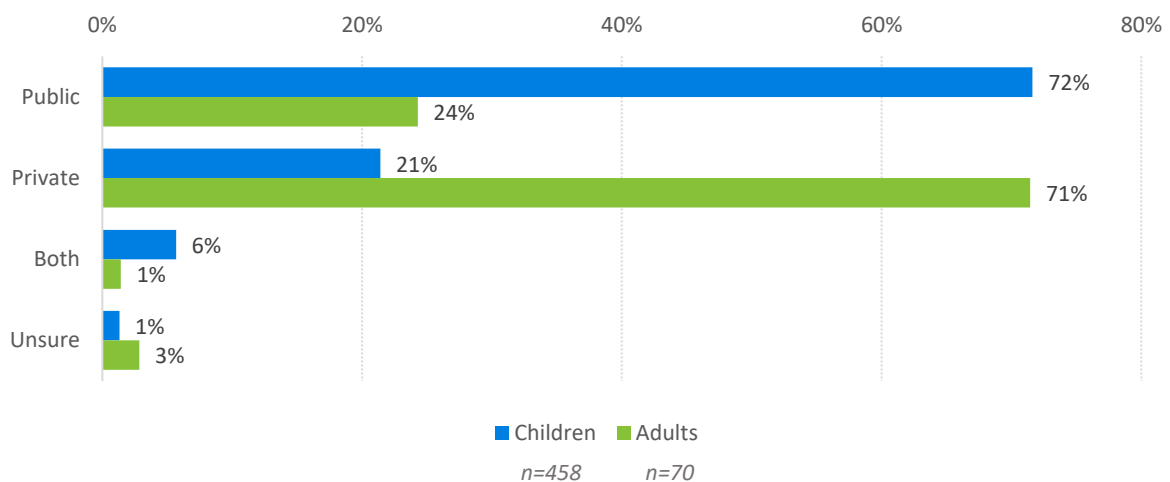
- More parents indicated stress and were less satisfied with the diagnostic process overall for their children, compared to adults. Diagnosis within private practice was perceived as significantly more satisfactory for both children and adults. This satisfaction was linked to greater satisfaction with initial help, the manner of the professional disclosing the diagnosis, involvement of fewer clinicians and shorter wait times to receive a diagnosis.

Large differences between public and private settings

Children went public, adults went private

The main stated reason that diagnostic assessments occurred in either the public or private setting for both children and adults (59% and 67%) was because a clinician referred them to this setting. Nearly one-third were not aware of another option, and in many localities this did not exist. This led to nearly three-quarters of children being assessed in the public system, while nearly three-quarters of adults were assessed in private practice. For children, there were some minor differences by region where Nelson and Auckland had at least one-third of assessments performed in the private setting (this may reflect lack of capacity within the public sector), but most regions were consistent with figure 10 below. With few adults receiving assessment within the public system, it suggests that there are service gaps for adults.

Figure 10. Diagnostic setting for children and adults



Adults and people in some regions travelled further to access assessments

Just over three quarters (80%) of children travelled less than hour (return trip) to their diagnostic assessment appointments. Adults had to travel further with only 59% travelling less than one hour (return trip). At least 50% of children and adults had to travel more than one hour in Northland, West Coast and Hawke's Bay. This indicates barriers to access for adults and in some regions.

"I had to move regions to be heard." - Parent

*"I had to fly across country."
- Adult*

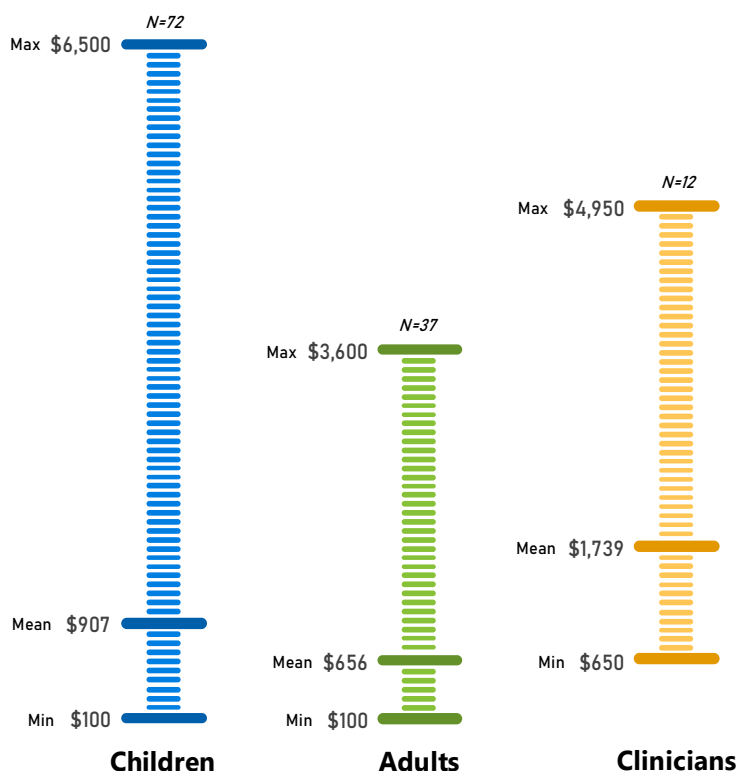
Higher costs for children to access private diagnosis

For individuals diagnosed privately, the average cost was higher for children (\$907) than adults (\$656). This is likely because children generally saw more clinicians than adults (see figure 11). A few respondents indicated additional costs for report writing which were (on average) \$247 for adults, and \$389 for children.

“Very quick and easy as I went privately, but very expensive. I had heard that it was potentially very slow and quite traumatic to go through the public system and I didn't want to make a difficult situation even more difficult for myself so I found the money to go privately.” – Adult

Clinicians indicated higher average costs of \$1,739 for diagnosis than that reported for children and by adults. It is uncertain why there is this such variation, although adult diagnosis was usually undertaken by a single clinician. A few clinicians indicated additional costs for report writing, which on average was \$352. Despite the higher cost for children, most were able to access a diagnostic assessment through the free public system, while most adults obtained a diagnosis through private practice, indicating cost is very likely to be a barrier to adults accessing a diagnostic assessment.

Figure 11. Costs for private diagnoses



“We have had to find our own team of specialists (all private) and many times we haven't been able to pay our mortgage as a result.” – Parent

More clinicians are involved in the public system, and for children

Figure 12 shows that more clinicians were involved in the diagnostic process in the public system, and for children. This corresponds with a higher frequency of multidisciplinary approaches in the public system (see figure 14). Clinicians involved in the diagnosis of children typically included Psychologists, Psychiatrists, Paediatricians, Speech-Language Therapists and/or Occupational Therapists. Flexibility and co-ordination is required to minimise bottlenecks (e.g., for specific clinicians), delays, variability and confusion that can be associated with multidisciplinary approaches.

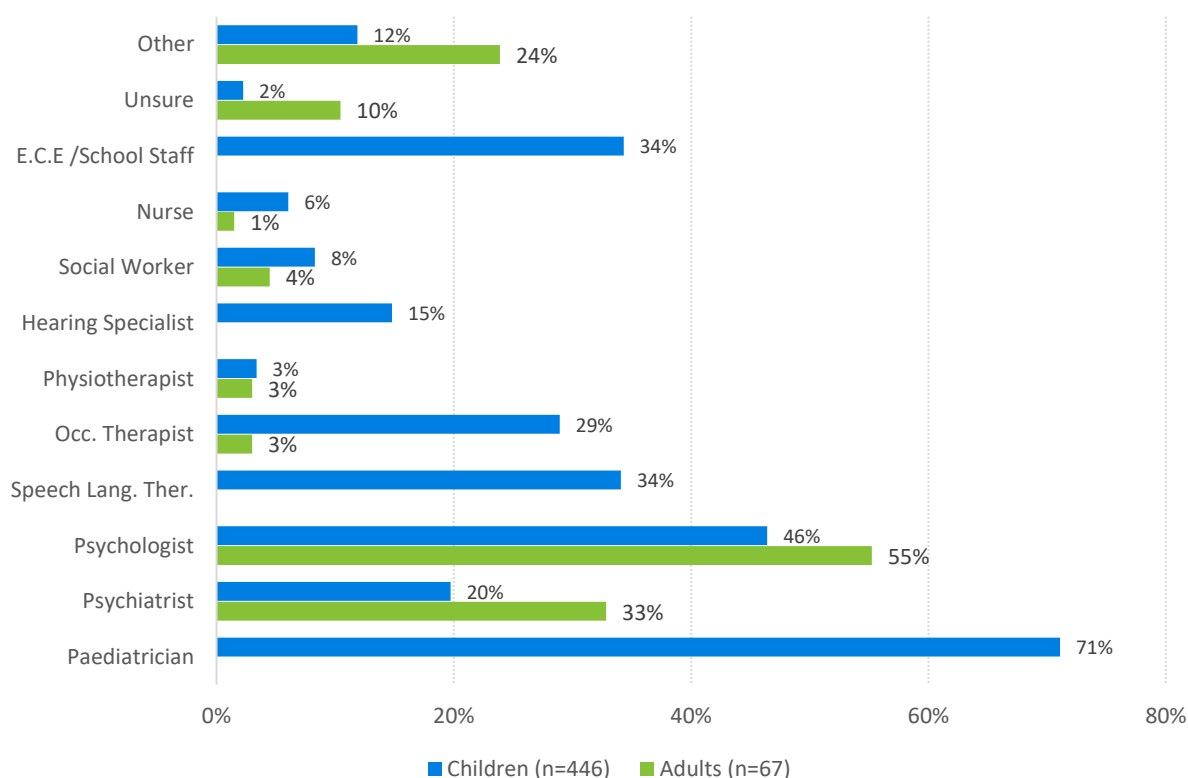
Most adults assessed in private practice saw just one clinician (typically Psychologists or Psychiatrists) and when other clinicians were involved, General Practitioners were the most frequently cited and allied health involvement was largely absent. While this may lead to a more efficient diagnosis, diagnostic accuracy is at risk if a robust multidisciplinary assessment is not undertaken. Additionally, specific sensory, communication or other important aspects that could benefit from the expertise of clinicians from other disciplines, could be overlooked.

Figure 12. Average number of clinicians who contributed to the assessment process for a



Furthermore, these findings contradict the Guideline recommendation that the initial assessment of children may be undertaken by a sole practitioner (and a multidisciplinary assessment if there are ongoing concerns), while for young people and adults a multidisciplinary assessment should be undertaken (and a diagnostic assessment should only be undertaken by a sole practitioner in the absence of a team). It is, however, evident that a team approach is not available for adults, again highlighting service gaps for adults.

Figure 13. Clinicians involved in the diagnostic assessment as indicated by parents for their children and by adults



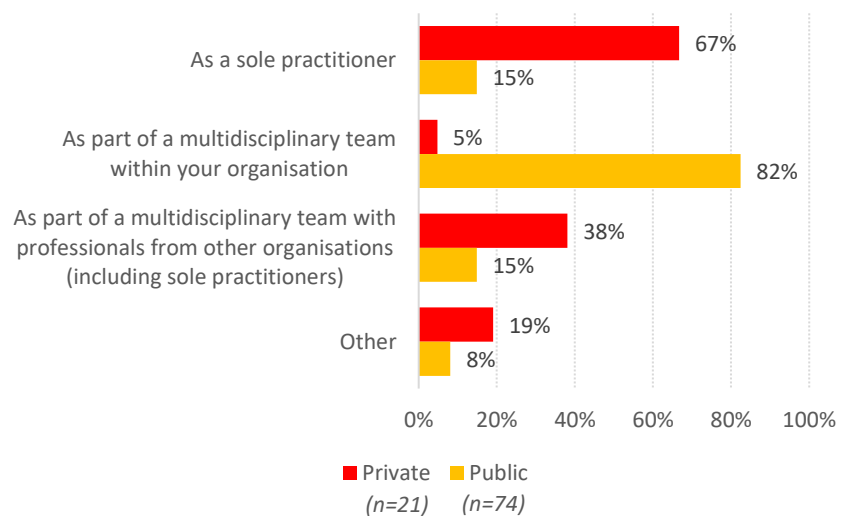
Different views about the makeup of multidisciplinary teams

Clinicians reported a range of different clinicians involved in the diagnostic process. Social Workers (40%) and Nurses (32%) were frequently involved in their multidisciplinary teams; however, parents and adults reported these same clinicians were rarely (<10%) involved. This may be because Social Workers and Nurses often play a role in case management activities, which may be perceived by parents as being less directly involved in the assessment process. It is unclear as to the extent to which each role and function contributes to, or influences, the assessment process, and further work could explore this topic. Such analysis may provide further insights to determine the effectiveness of different elements within a multidisciplinary approach against single clinician approaches.

Public approach is multidisciplinary, private is sole practitioner

Clinicians working in the public system indicated they work in a multidisciplinary team within their organisation (82%) significantly more than clinicians who work in private practice, for which 67% diagnose as a sole practitioner. However, more clinicians in private practice (38%) worked in a multidisciplinary team with clinicians from other organisations, compared to 15% in the public system. This contrast is not surprising but may lead to different experiences and outcomes.

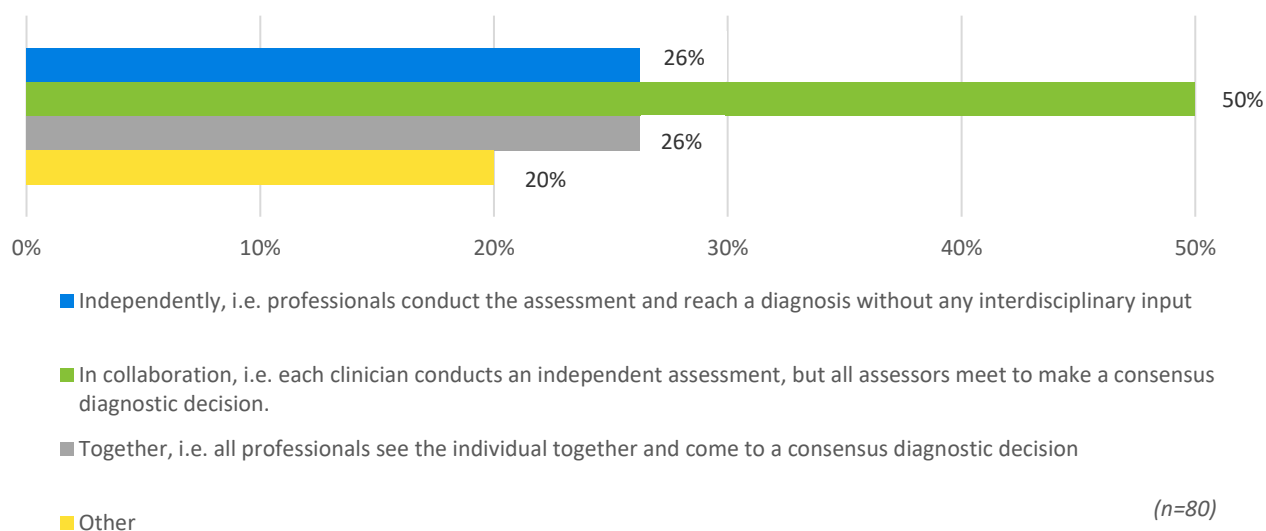
Figure 14. How clinicians provide a diagnosis



Over a quarter (28%) of clinicians reported always conducting a multidisciplinary assessment. The Guideline recommends that an assessment is undertaken concurrently by a collaborating team where possible (that is, clinicians see the individual together and come to a consensus diagnostic decision). This only occurred a quarter of the time with clinicians conducting a multidisciplinary assessment together (see Figure 15 below). More clinicians indicated the multidisciplinary assessment was in collaboration (that is, each professional conducts an independent assessment, but all contributing clinicians meet to make a consensus diagnostic decision). This suggests a sequential approach which, if not well coordinated, could add significant time to the diagnostic process. It also may affect consistency of diagnosis, stress levels of parents and children, and general experience which are discussed later in this section.

"The Psychologist was excellent at talking me through each step. We took our time and I found that therapeutic." - Adult

Figure 15. Multidisciplinary diagnosis process



Multidisciplinary team assessments were typically not implemented if the diagnosis was considered to be straightforward (41%) or if a partial assessment had already been completed (35%). However, more systemic reasons were also cited for not using multidisciplinary team assessments, including: clinicians were not available (40%) and if it was not considered part of everyday practice (10%). More work is required to support clinicians in systematically and consistently determining when a full multidisciplinary team process is required or whether an abbreviated assessment with 1-2 clinicians may be reasonable.

"I liked the multidisciplinary team who did the diagnosis. It was thorough."
- Parent

High levels of external collaboration

Few clinicians (9%) indicated they do not collaborate with clinicians external to their service. Clinicians regularly collaborate with external multidisciplinary teams (27%), other sole practitioners (46%), and early childhood/school staff (66%). Nearly a third (30%) of clinicians indicated they collaborate with 'other' professionals, including Ministry of Education learning support, autism professional groups/advisory panels, and clinical supervision. This shows that even if the diagnosis is made by a sole practitioner, there is still wider collaboration occurring. However, it seems there are many opportunities to improve further, ensuring individuals and families and whānau receive the right information and supports before, during and after the diagnostic process.

Assessments in the public system require more appointments

With more clinicians and multidisciplinary team approaches, there are subsequently more appointments required in the public system. This may well reflect greater severity and complexity of childhood presentations. Across public and private settings, over half of clinicians indicated diagnoses were provided after three or fewer sessions (public 59%; private 80%). Thirty-three percent of public clinicians saw an individual on 4-6 occasions, compared with 20% of private clinicians. Eight percent of clinicians working publicly saw an individual on more than 6 occasions, whereas there were no private clinicians who did the same. The higher the number of appointments, the more likely it will be a longer diagnostic pathway. However, in theory, there

are more opportunities to achieve greater accuracy, information exchange, and a more thorough assessment of needs. Further research on this aspect is required.

Assessment processes are variable

Clinicians use different assessments in the diagnostic process

Clinicians in the public system reported using standardised assessment tools, including standardised autism-specific assessment tools, in the diagnostic process significantly more often compared to clinicians in private practice. Across public and private settings, the Autism Diagnostic Observation Schedule (ADOS; 61%), Childhood Autism Rating Scale (CARS; 46%) and Autism Diagnostic Interview (ADI; 17%) were the three most commonly used autism-specific assessment tools.

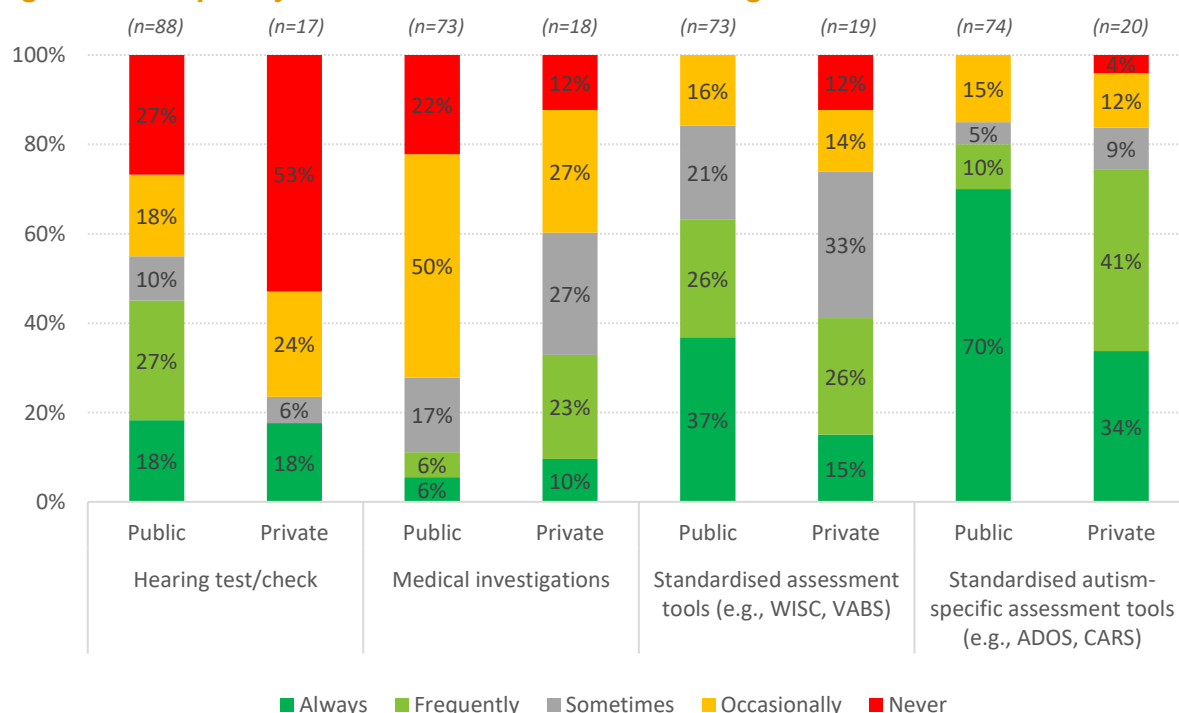
"The psychologist relied heavily on tests, rather than the evidence my symptoms presented. I, personally, believe that the tests are not always accurate, because ASD has so many different permutations, that tests simply can't pick up on all symptoms."
- Adult

The ADOS was used more commonly in the public system (67%), with the CARS being used more commonly in private practice (70%). This could be due to higher costs associated with the ADOS (purchase price and training), greater time required for administration and a

higher need for supervision, making it less accessible for private clinicians. Common 'other' autism-specific assessments were the Autism Quotient (AQ), Ritvo Autism Asperger Diagnostic Scale (RAADS), Social Responsiveness Scale (SRS), and Empathy Quotient (EQ).

"If it is clear enough from history taking, observation, history of parents and teachers, I will make the diagnosis myself, as I have years of experience, without a formal diagnostic tool. If it is not clear, then the psychologists may have time to do ... more formal assessment." - Clinician

Figure 16. Frequency of assessments used for the diagnosis



Across public and private settings, most clinicians rarely administered or referred for hearing tests/checks or medical investigations. This contrasted with the Guideline recommendation that a hearing evaluation should be conducted for all children suspected of having autism or another developmental delay. These results may well indicate resourcing issues. Furthermore, children also access a before school hearing check by the Well Child/Tamariki Ora schedule, suggesting that another check may not be necessary for older children.

Overall, inconsistency in assessment approaches may have an impact on the reliability and repeatability of diagnoses. However, it is also noted that the comprehensive diagnostic assessments that are recommended by the Guideline are lengthy and expensive. Time required to administer standardised assessments of autism symptomatology with input from various clinicians may be prohibitive if not utilised judiciously.

Routine assessment of developmental history and use of diagnostic criteria, but variable assessment of other areas of functioning

Developmental history was conducted routinely or as required 99% of the time. In line with the Guideline recommendation, cognitive assessments (e.g., WISC; Leiter, 63%) and adaptive behaviour/functioning (e.g., VABS, ABAS; 61%) were conducted regularly. Developmental assessments (e.g., Griffiths, Bayley; 29%) and language/communication assessments (e.g., CELF, PLS; 21%) were less common. This is likely because these assessments are not expected for older children, adolescents and adults. Across these assessments, there were few differences in frequency of use between public and private settings.

Again, variability in the assessment may impact quality of the diagnosis. However, nearly all (94%) clinicians used the Diagnostic and Statistical Manual (DSM-5) classification system to assign diagnoses. Appropriate use of diagnostic criteria supports formulation of a reliable diagnosis. Sixty-nine percent of clinicians assigned a severity rating to the diagnosis. Clinicians determined autism severity based mostly on: the DSM-5 descriptors for specified levels of support (86%); clinical judgement (63%); and in some cases an adaptive skills/functioning assessment (e.g., VABS, 30%). These severity ratings can be used to accurately determine the level of support required for the individual.

Complex presentation and diagnostic uncertainty

Few respondents sought a second opinion

Few respondents reported pursuing a second opinion for the diagnosis (children 16%; adults 10%). When a second opinion was pursued, this was typically either because they were not initially given an autism diagnosis (children 29%; adults 50%) or because they were given an alternative diagnosis that they did not agree with (children 30%; adults 33%). The diagnosis of adults includes more complicating factors, such as a wide range of expression of autism characteristics, more complex differential diagnosis, competing diagnoses which may overshadow autism, and difficulty obtaining accurate and detailed developmental history [8].

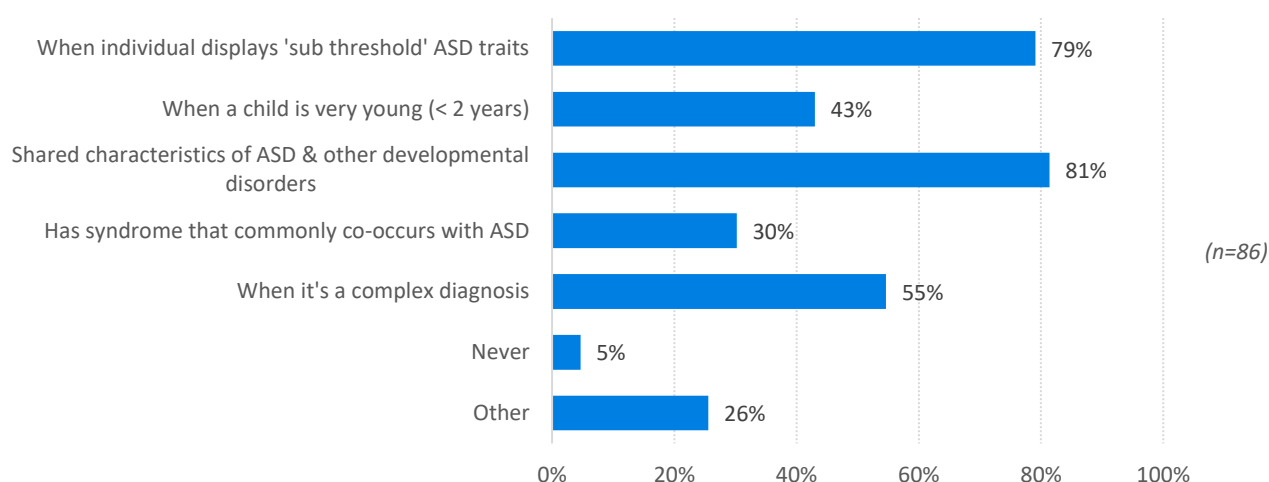
Qualitative data indicated clinicians need to be more aware of autism presentation in females and that assessment tools may often be less appropriate for females. This was also supported by data for children in which boys were diagnosed at a younger age and parents of boys were significantly more satisfied with the diagnostic process overall compared to girls. Together these results suggest that many females may be “slipping through the cracks”.

Clinicians consider many factors when diagnosing autism

There is no definitive test for autism. Figure 17 and 18 demonstrate circumstances in which clinicians defer making a diagnosis or give a diagnosis of autism when the individual does not meet full diagnostic criteria. These figures indicate ambiguity in the diagnostic process, in which clinicians consider various factors that influence diagnostic decisions.

"One of the big challenges is tools that work well with assessment of females, especially teenagers." - Clinician

Figure 17. Circumstances in which clinicians defer making an autism diagnosis



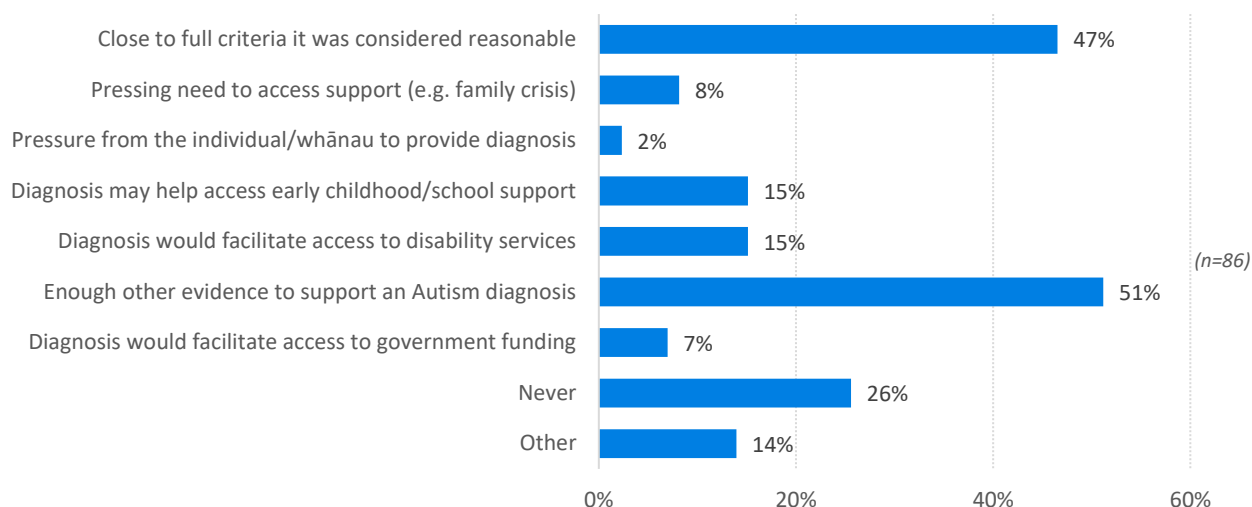
While the Guideline provides recommendations for differential diagnosis and co-morbidities, the range of reasons for either deferring or giving a diagnosis indicate possible ongoing uncertainty and/or variation in practice. Autism diagnosis appears to be complicated by both clinical and non-clinical factors, but for individuals on the autism spectrum and their family and whānau who require a diagnosis to access health support, any unnecessary delay can mean that needs go unmet, and may have longer term outcome implications. This can particularly impact outcomes for young children, where research consistently demonstrates early diagnosis (less than two years) is reliable and supports access to early intervention, significantly improving outcomes [7, 10]. Despite this, nearly half of clinicians indicated they deferred making a diagnosis when a child is very young. This suggests that children and their family and whānau should be linked to supports as needed before a diagnosis.

"A particular issue is significant underdiagnosis of mild to moderate presentations of ASD which is frustrating and confusing for families and unnecessary strains on already strained services as work is doubled." - Clinician

Alternatively, giving a diagnosis when an individual does not meet criteria may lead to inaccurate diagnoses and subsequently increased incidence of autism over time, putting further strain on support systems. Despite these risks, approximately three-quarters of clinicians provided circumstances this occurred. These findings highlight the complexity of diagnosis and challenges

when funding for support is based on diagnosis rather than need [4].

Figure 18. Circumstances in which clinicians give a diagnosis of autism when the individual does not meet full criteria for autism.



The diagnostic process is long

The duration of the diagnostic process is important for two main reasons:

- Diagnosis can enable access to supports and services within the health system [9] (educational supports are described as needs-based and do not require a diagnosis) [15].
- Diagnosis can support access to early intervention (particularly below 3 years of age) which evidence consistently demonstrates leads to a better developmental trajectory and long-term outcomes [10].

"Time delay was 2 and half years - this squandered the early intervention window."- Parent

For the sake of report clarity, the 'diagnostic process' begins when action is taken after queries were first raised. It ends at the point of diagnosis. For children, earlier identification would be beneficial for outcomes, but this would require much better system-wide

identification, improved public awareness regarding early indicators, and a more efficient referral and diagnostic pathway.

Age of initial queries and diagnosis

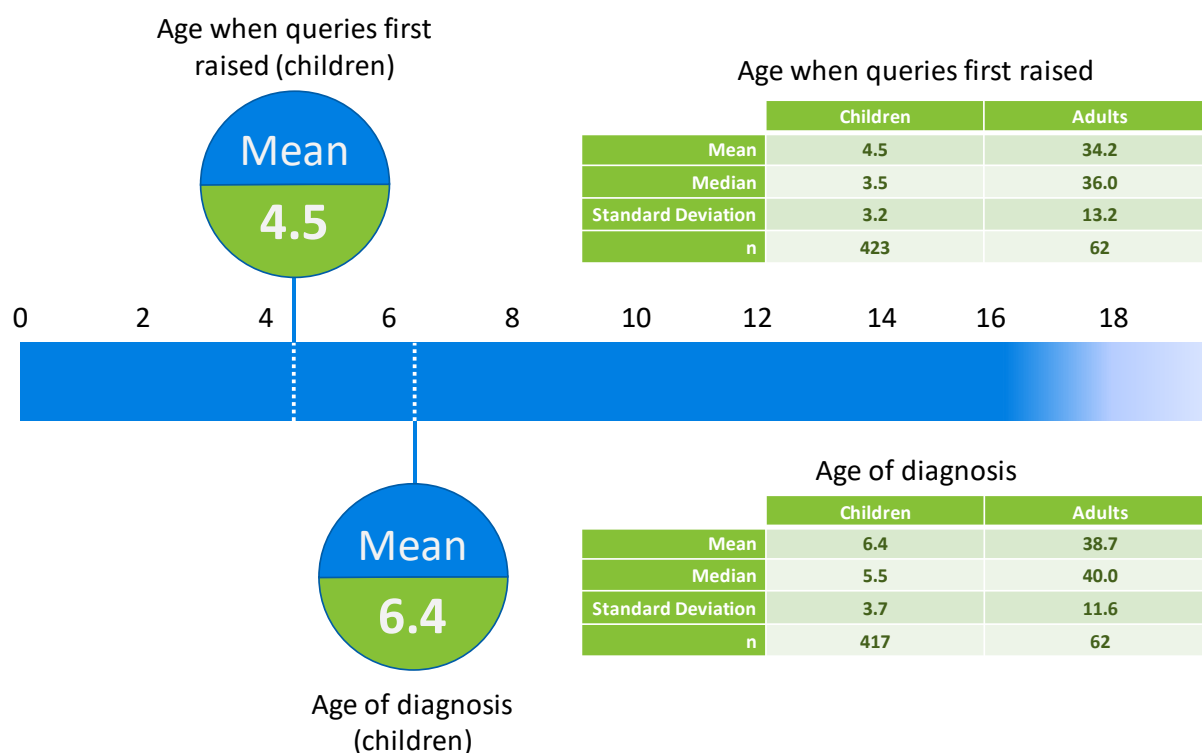
Initial queries were first raised (on average) at 4.5 years for children (median = 3.5 years), and 34.2 years (median = 36 years) for adults (see figure 19). The mean age of diagnosis was for children was 6.4 years, which is consistent with previous New Zealand research [5, 6]. This indicates that it takes children, on average, 1.9 years (median = 1 year) to move from the point of first query to diagnosis. Adults were not typically diagnosed for another 4.5 years (median = 1.2 years). This suggests that there is substantial room to reduce the delay to diagnosis, and analysis reveals that (at least) the following factors may contribute:

"People should not have to diagnose themselves in middle age. Parents, early child care workers, and teachers need to be aware of the signs of autism."- Adult

- Individuals or family and whānau may lack awareness of pathways to diagnosis.

- Clinicians may be uncertain regarding presentation and delay referral for further assessment.
- Both clinicians and individuals may lack urgency to pursue diagnosis.
- Barriers to access assessment services may exist (e.g. cost, travel, availability etc.).
- The wait time for initial assessments could be long.
- The assessment approach may require multiple assessments and could take a long time due to bottle-necks.
- A diagnosis may not be given initially due to various clinical factors.

Figure 19. Timeline of initial queries and diagnosis of autism for children and adults



Boys were diagnosed earlier

The average age of first queries was later for girls (5.2 years) than boys (4.3 years). On average, girls were also diagnosed later (7.3 years) than boys (6.2 years). The gap between first concerns and diagnosis was also somewhat longer for girls (2.1 years) than boys (1.9 years), suggesting perhaps a more subtle presentation and possible greater complexity in the diagnosis of girls. On average, gender diverse children had queries raised later (6.5 years) and were diagnosed with autism later (12.5 years), also suggesting complexity in diagnosis.

Pacific children were diagnosed earlier than Māori or NZ European children

The age of first queries and diagnosis for Pacific children was 3.6 years and 4.6 years respectively. For Māori children it was 4.1 years when first queries were raised, and 6 years when they were diagnosed. NZ European children took longer for both stages at 4.5 years and 6.5 years respectively. Based on the Māori and Pacific people who responded to this questionnaire, which may not be representative of the general population, these findings are in contrast to common inequities in accessing healthcare for Māori and Pacific peoples, but consistent with one report analysing rates of autism diagnoses in the Hutt Valley [6]. While these results suggest early access to autism assessment and more opportunity for better outcomes for Māori and Pacific, the reasons behind these ethnicity differences could be researched further.

"I feel the process was long and stressful, especially as there was three years where we could have a diagnosis and been receiving some support." - Parent

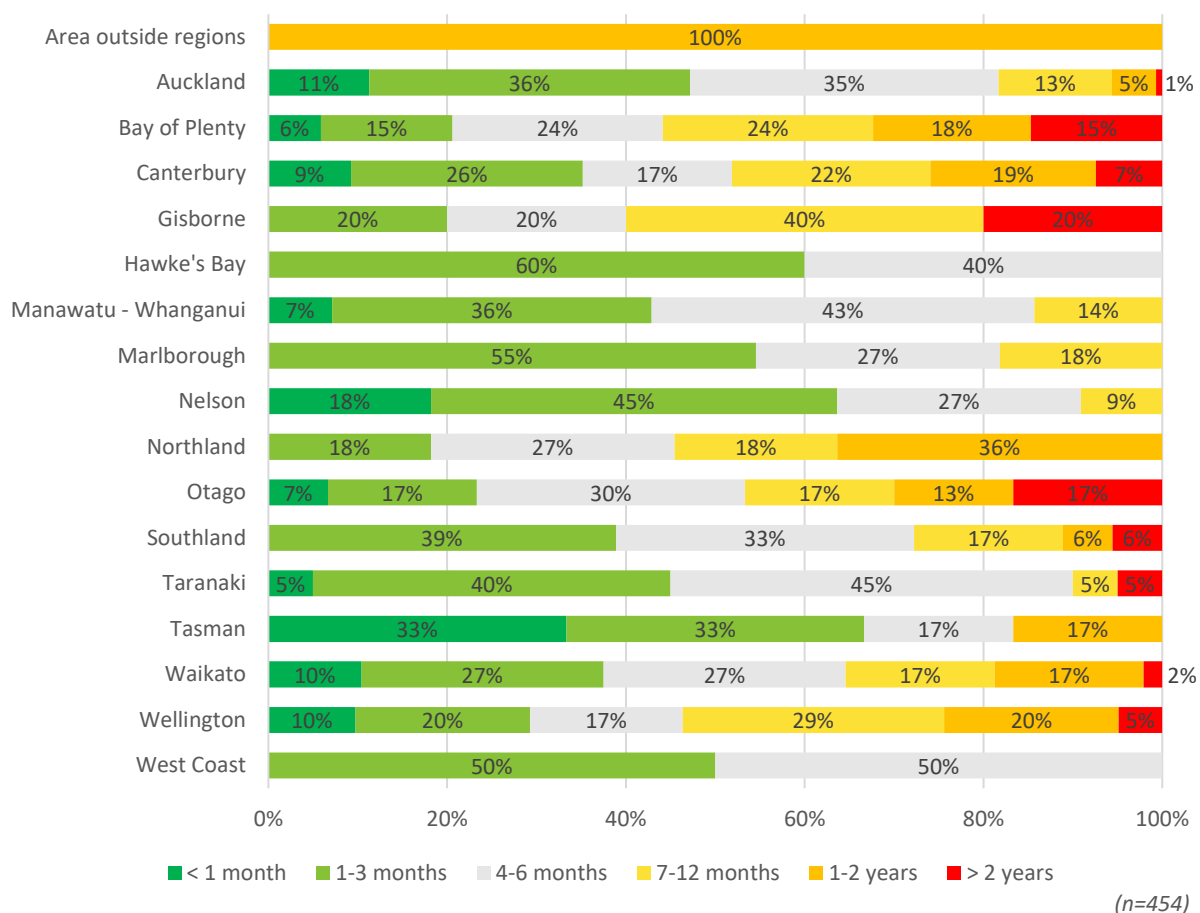
There were variable wait times for initial assessments

The wait times are different by region

There was substantial variation in wait time across regions, but there was a lack of an obvious geographical pattern. However, regardless of setting, the northern regions of the South Island (Tasman, Nelson, and

Marlborough) and Hawke's Bay showed some of the shortest wait times, with over 80% of children being seen in 6 months or less. Northland, Otago, and Bay of Plenty each had at least 30% of children waiting at least 1 year for their initial assessment.

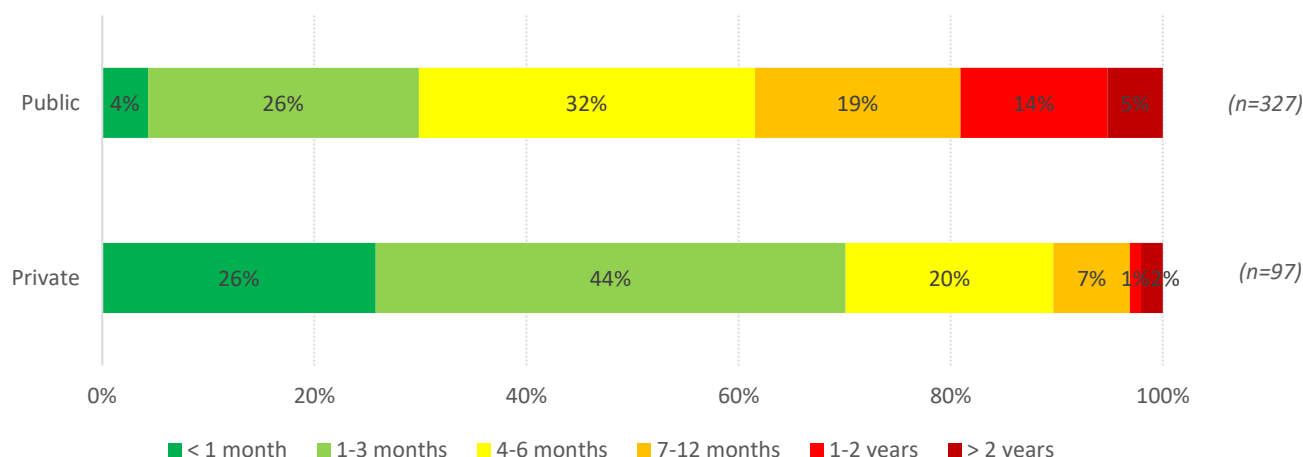
Figure 20. Child wait times for initial diagnostic assessment appointment by region (includes both public and private settings)



Wait times in private practice were shorter than wait times in the public sector.

The main influencing factor on wait time, was the proportion of initial assessments carried out publicly or privately. Figure 21 shows that private assessments had consistently less wait times than public assessments. Seventy percent of assessments for children in private practice were received within 6 months, compared with only 30% in the public setting over the same period. Alarming, over one-third of children wait more than 7 months for their initial public assessment.

Figure 21. Child wait times for initial diagnostic assessment appointment in the public versus private settings



Most children received a diagnosis in the public setting (72% public versus 24% private), and that corresponds with longer wait times for children than adults, where 84% of adults received an initial appointment within 3 months.

The Guideline specifies that the Ministry of Health requires referrals in the public setting to be seen within 6 months and assessments completed as quickly as possible within the available resources. Results from this research indicate the process can be considerably longer for some children. Figure 21 shows that only 62% of public assessments achieve this. It could easily be argued that a target of 6 months is too long.

Taking a closer look at the achievements of the public system (Figure 22) against a 6-month timeframe (excluding regions with less than five respondents), there is variation across regions. Of note, in Taranaki, Manawatu/Whanganui and Marlborough at least 80% of children were seen in 6 months or less. Conversely, over 50% of initial appointments in Northland, Wellington, Canterbury, and Bay of Plenty took at least 7 months. Together, wait times for the initial assessment appointment indicate the demand for autism diagnostic services are considerably higher than the available resources to meet the need.

Figure 22. Child wait times for initial diagnostic assessment appointment by region within the public setting

	% taking ≤ 6 months	% taking ≥ 7 months	n	% of children assessed in public system
Auckland	73%	27%	86	66%
Bay of Plenty	48%	52%	23	83%
Canterbury	42%	58%	38	81%
Manawatu/ Whanganui	85%	15%	13	93%
Marlborough	80%	20%	10	91%
Northland	25%	75%	8	73%
Otago	52%	48%	23	88%
Southland	62%	38%	13	76%
Taranaki	89%	11%	18	95%
Waikato	61%	39%	41	87%
Wellington	38%	62%	29	78%

"Comprehensive [multidisciplinary] team assessments have very long waiting times (over a year in some places)."- Clinician

Clinician responses seemed to support these findings, where wait times for an initial assessment appointment were significantly longer in the public system compared to private practice. Almost all clinicians working privately reported a wait time of 3 months or less, whereas less than half of those working publicly reported the same wait time.

Those in the public setting wait longer for a diagnosis

Children wait longer from the initial appointment to receive a diagnosis

Contributing to the overall duration of the diagnostic process is the wait time from the initial assessment to being given a diagnosis. Approximately half of all diagnoses (across children and adults) were received within 4 weeks from their initial assessment appointment. Diagnosis in the private sector and through a single clinician was significantly faster than in the public setting and through a multidisciplinary team assessment. As a result, nearly all adults waited less than 6 months to receive their diagnosis. However, over one quarter of children waited at least 7 months to receive a diagnosis following their initial assessment, this was particularly the case in Gisborne, Otago, Canterbury, Northland, and Bay of Plenty. This indicates systemic delays within the diagnostic process, and/or poor clinician capacity.

"It took too long to get the diagnosis, we reached crisis points and had to be referred to ICAMHS because our son became depressed and no longer wanted to live." - Parent

Conversely, in Waikato, Wellington, and Auckland over half of children received a diagnosis within 4 weeks of the initial appointment. While these North Island main centres have longer wait times for the initial assessment, they are quicker at providing a diagnosis for children once first reviewed. In the public setting this may indicate improved access to the range of specialities involved in an efficient multidisciplinary team assessment process. However, the speed of diagnosis in Auckland might also be due to the higher rate of private diagnoses (34%) for children, which typically have fewer assessment appointments and provide more efficient diagnoses than in the public system.

Private clinicians provide a diagnosis faster

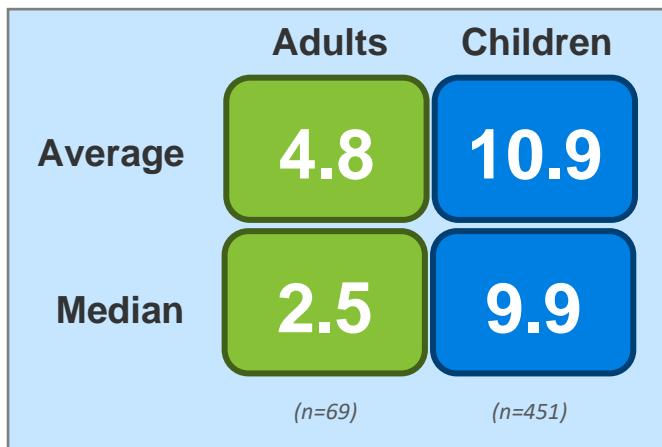
Again, public and private clinicians reported a significant difference in wait times to receive a diagnosis. More private clinicians (two-thirds) reported that they make a diagnosis in less than 4 weeks compared with clinicians working publicly (one quarter). Similarly, only one-quarter of those working in multidisciplinary teams could provide a diagnosis in less than 4 weeks.

"It was a quick process for me but that was because I saw a psychologist from the private sector and didn't have to endure the waitlists for a public assessment." - Adult

Total wait times are long, particularly for children

It is useful for individuals and family and whānau to understand how long the diagnostic process takes from the point at which they are referred. Figure 23 provides an estimate on the total elapsed time from requesting an initial appointment to receiving a diagnosis. This

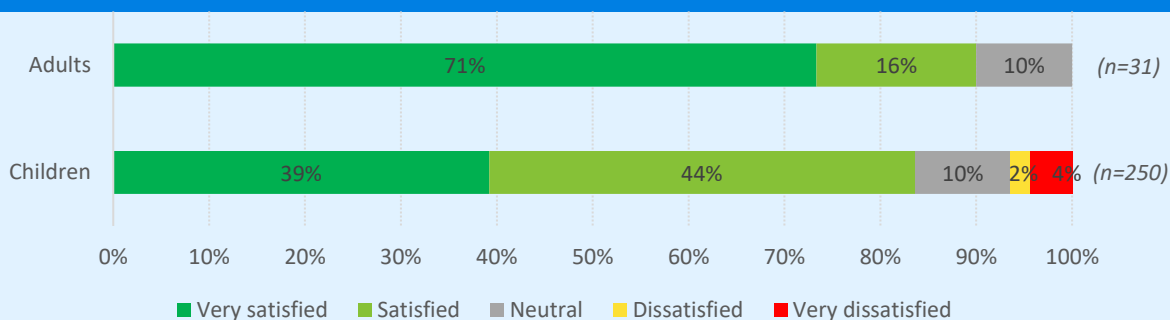
Figure 23. Total wait times (months) to obtain a diagnosis for children and adults



shows that the actual time faced by people going through this process is long, which is of particular concern for children (~10 months) whose outcomes are affected by delaying necessary supports.

Note: This estimate is based on an average of duration ranges captured in the survey. In this approach the middle value of each range was used to calculate these durations (i.e. 1-3 months became 2 months). Where the range had no end-point, the earliest time reference was used (i.e. >1 year became 1 year).

Figure 24. Satisfaction with the manner of the professional disclosing the diagnosis



Feedback appointments to discuss the diagnosis were not always used

Children and adult respondents reported they had feedback appointments about half the time (children 58%; adults 46%). By contrast, 85% of clinicians reported that they always provided a feedback appointment. There appears to be a discrepancy between these two views, and perhaps there may be a lack of mutual understanding and expectations about the nature and content of this feedback. It would be valuable to explore this further in future research.

For those who did receive a feedback appointment, there was a high level of satisfaction with the manner of the professional disclosing the diagnosis, particularly for adults. Most adults (76%) received a written diagnostic report, as did children (82%).

"Apart from an accurate diagnosis, the feedback is the most important part of the entire process." - Clinician

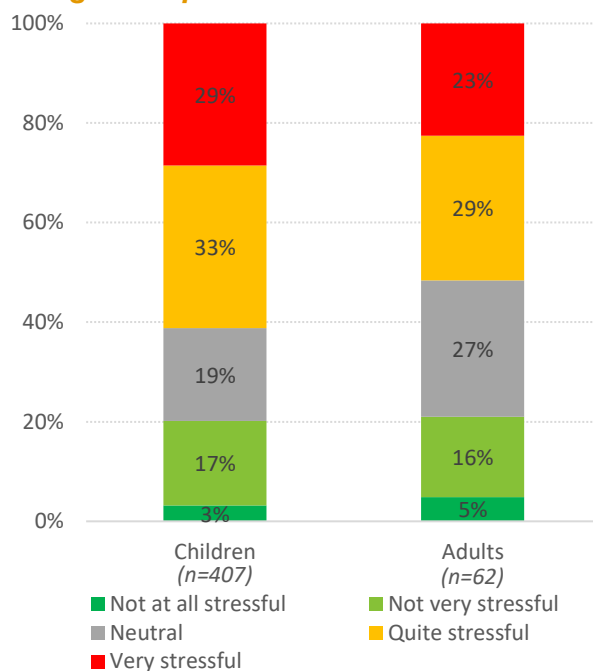
"[I] was never told about ASD diagnosis. [I] read it in the clinic letter received a few weeks after our appointment with [the] developmental paediatrician."
— Parent

The diagnostic process was stressful

Stress during the diagnostic process was high. More parents of children diagnosed with autism (62%) indicated the diagnostic process was stressful compared to adults (52%). In addition to anticipated elevated stress levels at home during a diagnostic process where supports may be required and not being received, the results suggest that there could be other contributing factors:

- Uncertainty about the diagnostic process.
- Lack of appropriate cultural supports.
- Wait times.
- Extended duration until diagnosis.
- Disagreement with initial diagnosis.
- Cost and time pressures with multiple appointments.

Figure 25. Overall stress during the diagnostic process



"The whole process has been soul destroying for myself and led to a marriage breakdown. My daughter was suicidal." - Parent

"It was awful and contributed to me getting very mentally unwell. Was hospitalised, which was extremely traumatic." - Adult

Moderate overall satisfaction with the diagnostic process

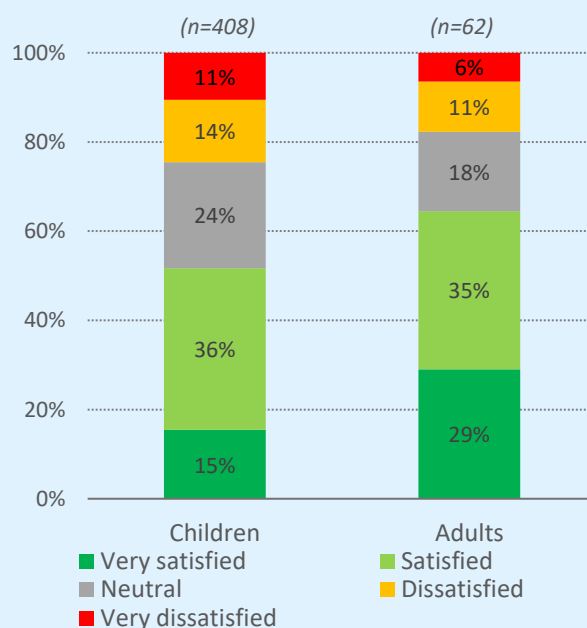
Lower satisfaction for children

For children, there were moderate levels of satisfaction with the overall diagnostic process (51%). This is consistent with previous research of New Zealand parents of children and adolescents diagnosed with autism surveyed in 2016-2017 [5], but higher than rates in other countries where parent satisfaction has been studied [16].

Statistical analysis identified that parents of children diagnosed with autism had greater overall satisfaction with the diagnostic process if:

- The diagnostic process was perceived as less stressful, emphasising the need for holistic supports to family and whānau members.
- They felt the pathway to a diagnosis was clear.

Figure 26. Overall satisfaction with the diagnostic process



- They were more satisfied with initial help received and with the professional's manner when disclosing the diagnosis.
- They were more satisfied with the post-diagnostic supports offered and their coordination.
- They consulted with fewer professionals.
- The time between the initial appointment and delivery of the diagnosis was shorter.
- They obtained a diagnosis in private practice.

"The actual process is fine, it's just accessibility that makes it hard, we waited years to be seen."-

Parent

When analysing **dissatisfaction**, qualitative feedback identified some common reasons for dissatisfaction included (1) the perception that the "process has taken so long"; and (2) was "hard to navigate". While there were some regional differences in overall satisfaction with the diagnostic process, like wait times, these lacked obvious geographical patterns with highest satisfaction in Nelson (which also had a higher rate of private diagnoses) and lowest satisfaction in Otago. Qualitative data indicated "postcode" variation in the diagnostic process and limited autism services and clinicians in some areas.

Adults were more satisfied

Nearly two-thirds of adults were satisfied with the diagnostic process overall, which contrasts with international research where lower satisfaction was found [17].

Statistical analysis identified that adults had greater overall satisfaction with the diagnostic process if:

- They were more satisfied with the initial help they received and with the professional's manner when disclosing the diagnosis, highlighting the importance of a positive experience during the entire diagnostic process.
- They consulted with fewer professionals.
- They obtained a diagnosis in private practice.

"Satisfied, but I was in a position to pay. I think it is not satisfactory overall."- Adult

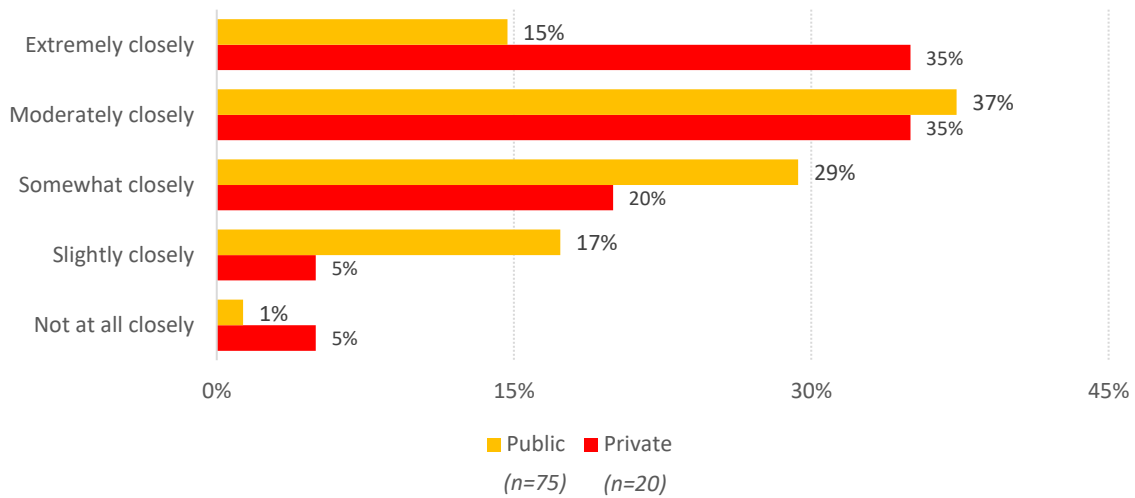
Uptake of the New Zealand Autism Spectrum Disorder Guideline

Clinicians are mostly aware of the Guideline but not all follow it closely

While the extent of familiarity was variable, all clinicians in private practice and 97% of clinicians in the public system indicated they were at least somewhat familiar with the Guideline. Clinicians working in private practice reported being more familiar with the Guideline (76% moderately or extremely familiar), than those working publicly (56% moderately or extremely familiar).

Most clinicians reported that they follow the Guideline moderately or extremely closely, but again, private clinicians reported that they followed the Guideline more closely than public clinicians.

Figure 27. How closely clinicians reported following the Guideline



A notable discrepancy between perceived uptake of the Guideline recommendations and findings from this research is that while more clinicians working in private practice indicated they follow the Guideline closely, clinicians working in private practice commonly diagnosed adults with brief single clinician (65%) assessment processes. This contrasts with the Guideline recommendation to conduct a comprehensive assessment with a multidisciplinary team when possible for older individuals. Qualitative data indicated resourcing reasons for not conducting a comprehensive multidisciplinary team assessment, but these results indicate more work may be needed to ensure greater awareness of the Guideline, particularly for private clinicians. This would support improved consistency of the diagnostic process.

Section 4 - Supports during and after diagnosis

Key findings and insights

- There was very poor satisfaction with post-diagnostic supports and their coordination, indicating that these services are not meeting expectations or needs.
- Only 43% of parents reported receiving support from Developmental Services/ASD Coordinator for their child, yet more clinicians indicated they routinely referred to this service. Results indicate more work is needed to better understand and support access to this service.
- While cultural supports were not required almost half the time for Māori and Pacific respondents, results also indicated substantial unmet cultural needs for Māori and Pacific peoples for the remainder. There was a need for better access to, and experience of, cultural supports. Promisingly, there was more satisfaction regarding clinicians' sensitivity to cultural needs.
- Parents indicated slightly higher satisfaction with post-diagnostic services and resources for their children compared to adults.
- Notable areas included both variable access to, and if received, dissatisfaction with counselling to adjust to the diagnosis and vocational support for children and adults.
- Adults indicated particularly high dissatisfaction with the disability allowance and needs assessment service coordination through the Ministry of Health, while parents indicated some of the highest levels of satisfaction with these services for their children.
- Parents indicated dissatisfaction with early intervention and learning support services through the Ministry of Education for their children.
- There was also considerable dissatisfaction with supports for specific areas of functioning impacted by autism, particularly support for gut health and physical movement. However, there was higher satisfaction with medication for both children and adults.
- Given the long-term impact of post-diagnostic supports on health and quality of life outcomes, the low satisfaction and coordination across a wide range of services, resources and needs clearly indicates a need for substantial improvement in this area.

Poor satisfaction with post-diagnostic supports

Post-diagnostic supports need to improve

Overall satisfaction for both parents and adults was very low with a quarter or less of parents (22%) and adults (25%) indicating they were satisfied with post-diagnostic supports. The main reasons for dissatisfaction were regarding:

- Nil, or not enough, supports provided and a sense they had to “deal with it themselves”.
- Being given pamphlets but no real supports.
- Delays in access to supports.

Some children (6%) and adults (16%) did not receive any post-diagnostic supports, but it is not clear if supports were required in all these instances.

Low satisfaction with post-diagnostic supports was consistent across regions. There was slightly higher satisfaction in the upper Tasman and Marlborough, and slightly lower satisfaction in Bay of Plenty and Canterbury.

Post-diagnostic supports are uncoordinated

Only 19% of parents and 13% of adults indicated that the coordination of post-diagnostic supports were clear, indicating major unmet need and a large opportunity for assessment, supports, and navigation service providers. It raises important questions regarding responsibility for coordinating supports, particularly what type of coordination those on the autism spectrum prefer, and whether there is funding, services and capacity for it. Further work to explore this is recommended.

"I feel like there are so many different organisations involved with autism and it's not so clear where they all fit, they seem to be doing their own thing."
- Parent

Figure 28. Overall satisfaction with post-diagnostic supports

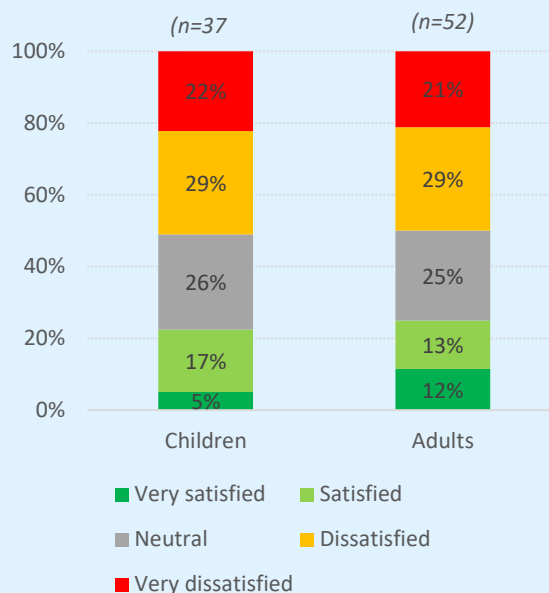
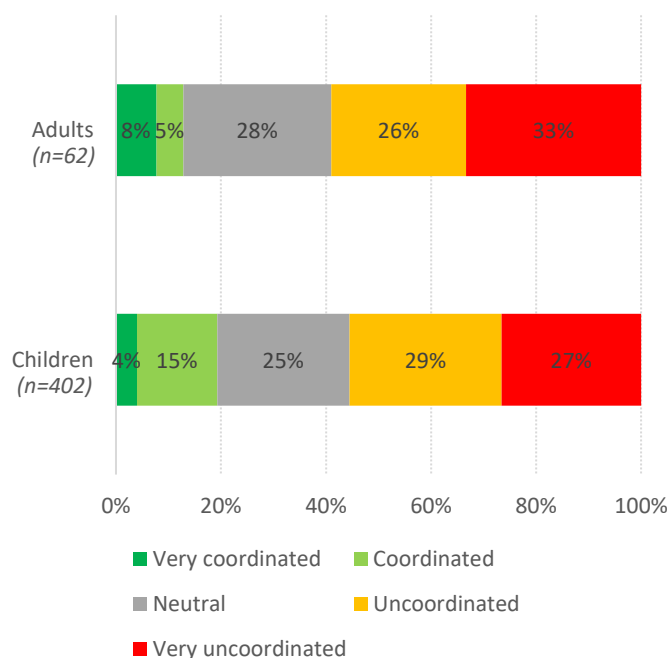


Figure 29. Overall coordination of post-diagnostic support



Most clinicians offer follow-up after a diagnosis

While three-quarters (76%) of clinicians reported that they provided ongoing follow-up once a diagnosis of autism had been confirmed some of the time, only 18% of clinicians always did, with 6% indicating they never do.

Opportunities to improve use of Developmental Services /ASD Coordinators*

Not many children are accessing Developmental Services/ASD Coordinators

In 2011 the Government funded District Health Boards to employ ASD Coordinators to ensure effective coordination of autism assessment and post-diagnostic support services. Previous

research has indicated the role is valued by service recipients, but District Health Boards have used the funding variably [18].

While a Developmental Services/ASD Coordinator should have been available in each District Health Boards region for individuals up to the age of 19 years, only 40% of parents reported that a Developmental Services/ASD Coordinator had been involved during some stage of the diagnostic process for their child. The number of children who accessed a Developmental Services/ASD Coordinator was higher (43%) when the diagnosis was made in the public setting, compared to private practice (32%). Clinicians often (73% always/frequently) referred to the Developmental Services/ASD Coordinator after a diagnosis was confirmed. These results indicate more work is needed to better support understanding of and access to this service.

“The ASD coordinator process was way too intense and overwhelming with information. It felt like we had pamphlets thrown at us that weren't even relevant to our area or to our son.”

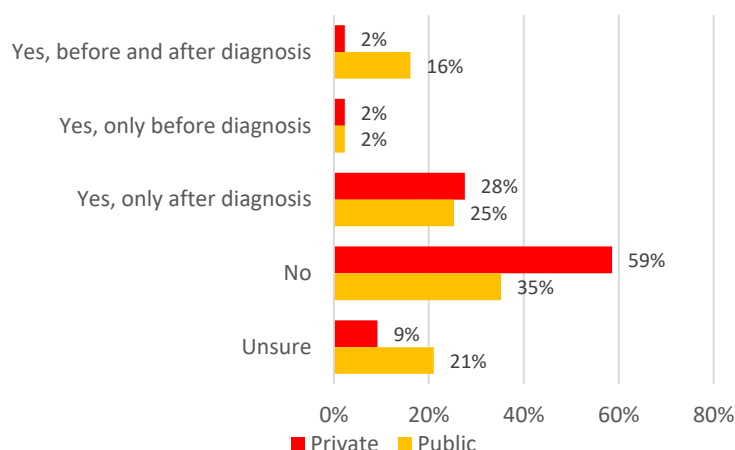
- Parent

Variable use of the service

The Developmental Services/ASD Coordinator* role was established to manage the referral process, to ensure assessment occurs in a timely manner, to support the family and whānau through the assessment process, and to coordinate post-diagnostic services.

The involvement of a Developmental Services/ ASD coordinator* appears to be variable, sometimes providing input before or after diagnosis (or both). Clinicians also indicated their involvement during the multidisciplinary assessment about one-third of the time (31%). This highlights flexibility, but also possible variation and ambiguity regarding their role.

Figure 30. Frequency of involvement of the Developmental Services/ASD Coordinator*



*While the Developmental Services and ASD Coordinators perform different roles, in some cases the roles are performed by the same person. To avoid confusion and ensure data on the ASD Coordinator was not missed, the terms were combined in the questionnaires.

Parents were more satisfied when Developmental Services/ASD Coordinators are involved

There was an 11% increase in satisfaction for both post-diagnostic supports and coordination of supports when Developmental Services/ASD Coordinators were involved when compared with all parents. This indicates potential for these types of services to improve satisfaction and improve service delivery, particularly with better uptake. However, qualitative comments also indicate they could be more effective and person-centred.

“Was given a lot of [information], but very overwhelming and not really sure what to do next. ASD coordinator was very helpful, but still not sure of exact path.”

- Parent

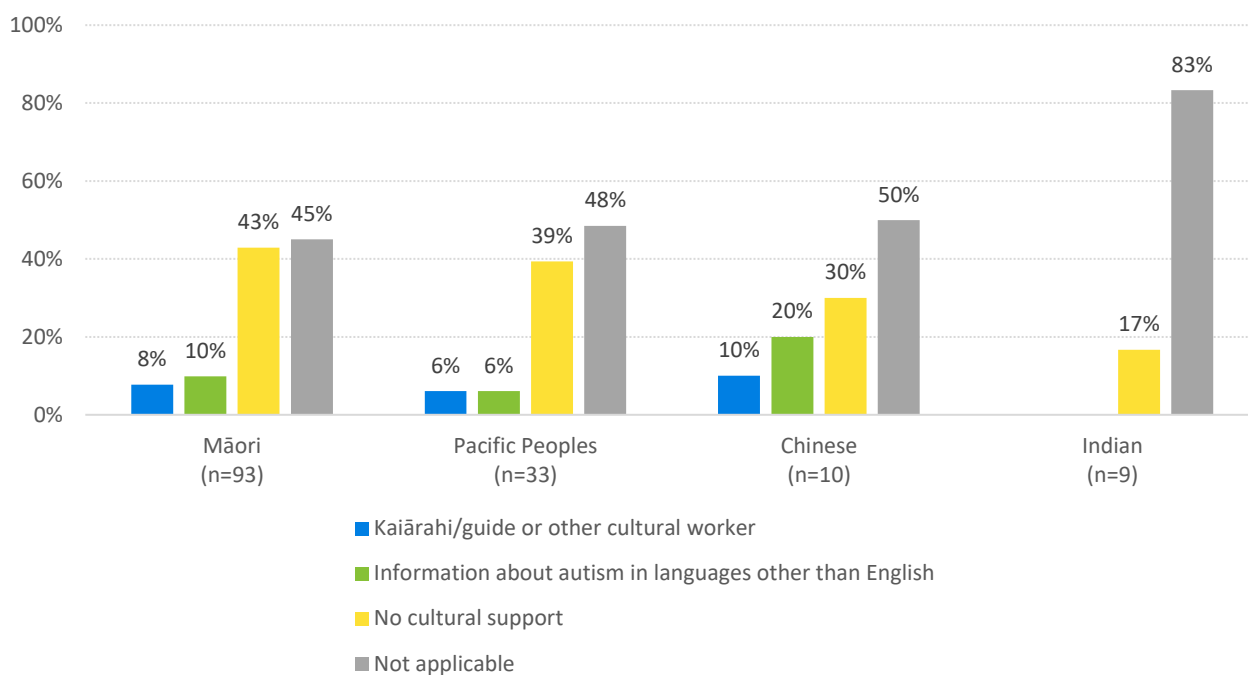
Not enough cultural supports

Poor satisfaction with cultural supports

For Māori and Pacific children, cultural supports were not required almost half the time. However, figure 31 shows that supports were frequently not provided to those that needed it. It is critical that supports adequately meet the obligations outlined in Te Tiriti o Waitangi, and it appears this is not currently the case. When cultural supports were provided, satisfaction was poor with only 26% of Māori and 35% of Pacific satisfied. For adult Māori, half indicated a need for cultural supports and in each case, none were provided. This indicates substantial unmet cultural needs for Māori and Pacific peoples, with a need for better access to, and experience of, cultural supports. Interestingly, some clinicians also recognised this gap and cultural competency training specific to autism was requested by a third of all clinicians. Fifty-nine percent said they already had access to this.

“The assessment process needs to be accessible for everyone and culturally and inclusive.” – Adult

Figure 31. Cultural supports provided for children or their parents



It is possible that the lack of cultural supports reported by parents of children diagnosed with autism and autistic adults is over represented for two key reasons that were not captured in the questionnaires: (a) cultural supports may have been offered but declined; or (b) the questionnaires did not allow respondents to record any other form of cultural supports than the two options listed. These two options were provided because they are recommended in the Guideline. It is also possible that clinicians may be aware of available cultural supports,

“I have now done three assessments where the child's first language is Te Reo and interesting our families are not routinely asked if they would like a Te Reo interpreter in the same way as speakers of other languages might be asked.” - Clinician

but these services are not being offered, leading to the lack of cultural supports reported by parents and adults. Thirty percent of clinicians indicated information about autism in languages other than English was available and 37% indicated a Kaiārahi/guide or other cultural worker was available.

Professionals appear sensitive to cultural needs

Importantly, there was more satisfaction regarding the professionals' sensitivity to cultural needs (see figure 32) despite nearly a third (29%) of clinicians indicating they were unsure of what cultural supports were available.

Dissatisfaction with post-diagnostic services and resources received

"They give you a diagnosis and then you are left to your own devices. There isn't really any support offers afterwards, everything we have found has been done by us alone."

- Parent

Variable access and need for supports and resources

For children and adults there were various services and resources they required, but did not receive access to, including:

- Counselling to adjust to the diagnosis (30% children and 27% adults).
- Needs assessment and service coordination [NASC] (39% adults).
- Support group (22% children).
- Autism education programme (18% children and 28% adults).
- Vocational support (37% adults).

"There is basically zero support after receiving the diagnosis and it can be a very challenging time." – Adult

These results suggest considerable unmet need for post-diagnostic supports and resources, which likely impact health and wellbeing outcomes. While most services and resources were deemed relevant for children, more adults indicated various services and resources were not relevant. These included:

- Multidisciplinary services (66%).
- Vocational support (56%).
- Ministry of Health disability allowance (52%) and NASC (50%).
- Autism education programmes (48%).

With the range of services so widespread, there is a need to totally reconsider what services and resources are needed and how these are provided. It is important to recognise that not all children and adults will require all supports and that these need to be individualised.

"I cried for three days. No one in our families understood. There was no immediate support for us following the diagnosis and we already had another son with severe intellectual impairment so we were devastated."

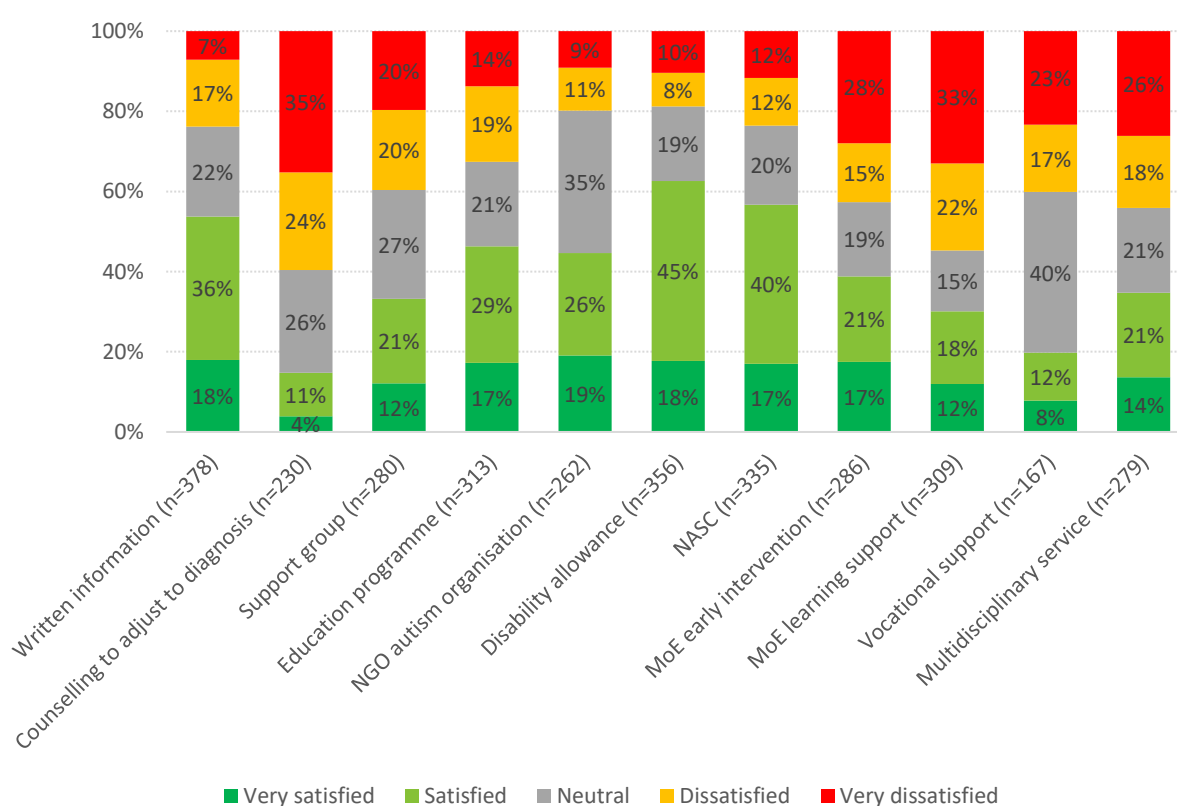
- Parent

Children and adults were dissatisfied across many services and resources

There was widespread dissatisfaction with post-diagnostic services and resources that both children and adults received access to (figures 33 and 34). Those with very high dissatisfaction ($\geq 40\%$) were:

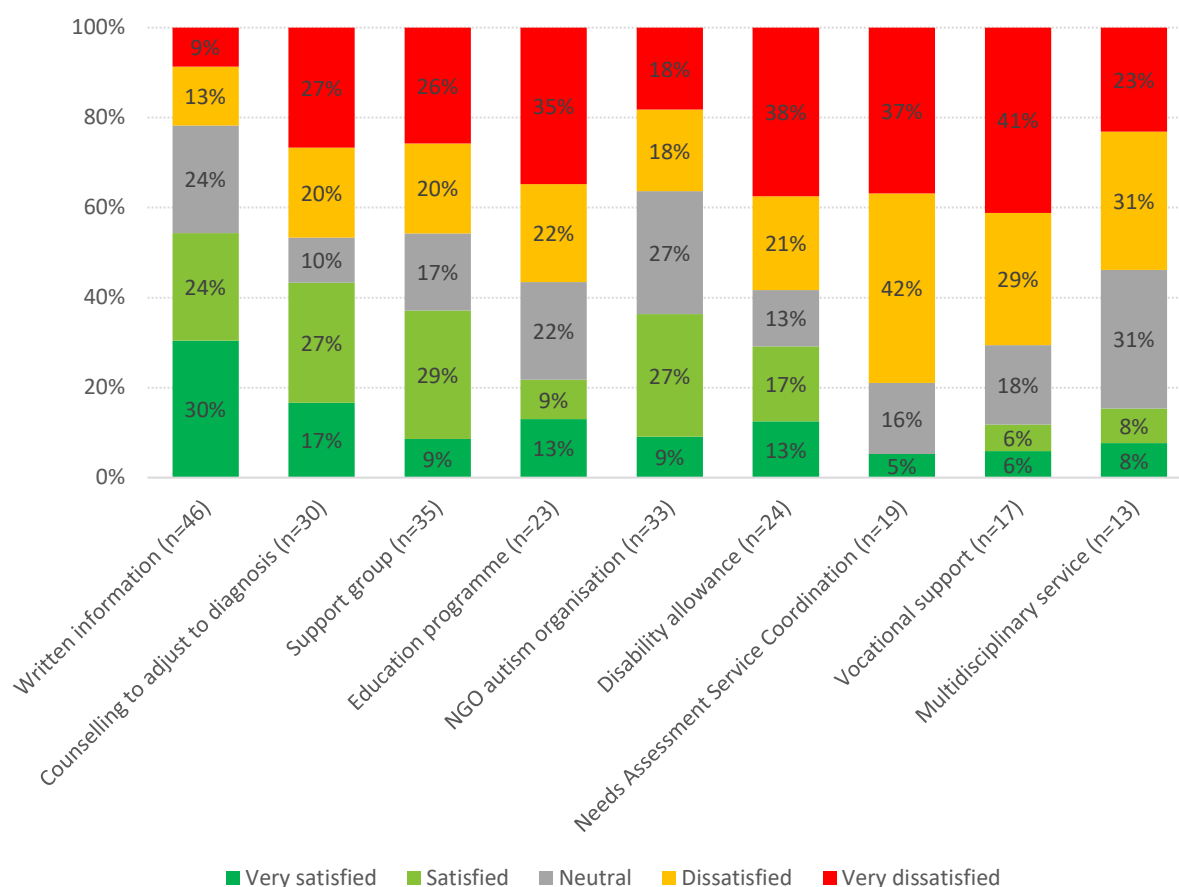
- Counselling to adjust to diagnosis (59% children and 47% adults).
- Support group (40% children and 46% adults).
- Education programme (57% adults).
- Ministry of Health disability allowance (59% adults) and NASC (79% adults).
- Ministry of Education early intervention (43% children) and learning support (55% children).
- Vocational support (40% children and 70% adults).
- Multidisciplinary service (44% children and 54% adults).

Figure 33. Satisfaction with post-diagnostic services and resources received for children



In contrast to results for adults, parents rated highest satisfaction with Ministry of Health disability allowance (63%) and NASC (57%) for their children. While adults were generally more dissatisfied, overall results are alarming. In fact, there were only a few instances where satisfaction exceeded 50%, with written information being the only element with a rating of 54% satisfaction for both children and adults. This shows needs across multiple areas are poorly met, with quality and experience well below expectation.

Figure 34. Satisfaction with post-diagnostic services and resources received for adults



Clinicians often recommended a range of services and resources

Clinicians commonly provided, recommended, or referred to written information about autism (82% always/frequently), NASC (76% always/frequently), NGO autism organisation (75% always/frequently), disability allowance (62% always/frequently), and support groups (62% always/frequently). However, in line with responses for children and by adults, clinicians were less likely to provide, recommend or refer individuals and family and whānau to vocational support (11% always/frequently) and counselling to adjust to the diagnosis (29% always/frequently). It is unclear from the survey if some of these services exist (e.g. vocational support), whether clinicians were aware of these services, or whether they knew about them but chose not to recommend them for other reasons. More work to explore this is recommended. In addition, clinicians from the public system appear to provide a wider range of post-diagnostic supports and recommendations, than those from private practice.

Low satisfaction with supports for specific autism characteristics

Consistent with earlier analysis of post-diagnostic satisfaction, there was very low satisfaction for both children and adults with most supports received for specific areas of functioning impacted by autism (see figure 35). Furthermore, results indicated a considerable number (approximately 15-25%) of children and adults did not receive access to supports for various specific areas of functioning impacted by autism. However,

"I didn't really understand the support I was given afterwards.... I wanted therapy, but they kept giving me people to take me shopping, but I've never really had too much trouble shopping."- Adult

across each area of functioning, supports were also more commonly (approximately 30-70%) deemed not relevant. This suggests significant systemic issues in the process to ensure that people are getting the right services, at the right time, and delivered in a person- and family- and whānau-centred manner that meets expectations. Although social interaction is a defining characteristic of autism, satisfaction with supports received in this area were low for both children and adults. The areas of greatest satisfaction across children and adults were with regards to medication.

Figure 35. Percentage of respondents satisfied or very satisfied with supports received for specific autism characteristics

Satisfaction with supports for specific autism characteristics	Children	Adults
Communication	34%	9%
Social	21%	17%
Behaviour	27%	12%
Eating and drinking	27%	N/A
Gut health	8%	18%
Bowel and bladder	25%	N/A
Physical movement	23%	8%
Sensory	28%	43%
Mental health	18%	46%
Sleep	32%	32%
Cognition	20%	8%
Medication	37%	47%

Clinicians do not frequently recommend or refer for supports for specific autism characteristics

Clinicians most commonly provided, recommended, or referred individuals, family and whānau supports with social interaction (42% frequently/always), sleep problems (41%), behaviour (41% frequently/always), and mental health (40% frequently/always).

Consistent with child and adult responses, most clinicians never/occasionally provided, recommended or referred for support with gut health (86%) and physical movement (74%). While such supports are not always relevant, this suggests opportunities for clinicians to improve individualised information, identification, recommendation, and referrals when services are needed to ensure a more holistic view of wellbeing for individuals on the autism spectrum.

“We just had ‘symptoms’ treated, like anxiety, sleeplessness. Not related to autism at all. She was sent to the public anxiety disorder programme which was a total disaster (they didn’t know how to work with autistic people - she had non-stop panic attacks).” - Parent

Section 5 - Recommendations and conclusion

Recommendations

Overall, the findings from this project suggest that while there are many clinicians who are doing their best to provide best-practice diagnosis, they are not guided by enough systems leadership, funding or resources to effectively support what they need to achieve. As a result, both public and private diagnostic assessments are performed differently, with the public system following the Guideline more closely. Across both public and private settings, people had varied experiences, but the pathway to pursue a diagnosis was unclear, the diagnostic process was perceived as a stressful experience, and satisfaction with post-diagnostic supports was low.

Children were typically diagnosed in the public system, which was characterised by delays and poor experience, particularly with the initial help received. Conversely, adults were usually diagnosed in private practice which was less likely to take a comprehensive and multi-disciplinary approach (recommended by the Guideline) and incurred cost. Despite this, private pathways made a diagnosis of autism more quickly with significantly higher levels of satisfaction. While this work has shed light how the diagnostic process differs, and has identified unmet need and poor experience, it points to the need for more leadership, work, funding and resources to understand and improve the most important elements of an optimal pathway to diagnosis in New Zealand's context. This is likely to include factors such as: access and cost; best-practice; accuracy; responsiveness/speed; cultural needs; and experience. Furthermore, results from this project indicated provision and satisfaction with post-diagnostic supports is particularly poor. Extensive work is needed to improve clarity of the diagnostic pathway and coordination of post-diagnostic supports. Autism New Zealand will actively work with the Government and other key stakeholders to ensure recommendations from this project are implemented.

Considerations for autism within the wider system

There is a pressing need to develop a long-term approach for autism in New Zealand that focuses on continuous improvement through:

1. Formation of an inter-ministry, inter-disciplinary, cross-sector, and consumer-oriented national steering committee who can lead New Zealand's strategic and long-term approach to autism using a hub and spoke model. This could be usefully supplemented by local stakeholder groups.

Formation of an inter-ministry, inter-disciplinary, cross-sector, and consumer-oriented group that is united by a desire to make system-wide improvements for autism within New Zealand. This will include identifying and bringing together the key stakeholders to form a steering committee that can take responsibility to lead New Zealand's strategic and long-term approach to autism. This could be supported by local stakeholder groups to ensure access and consistency in implementation of recommendations across regions.

An initial objective could be to collaboratively identify key priorities, which if implemented will most improve outcomes for people within the autism sector. The national group could take

responsibility for planning and co-ordinating implementation activities, including a more formal process for promoting uptake of the Guideline, as well as considering the recommendations arising from findings from this project.

There are system-level improvements that could make a big difference for the outcomes and experience of people on the autism spectrum and their families and whānau. Some of these would incur minimal cost. Others may require further investment. There are opportunities to review factors such as the current entire diagnostic process (which includes entry into the process) and determine whether there is adequate capacity and capability within the system to enable accurate diagnoses are provided as quickly as possible, and that the process is collaborative and informed by consumer experience.

While the Guideline outlines how the ASD Coordinator role includes data collection to improve efficiency of service provision and service gaps, results from this project indicate considerable further work is still needed to support this goal across both the public system and private practice. Data from this report could be used as a baseline and assist in monitoring progress over time.

Identification and initial help

To support timely identification of autism and clarity in the diagnostic pathway, we propose:

2. Increasing public awareness of autism, including early signs of autism.
3. Providing continually available and up-to-date evidence-informed training for primary health clinicians and education professionals on the early signs of autism to enable earlier identification.
4. Developing and promoting clear and explicit national autism diagnostic pathways for children and adults within the public system.

While the Guideline recommends comprehensive developmental surveillance for all children and that health and education professionals should have training on 'alerting signals' of possible autism, this is clearly not happening. There is a need for increasing greater public awareness of early signs of autism, including training for clinicians and others who regularly work with children (i.e., Well Child/Tamariki Ora staff, General Practitioners, Nurses, Paediatricians, Psychologists, and Early Childhood/School Staff). Early childhood autism surveillance and assessment tools allow for accurate early identification of autism by parents, family and whānau (e.g., ASDetect - <http://asdetect.org/>) and clinicians (e.g., the Social Attention and Communication Scale [SACS]) [19]. There is a need to evaluate whether such tools are appropriate and effective within the New Zealand context, or whether there are different approaches that might be better used.

While the Guideline recommends District Health Boards have referral pathways for children and adults that are clearly understood by clinicians, work is needed to further develop clear and explicit national/local referral pathways. These should outline the autism diagnostic pathway and referral routes. They should provide guidance on how to recognise autism at different ages, how to refer, including what information is needed for a referral, and what to expect after referral.

The Guideline also suggests a pathway for the identification and assessment process for adults. This has not been implemented and as a result, adults are clearly underserved through the public system. There is an immediate need for development, implementation and clarity of a diagnostic pathway for adults in the public system. Autistic adults, clinicians involved in the diagnostic process, and other key stakeholders need to be involved in co-design of this diagnostic pathway to ensure that it meets both individual needs and best practice recommendations. This may require additional resourcing.

Primary health clinicians, education professionals, and organisations (e.g. NGO autism organisations) involved in the initial points of contact when an autism diagnosis is suspected should provide clear, consistent, and accurate information about the diagnostic pathway in order to improve clarity. Given adults' higher use of online information seeking, helpful and accurate online information that is specific to New Zealand needs to be readily available.

The diagnostic process

To support timeliness, consistency and accuracy in autism diagnosis, we propose:

5. Updating the Guideline to revise and add recommendations, including further guidance to determine when a full multidisciplinary team assessment is required or whether an abbreviated assessment with 1-2 clinicians is sufficient.
6. System-level implementation of existing Guideline recommendations, including exploring establishment of specialist autism services and a network of tertiary centres to support complex diagnoses.
7. Promoting understanding and consistent clinical uptake of the Guideline recommendations.
8. Providing continually available and up-to-date evidence-informed specialist autism training for clinicians involved in the diagnosis of children and adults.

Although the Guideline recommends a comprehensive multidisciplinary diagnostic assessment that is provided in a timely manner, extensive wait times and variability in multidisciplinary approaches within the public system indicate this is not being achieved. Furthermore, diagnosis in private practice typically involves a brief single clinician approach. We propose consideration of an update to the Guideline in which further recommendations outline a consistent triage process to determine whether an abbreviated assessment with 1-2 clinicians may be sufficient for people with "clear-cut" autism, reserving more comprehensive team assessments for those with more subtle or complex presentations. Assessment regarding needed multi-disciplinary supports could potentially occur after diagnosis in these cases. Implementation of early childhood autism surveillance and assessment tools will also allow for accurate pre-referral information to support this process. This has been proven to increase consistency and timeliness of diagnosis [20].

In cases when a dedicated multidisciplinary team is necessary, more work can be done to support implementation of efficient multidisciplinary team processes which review children at the same appointment and reach a consensus decision, as indicated in the Guideline. Research may be helpful to determine the processes that contribute to this delay. Resourcing may well be an issue. While the Guideline discusses development of specialist autism services and a network of tertiary centres where a tertiary level assessment can be undertaken when diagnosis is complex, these services and centres have not been established. Given the ongoing variability in diagnosis when clinical features are atypical or complex, further exploration of the development and implementation these specialist services is needed to support assessment when local teams are unable to make a diagnosis.

Given parents and adults indicated they want timely diagnosis, that involves fewer clinicians who take a consultative and strengths-based approach, work is needed to develop and implement Guideline recommendations that provide an individual and family and whānau centred process through supportive and compassionate practice. This approach to co-designing services has already occurred with parents of children with disabilities through the 'A Good Start' project [21], which should continue to be promoted and integrated into the autism diagnostic process for children.

Finally, more work is needed to promote understanding of and adherence to the Guideline recommendations, particularly in private practice. This will help ensure consistency of the diagnostic process between public and private practice. It could be the role of the national steering committee to conduct regular reviews of implementation of the Guideline. Furthermore, in order to support clinical competency, it is evident that more specialist autism training for clinicians is needed in the following areas: diagnostic assessment tools, complex presentation and subtleties of differential diagnosis, diagnosis in very young children (<2 years), diagnosis of adults and females, and cultural competency specific to autism. As a result of findings from this research, Autism New Zealand has started hosting ADOS training for which the Ministry of Health has allocated some funding to sponsor clinicians to attend.

Supports during and after diagnosis

To support access, coordination, and satisfaction with post-diagnostic supports, we propose:

9. Development of a formal pathway for supports that is person-centred, strengths-based, and collaborative. This should include earlier provision of supports informed by a comprehensive needs assessment.
10. Analysis of how to improve understanding of and access to the Developmental Services/ASD Coordinator, including consideration for extension of this service to adults.
11. Providing continually available and up-to-date evidence-informed professional development and training for clinicians on effective supports for individuals on the autism spectrum.
12. Ensuring timely access to effective early intervention.
13. Improved access to support services where there is a high unmet need.

The Guideline indicates there is a need to investigate formal pathways for post-diagnostic supports for newly diagnosed people on the autism spectrum, an action supported by the findings of the current project. Across all supports and services much work needs to be done. There is plenty of room to make substantial improvements, but it suggests that a very different approach from the status quo is required to understand and meet the diverse needs of people on the autism spectrum and their family and whānau.

With the wide range of services, resources and needs, there are many different stakeholders. A person-centred, strengths-based, and collaborative approach is likely to result in the most helpful and meaningful progress. It is this support and intervention that assists people on the autism spectrum to reach their full potential and participate in society. As such, consideration regarding provision of support earlier in the diagnostic process should be explored. This should start with a comprehensive needs assessment to inform timely access to supports. Research in Australia led to the development of their national guideline for the assessment and diagnosis of autism, in which a comprehensive needs assessment is at the forefront of the diagnostic process [22].

In-depth analysis of the Developmental Services/ASD Coordinator role to better understand what they do and how they can best support children diagnosed with autism would be valuable. National consistency may be important. This includes work to increase funding and resources for the Developmental Services/ASD coordinators to ensure access by all people diagnosed with autism. Work is therefore also needed to explore extension of the ASD Coordinator role to adults diagnosed with autism.

Key to improving post-diagnostic supports is investment in quality assurance processes, such as continual professional development and training, as well as translation of research and the Guideline and its updates into clinical practice. Given clinicians indicated a need for training in cultural competency specific to autism, and parents and adults also identified service gaps, this

should be a priority. Although the Guideline provides recommendations to support culturally appropriate services for Māori and Pacific peoples, results from this project suggest more time and work are necessary to better understand cultural needs and how to best provide appropriate supports. This might focus on evaluating who initiates and provides cultural supports, when it is provided, and what this specifically involves. Given Crown obligations to Te Tiriti o Waitangi and with strategic objectives of improving equity, these supports and services should be adequately funded in the future.

Given the exponential impact of early intervention on long-term developmental outcomes for children on the autism spectrum, and in order to reduce delays, early identification of possible autism needs to be directly linked to both a diagnostic referral and immediate access to relevant supports and early intervention. While the Ministry of Education early intervention service does not require a diagnosis, there are lengthy wait lists [23]. More work is therefore needed to ensure timely early intervention is provided. Research investigating low cost parent-led early intervention is needed to determine a model appropriate to the culturally diverse context of New Zealand that will support optimal outcomes for the child and their family and whānau. The model could take a response to intervention approach, in which intensity of intervention and supports are increased if considerable progress is not made with the first low-cost intervention.

Several other areas of post-diagnostic supports warrant improvement. This includes more widespread immediate provision of quality counselling to adjust to the diagnosis. Outcomes from this research indicate this is especially important for parents of children newly diagnosed with autism. For young people and adults, more work is needed to provide high quality vocational support. As an example, DXC Technology and Autism New Zealand have identified this need and are working to develop an Enterprise Centre to help people on the autism spectrum gain high-skilled jobs in industries such as hospitality, accounting, agriculture and IT [24].

Conclusion

The challenge is to achieve high-quality diagnosis and post-diagnostic supports that is accessible, evidence-based, timely, culturally appropriate, and person-centred, spanning the health and disability, education, and social systems. It is not enough to simply recommend that people become more aware of autism or that services become more available as these types of recommendations by themselves will not lead to action. Each participant within the system can easily point to a wide range of shortcomings, and there is little incentive for any group to take responsibility for the many elements that are outside their control. In order to make improvements in the diagnosis and supports for people on the autism spectrum within New Zealand, no single ministry, service or organisation can do it alone. While gains can be made, they will be slow and less effective without the critical support of the Government. Some improvements may be possible without additional funding and resources, although this will not be the case for others. The key recommendation, or call to action, is that a collaborative, inter-ministry, inter-agency, and consumer-oriented approach is required to provide clear leadership and direction for those willing and able people who want to improve the lives of people on the autism spectrum and their families and whānau.

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Appendix 1

New Zealand Autism Spectrum Disorder Guideline key recommendations

Table 1. New Zealand Autism Spectrum Disorder Guideline key recommendations (replicated with permission):

Number*	Key recommendations for diagnosis and initial assessment:	Grade**
1	Early identification of children with autism is essential. Early identification enables early intervention and is likely to lead to better function in later life. Early identification is achieved by: <ul style="list-style-type: none"> a. Comprehensive developmental surveillance of all children so that deviations from normal development are recognised early b. Valuing and addressing parental concerns about their child's development c. Prompt access to diagnostic services 	B
2	All DHBs should have in place processes that ensure: <ul style="list-style-type: none"> a. Referral pathways for children and adults who may have autism are clearly understood by clinicians b. Services are coordinated within and across sectors c. Multidisciplinary, multiagency assessments are provided d. All services are provided in a timely manner 	C
3	All children suspected of having autism or another developmental delay should have an audiology assessment	✓
4	Preferably, a multidisciplinary team of health care practitioners experienced in ASD should undertake diagnostic assessment of young people and adults suspected of having ASD. In the absence of an assessment team, a health care practitioner trained and highly experienced in ASD may undertake diagnostic assessment	B
5	Diagnostic assessment of young people and adults should be comprehensive and involve the person concerned in interview and observation.	C
5.1	Standardised ASD assessment interviews and schedules should be used. The intellectual, adaptive, and cognitive skills associated with ASD should be seriously considered and, where possible and appropriate, formally assessed	B
6	Health care practitioners must have a good understanding of the different forms of expression of autism symptomatology across developmental stages and the symptomatology of common coexisting and alternative diagnoses	B
	Key recommendations for formulation, disclosure of diagnosis and post-diagnosis support	
1.4.4	All diagnostic assessments should include a detailed written report covering the person's strengths and weaknesses, developmental course, ASD symptoms, recommendations for intervention and information on support networks	C
1.4.6	Information on ASD and support services should be available at all diagnostic disclosure interviews and through health and disability services	B
1.4.7	Sources of post-diagnostic support should be identified for the person with ASD	C

	Key recommendations for support	
2	ASD-related counselling and/or advocacy services and education should be available to all family members and carers	C
12	A coordinated approach to planning and implementing services should be developed to meet the identified needs of an individual with autism, including linkage or integration and coordination of multiple services	✓
	Key recommendations for Māori perspectives	✓
1	Information packages in appropriate and relevant language about ASD using a range of media should be developed. This information could be distributed through Māori, mainstream and community providers of health, education and disability services.	✓
2	The appointment of a kaiarahi (guide) who would work in conjunction with, and be supported across, the health, education and disabilities sectors involved with ASD should be considered.	✓

*Refers to the recommendation number given in The Guideline

**Grades A (good evidence), B (fair evidence), C (expert opinion), ✓ (good practice point)

Appendix 2

Research Method

Participants

Children and adults

To participate in the research, parents of children diagnosed with autism and adults diagnosed with autism needed to have participated in the autism diagnostic process in New Zealand within the past 10 years. Recruitment took a two-pronged approach: First, members of the Autism New Zealand database were emailed and invited to participate in the research. Specifically, 7,396 members were emailed of which 3,438 opened the email with 725 unique click throughs giving a unique click through rate of 7.24%. Second, an invitation to participate in the research was also sent to various autism social media groups, including Autism NZ's Facebook page, which has approximately 13,000 followers.

A total of 502 parents of children diagnosed with autism responded to the questionnaire. Forty-four of these respondents did not move beyond the first question and were therefore excluded from data analysis, leaving a sample of 458. A total of 76 adults diagnosed with autism responded to the questionnaire. Six of these respondents did not move beyond the first question and were therefore excluded from data analysis, leaving a final sample of 70.

Clinicians

Clinicians currently involved in the autism diagnostic process in New Zealand were eligible to participate in the research. Recruitment took a multifaceted approach: (1) the Child Development Service, Paediatrics, Child and Adolescent Mental Health (CAMHS), and Mental Health departments within all 20 District Health Boards (DHB) across New Zealand were emailed and invited to participate in the research, (2) private practices known to diagnose autism with contact details publicly listed were emailed and invited to participate in the research, (3) relevant member bodies and professional organisations, including the Paediatric Society of New Zealand, New Zealand Psychological Society, and College of Clinical Psychologists, distributed information about the questionnaire via mailing lists and newsletters, and (4) the researchers used individual networks to distribute the questionnaire to colleagues.

A total of 117 clinicians responded to the questionnaire. Five of these respondents indicated that they were not currently involved in autism diagnosis and were therefore excluded from data analysis, leaving a sample of 112.

Procedure

In order to reflect the diversity of experiences related to autism the diagnostic process in New Zealand, three questionnaires were developed to allow for responses from all key stakeholders. This included a questionnaire for: (1) parents of children diagnosed with autism, (2) adults diagnosed with autism, and (3) clinicians involved in the diagnosis of autism in both public and private sectors. Ethical approval was granted by the New Zealand Ethics Committee (Reference number 2018_28). Informed consent was obtained via completion of the anonymous online questionnaires hosted by SurveyMonkey® for a one-month period (August 2019). All questions were optional, participants did not have to respond to questions they did not feel comfortable answering. This resulted in different numbers of responses for different questions.

Materials

Child and adult questionnaires

The 32-item parent and adult questionnaires (available from Autism New Zealand upon request) were based on previous surveys administered in England [16] and New Zealand [5], along with suggestions from clinicians who attended three workshops across New Zealand during the planning phase. The questionnaires were revised several times based on feedback from 8 people, including autistic adults, parents of children on the autism spectrum, clinicians, and researchers. The resulting SurveyMonkey® questionnaire was also piloted by two parents of children on the autism spectrum and revised based on feedback prior to being administered. The questionnaire contained questions that fell into four categories: (1) demographic information, (2) first queries and help sought, (3) autism spectrum disorder diagnosis, and (4) post-diagnostic supports. Questions were presented in a categorical format (Yes/No), or on a five-point Likert scale (e.g. where 1 = Very Dissatisfied and 5 = Very Satisfied). Some questions, for example the cost of diagnostic assessments, required numerical responses and other questions allowed for multiple descriptive responses. Some questions had space for optional qualitative comments.

Clinician questionnaire

The 29-item questionnaire (available from Autism New Zealand upon request) was based on previous surveys administered in Australia [4] and New Zealand [25], along with suggestions from clinicians who attended three workshops across New Zealand during the planning phase. The questionnaire was revised several times based on feedback from 17 researchers and clinicians. The resulting questionnaire was also piloted by one clinician and revised based on feedback prior to being administered. The questionnaire contained questions that fell into five categories: (1) diagnostic services, (2) implementation of the Guideline, (3) the diagnostic process, (4) post-diagnostic support, and (5) training and cultural issues. Questions were presented in a categorical format (Yes/No), or on a five-point Likert scale (e.g. where 1 = Never and 5 = Always). Some questions, for example the cost of diagnostic assessments, required numerical responses and other questions allowed for multiple descriptive responses. Some questions had space for optional qualitative comments.

Data analysis

Data were analysed based on the number of responses recorded for each question. Furthermore, some questions allowed for multiple response options to be selected. In these cases, percentages were calculated out of the number of people who responded to the question rather than the total number of responses for that question. In these cases, totals may equal more than 100%. Statistical analysis was performed using the Microsoft Excel® software platform to attain descriptive statistics, such as frequency (count and/or percentage), mean and standard deviation. The R integrated suite of software facilities was used to explore if responses to questions were associated with each other, using Spearman's correlation, chi-squared test, one-way analysis of variance (ANOVA) and Fisher's exact test of independence. Only significant associations are reported.

Thematic analysis of qualitative responses occurred through an iterative process [26]. Text was initially coded in NVivo software by two researchers according to set codes, such as stakeholder type, question topic, diagnostic phase and if the experience was positive or negative. During this process, each researcher compiled a set of key concepts that had emerged from the data and these concepts were discussed. A new set of codes were developed based on this discussion, and the full dataset was then coded to these new codes. Repeated review of these codes led to the formation of themes and sub-themes, which were refined throughout the analysis process. Two additional members of the research team were consulted to discuss and confirm the findings. Key quotes and themes were selected by the research team to best reflect the sub-sections of the report.

Appendix 3

Limitations

Interpretation of results presented in this research should occur with consideration of several limitations. Although typical for online questionnaires, the response rate is estimated to be low and in the vicinity of 7% for the child and adult questionnaire given it was emailed to approximately 7,000 Autism New Zealand members. Furthermore, all three questionnaires (child, adult, and clinician) were distributed through various avenues preventing an accurate calculation of response rate. However, given the sample size of the current questionnaires and population in New Zealand, the participation rate may be proportionally higher than similar international research [4, 16, 17]. Despite this, respondents are unlikely to be representative of all New Zealand parents of children on the autism spectrum, autistic adults or clinicians involved in the autism diagnostic process. For example, parents and adults might have been more likely to participate if they had experienced a particularly positive or negative diagnostic process. Likewise, clinicians might have been more likely to participate if they were particularly positive or negative about the autism diagnostic process in New Zealand.

Furthermore, online questionnaires can be subject to selection bias against those with limited internet access, lower literacy and cultural or linguistic diversity. For this reason, the online questionnaire was made accessible through hardcopy and interview. However, given that the questionnaire was hosted and completed online, the study sample may not include many individuals who do not have relatively easy access to internet.

Eligibility could not be confirmed given the questionnaires were online and anonymous. Although approximately 70% of diagnoses were made within the last five years for children and adults and clinicians had to be currently involved in the diagnosis of autism, responses may be subject to recall bias. As a result, systematic errors, inaccurate recall of experiences, or details may have been omitted. The sample size for smaller subgroups may have affected the ability to detect significant relationships. Finally, causal relationships between the key aspects assessed in the study cannot be determined given the correlational design of the study.

Appendix B –The Autism Diagnostic Process in New Zealand: A Cross-sectional Survey of Satisfaction amongst Autistic Adults

Evans, K., van der Meer, L., Eggleston, M.J.F., Taylor, L., Thabrew, H., Waddington, H. & Whitehouse, A.J.O. (2022). A Survey of Autistic Adults from New Zealand on the Autism Diagnostic Process During Adolescence and Adulthood. *J Autism Dev Disord* 52, 771–781. <https://doi.org/10.1007/s10803-021-04983-0>

Link to the publication

<https://link.springer.com/article/10.1007/s10803-021-04983-0>

Appendix C – Strategies for Improving Satisfaction with the Autism Diagnostic Process in New Zealand – An Autistic Adult Perspective

Authors

Kiah Evans, Larah van der Meer, Sasha Johnston, Maryam Boutrus, Matthew J. F. Eggleston, Hiran Thabrew, Hannah Waddington and Andrew J.O. Whitehouse

Aim

This survey aimed to explore strategies to improve satisfaction with the autism diagnostic process from the perspectives of autistic adults.

Method

Fifty-eight autistic adults who had received their autism diagnosis in New Zealand in the previous decade provided open-ended responses through an online survey about their experiences of the autism diagnostic process. Questions focussed on what is working well with the process, how the process can be improved and targeted questions about each stage. Qualitative data were analysed using a template approach by three researchers.

Results

Qualitative analysis revealed eight themes in relation to suggestions to improve satisfaction with the autism diagnostic process in New Zealand. The three themes associated with the identification stage were 'be aware of the signs of autism', 'a much clearer and more streamlined path to diagnosis' and 'easier access and cost less'. The three themes associated with the diagnostic assessment stage were 'health professionals who are experienced and aware of the complexities of autism', 'clearer guidelines for the assessment of adults' and 'be neurodiversity friendly'. Finally, the two themes associated with the post-diagnostic support stage were 'more support needs to be offered post-diagnosis' and 'wrap around support is vital'.

Be Aware of the Signs of Autism

Although one adult had a GP who "was supportive of [their] ideas to request a diagnosis", other adults "felt like [they were] not taken seriously", perceived that health professionals had a "lack of interest or understanding of autistic adults, especially autistics who are not male" and found it "upsetting to see others 'fly under the radar' or 'slip through the cracks' because they had been ... taught to appear as normal as possible." One adult explained the repercussions as: "The health professional didn't recognise that many of the problems I was experiencing was strongly related to

autism. So they mis-diagnosed me for many years.” Adults encouraged professionals to “listen to what people say” and “be better informed”, with a focus on raising “awareness of ‘internalised phenotypes’ (such as masking and compensating behaviours)”. The essence of this theme was captured with:

“People should not have to diagnose themselves in middle age. Parents, early childcare workers, and teachers need to be aware of the signs of autism. GPs and mental health professionals who seem to assume autism is a paediatric diagnosis need to be aware that it wasn't for my generation.”

A Much Clearer and More Streamlined Path to Diagnosis

Some adults had experienced “a clear path” at the beginning of their diagnostic journey, through referrals from health professionals, autism organisations or acquaintances working within related fields. Other adults experienced “a lack of options” in some areas, false starts upon referral to “someone who couldn’t diagnose me”, “a system that is generally hard to navigate”, and the absence of “formal pathways in place, in fact the only way to pursue a diagnosis was through assessment for other conditions.” One adult stated “I basically only got my diagnosis by luck” and another adult explained that success “depends on whether you have the ability/opportunity to investigate these sorts of things, as it’s certainly not advertised” and some GPs were “ignorant of the process or who was best qualified for adult diagnosis”. Adults advocated for government to “make a much clearer and more streamlined path to diagnosis” and to provide “a free ... support service ... that guides people through the process (from pre-diagnosis to post-diagnosis)”, where “this first point of contact [is] easily available online for those who hate telephones”. Adults also wanted “more options”, “more information about where to find experienced professionals for adult diagnosis” and “directions of where to go and what happens.”

Easier to Access and Lower Cost

One adult stated “it is a very good system so far, there are just a few minor flaws in the public system”, whilst a number of adults reported an initial process that was “quick and easy” because they had “found the money to go privately”. However, they acknowledged that “getting a diagnosis in New Zealand is still hard as not everyone can afford private diagnosis”. Along with “cost [as] a barrier”, adults described “the years of waiting”, requirements for their “situation to become ‘severe’ enough to receive access to a diagnostic pathway” and “people who were either too busy or did not want to see me”. This led some adults to lose hope, as illustrated with “I wasn’t even sure I would be able to get a diagnosis” and the concern that these barriers may lead some to “languish in self-

diagnosis, which is unfair”. Adults hoped for a future where a “fully funded diagnosis by expert professionals” was “easier to access and cost less”, “accessible to everyone” (including “all ages and genders”), “culturally inclusive” and involve “realistic waiting lists”.

Health Professionals who are Experienced and Aware of the Complexities of Autism

Some adults described health professionals they had consulted for their diagnostic assessment were “smart and informed”, had “a great breadth and depth of knowledge”, “deeply understood autism and its wide variations” and were “able to see through my extreme masking”. Other adults “didn’t have confidence” in their health professionals or felt that they were “poorly informed of, and prejudiced against, ASD”. A specific gap in health professional knowledge was “limited understanding of women of my age getting a diagnosis”. Adults explained that there “needs to be many more [health professionals] who are experienced and aware of the complexities of ASD, including the differences between girls/women and boys/men”, and that that “it would be good to have more autistic assessors” and a “common knowledge repository for all [health] professionals with up to date research which covers the spectrum for all genders, children and adults”. One participant explained:

“ASD is a very complex condition that manifests in all kinds of different ways in different individuals. It is all too easy to miss the symptoms of ASD if one is too narrow in one's thinking; and/or if one doesn't have the ability to pay attention to detail; and/or if one doesn't have the inordinate depth of knowledge that is required to make a diagnosis.”

Clearer Guidelines for the Assessment of Adults

Several adults described elements of the diagnostic assessment that “helped a LOT”, including health professionals that “let me do most of the talking” and “being able to fill out paperwork [and] details about [my] current life and childhood in my own home”. In contrast, challenging aspects of the diagnostic assessment location included travel to a capital city, having to “go somewhere new”, being “anxious about getting there” and distressing physical environments (especially “LED lights and fluorescent lights”). Challenging aspects of the diagnostic assessment tasks were activities perceived as “pathetic” for adults, “a mountain of ... forms to complete”, “long and difficult” interviews (where it was “hard to remember relevant events from my childhood”) and a heavy reliance on “tests, rather than the evidence my symptoms presented”. Other adults complained that a “non-diagnosis was made after a 10-minute conversation and was completely based on visual

observations” or that their diagnostic assessment “could have been more comprehensive”. Adults felt that there was a need to “have clearer guidelines for the assessment of adults”. They made practical suggestions to inform these guidelines, such as a location that requires “minimal transport” and “a pleasant sensory environment”, along with a process that includes “assessment tools that cater specifically for different groups” and “allows frequent breaks during in-person assessments”. Along with assessing if the adult meets the diagnostic criteria for autism, they felt these guidelines should require the assessment (and if appropriate, diagnosis) of “other common co-diagnoses” and a “functional assessment”.

Be Neurodiversity Friendly

Some adults felt the “diagnostic process was not stressful” and “the atmosphere was supportive”, with this facilitated by health professionals being “understanding”, “kind” or “helpful”, along with using a “straight-forward” approach, “talking me through each step” and “tak[ing] our time”. Other adults “did not enjoy the attitude” of the health professionals involved in their diagnostic assessment, particularly if they had not been “informed of the evaluation taking place” or if the assessor was perceived to be “insensitive and unprofessional”. Another adult felt the deficit focus during their diagnostic assessment was inappropriate, stating “I am NOT BROKEN and don’t need to be fixed”. Adults highlighted the importance of “transparency around diagnosis and removal of stigma”, including the provision of “autistic-positive information” during the diagnostic assessment. One adult explained “I feel things may have been better if my diagnosis hadn’t been viewed as a deficit, or suggestion that something was wrong with me... Had I received neurodiversity-friendly information, I may have felt less ‘broken and self-loathing”.

More Support Needs to be Offered Post-diagnosis

One adult was satisfied that their autism diagnosis “helped me access services that were more relevant for my needs”, whilst others stated “I had supports already in place which I continued” or “I chose not to pursue any supports – for me the diagnosis was the end goal”. Other adults varied from “[my] only support is from [my] GP, who is fantastic, yet limited in ability to provide diverse support” through to reports that required supports are not available “within my region that I can find” or “the supports are non-existent”. Some post-diagnostic supports offered were not appropriate, due to incompatibility with needs (illustrated with “I wanted therapy, but they kept giving me people to take me shopping”) and other members of group-based programs (for example, due to age difference or distressing psychiatric symptoms). Inaccurate and unofficial diagnostic labels were also a barrier to post-diagnostic support, as illustrated with “reduction of [these labels] may allow ‘high’ functioning autistics to receive much-needed support and ‘low’

functioning autistics to access inclusive and positive environments”. The “lack of support” led one adult to feel like they had been “thrown back into the ocean. [It] was very depressing” and another adult to say “I’m only finding supports now ... but now the damage has been done”. Adults stated “more support needs to be offered post-diagnosis”, and expressed a desire to “be told the supports we can have” and for there to be “better reach of service provision and referral”. Adults indicated that the following types of support were required post-diagnosis:

- Education and resources from autism organizations (e.g. Autism New Zealand were “helpful in providing information” and “online information about services” was useful. One adult stated “I also wish I had received information around sexuality and gender-nonconformity”, whilst another wanted “more information and more support services for employers and employees”. Another valuable topic for education was “learning that it is OK to appear visibly autistic, learning that it is OK to seek accommodations and to regulate my environment, that it is OK to pursue my special interests — these have allowed me to experience many fewer issues”.
- Practical help through disability allowances provided “financial support” for some adults and medication was reported to alleviate symptoms and impacts of co-occurring conditions. One adult stated their “support was from my workplace”, whereas another described that accommodations at university (such as “small group supervision” and “headphones”) have led to them “thriving”. Further suggestions for practical supports include services to address insomnia and “access to alternative methods of communication, such as AAC, letter-boards, typing, and sign-language”.
- Social connection was beneficial, such as receiving “peer support”, access to “communities of like-minded individuals” and a “caring community of autistics, capable of embracing neurodiversity, disability, and intersectionality”. One adult suggested the “immediate referral to support groups” after an autism diagnosis.
- Finally, individualized assistance to create meaning and optimize participation was also considered helpful, with numerous adults suggesting “regular” and “ongoing access to psychologists should be available for free to autistics”, particularly those “who specialize in autism” as it “helped tremendously [if they] had knowledge of ASD”. Along with psychologists, other health professionals were seen to have a potential role in providing this assistance, such as “life coaches who specialize in ASD issues” because they believed autistic adults would “respond better to coaches than counsellors... and would likely be more receptive to being guided ... by a coach who can offer ‘advice’”. Counselling and/or coaching was described as beneficial, because using a “CBT modality can prove helpful ... by assisting them to rule out ‘distorted thinking’”; it provided “an empathetic, compassionate ‘listening ear’” and “a trustworthy (and neutral third-party) source in which an autistic [individual] can discuss, vent

and learn about themselves”; it allowed adults to “discuss managing my condition”; and it offered “a realistic and accurate (truthful) reflective surface for them to see their themselves and their lives in”.

Wrap-around Support is Vital

Adults did not share any positive experiences of an individualised and coordinated post-diagnostic support process. Instead, they described that suggested supports “never turned into anything”, with one adult explaining “I was given the name of some support organisations if I wanted to contact them. I don’t like contacting people, so I didn’t. I probably should have.” Other adults described barriers of cost, where “I’d spent all my funds on the diagnosis so it stopped there” and another adult highlighted “there was little to no collaboration” between health professionals who completed the diagnostic assessment and environments in which they participated (e.g. school, workplace). It was common for adults to express the sentiment that they “had to seek out [supports] myself” or “fend for myself”. Adults suggested that post-diagnostic supports could be “streamlined”, “fast-tracked” and “integrated ... so necessary supports are immediately available”. Another adult suggested that “wrap-around support is vital”, where this collaborative case management approach may address the issue that “those in the know, know where to seek help ... others do not”.

Appendix D – The Autism Diagnostic Process in New Zealand: A Call for Action from Caregivers

Authors

Kiah Evans, Larah van der Meer, Sasha Johnston, Maryam Boutrus, Matthew J. F. Eggleston, Hiran Thabrew, Hannah Waddington and Andrew J.O. Whitehouse

Aim

This survey aimed to explore the satisfaction of caregivers of individuals on the autism spectrum during the autism identification, diagnostic assessment and post-diagnostic support stages in New Zealand, along with their suggestions for improving the autism diagnostic process.

Method

Sample

Caregivers who are a parent or primary caregiver of an individual who has a diagnosis of autism were invited to participate in this study using a convenience sampling approach. In addition, the following inclusion criteria applied: (1) the diagnosis of autism was made in New Zealand during the past 10 years; and (2) the participant was living in New Zealand. Recruitment for the online survey occurred using two approaches. Firstly, 7,396 members of the Autism New Zealand database were emailed and invited to complete the online survey, with a 7% unique click through rate. Secondly, the online survey was advertised through various autism social media groups, including Autism New Zealand's Facebook page (approximately 13,000 followers). A total of 502 caregivers commenced the online survey, however 44 caregivers did not move beyond the first question and were therefore excluded, leaving a final sample of 458 caregivers. The demographic features of the sample are described under the Participant Demographics and Contextual Factors sub-heading of the results section and Table 1.

Table 1: Caregiver Demographic and Context Variables

Demographic and Context Variables	Children	Comparison with Adult Sample (Appendix B)
Gender Male (%) Female (%) Gender Diverse (%) Sample size	79.5 19.4 0.9 n=458	$\chi(1) = 70.763$ $p < 0.001$
Ethnicity Median (Number of categories) Range (Number of categories) NZ European (%) Māori (%) Pacific (%) Other (%) Sample size	1 (1-4) 83.8 20.3 7.2 14.2 n=456-458	$U=13630.5$ $p=0.01$
Location by population size of region Large region (%) Medium region (%) Small region (%) Sample size	31.8 31.4 36.8 n=456	Not significant
Age of initial queries Median (years) Range (years) Sample size	3.5 0.2-46.0 n=447	$U=529.5$ $p<0.001$
Age of diagnosis Median (years) Range (years) Sample size	5.6 1.0 - 47.2 n=447	$U=289.0$ $p<0.001$
Initial queries to diagnosis Median (years) Range (years) Sample size	1.1 0.0 - 19.2 n=447	$U=13166.5$ $p=0.050$
Setting Public (%) Private (%) Both (%) Sample size	72.6 21.7 5.7 n=452	$\chi(1) = 73.438$ $p < 0.001$
Developmental Services / ASD Coordinator No (%) Yes (%) before and after (%) only before (%) only after (%) Sample size	50.0 50.0 31.8 7.1 61.2 n=340	Not applicable

Measures

The online survey (Appendix G) was based on previous surveys administered in England [1,2] and New Zealand [3], along with suggestions from 17 professionals at three workshops held across New Zealand (see Appendix F). The online survey items were revised several times based on feedback from eight people, including autistic adults, parents of children on the autism spectrum,

health professionals and researchers. The online survey was piloted by two parents of children on the autism spectrum and revised based on feedback prior to being administered to the final sample. The online survey contained 32 optional questions, estimated to take approximately 15 minutes to complete. The online survey was hosted by SurveyMonkey® for a one-month period during August 2019 and participants were given the option of answering the questions on a hardcopy survey or through an interview with an interpreter (if required). A single online survey was utilised for autistic adults (see Appendix B) and caregivers. Ethical approval was granted by the New Zealand Ethics Committee (Reference number 2018_28).

The online survey commenced with information about the study and a statement that undertaking the online survey was an indication of informed consent. Participants initially completed a series of closed questions to confirm participant eligibility and to correctly stream the participant to questions as an autistic adult or caregiver. The three dependent variables for this study were satisfaction with the identification, diagnostic assessment and post-diagnostic support stages. These three items were measured using closed questions on a five-point scale, ranging from 1 = very dissatisfied to 5 = very satisfied. The remaining online survey items explored contextual factors or process factors during the identification, diagnostic assessment and post-diagnostic stages. Contextual information was collected from caregivers in a proxy-report capacity about the person on the autism spectrum within their care. The contextual information questions covered participant demographics, including gender, ethnicity and location in which the diagnostic assessment occurred. Caregivers also indicated the relationship with the person on the autism spectrum within their care. Additional contextual information was collected regarding the age of initial queries about a possible diagnosis and the age this diagnosis occurred, along with the setting accessed for the diagnostic assessment. Finally, caregivers of a person diagnosed before the age of 20 years were asked if a Developmental Services / ASD Coordinator was involved in the diagnostic process. The identification stage section explored first queries and initial help, including who first had queries about a possible diagnosis, how they found out about the pathway to pursue a diagnosis, the clarity of the pathway to pursue a diagnosis (a five-point scale, ranging from 1 = very unclear to 5 = very clear), who they first consulted when they sought a diagnosis, outcome of this initial help and the wait time for the initial diagnostic assessment appointment (within set time ranges). The diagnostic assessment stage section explored the professionals who contributed to the diagnostic assessment, including the total number of professionals consulted and satisfaction with cultural sensitivity (using the above scale). Diagnostic disclosure was explored in relation to if they participated in a feedback interview, received a diagnostic report and were satisfied with the manner of disclosure (using the above scale). Participants were asked if they had sought a second opinion for the diagnosis, and if so the reason for this action was sought. Finally, questions sought

to understand the overall stress (a five-point scale, ranging from 1 = very stressful to 5 = not at all stressful), duration (within set time ranges) and cost associated with the diagnostic assessment. The post-diagnostic support stage section explored the overall level of coordination of post-diagnostic supports (a five-point scale, ranging from 1 = very uncoordinated to 5 = very coordinated) and satisfaction with twelve post-diagnostic support services and twelve post-diagnostic support areas (using the above scale, with the addition of response options stating that the support was required but not received or not relevant). Finally, reflections on autism diagnosis in New Zealand were collected using open-ended questions on how the autism diagnostic process in New Zealand can be improved, along with what is working well with the autism diagnostic process in New Zealand. In addition, free text responses were allowed at a variety of places during the online survey.

Analysis

Prior to commencing data analysis, data processing occurred by condensing the number of response options for several variables and creating new summary variables, primarily related to demographic features and contextual factors. Ethnicity response options were transformed into New Zealand European, Māori, Pacific People (Samoan, Cook Island Māori, Tongan or Niuean) and/or other (Chinese, Indian or other). The number of ethnicity categories that participants identified with was also calculated. Location response options were transformed into three categories according to the population size of the 16 regions of New Zealand (those from an area outside region were excluded for this analysis). Approximately one-third of the New Zealand population lives in the Auckland region (labelled as a large region, with just over 1.5 million residents), a further one-third of the New Zealand population live in the Canterbury, Waikato or Wellington regions (labelled as medium regions, with populations of approximately half a million residents each) and the remaining one-third of New Zealanders live in the Bay of Plenty, Gisborne, Hawke's Bay, Manawatu – Whanganui, Marlborough, Nelson, Northland, Otago, Southland, Taranaki, Tasman or West Coast regions (labelled as small regions, with populations ranging between approximately 30,000 to 300,000 residents each). Age related data was converted from years and months to a decimal value in years, and the time period between initial queries to diagnosis was calculated (age related data were deleted when diagnosis was reported to occur before initial queries were noted, and this was subsequently treated as missing data). Responses confirming involvement of a Developmental Services / ASD Coordinator were summed. The professionals who were consulted when the participant first sought a diagnostic pathway and those who contributed to the diagnostic assessment stage were examined to create a variable indicating if a medical professional was involved during the diagnostic assessment process. Finally, in

relation to satisfaction with the twenty-four post-diagnostic support services and areas a support was considered required and received if the participant provided a satisfaction rating and considered required and not received if this response was selected by the participant. These two responses were summed to indicate that a support was required, and conversely a support was considered not required if the participant responded with the not relevant option.

Statistical analysis was performed using IBM SPSS Statistics 26 software [4]. Non-parametric statistical tests were used as the three dependent variables were not normally distributed for both the adult and caregiver samples [5]. Data were analysed based on the number of responses for each question (responses indicating the participant was unsure, if this option was provided, was treated as missing data). Data were described by calculating the frequency (percentage), median and range. The sum of frequencies equals 100% where only a single response was possible, however the sum of frequencies exceeded 100% where multiple responses were possible. Adult and caregiver responses were compared using the Pearson's chi-square test (χ^2) for categorical variables and the Mann-Whitney U test (U) for ordinal or continuous variables. The relationship between demographic, contextual and process variables with the three dependent variables (satisfaction with the identification, diagnostic assessment and post-diagnostic support stages) were explored using: (1) the Kruskal-Wallis H test χ^2 for variables with three or more categorical response options; (2) the Mann-Whitney U test (U) for post-hoc analysis following a significant Kruskal-Wallis H test result and for variables with two categorical response options (including yes or no for each response option in questions where multiple responses were possible); and (3) Spearman's rho correlation coefficient (r_s) for ordinal or continuous variables. Categories and samples were only compared if the sub-sample consisted of at least ten participants. The significance level of $p=0.05$ was selected and only significant findings are described in the results section.

Most caregivers (82%) provided qualitative responses, resulting in over 30,000 words of data. Thematic analysis of qualitative responses occurred through an iterative process by three researchers using a template analysis approach [6]. All three researchers read the entire qualitative data set. Text responses were initially coded in QSR NVivo 12 software [7] by two researchers according to set codes, such as stakeholder type, stage during the autism diagnostic process and if the experience was positive or negative. During this phase, each researcher compiled a set of additional preliminary codes that had emerged from the data and these concepts were discussed. An expanded template of codes was developed based on this discussion, and the full dataset was then coded to these new codes. Repeated review of these codes led to the formation of themes and sub-themes, which were refined throughout the analysis process. Short

and long quotes from the data were selected to illustrate themes and sub-themes, with all identifying details removed. Another member of the research team was consulted to discuss and confirm the findings.

Results

Participant Demographics and Contextual Factors

As outlined in Table 1, the vast majority of caregiver participants were parents (97%), with a smaller proportion reporting to be grandparents (<2%), legal guardians (<1%) or other / not specified (<1%). Participants reported about 438 individuals who received their autism diagnosis during childhood (96%) and 13 individuals who received their autism diagnosis during adulthood (3%). The participants reported about experiences associated with the autism diagnosis of male (79%), female (19%) and gender diverse (<1%) individuals. These individuals were primarily of New Zealand European background (84%), with strong representation from Māori (20%), Pacific Islander (7%) and other backgrounds (14%). Children belonged to a median of one category of cultural backgrounds, with a range of up to 4 categories (78% belonged to one culture and 18% belonged to two cultures). Participants reported on autism diagnostic processes that had occurred across all 16 regions of New Zealand, with a relatively even split across large (32%), medium (31%) and small (37%) regions. Children were initially queried as being on the autism spectrum at a median age of 3.5 years and the median age of diagnosis was 5.6 years, however the median gap between initial queries and diagnosis was 1.1 years. There were children who were first queried, and diagnosed, as being on the autism spectrum in early infancy through to middle adulthood. Children more often received their autism diagnosis through the public setting (73%), with just over a fifth of children diagnosed in a private setting and one in twenty children undergoing the diagnostic process in both public and private settings. The most commonly cited reason for caregivers choosing a public setting was being referred to this service by a professional (67%) and selecting a private setting was most common due to shorter wait times (54%). Only half of the caregivers reported the involvement of a Developmental Services / ASD Coordinator, and this was substantially more common to be provided after the diagnosis only.

When compared to the adult sample described in Appendix B (Table 1), children were significantly more likely to be male than female. In addition, children were significantly more likely to be from a Māori or Pacific background and belonged to significantly more cultural backgrounds each compared to adults. As would be expected, children in this study had a lower age of initial queries and age of diagnosis than adults. In addition, children waited a slightly shorter, but significant, period of time from initial queries to diagnosis than adults. Children were also more likely to receive

their diagnosis in a public setting, compared to adults who more frequently accessed a private setting.

Experiences of the Autism Diagnostic Process in New Zealand

Identification Stage

Almost two-third of caregivers were the first person to raise initial concerns about their child's autism related traits, with a similar number of queries being raised by health professionals and family / whānau or friends (Table 2). Nearly a quarter of initial queries were originally raised by others. Caregivers most frequently learnt about the autism diagnostic pathway from health professionals (nearly two-thirds of cases) or early childhood / education professionals (over one-quarter of cases). Overall, caregivers also found the diagnostic pathway to be unclear during the identification stage. Caregivers took their child to see a GP for initial help in nearly one half of cases, with paediatricians being consulted in one-third of cases. Early childhood / educational professionals or additional health professionals (such as well child nurses, psychologists and speech pathologists) were consulted on a regular basis. The outcome of this initial help was most frequently an autism diagnosis or referral to another professional (over one-third each), although other common outcomes included an alternative diagnosis, referral for tests, or being told that there was no problem. Children typically waited four to six months for a diagnostic assessment and in total 68% waited less than six months, however a very small proportion of children (5%) waited over two years. Children waited significantly longer than adults for their diagnostic assessment.

Table 2: Caregiver Identification Variables	Children	Comparison with Adult Sample (Appendix B)
Source of first autism queries		
Participant (%)	65.6	Not calculated
Health professional (%)	14.6	
Family / whānau / friend (%)	12.8	
Other (%)	22.1	
Sample size	n=453	
Source of diagnostic pathway information		
Health professional	64.7	Not calculated
Early childhood / school staff (%)	27.5	
NGO Autism organisation (%)	4.0	
Website (%)	8.0	
Social media (%)	2.0	
Personal networks (%)	13.7	
Other (%)	12.4	
Sample size	n=451	
Clarity of diagnostic pathway		
Median	Unclear (2)	Not significant
Range	Very unclear (1) to very clear (5)	
Sample size	n=450	

First saw when sought diagnostic pathway		
Well child nurse (%)	13.8	Not calculated
General practitioner (%)	48.4	
Paediatrician (%)	36.5	
Psychiatrist (%)	8.8	
Psychologist (%)	13.6	
Speech language therapist (%)	13.4	
Occupational therapist (%)	5.5	
Social worker (%)	3.3	
Nurse (%)	2.2	
Early childhood / school staff (%)	17.1	
Other (%)	12.3	
Sample size	n=458	
Outcome when sought diagnostic pathway		
Autism diagnosis made (%)	38.3	Not calculated
Given an alternative diagnosis (%)	18.6	
Referred to another professional (%)	36.1	
Referred for tests (%)	16.0	
Told no problem or not to worry (%)	19.0	
Told return if problems do not improve (%)	9.2	
Other (%)	9.6	
Sample size	n=457	
Wait time for diagnostic assessment		
Median	4-6 months	U=7814.0 p<0.001
Range	< 1 month - > 2 years	
Sample size	n=454	

Diagnostic Assessment Stage

Paediatricians contributed to more than two-thirds of children's diagnostic assessments, psychologists were involved in nearly half of all cases, whilst early childhood / education professionals, speech pathologists and/or occupational therapists were involved approximately one-third of the time (Table 3). The vast majority (92%) of children were evaluated by a medical practitioner during the identification and/or diagnostic assessment stage, with only 8% of caregivers not reporting any contribution from a medical practitioner. Children were typically assessed by three health professionals during their diagnostic evaluation, with 85% involving at least two health professionals. Caregivers were generally satisfied with cultural sensitivity where this was required. Diagnostic assessments concluded with approximately two-thirds of caregivers participating in a feedback interview and nearly all caregivers receiving a diagnostic report. Overall, caregivers were satisfied with the manner of the diagnostic disclosure. Nearly one in six caregivers sought a second opinion following the diagnostic disclosure, with the three most common reasons being that they weren't given an autism diagnosis (30%), they were given an alternate diagnosis (29%) or they were told there was no problem (21%). Caregivers reported that the diagnostic assessment process was quite stressful overall, typically lasted less than three months and cost NZ\$600 (private sector). Compared to adults, children were assessed by significantly more professionals over a longer period of time. In addition, caregivers were significantly more likely to

receive a diagnostic report, but significantly less satisfied with the manner of diagnostic disclosure, when compared to adults.

Table 3: Caregiver Diagnostic Assessment Variables

Diagnostic Assessment Variables	Children	Comparison with Adult Sample (Appendix B)
Professionals who contributed		
Paediatrician (%)	71.7	Not calculated
Psychiatrist (%)	19.9	
Psychologist (%)	46.8	
Speech language therapist (%)	34.4	
Occupational therapist (%)	29.2	
Physiotherapist (%)	3.4	
Audiologist or hearing specialist (%)	14.9	
Social worker (%)	8.4	
Nurse (%)	6.1	
Early childhood / school staff (%)	34.6	
Other (%)	11.8	
Sample size	n=442	
Number of professionals involved		
Median (Range)	3 (1 - 6 or more)	U=7696.0
Sample size	n=441	p<0.001
Satisfaction with cultural sensitivity		
Median	Satisfied (4)	Not significant
Range	Dissatisfied (2) – Very satisfied (5)	
Sample size	n=41	
Participated in a feedback interview		
Yes (%)	64.3	Not significant
No (%)	35.7	
Sample size	n=398	
Received a diagnostic report		
Yes (%)	89.1	$\chi^2(1) = 4.297$ p=0.038
No (%)	10.9	
Sample size	n=441	
Satisfaction with manner of disclosure		
Median	Satisfied (4)	U=2754.5 p=0.004
Range	Very dissatisfied (1) – Very satisfied (5)	
Sample size	n=250	
Sought a second opinion		
Yes (%)	15.8	Not significant
No (%)	84.2	
Sample size	n=442	
Overall stress		
Median	Quite stressful (2)	Not significant
Range	Very stressful (1) – Not at all stressful (5)	
Sample size	n=407	
Duration of diagnostic assessment		
Median	1-3 months	U=11401.5 p<0.001
Range	1-2 weeks – >1 year	
Sample size	n=453	
Cost of diagnostic assessment (NZ \$)		
Median (Range)	\$600 (\$100 - \$6500)	Not significant
Sample size	n=71	

Post-diagnostic Support Stage

Caregivers felt that post-diagnostic supports were uncoordinated overall (Table 4). Caregivers most frequently required post-diagnostic support services in the form of written information about autism, autism education programs and disability allowance, whilst the post-diagnostic support areas most required by caregivers were social, sensory and behaviour. Caregivers least frequently required post-diagnostic support services in the form of cultural support, vocational support and autism organisations, whilst the post-diagnostic support areas least required by caregivers were physical movement, gut health and toileting. Caregivers reported the highest level of met need for post-diagnostic support services in the form of disability allowance, written information about autism and needs assessment / coordination, along with post-diagnostic support areas related to medication, communication and sleep. The greatest levels of unmet need in relation to post-diagnostic support services for caregivers were adjustment counselling, support groups and autism education programs, whilst the greatest unmet needs for post-diagnostic support areas for caregivers were in relation to gut health, social and mental health. The only post-diagnostic support services or areas that caregivers were satisfied with were written information about autism, disability allowance and needs assessment / coordination, with all other items associated with a median satisfaction rating of neutral or dissatisfied. Adults were significantly more satisfied than caregivers with adjustment counselling and mental health, whilst caregivers were significantly more satisfied than adults with autism education programs, cultural support, disability allowance, needs assessment / coordination and vocational support.

Table 4: Caregiver Post-diagnostic Support Variables

Post-diagnostic Support Variables	Required (%)	Required and ...		Required and received	
		Received (%)	Not received (%)	Median satisfaction level	Correlation with Satisfaction – Post-diagnostic support
Coordination of supports (n=373)				Uncoordinated (2)	0.693** (n= 359) U=6723.0, p=0.422
Satisfaction - Support service:					
Written information about ASD (n=409)	98.5	93.8	6.2	Satisfied (4)	0.477** (n= 347) Not significant
Adjustment counselling (n=407)	80.3	70.3	29.7	Dissatisfied (2)	0.623** (n=213) U=2637.0, p=0.028
Support group Children (n=405)	88.4	78.2	21.8	Neutral (3)	0.547** (n=260) Not significant
ASD education programme (n=405)	93.8	82.4	17.6	Neutral (3)	0.584** (n=295) U=2494.5, p=0.012
Cultural support (n=402)	33.3	85.8	14.2	Neutral (3)	0.322** (n=108) U=365.0, p=0.001
Autism organisation (n=395)	76.5	86.8	13.2	Neutral (3)	0.360** (n=241) Not significant
Disability allowance (n=407)	91.9	95.2	4.8	Satisfied (4)	0.384** (n=330) U=2552.0, p=0.001
Needs assessment/coordination (n=405)	90.6	91.3	8.7	Satisfied (4)	0.451** (n=309) U=1251.0, p<0.000
Education - early intervention (n=404)	79.7	88.8	11.2	Neutral (3)	0.468** (n=270) Not applicable
Vocational support (n=405)	88.4	86.3	13.7	Dissatisfied (2)	0.415** (n=289) Not applicable
Vocational support (n=393)	49.6	85.6	14.4	Neutral (3)	0.575** (n=161) U=1007.5, p=0.040
Multidisciplinary service (n=401)	80.3	86.6	13.4	Neutral (3)	0.539** (n=263) Not significant
Satisfaction with support area:					
Communication (n=408)	70.8	88.9	11.1	Neutral (3)	0.498** (n=247) Not significant
Social (n=406)	91.6	74.5	25.5	Dissatisfied (2)	0.584** (n=266) Not significant
Behaviour (n=407)	86.5	81.8	18.2	Dissatisfied (2)	0.550** (n=274) Not significant
Eating and drinking (n=406)	67.0	82.7	17.3	Neutral (3)	0.589** (n=216) Not applicable
Gut health (n=403)	54.6	74.1	25.9	Dissatisfied (2)	0.572** (n=157) Not significant
Toileting (n=405)	57.3	86.6	13.4	Neutral (3)	0.610** (n=192) Not applicable
Physical movement (n=404)	49.3	82.9	17.1	Neutral (3)	0.588** (n=158) Not significant
Sensory (n=400)	88.2	77.7	22.3	Neutral (3)	0.595** (n=260) Not significant
Mental health (n=404)	84.9	77.3	22.7	Dissatisfied (2)	0.628** (n=253) U=3588.5**, p=0.001
Sleep (n=401)	71.8	87.2	12.8	Neutral (3)	0.462** (n=241) Not significant
Cognition (n=402)	76.6	78.6	21.4	Dissatisfied (2)	0.603** (n=231) Not significant
Medication (n=400)	70.8	93.6	6.4	Neutral (3)	0.422** (n=248) Not significant

Note. Coordination and satisfaction scores range 1-5 for all items.

Satisfaction During the Autism Diagnostic Process in New Zealand

Identification Stage

Caregivers were neutral overall in relation to their median satisfaction with identification stage (Figure 1), with less than half expressing satisfaction (43%). Caregivers were significantly less satisfied than adults with the identification stage ($U=10813.0^{**}$). Satisfaction with the identification stage was related to several contextual factors. There were weak relationships noted in relation to temporal factors, where caregivers had significantly lower satisfaction with the identification stage if their child was diagnosed with autism at an older age ($r_s=-0.141^{**}$) or if the time from the initial autism queries to diagnosis was longer ($r_s=-0.138^{**}$). Satisfaction with the identification stage was also related to a number of identification process factors. Caregivers experienced greater satisfaction with identification stage if they were not the person who had the initial queries about their child's autistic traits ($U=16903.5^{**}$, median = satisfied) and if a health professional first queried autism ($U=9076.5^{**}$, median = satisfied), as well as if a health professional ($U=19151^*$, median = neutral) or early childhood / education professional ($U=17093.0^*$, median = neutral) provided information regarding the diagnostic pathway. Caregivers were more satisfied with this stage if there was greater clarity of the autism diagnostic pathway (weakly correlated with $r_s=0.442^{**}$) and if they saw a paediatrician when they first sought a diagnostic pathway ($U=20034^*$, median = neutral). Caregivers experienced greater satisfaction if the outcome was an autism diagnosis ($U=13312^{**}$, median = satisfied), they were referred to another professional ($U=19068.5^{**}$, median = neutral), their concerns were not dismissed ($U=5723.5^{**}$, median = satisfied) and they were not told to return if their child did not improve ($U=5107.5^{**}$, median = neutral). Caregivers were also more satisfied with the identification stage when they waited a shorter amount of time for the first diagnostic assessment (again this relationship was weak, with $r_s=-0.176^{**}$).

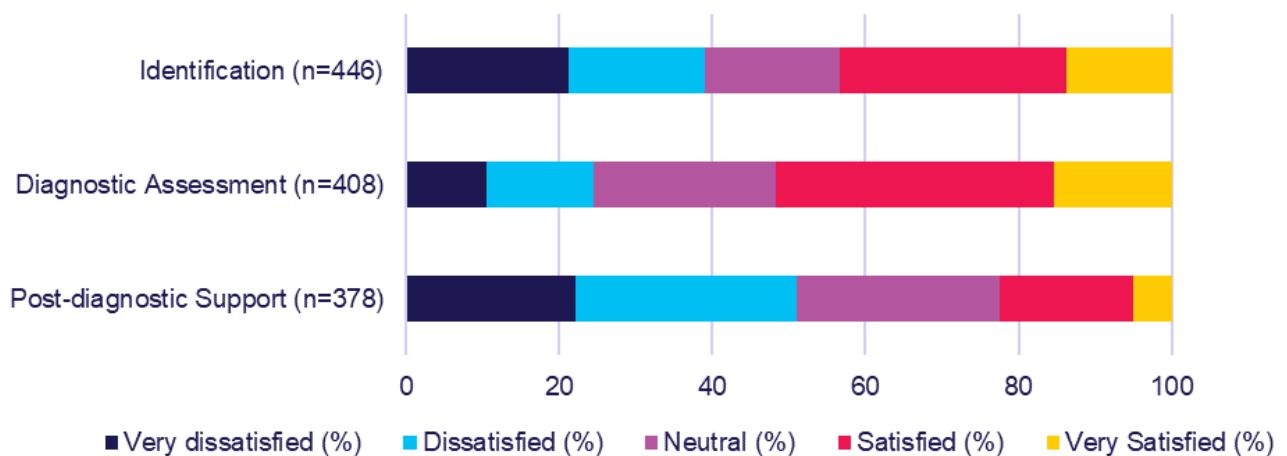


Figure 1: Caregiver Satisfaction Variables

Diagnostic Assessment Stage

Caregivers were satisfied overall with the diagnostic assessment stage (median, Figure 1), with just over half of caregivers expressing satisfaction (52%). There was no significant difference between adults and caregivers in relation to satisfaction with the diagnostic assessment stage. Satisfaction with the diagnostic assessment stage was related to a number of contextual factors. Satisfaction with the diagnostic assessment stage was significantly associated with satisfaction with the identification stage for caregivers (weak relationship, $r_s=0.423^{**}$). Satisfaction with the diagnostic assessment stage was also significantly different according to the setting accessed for caregivers ($\chi^2(2) = 21.974^{**}$). Specifically, caregivers experienced greater satisfaction in a private setting compared to a public setting ($U=9084.5^{**}$, median = satisfied) or both public and private settings ($U=424.5^{**}$, median = satisfied), as well as a public setting compared with both public and private settings ($U=2256.5^{**}$, median = satisfied). Finally, caregiver satisfaction with the diagnostic assessment was weakly correlated with the time from the initial autism queries to diagnosis, with greater satisfaction related to a quicker process ($r_s=-0.138^{**}$), and if they had a male child ($U=11140.5^*$, median = satisfied). Satisfaction with the diagnostic assessment stage was related to several diagnostic assessment process factors. Caregivers were more satisfied with the diagnostic assessment stage if a psychiatrist was not involved ($U=11224.5^*$, median = satisfied), if fewer professionals contributed to the diagnosis (weakly correlated with $r_s=-0.211^{**}$), caregivers were more satisfied with cultural sensitivity (weakly correlated with $r_s=0.409^*$), a diagnostic report was provided ($U=4458.5^{**}$, median = satisfied) and where there was greater satisfaction with the manner of diagnostic disclosure (weakly correlated with $r_s=0.423^{**}$). Finally, caregiver satisfaction with the diagnostic assessment was higher if they did not seek a second opinion ($U=6677.0^{**}$, median = satisfied), experienced less stress during this stage (moderately correlated with

$r_s=0.568^{**}$) and the duration of the diagnostic assessment was shorter (weakly correlated with $r_s=-0.277^{**}$).

Post-diagnostic Support Stage

Caregivers were dissatisfied overall in relation to the post-diagnostic support stage (median, Figure 1), with less than a quarter expressing satisfaction (22%). There was no significant difference between adults and caregivers in relation to satisfaction with the post-diagnostic support stage. Satisfaction with the post-diagnostic support stage was related to a number of contextual factors. Satisfaction with the diagnostic assessment stage was significantly, but weakly, associated with satisfaction with the identification and diagnostic assessment stages for caregivers ($r_s=0.239^{**}$ and $r_s=0.356^{**}$ respectively). In addition, caregivers experienced greater satisfaction with the post-diagnostic support stage if their child was younger at the time of initial queries and diagnosis (weak relationships of $r_s=-0.147^{**}$ and $r_s=-0.176^{**}$ respectively), had a Developmental Services / ASD Coordinator involved ($U=6319^{**}$, median = neutral) or were from a Pacific background ($U=3364^*$, median = neutral). Satisfaction with the post-diagnostic support stage was positively related to all post-diagnostic support process factors, including moderately correlated with coordination (Table 4). Caregiver satisfaction with the post-diagnostic support [insert sentence about coordination and satisfaction for caregivers]. Caregivers who required and received support experienced greater satisfaction with the post-diagnostic support stage, when compared to caregivers who required but did not receive support, for all support services ($U=654^*$ to $U=7650^{**}$) and areas ($U=57^*$ to $U=8501.5^*$), with the exception of communication, gut health, physical movement and mental health. Amongst caregivers who received a particular support, satisfaction with the post-diagnostic support stage was moderately (five services and nine areas) or weakly (seven services and three areas) correlated to satisfaction with numerous post-diagnostic support services and areas (Table 4).

Suggestions for Improving the Autism Diagnostic Process in New Zealand

Qualitative analysis revealed eleven themes that were a call to action from caregivers for key stakeholders to work together to improve the autism assessment process in New Zealand (Figure 2). The first seven themes called on professionals involved in the autism assessment process to act. Educational and health professionals were called to 'Notice' and 'Listen' during the identification stage. Assessors were called to 'Investigate' and 'Explain' during the diagnostic assessment stage. All professionals were called to 'Help' and 'Coordinate' during the post-diagnostic support stage. Finally, educational, health and other professionals were called to 'Expediate' activities during the identification and diagnostic assessment stages, so that individuals

and caregivers were streamlined to the post-diagnostic support stage. The last four themes were a call to action for peak bodies and government departments to 'Guide', 'Include', 'Provide' and 'Train' during all stages of the autism assessment process.

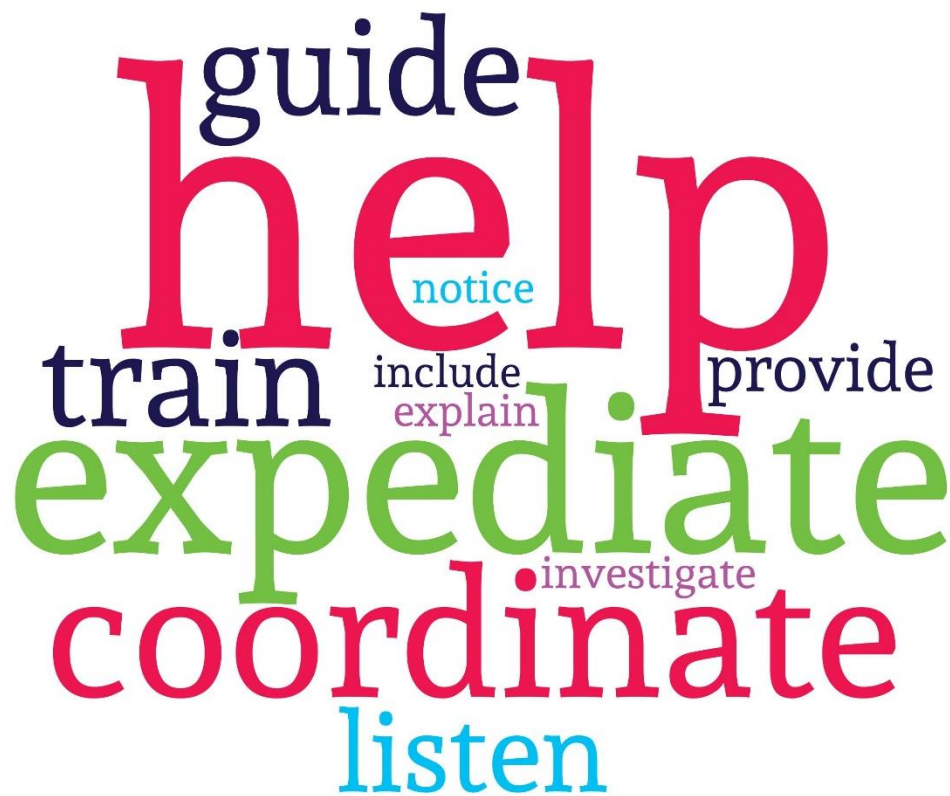


Figure 2: Caregiver Qualitative Themes

Notice

Caregivers called for educational and health professionals to notice and act on early signs of autism. Some caregivers recognised that they relied on this expertise due to their own lack of awareness, as one caregiver explained, “in hindsight the symptoms were there from 18 months but we didn’t recognise the behaviour as autistic as we have no experience of autism”. Within an educational setting, noticing would involve “early detection through classrooms” by early childhood educators, teachers and principals. They would have expertise in “recognising ... flags” and “obvious cues”, followed by “speak[ing] up” through finding “a way to be able to prompt parents to seek help” or “flag[g]ing symptoms to health professionals early”. Caregivers warned against educational professionals being “so quick to judge” signs of autism as “difficult” behaviour, or conversely fail to notice signs because a child is “quiet in class”. Within a health setting, noticing would involve general practitioners, “nurses and paediatricians to maybe ask a few more questions

when a parent expresses concern[s]", if a child "isn't reaching their milestones" and during regular "developmental check[s]". Caregivers felt that educational and health professionals should use "a 'cheat sheet' checklist for parents" to elicit potential developmental concerns and signs of autism. Finally, caregivers explained that the process of noticing also involved sharing this information with individuals / caregivers, as illustrated with: "Professionals need to speak up more if they believe someone may have ASD (or anything else!) ... be gentle, but pass on their concerns, rather than trying not to offend everyone."

Listen

Caregivers called for educational and health professionals to listen and act on initial developmental concerns. Caregivers described that they had felt "blamed", "judged", "fobbed off" and "dismissed" while attempting to seek an explanation for their "worries", and they needed to "fight" so that professionals would "take initial concerns seriously". One caregiver said, "I was told I was wrong about my son at age 2 and he's actually on the severe end of the spectrum". This approach was explained by one caregiver with: "Listening to parents the first time when they feel something is not right with their child, not just brushing them off into the too hard basket".

Investigate

Caregivers called for assessors to investigate if their child / care recipient met the diagnostic criteria for autism using a comprehensive and person-centred approach. A comprehensive approach involved a "multidisciplinary assessment" with "multiple ways of completing the assessment to have an objective outcome". Caregivers explained this would "take into account all the information ... and look at the wider picture". They warned against "trying to tick boxes and spend more time observing the child", with one caregiver explaining that once the assessor had spent time "chatting to my son [they] realised quickly how much masking he was doing". Caregivers felt multiple potential diagnoses should be considered, including "sensory processing and other commonly co-morbid condition tested for on the same day". Multiple and/or alternative settings were also suggested, for example "observations need to be made both at school and the home environment" and "if a child is too anxious to attend [a clinic based] appointment ... [assessors] need to come to them in their safe environment". Multidisciplinary and comprehensive assessments have a further requirement, where "communication and gathering of data has to be accepted across [District Health Boards]". A person-centred approach involved "look[ing] at the condition from the neurodevelopmental perspective" and recognising that "each individual is different". One caregiver expressed hope for "a system that is oriented to place people with autism, and their families/carers, at the centre".

Explain

Caregivers called for assessors to explain the diagnostic process at each step to improve coping. Without adequate explanations, caregivers felt they were “left completely in the dark” or “left out in the cold”. Caregivers suggested that assessors explain each step of the process, commencing with “honest communication about the wait time”. This would be followed by “information about what is expected in assessments” and “who will be involved and why”, with an opportunity for caregivers to “ask questions”. One caregiver stated “a meeting with us as parents beforehand, with a topic of something like ‘we think your child might be autistic because of ... and we’re going to use this testing regime to confirm...’ would be tremendously helpful”. At the conclusion of the assessment, caregivers wanted to be provided with “a clear diagnosis letter” and “offer[ed] a feedback appointment” to support “parents and children to understand the diagnosis” and “advise caregivers of differential [or co-occurring] diagnoses”. Along with being informative, this feedback appointment was an important step in providing the individual with “positive support for acceptance of their diagnosis and how to manage it” and reassurance “for parents to say ‘It’s not your fault and it will be ok’”. One caregiver provided a sample script for improving understanding and acceptance of an autism diagnosis with “‘You told me your child only eats certain foods: this can be related to sensory processing, tastes/textures - children with ASD have difficulties processing some senses due to.... etc.’ That would’ve made the diagnosis more personal.” Finally, caregivers wanted the assessor to explain “what the process entails after the diagnosis, what help is out there”.

Help

Caregivers called for assessors and other professionals to ensure that help is offered and received to address a myriad of support needs. Post-diagnostic supports were the greatest unmet need described by the caregivers, with “you go home to nothing after a life changing appointment” and where “even if you are a squeaky wheel you still miss out or can fall through the cracks”. Caregivers felt that “research is very clear on [the] benefits of early intervention”, however many were frustrated by long waiting lists to firstly receive a diagnosis, and then secondly to commence services, as they worried this had “squandered” “such a precious window”. A suggestion was to “have a standardised post-diagnosis support pathway for caregivers. Provide a coherent list of available supports and opportunities” to “ensure that parents are aware of what supports exist and how to access them”. Examples of required supports included “funding”, “better access to speech and occupational therapy, and more support groups”, along with “behavioural, social and emotional support”. There were some groups who were perceived to be at greater risk of missing out on help, including adults, individuals living in “more remote areas” and those who have been labelled as “high functioning ... as this can be viewed as mild or not as important or needing support”. One

caregiver explained that help is not just required for the individual who had received an autism diagnosis, but there is also a need for “way more pre- and post- diagnosis support for the whole family - including grandparents, teachers or anyone else significant in the child's life”.

Coordinate

Caregivers called for a central person to coordinate service provision throughout the autism diagnostic pathway. Without this coordination, caregivers felt that “it can be very overwhelming and even though there is a lot out there it's hard to know where to start and you have to do it on your own”. “Having a central support worker to help you navigate the system would be so helpful” according to numerous caregivers, with example benefits being that a coordinator can assist “professionals to be on the same page”, “guide you along the journey instead of being passed from person to person”, “checking in with the families to keep them informed” and ensure supports are “tailored to specific family needs”. Along with the important role of coordination through a case management approach, it was also highlighted that government “agency's need to communicate with each other better as well”.

Expediate

Caregivers called for all professionals involved in the autism diagnostic process to expediate each step, as each delay accumulates and causes distress and missed opportunities. Caregivers stated that it “can be a very drawn out process” and a “long road of struggles”, especially as “waiting lists [are] incredibly high with little or no support in the interim”. The sentiment that “waiting is the most stressful part” was common, with one caregiver explaining that “having to wait so long for the diagnosis puts incredible stress and strain on the family unit” whilst another stated waiting “adds to the parents’ frustrations and anxieties about their child”. Caregivers advocated for a “timely service” with “more speed” and activities to be “done more quickly” with “shorter wait times” to “reduce a lot of the anxiety.” At the conclusion of the diagnostic assessment, caregivers felt that “a written [report] needs to ... be delivered faster” and “timeframes more realistic for support”. As mentioned previously, the opportunity to access “early intervention” was a strong driver for caregivers wishing to expediate the autism diagnostic process, as illustrated with: “Shorter waiting times in the public system would mean more timely diagnosis and therefore earlier intervention - assistance in those crucial pre-school years”. One suggestion was made for professionals from different sectors to collaborate “to have you seen sooner”.

Guide

Caregivers called for peak bodies and government departments to guide the autism diagnostic process through a consistent and clear pathway across New Zealand. Caregivers advocated for a “clear pathway nationally rather than each region having [their] own plan”, where this would be a “consistent pathway that is the same or similar for everyone”. There would be “a set protocol to follow” and “an agreed pathway for diagnosis of ASD”, and documents would outline “the exact steps that need to be done in what order” and guide caregivers on “where to from here”. This would provide both a “clearer pathway to diagnosis” and “clearer pathways for help and assistance available following diagnosis”, where this is “from the right professional”. Along with improving clarity and consistency, guidance would make “processes transparent, accountable, and subject to independent audit”. Possible formats for these documents include a “guideline” and supporting resources, such as an “A-Z checklist”, a “website dedicated to explain pathways and clear information about ASD”, “a centralised information body”, “a database of services”, a “list of available supports and opportunities” and/or a flow chart (for example “Issues or concerns with this, this or this? Start here ... Still issues? No progress? Start here.”).

Include

Caregivers called for peak bodies and government departments to include members of the population within the autism diagnostic process if required, where services are accessible regardless of age, gender, diagnostic labels, socio-economic status, culture and location. Caregivers explained that the process “needs to be accessible” and “more equal for all”, and they wanted “a fairer system that covers the whole of NZ!”. The process needs to be “accessible for all ages”, with one caregiver explaining the challenges faced by their adult child with “He needs the same help as my daughter but because he is older he's being pushed away by the system”. The process also needs to be “accessible for all ... genders”, including being “accessible for diverse genders”. Caregivers explained that individuals with a “high functioning” or ASD severity level 1 diagnostic label need to be provided with more support, as illustrated with “ASD 1 kids and families deserve help too”. In addition, some interesting service gaps were noted in relation to “mental health services”, as one caregiver was “told [autism] 'doesn't fit into their treatment model'” and another caregiver explained that autism services created a barrier when their “son was suicidal but there was no support unless he would come in”. In relation to socio-economic status, caregivers advocated for an “affordable” process with “better access to public funded practitioners”. Without this caregivers are faced with difficult decisions, such as “there was no way we could afford the money we paid, but no way we could wait 6 months to be seen to find out ‘what was wrong’ and how my daughter could be helped”. Some caregivers described “many times we haven't been able

to pay our mortgage as a result” of private assessment and support expenses, and another caregiver explained that governments need to “resource the system so that children from families who are not able to fund care in the private system are not markedly disadvantaged in terms of their outcomes”. There was an expressed need to include culturally diverse populations in the process, with a “push for more cultural LOCAL support groups”. Finally, caregivers emphasised the need to include individuals in the process regardless of the location in which they live and that the availability of services “needs to be looked at region by region”. There were particular shortages in less populated areas, as illustrated with “small towns don’t have the same resources”, “other parts of the country seem to have much less wait time and more support; especially bigger cities” and a suggestion for “more support, especially in the more remote areas, just because I live [smaller region] I shouldn’t be treated any different to a client in [larger region]”. This inequity was summed up by one caregiver with “Services for diagnosis and subsequent help seem very inconsistent and different across the regions. Need better access to help after diagnosis and need equitable access across the country”.

Provide

Caregivers called for peak bodies and government departments to provide sufficient funding, resources and workforce capacity to ensure that the autism diagnostic process can be delivered in a comprehensive and expediated manner. Diagnosis and supports through the private setting were thought to “cost a lot”, and there was a perception the system “needs a lot of funding” and “more resources to reduce wait lists and provide appropriate supports” and “meet the demand”. Specifically, caregivers sought the provision of “more people trained in ASD working with ASD diagnosis”, “more money for help at school”, “provide treatment options through the public system for all the things he actually needs - like PT, OT, Speech” and “ASD education”. The implications of providing sufficient funding was explained with “The system must be resourced so that wait times for initial assessment in both public and private support, rather than preclude, successful early intervention.” This was further articulated with “There is a strong case - social, economic, wellness, etc. - for investment in early intervention yet NZ seems to lag behind comparable jurisdictions in terms of availability of timely and quality therapeutic and support services.” One caregiver acknowledged that “it is a system that is already stressed, but so are the families who live with ASD every day”, which was supported by “the need outweighs the resources” and “the ASD coordinator process ... needs a lot of ... work on! I know there is a high demand ... as there has been a large increase in diagnosis, but ... there needs to be an increase in services.” Many of these challenges, and the need for resources to be provided, are explained with:

“I think the whole process takes far too long and the people working with autistic children are overwhelmed with demand. More funding and specialists are needed. The people we have dealt with have been amazing, but high demand has meant that it’s taken over 2 years from expressing my concerns with [the] GP to getting a diagnosis. The paediatrician ... was able to diagnose within an hour of meeting him, so it wasn’t an issue of not being sure. It was that they are in such high demand that we were unable to get an appointment.”

Train

Caregivers called for peak bodies and government departments to train caregivers and professionals to improve awareness and competencies in relation to autism and the autism diagnostic process. Caregivers suggested “further training to aid recognition of ASD in girls as well as boys, also atypical presentation of ASD” and to “up skill initial points of contact so they can explain pathways”. These initial points of contact included nurses, doctors (notably GPs and paediatricians) and teachers. This was further demonstrated with “for more health professionals to know what the diagnosis process is” and that “schools need to get on board. They need to be clear what the process is” and be “better trained to identify issues that aren’t just naughty behaviour”. This was extended to broadly recommend “more awareness of ASD behaviours for everybody” and “there is not enough awareness, should be emphasised in schools, workplaces, tertiary units”. There was a belief that “we need to have more trained people into our system”, in particular that there was “a shortage of professionals who are qualified to do these complex assessments” and that we should “only allow skilled professionals to assess for ASD. [The] majority of clinicians who assess ASD do not have sufficient knowledge about ASD.” There were specific topics for training assessors, including “just because a kid makes eye contact, and maybe even laughs, doesn’t mean they aren’t [autistic]” and “latest research that includes experiences and voices of adult autistics”. Post-diagnosis, there was an expressed need to “teach [professionals] about ASD and how to help people and their family”.

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Appendix E – The Clinical Landscape of Autism Diagnosis in New Zealand

Taylor, L.J., Eggleston, M.J., Thabrew, H., van der Meer, L., Waddington, H., Whitehouse, A.J.O. & Evans, K. (2021). An investigation of adherence to best practice guidelines for autism diagnosis in New Zealand. *Autism*. 2021;25(7):2087-2100. doi:10.1177/13623613211015757

Link to the publication

<https://journals.sagepub.com/doi/abs/10.1177/13623613211015757>

Appendix F – Summary of Qualitative Themes from the Clinician Survey

Authors

Sasha Johnston, Larah van der Meer, Maryam Boutrus, Lauren Taylor, Andrew Whitehouse and Kiah Evans

Aim

The aim of the open-ended survey questions was to allow clinicians to provide additional information about the autism diagnostic process in New Zealand.

Method

Forty-three clinicians who completed the online survey provided open-ended responses on their training needs and/or general thoughts related to the autism diagnostic assessment process. Qualitative data were analysed thematically by one researcher and checked by two other researchers.

Results

Survey respondents identified a number of gaps in New Zealand's current diagnostic assessment process for autism. A lack of funding and resources was by far the chief concern, with clinicians describing how this led to poorer outcomes for families. Down-stream effects of inadequate funding included long wait times for assessment and support services (sometimes over 12 months), high costs for families, short appointments once families were seen, geographical discrepancies in service availability, and a lack of available training.

Issues regarding the jurisdiction of certain agencies were also reported, with frequent mention made of disagreements between district health boards and other government agencies over responsibility for diagnosis and/or support. Individuals with comorbidities were reportedly more likely to encounter difficulties in this regard, with one respondent describing how children diagnosed with both autism and ADHD were being referred to both CAMHS and paediatric services as CAMHS “do ADHD” and the latter “do ASD”. Another reported that paediatric services were “reluctant” to accept a referral if the child had already been seen by CAMHS, making it difficult for families to access necessary supports.

Families' difficulties in accessing support services "without a label" were also addressed, with one respondent describing the positive community response to their clinic offering an 'ASD-Incredible Years' program. This allowed families to access supports at the time of initial contact, rather than after a diagnostic assessment has been completed, in some cases resulting in over a year of extra early intervention for young children. In areas without access to such programs, clinicians reported lengthy wait times for necessary supports, even post-diagnosis. Respondents also highlighted how families from cultural backgrounds other than Pākehā lacked access to culturally specific services, with one clinician describing how families who spoke Te Reo Māori as their first language were not routinely offered interpreters as speakers of other languages would be.

Respondents reported a clear gap in the availability of adult assessment and support. Clinicians explained that adult diagnosis was not readily available through district health boards, leading to an "eclectic" diagnostic process for adults, usually through private service providers. The issue is reportedly compounded by a lack of "official guidelines" for adult diagnosis, coupled with clinicians' limited training and experience in identifying autism in adults. While adults were described as facing significant hurdles in accessing services, discrepancies in assessment were reportedly not limited to older people, with many also describing assessment for children as highly variable in terms of clinical judgement and processes followed.

Unsurprisingly, when asked about types of training they would like to access, clinicians recommended training in adult assessment and diagnosis. Training relating to specific diagnostic assessments was also suggested, with respondents interested in training on both the ADOS and a wider battery of tools. Training on recognising different presentations of autistic traits (including in females and those with trauma histories or other comorbidities) was also requested by clinicians. In terms of "cultural" training, responses referred to a variety of culture-related training, with some wanting to access professional development in culturally competent practice, while others were specifically interested in cultural perspectives of autism and child development, or in training addressing autism diagnosis in former refugee populations. Specific mention was also made of the 'Takarangi Competency Framework' and a desire for "cultural supervision". It was important to respondents that any training was made accessible, either by being held locally or online.

Appendix G – Summary of Qualitative Themes and Suggestions from the Workshops

Authors

Larah van der Meer, Sasha Johnston, Maryam Boutrus, Kirsty Herapath, Lauren Taylor, Andrew Whitehouse and Kiah Evans

Aim

The aim of the workshops was to obtain an initial understanding of the autism diagnosis and support landscape in New Zealand as well as inform development of the surveys.

Method

Three workshops for clinicians involved in the diagnosis and support of individuals on the autism spectrum were conducted in different locations across New Zealand. A total of 17 clinicians attended the workshops (two in Wellington, seven in Hamilton, and eight in Auckland). Participants included seven Psychologists, four Developmental Services / ASD Coordinators, two Psychiatrists, two End-User Service Managers, one Occupational Therapist, and one Researcher. The workshops included an initial presentation outlining the background and aims of the project. This was followed by discussion topics, including recommendations for the surveys, strategies to overcome barriers, positive and negative experiences of the diagnostic process in New Zealand, and diagnosis of individuals who come from a Māori background, live in remote areas, are female or adults. Qualitative analysis of workshop data involved summarising discussion points and colour coding according to the following set codes: intent/purpose of the research, language use, survey length/time, survey features, question content, and dissemination of the survey.

Results

Participant Suggestions to Inform Survey Development

Workshop participants indicated it was important for information about the survey to clearly communicate that it is a New Zealand led research project, with support from Australian researchers. They indicated it was necessary to collaborate with New Zealand researchers and Universities. Participants suggested the information sheet should clearly articulate that while challenges exist in autism diagnosis in New Zealand, this research is an opportunity to raise awareness and improve best practice in autism diagnosis and supports. Participants recommended making clear links to the New Zealand Guideline and obtaining endorsement from the Living Guideline Group for the research.

Participants recommended the use of simple language. In terms of autism specific language, they suggested using *takiwātanga*, the Māori name for autism, identity first language, and terms such as ‘autism spectrum’ or ‘on the spectrum’ instead of autism spectrum disorder. They also suggested the survey should be available in multiple languages. Participants recommended that the clinician survey be kept to a minimal time requirement, and that potential participants be advised of the expected completion time when they are invited to complete the survey. An online survey format with the ability to save and return later was recommended. However, it was also recommended that paper-based and interview formats be available. Participants emphasised the survey should be accessible, simple and user friendly, primarily with tick boxes and some optional free text comment boxes. Prizes for participation were recommended as an incentive to participate.

For the clinician survey, it was suggested that questions include confidence and competence, training and supervision as well as cultural perspectives in autism assessment. For the consumer survey, participants suggested questions include wait times, co-occurring conditions, and supports, differentiating between what is needed and what is accessed. It was also suggested that different questions are needed for adult diagnosis and that survey questions should address self-diagnosis. A multi-faceted, snowball approach to dissemination of the survey was recommended. For the clinician survey, this included asking relevant member bodies and professional organisations to distribute information about the survey. For the consumer survey, this included asking the autistic community to disseminate through their networks, including social media. It was suggested by some participants that time was needed to build relationships with the adult autistic community and Māori and Pacific peoples to ensure buy in for accurate data.

Participant Reflections on the Autism Diagnosis and Support Landscape

Workshop participants indicated that some aspects of the existing Guideline was working well, including the ability to involve families in assessments, the use of multi-disciplinary teams, and it being simple in nature and easy to read. Participants recommended the use of the ADOS assessment, as well as the app ‘ASDetect’. Conversely, several issues were raised in relation to New Zealand’s current diagnostic pathways and support services. These included a lack of follow up support post-diagnosis, inadequate resources and training, and inconsistent pathways for diagnosis and supports.

Participants felt that clinicians were generally aware of the content of the existing Guideline, but that implementation was an issue. Several potential reasons for this were suggested by participants, including a lack of resources and staff, and differing interpretations of the Guideline by clinicians. Participants suggested funding ongoing training for both clinicians and District Health

Boards. Discrepancies in the requirements of different agencies was also raised as an issue, with participants describing how agencies often disagreed with one another over the administration of diagnostic and support services, and the requirements for accessing each. Further, several groups adversely affected by the nature of currently available services were identified over the course of each workshop. These were adults, women, transgender people, people in rural areas, and Māori and Pacific families.

The need for training in adult diagnosis was emphasized, with some relaying stories of other clinicians' failure to recognise autistic traits in adult patients. Several suggestions were made for the support of autistic adults, or those querying an autism diagnosis. In particular, participants felt that support services for major life transitions (e.g. school to work or further study) and significant life events (such as the death of a parent) would be beneficial. Participants also recommended an increase in support for adults who were labelled as "high functioning", as many reported adults missing out on necessary supports due to their ability to function in some areas. Employment, relationships, and accessing higher education were suggested as potential areas of focus for such services.

Participants also felt that the diagnostic process was difficult for women and transgender people. It was suggested that separate diagnostic criterion reflecting the different presentations of autistic traits in women would be beneficial, and that the current criteria were a barrier to diagnosis for women and transgender people. It was also recommended that the supports available post-diagnosis be tailored to suit girls, women, and transgender people, as participants reported that these services generally cater to boys.

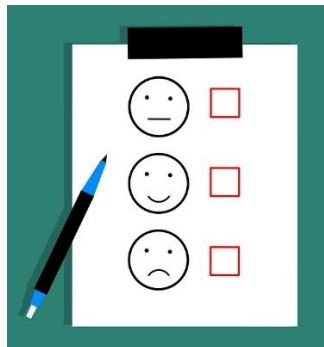
Participants felt that people living in rural areas faced a unique set of challenges when pursuing diagnosis or support. In particular, participants described how living in a more isolated location may contribute to feelings of despair at diagnosis due to the lack of accessible support services. As such, it was recommended that diagnosis was linked with support services, and that clinics providing multi-disciplinary services be set up in remote areas. Further, participants stated that rural areas often lacked suitably experienced clinicians, with some describing how diagnosis could take over three years due to the need to "import" specialists. In light of this, participants recommended strategies such as giving rural patients priority access to services in urban areas, creating incentives to entice clinicians to remote areas, programs that allowed local people to train and upskill, and using tele-health services to connect patients and professionals. Other suggestions included the use of travelling clinics and the potential to identify children with possible autism through preschools.

The challenges faced in providing quality services to Māori and Pacific families were also discussed by participants. Many described how following up with Māori families could be difficult, which was put down to prohibitive “circumstances” and families not wanting to engage with “the system”. Participants suggested that working with local iwi, the district health board, or other service providers with strong ties to the Māori community may allow clinicians more consistent contact with families through existing networks, and that employing key-workers could assist in building relationships with families. Marae-based consultations were also suggested, as was the use of Facebook to connect to networks of families. Participants felt that more time was often needed to provide quality services to Māori and Pacific families, and expressed concern that funding limited the amount of time available for each family. They also described how some Māori and Pacific families seemed to accept diagnosis more easily than some Pākehā families, perhaps due a cultural emphasis on accepting children “as they are”. This worldview is seen reflected in the Māori word for autism, ‘takiwātanga’, meaning “his or her own time and space”. The differences between iwi and individual families were also highlighted, with participants emphasising the need to ensure that generalisations were not applied to all Māori.

Several strategies for the implementation of a national autism diagnosis and assessment guideline were suggested. Participants recommended that consistent supervision be used to ensure that any new guideline recommendations were put into practice, with the suggestion made that this be linked to professional registrations. Further, a lack of funding and weak links between diagnostic and support services were suggested as barriers to successful implementation, with participants recommending improvements in these areas. Flexibility in catering assessments to individual needs and accessibility for minority groups were both raised as important considerations. Participants recommended the use of an ecological approach, ensuring information was available to clinicians regarding culture, age, and medical histories so that appropriate accommodations could be made. The need for community approval was also highlighted, with participants suggesting this could be increased through a combination of clear, concise guideline recommendations, frequent contact with the autism community, and opportunities for workshops and professional development.

Appendix H – Autistic Adult and Caregiver Survey

We want your feedback!!



Invitation:

You are invited to participate in a project to review autism spectrum disorder (ASD)/takiwātanga diagnostic processes in New Zealand.

What are the aims of the research?

Autism New Zealand is doing this research to better understand ASD diagnostic and follow-up care. Our aim is for this research to be a first step in helping people gain earlier consistent, quality diagnosis and support.

What does participation involve?

Completing an online survey. The survey has up to 40 questions and will take up to 20 minutes to complete.

You can go in the draw to win one of 30 \$50 Prezzy Cards.

Who can participate?

To participate in the survey, you will need to be:

- A person diagnosed with autism during adulthood; or
- A parent/primary caregiver of a person diagnosed with autism

Your diagnosis needs to have been made in New Zealand in the last 10 years.

Your privacy

Completing the survey is completely anonymous.

Further information

If you would like further information, please read the Additional Information below. If you would like to talk about any aspect of this study, please contact:

Kirsty Herapath (Project Coordinator)

Ph. (04) 803 3501

Email. research@autismnz.org.nz.

Thank you for your participation!

Please follow this link to complete the survey:

https://www.surveymonkey.com/r/Consumer_Survey

Additional Information

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Project Title: Autism Spectrum Disorder Diagnostic Processes in New Zealand

Aim of the research

The New Zealand Autism Spectrum Disorder Guideline was published in 2008 and a second edition released in 2016. It is updated annually on specific topics by the Living Guideline Group. The Guideline provides recommendations for best practice in the diagnosis and initial assessment of ASD. This research project aims to gain an understanding of current diagnostic processes and implementation of the Guideline recommendations. This project builds on previous research investigating parents' and District Health Board perspectives of diagnostic practices in New Zealand. Our key objectives are to:

- 1) Describe individual, family, and clinician perspectives on ASD diagnostic and follow-up practices in New Zealand and;
- 2) Inform recommendations for improving best practice in the diagnosis and care of New Zealand individuals with ASD.

Who is doing the research?

This project is a collaboration between Autism New Zealand, the University of Auckland, and Canterbury District Health Board as well as researchers from the University of Western Australia and Kings College London who have completed a similar project in Australia. It is funded by the Co-Operative Research Centre for Living with Autism Spectrum Disorders (Autism CRC).

Research Team:

Dane Dougan (Chief Executive, Autism New Zealand)
Dr Larah van der Meer (PhD, Project Leader, Autism New Zealand; Adjunct Research Fellow Victoria University of Wellington)
Kirsty Herapath (Project Coordinator, Autism New Zealand)
Dr Hiran Thabrew (Child and Adolescent Psychiatrist, Paediatrician, Senior Lecturer, The University of Auckland)
Dr Matthew Eggleston (Child and Adolescent Psychiatrist, Canterbury District Health Board)
Professor Andrew Whitehouse (PhD, Speech Pathologist, The University of Western Australia; Chief Research Officer Autism CRC)
Dr Kiah Evans (PhD, Occupational Therapist, The University of Western Australia)
Dr Lauren Taylor (PhD, Kings College London)

What does participation involve?

Survey items cover topics such as the diagnostic process, length of time an ASD diagnosis takes, and services that an individual may be eligible for following an ASD diagnosis.

If you are unable to complete the survey online, you have the option of providing your responses via a hard copy survey interview (during a telephone or face-to-face meeting, where information will be collected as an audio recording or written notes according to your preference). We will also endeavour to support completion of the survey in another language upon request. If you would like to complete the survey in an alternative format, please contact Kirsty Herapath (Project Coordinator) on **(04) 803 3501** or research@autismnz.org.nz.

If you wish to receive a copy of the survey results and/or to enter the draw to win one of 30 \$50 Prezzy Cards, details will be provided at the end of the survey.

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How will the research results be used?

The results of this survey will be submitted for publication in an international peer-reviewed journal and may be presented at a national or international conference. A report outlining the research findings and recommendations will also be submitted to the Ministry of Health and the NZ ASD Guideline's Living Guideline Group.

Ethics approval

Approval to conduct this research has been provided by the New Zealand Ethics Committee (NZEC18_28), in accordance with its ethics review and approval procedures. If you have any questions regarding ethics, you can visit www.nzethics.com or email Dr Lily George, Chair, on chair@nzethics.com

Your privacy

Completion of the survey will be anonymous. At the end of the survey we will ask you to indicate your willingness for the research team to contact you to gather further information related to this project. If you provide consent for future contact, we will ask you to complete a separate online questionnaire at the end of this survey to obtain your contact details. Your contact details cannot be linked to your survey responses. Your survey responses will remain anonymous and your contact details will remain confidential.

The data will be kept on a secure computer for a minimum of seven years. Any paper questionnaires will be stored in a locked filing cabinet. Data will only be accessed by members of the research team.

Voluntary participation and withdrawal from the study

Participation in this research is voluntary and completing the survey is considered evidence of consent to participate in the study. Because survey responses are anonymous, you cannot withdraw your consent to participate after submitting your survey responses. There will be no consequences associated with your decision regarding participation in this research study.

Possible benefits

This research will provide further evidence of current diagnostic practices, including possible service gaps and variation in practice, as well as direct efforts to ensure current best practice.

Possible risks and risk management plan

To minimise the risk of participant or service identification, results will only be presented at a regional or national level. No other risks of participation are anticipated.

Sincerely,
Research Project Team:

With thanks to the Autism New Zealand Expert Panel, Autism New Zealand Consumer Panel, as well as clinicians, researchers, autistic adults, and parents of children diagnosed with autism who provided feedback in development of the survey

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The survey

The survey will remain open for 4 weeks. If you do not finish the survey in one sitting, you are able to return to it at a later time 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 responses. Your previous responses will be unchanged. **All questions are optional, you do not have to answer questions that you do not want to.**

This survey includes several question types. If you are unable to give an exact response for questions that ask for a number response, please give an approximation.

Please note: If you would like to complete this survey for your own diagnosis as well as the diagnosis for the individual(s) you care for, please complete the survey separately for each person. If you have pursued more than one diagnostic pathway either for yourself or the individual(s) you care for, please complete the survey based on the latest diagnostic assessment you have received. You are welcome to complete the survey a second time for another diagnosis you have pursued.

If you would like to complete the survey a second time a new link will be provided at the end of this survey.

Thank you for taking the time to complete this survey.

1. Which of the following applies to you?

- ☐ I am the parent/primary caregiver for a person with a diagnosis of autism
- ☐ I was diagnosed with autism

1a. If you have a diagnosis or care for someone with a diagnosis of autism was the diagnosis made in New Zealand?

- ☐ Yes
- ☐ No (Thank you for agreeing to participate in this research. Unfortunately, because the diagnosis was not made in New Zealand, you are not eligible to complete the survey.)

1b. In what year was the diagnosis of autism made?

- ☐ Before 2009 (Thank you for agreeing to participate in this research. Unfortunately, because the diagnosis was not made in the last 10 years, you are not eligible to complete the survey.)
- ☐ 2009
- ☐ 2010
- ☐ 2011
- ☐ 2012
- ☐ 2013
- ☐ 2014
- ☐ 2015
- ☐ 2016
- ☐ 2017
- ☐ 2018

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1.0. Caregivers of people diagnosed with autism

Please complete this survey if you selected: ***I am the primary caregiver for a person with a diagnosis of autism.***

Demographic information:

These questions will ask for demographic information about yourself and the person you care for.

2. What is your relationship to the person with autism that you care for?

- ☐ I am their parent
- ☐ I am their grandparent
- ☐ I am their sibling
- ☐ I am their child
- ☐ I am their spouse
- ☐ Other (please specify) _____

3. What is the gender of the person with autism who you care for?

- ☐ Male
- ☐ Female
- ☐ Gender diverse

4. Which ethnic group does the person with autism that you care for you belong to? (Select all that apply)

- ☐ New Zealand European
- ☐ Māori
- ☐ Samoan
- ☐ Cook Island Māori
- ☐ Tongan
- ☐ Niuean
- ☐ Chinese
- ☐ Indian
- ☐ Other such as DUTCH, JAPANESE, TOKOLAUAN. Please state: _____

First queries and help sought

These questions will ask about the help you sought when you or someone else first had queries about a possible autism diagnosis for the person you care for.

5. Who first had queries about a possible autism diagnosis for the person you care for?

- ☐ Myself
- ☐ Health professional
- ☐ Family/whānau/friend
- ☐ Other (please specify) _____
- ☐ Unsure

6. How did you find out about the pathway to pursue a diagnosis? (Select all that apply)

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- ☐ Health Professional
- ☐ Early Childhood/School Staff
- ☐ NGO Autism organisation
- ☐ Website
- ☐ Social media
- ☐ Personal networks
- ☐ Other (please specify) _____
- ☐ Unsure

7. How old was the person you care for when queries were first raised about a possible diagnosis? (Please estimate)

Years: ____ Months: ____

8. How old was the person you care for when you first sought a diagnosis? (Please estimate)

Years: ____ Months: ____

9. Who did you see when you first sought a diagnosis? (Select all that apply)

- ☐ Well Child/Tamariki Ora/Plunket nurse
- ☐ General Practitioner (GP)
- ☐ Paediatrician
- ☐ Psychiatrist
- ☐ Psychologist
- ☐ Speech Language Therapist
- ☐ Occupational Therapist
- ☐ Social Worker
- ☐ Nurse
- ☐ Early Childhood/School Staff
- ☐ Other (please specify) _____
- ☐ Unsure

10. What was the outcome of this? (Select all that apply)

- ☐ Autism diagnosis made
- ☐ Given an alternative diagnosis (e.g., Developmental delay, ADHD, Dyspraxia, etc.)
- ☐ Referred to another professional
- ☐ Referred for tests (e.g., audiology)
- ☐ Told "no problem" or not to worry (e.g., "they'll grow out of it")
- ☐ Told to return if problems did not improve
- ☐ Cannot recall the outcome
- ☐ Other (please specify) _____

11. Overall, how satisfied were you with the experience of this initial help?

Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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12. How many professionals did you see regarding a possible autism diagnosis between seeing the first professional and the final assessment when the autism diagnosis was made?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6 or more
- ☐ Unsure

13. How clear do you think the pathway to pursue a diagnosis is?

Very unclear	Unclear	Neutral	Clear	Very clear
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Autism spectrum disorder diagnosis

These questions will ask about the assessment processes when you sought a diagnosis for the person you care for.

14. How old was the person you care for at the time of diagnosis?

Years: ____ Months: ____

14.1. If the person you care for was diagnosed before the age of 20, was a Developmental Services/ASD Coordinator involved in the diagnostic process?

- ☐ Yes, only before diagnosis
- ☐ Yes, only after diagnosis
- ☐ Yes, before and after diagnosis
- ☐ No
- ☐ Unsure

15. How long did the person you care for wait for their initial diagnostic assessment appointment?

< 1 month	1-3 months	4-6 months	7-12 months	1-2 years	> 2 years
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. How long did the diagnosis take, from the initial appointment to the delivery of the diagnosis?

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1-2 weeks	3-4 weeks	1-3 months	4-6 months	7-12 months	> 1 year
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

17. What was the region where you lived at the time of the diagnostic assessment?

- ☐ Northland
- ☐ Auckland
- ☐ Waikato
- ☐ Bay of Plenty
- ☐ Gisborne
- ☐ Hawke's Bay
- ☐ Taranaki
- ☐ Manawatu-Wanganui
- ☐ Wellington
- ☐ Tasman
- ☐ Nelson
- ☐ Marlborough
- ☐ West Coast
- ☐ Canterbury
- ☐ Otago
- ☐ Southland
- ☐ Area outside region (Chatham Island Territory; Area outside Territorial Authority)

18. How far did you have to travel for the diagnostic assessment (return trip)?

- ☐ Less than one hour
- ☐ 1 – 2 hours
- ☐ 3 – 4 hours
- ☐ 4 – 5 hours
- ☐ More than 5 hours
- ☐ Unsure
- ☐ Assessment occurred at my home

19. What service setting was the diagnostic assessment completed through?

- ☐ Public
- ☐ Private
- ☐ Both
- ☐ Unsure

19.1 What were some of the major reasons that led to your decision to follow this pathway? (Select all that apply)

- ☐ I was not aware of other options
- ☐ I was referred to this service by a professional
- ☐ This service was recommended by family/whānau/friend/colleague/acquaintance
- ☐ I wanted the assessment to be with a particular professional
- ☐ I believed there would be better service
- ☐ Shorter wait time
- ☐ Cost (i.e., more affordable)

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- ☐ Confidentiality or privacy concerns
- ☐ Other (please specify) _____

19.2. If you had a private diagnostic assessment, what was the estimated cost you had to pay? (Only select the options that apply best).

- ☐ Hourly rate: \$ _____
 - ☐ Total number of hours for the assessment: _____
- ☐ Cost for initial session: \$ _____
- ☐ Cost per session: \$ _____
 - ☐ Total number of sessions for the assessment: _____
- ☐ Cost for report writing: \$ _____
- ☐ Total cost for the diagnostic assessment: \$ _____

20. Which professionals contributed to the assessment process for a diagnosis? (Select all that apply)

- ☐ Paediatrician
- ☐ Psychiatrist
- ☐ Psychologist
- ☐ Speech Language Therapist
- ☐ Occupational Therapist
- ☐ Physiotherapist
- ☐ Audiologist or Hearing Specialist
- ☐ Social Worker
- ☐ Nurse
- ☐ Early Childhood/School Staff
- ☐ Other (please specify) _____
- ☐ Unsure

21. Did you have a feedback appointment to receive and review the diagnosis?

- ☐ Yes
- ☐ No
- ☐ Unsure

21.1. If you answered Yes to Question 21, how satisfied were you with the manner of the professional disclosing the diagnosis?

Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

22. Did you receive a written diagnostic report?

- ☐ Yes
- ☐ No
- ☐ Unsure

23. Which of the following cultural supports were available during the diagnostic process? (Select all that apply)

- ☐ Kaiārahi/guide or other cultural worker
- ☐ Information about autism in languages other than English
- ☐ No cultural support
- ☐ Not applicable

24. Overall, how satisfied were you with the professionals' ability to be sensitive to your cultural needs throughout the diagnostic process?

Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	Not applicable
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. Have you pursued a "second opinion" for the diagnosis (i.e., after having a previous assessment from another diagnostic service)?

- ☐ Yes
- ☐ No

25.1. If you answered Yes to Question 25, for which of the following reasons did you pursue a "second opinion"? (Select all that apply)

- ☐ Given an autism diagnosis that I did not agree with
- ☐ Was not given an autism diagnosis
- ☐ Given an alternative diagnosis (e.g., Developmental delay, ADHD, Dyspraxia, etc.)
- ☐ Told "no problem" or not to worry (e.g., "they'll grow out of it")
- ☐ Told to return if problems did not improve
- ☐ Child was too young
- ☐ Complex diagnosis
- ☐ Other (please describe) _____

26. Overall, how satisfied were you with the diagnostic process as a whole?

Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27. Overall, how stressful did you find the diagnostic process to be?

Very stressful	Quite stressful	Neutral	Not very stressful	Not at all stressful
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Post diagnostic support

These questions will ask about the supports that you and/or the person you care for received after obtaining a diagnosis.

28. After obtaining the diagnosis, how satisfied were you with each of the following services and/or resources?

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	Required but not received	Not relevant
Written information about ASD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Counselling to adjust to ASD diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ASD education programme	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cultural support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NGO Autism Organisation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disability allowance (Work and Income)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Needs Assessment Service Coordination (NASC)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ministry of Education early intervention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ministry of Education learning support (school teams)	<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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Vocational support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Multidisciplinary service (e.g., speech language therapy, music therapy and physiotherapy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify) -----	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

29. After obtaining the diagnosis, how satisfied were you with supports for each of the following areas?

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	Required but not received	Not relevant
Communication (e.g., speech and language therapy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social (e.g., social skills training)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Behaviour (e.g., specialist behaviour support; Applied Behaviour Analysis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eating and drinking (e.g., food sensitivities)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gut health (gastrointestinal complaints)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bowel and bladder (toileting issues)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical movement	<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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(e.g., physiotherapy)							
Sensory (e.g., sensory processing difficulties)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health (e.g., anxiety, depression)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep (sleep problems)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cognition (e.g., specific learning issues)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medication (e.g., anxiety, sleep, ADHD)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify) -----	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. Overall, how satisfied were you with the support offered post-diagnosis?

Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	Didn't receive support
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

31. Overall, how well coordinated did you think the supports were?

Very uncoordinated	Uncoordinated	Neutral	Coordinated	Very coordinated	Didn't receive support
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Open-ended questions

32. How can the autism diagnostic assessment process in New Zealand be improved?

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33. What is working well with the autism diagnostic assessment process in New Zealand?

Please follow the link below to provide contact details if:

- ☐ You would be willing for us to contact you in the future, if we seek further information relevant to this research project
- ☐ You would be willing for us to contact you in the future to be invited to participate in other autism-related research projects
- ☐ You would like a copy of the results of the research project
- ☐ You would like to go in the draw to win one of 30 \$50 Prezzy Cards

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:

https://www.surveymonkey.com/r/Consumer_Contact_Information

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2.0. People diagnosed with autism during adulthood

Please complete this survey if you selected: ***I have a diagnosis of autism.***

Demographic information:

These questions will ask for demographic information about yourself.

2. What is your gender?

- ☐ Male
- ☐ Female
- ☐ Gender diverse

3. Which ethnic group do you belong to? (Select all that apply)

- ☐ New Zealand European
- ☐ Māori
- ☐ Samoan
- ☐ Cook Island Māori
- ☐ Tongan
- ☐ Niuean
- ☐ Chinese
- ☐ Indian
- ☐ Other such as DUTCH, JAPANESE, TOKOLAUAN. Please state: _____

First queries and help sought

These questions will ask about the help that was sought when you or someone else first had queries about a possible autism diagnosis.

4. Who first had queries about a possible autism diagnosis?

- ☐ Myself
- ☐ Health professional
- ☐ Family/whānau/friend
- ☐ Other (please specify) _____
- ☐ Unsure

5. How did you find out about the pathway to pursue a diagnosis? (Select all that apply)

- ☐ Health Professional
- ☐ NGO Autism organisation
- ☐ Website
- ☐ Social media
- ☐ Personal networks
- ☐ Other (please specify) _____
- ☐ Unsure

6. How old were you when queries were first raised about a possible diagnosis? (Please estimate)

Years: ____ Months: ____

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7. How old were you when you first sought a diagnosis? (Please estimate)

Years: ____ Months: ____

8. Who did you see when you first sought a diagnosis? (Select all that apply)

- ☐ General Practitioner (GP)
- ☐ Psychiatrist
- ☐ Psychologist
- ☐ Speech Language Therapist
- ☐ Occupational Therapist
- ☐ Social Worker
- ☐ Nurse
- ☐ Other (please specify) _____
- ☐ Unsure

9. What was the outcome of this? (Select all that apply)

- ☐ Autism diagnosis made
- ☐ Given an alternative diagnosis (e.g., ADHD, anxiety, depression etc.)
- ☐ Referred to another professional
- ☐ Told “no problem” or not to worry (e.g., “you’re fine now”)
- ☐ Told to return if problems did not improve
- ☐ Cannot recall the outcome
- ☐ Other (please specify) _____

10. Overall, how satisfied were you with the experience of this initial help?

Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Optional Comment: _____

11. How many professionals did you see regarding a possible autism diagnosis between seeing the first professional and the final assessment when the autism diagnosis was made?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6 or more
- ☐ Unsure

12. How clear do you think the pathway to pursue a diagnosis is?

Very unclear	Unclear	Neutral	Clear	Very clear
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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Optional Comment: _____

Autism spectrum disorder diagnosis

These questions will ask about the assessment processes when you sought a diagnosis.

13. How old were you at the time of diagnosis?

Years: ____ Months: ____

14. How long did you wait for your initial diagnostic assessment appointment?

< 1 month	1-3 months	4-6 months	7-12 months	1-2 years	> 2 years
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. How long did the diagnosis take, from the initial appointment to the delivery of the diagnosis?

1-2 weeks	3-4 weeks	1-3 months	4-6 months	7-12 months	> 1 year
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. What was the region where you lived at the time of the diagnostic assessment?

- ☐ Northland
- ☐ Auckland
- ☐ Waikato
- ☐ Bay of Plenty
- ☐ Gisborne
- ☐ Hawke's Bay
- ☐ Taranaki
- ☐ Manawatu-Wanganui
- ☐ Wellington
- ☐ Tasman
- ☐ Nelson
- ☐ Marlborough
- ☐ West Coast
- ☐ Canterbury
- ☐ Otago
- ☐ Southland
- ☐ Area outside region (Chatham Island Territory; Area outside Territorial Authority)

17. How far did you have to travel for the diagnostic assessment (return trip)?

- ☐ Less than one hour
- ☐ 1 – 2 hours
- ☐ 3 – 4 hours
- ☐ 4 – 5 hours

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- ☐ More than 5 hours
- ☐ Unsure
- ☐ Assessment occurred at my home

18. What service setting was the diagnostic assessment completed through?

- ☐ Public
- ☐ Private
- ☐ Both
- ☐ Unsure

18.1 What were some of the major reasons that led to your decision to follow this pathway? (Select all that apply)

- ☐ I was not aware of other options
- ☐ I was referred to this service by a professional
- ☐ This service was recommended by family/whānau/friend/colleague/acquaintance
- ☐ I wanted the assessment to be with a particular professional
- ☐ I believed there would be better service
- ☐ Shorter wait time
- ☐ Cost (i.e., more affordable)
- ☐ Confidentiality or privacy concerns
- ☐ Other (please specify) _____

18.2. If you had a private diagnostic assessment, what was the estimated cost you had to pay? (Only select the options that apply best).

- ☐ Hourly rate: \$ _____
 - ☐ Total number of hours for the assessment: _____
- ☐ Cost for initial session: \$ _____
- ☐ Cost per session: \$ _____
 - ☐ Total number of sessions for the assessment: _____
- ☐ Cost for report writing: \$ _____
- ☐ Total cost for the diagnostic assessment: \$ _____

19. Which professionals contributed to the assessment process for a diagnosis? (Select all that apply)

- ☐ Psychiatrist
- ☐ Psychologist
- ☐ Speech Language Therapist
- ☐ Occupational Therapist
- ☐ Physiotherapist
- ☐ Social Worker
- ☐ Nurse
- ☐ Other (please specify) _____
- ☐ Unsure

20. Did you have a feedback appointment to receive and review the diagnosis?

- ☐ Yes
- ☐ No

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☐ Unsure

20.1. If you answered Yes to Question 20, how satisfied were you with the manner of the professional disclosing the diagnosis?

Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Optional Comment: _____

21. Did you receive a written diagnostic report?

- ☐ Yes
☐ No
☐ Unsure

22. Which of the following cultural supports were available during the diagnostic process? (Select all that apply)

- ☐ Kaiārahi/guide or other cultural worker
☐ Information about autism in languages other than English
☐ No cultural support
☐ Not applicable

23. Overall, how satisfied were you with the professionals' ability to be sensitive to your cultural needs throughout the diagnostic process?

Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	Not applicable
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Optional Comment: _____

24. Have you pursued a "second opinion" for the diagnosis (i.e., after having a previous assessment from another diagnostic service)?

- ☐ Yes
☐ No

24.1. If you answered Yes to Question 24, for which of the following reasons did you pursue a "second opinion"? (Select all that apply)

- ☐ Given an autism diagnosis that I did not agree with
☐ Was not given an autism diagnosis
☐ Given an alternative diagnosis (e.g., ADHD, anxiety, depression etc.)
☐ Told "no problem" or not to worry
☐ Told to return if problems did not improve
☐ Complex diagnosis
☐ Other (please describe) _____

25. Overall, how satisfied were you with the diagnostic process as a whole?

Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Optional Comment: _____

26. Overall, how stressful did you find the diagnostic process to be?

Very stressful	Quite stressful	Neutral	Not very stressful	Not at all stressful
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Optional Comment: _____

Post diagnostic support

These questions will ask about the supports that you received after obtaining a diagnosis.

27. After obtaining the diagnosis, how satisfied were you with each of the following services and/or resources?

	Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	Required but not received	Not relevant
Written information about ASD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Counselling to adjust to ASD diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ASD education programme	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cultural support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NGO Autism Organisation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disability allowance (Work and Income)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Needs Assessment Service Coordination (NASC)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vocational support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Multidisciplinary service (e.g., speech language therapy, music therapy and physiotherapy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify) -----	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

28. After obtaining the diagnosis, how satisfied were you with supports for each of the following areas?

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	Required but not received	Not relevant
Communication (e.g., speech and language therapy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social (e.g., social skills training)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Behaviour (e.g., specialist behaviour support)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gut health (gastrointestinal complaints)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical movement (e.g., physiotherapy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sensory (e.g., sensory processing difficulties)	<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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Mental health (e.g., anxiety, depression)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep (sleep problems)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cognition (e.g., specific learning issues)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medication (e.g., anxiety, sleep, ADHD)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify) -----	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

29. Overall, how satisfied were you with the support offered post-diagnosis?

Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	Didn't receive support
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Optional Comment: _____

30. Overall, how well coordinated did you think the supports were?

Very uncoordinated	Uncoordinated	Neutral	Coordinated	Very coordinated	Didn't receive support
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Optional Comment: _____

Open-ended questions

31. How can the autism diagnostic assessment process in New Zealand be improved?

32. What is working well with the autism diagnostic assessment process in New Zealand?

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- ☐ You would be willing for us to contact you in the future to be invited to participate in other autism-related research projects
- ☐ You would like a copy of the results of the research project
- ☐ You would like to go in the draw to win one of 30 \$50 Prezzy Cards

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

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Appendix I – Clinician Survey

Project Title: Autism Spectrum Disorder Diagnostic Processes in New Zealand

Research Team: **Dane Dougan** (Chief Executive, Autism New Zealand)
Dr Larah van der Meer (PhD, Project Leader, Autism New Zealand; Adjunct Research Fellow Victoria University of Wellington)
Kirsty Herapath (Project Coordinator, Autism New Zealand)
Dr Hiran Thabrew (Child and Adolescent Psychiatrist, Paediatrician, Senior Lecturer, The University of Auckland)
Dr Matthew Eggleston (Child and Adolescent Psychiatrist, Canterbury District Health Board)
Professor Andrew Whitehouse (PhD, Speech Pathologist, The University of Western Australia; Chief Research Officer Autism CRC)
Dr Kiah Evans (PhD, Occupational Therapist, The University of Western Australia)
Dr Lauren Taylor (PhD, Kings College London)

Invitation:

You are invited to participate in a project to review clinician perspectives on autism spectrum disorder (ASD)/takiwātanga diagnostic processes in New Zealand.

Who is undertaking the research?

This project is a collaboration between Autism New Zealand, the University of Auckland, and Canterbury District Health Board, as well as researchers from the University of Western Australia and Kings College London who have completed a similar project in Australia. It is funded by the Co-Operative Research Centre for Living with Autism Spectrum Disorders (Autism CRC).

What are the aims of the research?

The New Zealand Autism Spectrum Disorder Guideline was published in 2008 and a second edition released in 2016. It is updated annually on specific topics by the Living Guideline Group. The Guideline provides recommendations for best practice in the diagnosis and initial assessment of ASD. This research project aims to gain an understanding of current diagnostic processes and implementation of the Guideline recommendations. This project builds on previous research investigating parents' and District Health Board perspectives of diagnostic practices in New Zealand. Our key objectives are to:

- 1) Describe clinician perspectives on ASD diagnostic and follow-up practices in New Zealand and;
- 2) Inform recommendations for improving best practice in the diagnosis and care of New Zealand individuals with ASD.

What does participation involve?

You will be asked to complete an online survey of diagnostic and follow-up practices for individuals with ASD. To participate in this survey, you will need to be a clinician actively involved in the diagnosis of ASD working in the public sector or private practice in New Zealand.

Survey items cover topics such as the diagnostic process, length of time an ASD diagnosis takes, and services that an individual may be eligible for following an ASD diagnosis. The survey contains 38 questions and will take up to 20 minutes to complete.

If you are unable to complete the survey online, you have the option of providing your responses via a hard copy survey interview (during a telephone or face-to-face meeting, where

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information will be collected as an audio recording or written notes according to your preference). We will also endeavour to support completion of the survey in another language upon request. If you would like to complete the survey in an alternative format, please contact Kirsty Herapath (Project Coordinator) on **(04) 803 3501** or research@autismnz.org.nz.

If you wish to receive a copy of the survey results and/or to enter the draw to win one of 10 \$50 Prezzy Cards, details will be provided at the end of the survey.

How will the research results be used?

The results of this survey will be submitted for publication in an international peer-reviewed journal and may be presented at a national or international conference. A report outlining the research findings and recommendations will also be submitted to the Ministry of Health and the NZ ASD Guideline's Living Guideline Group.

Ethics approval

Approval to conduct this research has been provided by the New Zealand Ethics Committee (NREC18_28), in accordance with its ethics review and approval procedures. If you have any questions regarding ethics, you can visit www.nzethics.com or email Dr Lily George, Chair, on chair@nzethics.com

Your privacy

Completion of the survey will be anonymous. At the end of the survey we will ask you to indicate your willingness for the research team to contact you to gather further information related to this project. If you provide consent for future contact, we will ask you to complete a separate online questionnaire at the end of this survey to obtain your contact details. Your contact details cannot be linked to your survey responses. Your survey responses will remain anonymous and your contact details will remain confidential.

The data will be kept on a secure computer for a minimum of seven years. Any paper questionnaires will be stored in a locked filing cabinet. Data will only be accessed by members of the research team.

Voluntary participation and withdrawal from the study

Participation in this research is voluntary and completing the survey is considered evidence of consent to participate in the study. Because survey responses are anonymous, you cannot withdraw your consent to participate after submitting your survey responses. There will be no consequences associated with your decision regarding participation in this research study.

Possible benefits

This research will provide further evidence of current diagnostic practices, including possible service gaps and variation in practice, as well as direct efforts to ensure current best practice.

Possible risks and risk management plan

To minimise the risk of participant or service identification, results will only be presented at a regional or national level. No other risks of participation are anticipated.

Contacts

If you would like to discuss any aspect of this study, please feel free to contact Kirsty Herapath (Project Coordinator) on **(04) 803 3501** or research@autismnz.org.nz.

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Sincerely,
Research Project Team

With thanks to the Autism New Zealand Expert Panel, Autism New Zealand Consumer Panel, INSIGHT Research, as well as clinicians, researchers, autistic adults, and parents of children diagnosed with autism who provided feedback in development of the survey.

Please follow this link to complete the survey:
https://www.surveymonkey.com/r/Survey_Clinicians

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The survey

The survey will remain open for 4 weeks. If you do not finish the survey in one sitting, you are able to return to it at a later time 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 responses. Your previous responses will be unchanged.

All questions are optional, you do not have to answer questions that you do not want to.

Thank you for taking the time to complete this survey.

Are you currently involved in the diagnosis of ASD in New Zealand?

- ☐ Yes
- ☐ No (Thank you for agreeing to participate in this research. Unfortunately, because you are not involved in ASD diagnostic assessments in a New Zealand setting, you are not eligible to complete the survey.)

Background Information

The first series of questions will ask about your profession and workplace. Completion of the survey is anonymous. Results will only be presented at a regional or national level to further minimise the risk of participant or service identification.

1. What is your professional discipline? (Select all that apply)

- ☐ General Practitioner
- ☐ Developmental Paediatrician
- ☐ Paediatrician
- ☐ Child Psychiatrist
- ☐ Adult Psychiatrist
- ☐ Psychologist
- ☐ Counselling Psychologist
- ☐ Clinical Psychologist
- ☐ Educational Psychologist
- ☐ Neuropsychologist
- ☐ Speech Language Therapist
- ☐ Occupational Therapist
- ☐ Other (please specify) _____

2. In which of the following service settings do you practice?

- ☐ Private
- ☐ Public
- ☐ Both

2a. If you answered Both to Question 2, please complete this survey based on **one** setting. Please indicate which setting you are completing this survey for. You are welcome to complete the survey a second time for the other service setting you work in.

- ☐ Private

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☐ Public

3. In which region do you currently practice?

- ☐ Northland
- ☐ Auckland
- ☐ Waikato
- ☐ Bay of Plenty
- ☐ Gisborne
- ☐ Hawke's Bay
- ☐ Taranaki
- ☐ Manawatu-Wanganui
- ☐ Wellington
- ☐ Tasman
- ☐ Nelson
- ☐ Marlborough
- ☐ West Coast
- ☐ Canterbury
- ☐ Otago
- ☐ Southland
- ☐ Area outside region (Chatham Island Territory; Area outside Territorial Authority)

4. How frequently do you assess the following individuals for an ASD diagnosis? Please also indicate if you consider that you have a specific area of expertise in relation to any of these populations.

	Do not assess	Occasionally assess	Sometimes assess	Frequently assess	Specific area of expertise
0 – 5 years	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6 – 12 years	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13 – 18 years	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adults	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Male	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Female	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gender diverse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. How frequently do you see the following severity categories for ASD diagnoses? Please also indicate if you consider that you have a specific area of expertise in relation to any of these severity ratings.

	Do not assess	Occasionally assess	Sometimes assess	Frequently assess	Specific area of expertise
DSM-5 Severity Level 1 (mild; or equivalent severity description)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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DSM-5 Severity Level 2 (moderate; or equivalent severity description)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
DSM-5 Severity Level 3 (severe; or equivalent severity description)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

New Zealand Autism Spectrum Disorder Guideline

This series of questions will ask about your knowledge and implementation of the New Zealand Autism Spectrum Disorder Guideline.

6. How familiar are you with the New Zealand Autism Spectrum Disorder Guideline?

Not at all familiar	Slightly familiar	Somewhat familiar	Moderately familiar	Extremely familiar
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7. How closely to you believe you follow the Guideline recommendations for diagnosis and initial assessment of ASD?

Not at all closely	Slightly closely	Somewhat closely	Moderately closely	Extremely closely
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7a. Please provide any other comments on how the Guideline is used in your service

Assessment Process

This series of questions will ask for details about your team and assessment processes that you have adopted within your practice/ASD diagnostic assessment service.

8. How do you currently provide a diagnostic assessment service for individuals with suspected ASD? (Select all that apply)

- ☐ As a sole practitioner
- ☐ As part of a multidisciplinary team within your organisation
- ☐ As part of a multidisciplinary team with professionals from other organisations (including sole practitioners)
- ☐ Other (please describe) _____

8a. If you work in a multidisciplinary team, which of the following professionals are included in your team? (Select all that apply)

- ☐ Paediatrician
- ☐ Developmental Paediatrician
- ☐ Child Psychiatrist
- ☐ Adult Psychiatrist
- ☐ Psychologist

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- ☐ Counselling Psychologist
- ☐ Clinical Psychologist
- ☐ Educational Psychologist
- ☐ Neuropsychologist
- ☐ Speech Language Therapist
- ☐ Occupational Therapist
- ☐ Physiotherapist
- ☐ Social Worker
- ☐ Nurse
- ☐ ASD/Developmental Services Coordinator
- ☐ Other (please specify) _____

8b. If you work in a multidisciplinary team, how does your diagnostic assessment service usually work? (Select all that apply)

- ☐ Independently, i.e. professionals conduct the assessment and reach a diagnosis without any interdisciplinary input
- ☐ In collaboration, i.e. each clinician conducts an independent assessment, but all assessors meet to make a consensus diagnostic decision.
- ☐ Together, i.e. all professionals see the individual together and come to a consensus diagnostic decision
- ☐ Other (please describe) _____

8c. In which of the following circumstances would you not conduct a multidisciplinary team assessment? (Select all that apply)

- ☐ Not part of everyday practice
- ☐ Individual too young
- ☐ Individual too old
- ☐ 'Frank presentation' (confirming diagnosis is straightforward)
- ☐ Clinicians not available
- ☐ Individual has had a partial assessment from another diagnostic service
- ☐ Individual and/or whānau/family has requested a single clinician only
- ☐ Other (please describe) _____
- ☐ I always conduct a multidisciplinary team assessment

9. Which professionals **external** to your service do you collaborate with during an ASD diagnostic assessment? (Select all that apply)

- ☐ Sole practitioner (Medical)
- ☐ Sole practitioner (Psychology)
- ☐ Sole practitioner (Speech and Language Therapy)
- ☐ Sole practitioner (Occupational Therapy)
- ☐ Multidisciplinary team (e.g. Psychologist and Speech Language Therapist)
- ☐ School/Early Childhood staff
- ☐ Other (please describe) _____
- ☐ I do not collaborate with professionals external to my service

10. Once an individual has been referred to you/your diagnostic service, and a decision to assess for possible ASD has been made, how long on average is the waiting list for an assessment?

< 1 month	1-3 months	4-6 months	7-12 months	1-2 years	> 2 years
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11. In your service, how long does a typical ASD diagnostic assessment take, from the initial appointment to the completion and delivery of the diagnosis?

1-2 weeks	3-4 weeks	1-3 months	4-6 months	7-12 months	> 1 year
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

12. On how many occasions do you (if working as a sole practitioner) or your team (if working in a multidisciplinary team) typically see an individual prior to making a final diagnosis?

Once	2-3 occasions	4-6 occasions	7-9 occasions	≥ 10 occasions
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Assessment Measures

This series of questions asks about the tools that you use as part of the assessment process.

13. How frequently do you use the following tests as part of your assessment when you suspect ASD?

	Never	Occasionally	Sometimes	Frequently	Always
Hearing test/check	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical investigations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Standardised psychometric assessment tools (e.g., WISC, VABS)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Standardised ASD-specific assessment tools (e.g., ADOS, CARS)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14. Which of the following assessments are used routinely or sometimes as required as part of the ASD diagnostic assessment? (Select all that apply)

- ☐ Developmental history
- ☐ Developmental assessment, e.g., Griffiths, Bayley
- ☐ Cognitive assessment, e.g., WISC, Leiter
- ☐ Language/communication assessment, e.g., CELF, PLS
- ☐ Assessment of adaptive behaviour/functioning, e.g., VABS, ABAS
- ☐ Other psychometric assessment (please specify) _____
- ☐ Other specialist reports (please specify) _____
- ☐ None

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15. Which of the following ASD-specific assessments are used routinely or sometimes as required as part of the ASD diagnostic assessment? (Select all that apply)

- ☐ Autism Diagnostic Observation Schedule (ADOS)
- ☐ Autism Diagnostic Interview (ADI)
- ☐ Childhood Autism Rating Scale (CARS)
- ☐ Diagnostic Interview for Social and Communication Disorders (DISCO)
- ☐ Developmental, Dimensional and Diagnostic Interview (3di)
- ☐ Other (please specify) _____
- ☐ None

Classification System for Assigning Diagnoses

This series of questions asks about the classification system that your service employs in ASD diagnostic assessments.

16. Which classification system do you currently use to assign diagnoses?

- ☐ ICD-10
- ☐ ICD-11
- ☐ DSM-IV
- ☐ DSM-5
- ☐ Other (please specify) _____

17. Do you assign a severity rating to ASD diagnoses?

- ☐ Yes
- ☐ No

17a. If you answered Yes to Question 17, how do you decide about the severity of an individual's ASD? (Select all that apply)

- ☐ According to the DSM-5 specified levels of support, i.e., Level 1, Level 2, Level 3
- ☐ Based on scores of standardised assessments, e.g., the CSS on the ADOS
- ☐ Based on the adaptive skills/functioning of the individual, e.g., VABS scores
- ☐ Based on clinical judgement
- ☐ Other (please describe) _____

Providing Diagnostic Assessment Results

This series of questions asks about the processes you take to inform the individual/whānau/family about the diagnosis.

18. How frequently do you offer to meet with the individual/whānau/family to provide diagnostic assessment results in person?

Never	Occasionally	Sometimes	Frequently	Always
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. How frequently do you provide the individual/whānau/family with a written, diagnostic report following an ASD diagnostic assessment?

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Never	Occasionally	Sometimes	Frequently	Always
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Cost of ASD Diagnostic Assessments

20. Does your service charge individuals/whānau and families for ASD diagnostic assessments?

- ☐ Yes
☐ No

20a. If you answered Yes to Question 20, how do you charge the individual/whānau/family? (Only select the options that apply best). Note: this is the amount the **individual/whānau/family pay**, not the cost of the assessment **for the service**.

- ☐ Hourly rate: \$ _____
☐ Average number of hours per assessment: _____
☐ Cost for initial session: \$ _____
☐ Cost per session: \$ _____
☐ Average number of sessions per assessment: _____
☐ Cost for report writing: \$ _____
☐ Average total cost for ASD diagnostic assessment: \$ _____

Diagnostic Uncertainty

This series of questions will ask about times where there is uncertainty in the diagnosis, leading to either 'deferring' from making a diagnosis or giving a diagnosis when the individual does not meet full criteria for ASD.

21. What are the circumstances in which you would 'defer' making an ASD diagnosis? (Select all that apply)

- ☐ When an individual is displaying 'sub threshold' ASD traits
☐ When a child is very young (< 2 years)
☐ When an individual has characteristics that are shared between ASD and other developmental disorders and the diagnosis is not clear either way
☐ When an individual has a syndrome that commonly co-occurs with ASD, e.g., Fragile X, ADHD
☐ When it is a complex diagnosis
☐ Other (please describe) _____
☐ Never

22. What are the circumstances in which you would diagnose ASD when the person does not meet full diagnostic criteria for the disorder? (Select all that apply)

- ☐ When the individual was so close to full criteria it was considered a fair and reasonable assessment
☐ When there was enough evidence from other settings to support an ASD diagnosis, though the characteristics of ASD were not fully apparent during the assessment context
☐ When there was a pressing need for the individual/whānau/family to access support, e.g. due to whānau/family crisis or significant behavioural difficulties
☐ When there was pressure from the individual/whānau/family to provide an ASD diagnosis

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- ☐ When the diagnosis would facilitate access to support in the early childhood/school environment
- ☐ When the diagnosis would facilitate access to disability services
- ☐ When the diagnosis would facilitate access to government funding
- ☐ Other (please describe) _____
- ☐ Never

Services and Supports Following an ASD Diagnosis

This series of questions asks about the supports that you provide or refer the individual/whānau/family to after an ASD diagnosis is made.

23. Once a diagnosis of ASD has been confirmed, how frequently do you provide ongoing follow-up?

Never	Occasionally	Sometimes	Frequently	Always
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

24. Once a diagnosis of ASD has been confirmed for individuals under the age of 20 years, how frequently do you refer to the Developmental Services/ASD Coordinator at your local DHB?

Never	Occasionally	Sometimes	Frequently	Always
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. How frequently do you provide, recommend, or refer the individual/whānau/family to each of the following services and/or resources after an ASD diagnosis?

	Never	Occasionally	Sometimes	Frequently	Always
Written information about ASD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Counselling to adjust to ASD diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ASD education programme	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cultural support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NGO Autism Organisation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disability allowance (Work and Income)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Needs Assessment Service Coordination (NASC)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ministry of Education early intervention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Ministry of Education learning support (school teams)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vocational support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Multidisciplinary service (e.g., speech language therapy, music therapy and physiotherapy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify) _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26. How frequently do you provide, recommend, or refer the individual/whānau/family to supports to address each of the following areas after an ASD diagnosis?

	Never	Occasionally	Sometimes	Frequently	Always
Communication (e.g., speech and language therapy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social (e.g., social skills training)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Behaviour (e.g., specialist behaviour support; Applied Behaviour Analysis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eating and drinking (e.g., food sensitivities)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gut health (gastrointestinal complaints)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bowel and bladder (toileting issues)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical movement (e.g., physiotherapy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sensory (e.g., sensory processing difficulties)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health (e.g., anxiety, depression)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep (sleep problems)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cognition (e.g., specific learning issues)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pharmacological management (e.g., anxiety, sleep, ADHD)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify) _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Training in ASD Diagnostic Assessments

27. What training in ASD diagnostic assessments have you had? (Select all that apply)

- ☐ No training
- ☐ Undergraduate training
- ☐ Postgraduate training (including specialist qualification)
- ☐ Observation of experienced clinicians
- ☐ Participation in parts of ASD assessments under supervision
- ☐ Completing a full diagnostic assessment for ASD under supervision
- ☐ Case discussions
- ☐ Training in diagnostic tools (please describe) _____
- ☐ Other (please describe) _____

Cultural Issues in ASD Diagnostic Assessments

This series of questions will ask about provision of cultural resources throughout the ASD diagnostic assessment and training in cultural competency.

28. Which of the following cultural supports are available during the ASD diagnostic assessment where needed? (Select all that apply)

- ☐ Kaiārahi/guide or other cultural worker
- ☐ Information about autism in languages other than English
- ☐ None
- ☐ Unsure

29. Would you like to access training in cultural competency?

- ☐ Yes
- ☐ No
- ☐ Already have access

29a. If you answered Yes to Question 29, what sort of training would you like to access? _____

Additional comments

30. Please feel free to share any additional comments about the ASD diagnostic assessment process:

Please follow the link below to provide contact details if:

- ☐ You would be willing for us to contact you in the future, if we seek further information relevant to this research project

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- ☐ You would be willing for us to contact you in the future to be invited to participate in other autism-related research projects
- ☐ You would like a copy of the results of the research project
- ☐ You would like to go in the draw to win one of 10 \$50 Prezzy Cards

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:

https://www.surveymonkey.com/r/Clinicians_Contact_Information

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Our values

**Inclusion**

Working together with those with the lived experience of autism in all we do

**Innovation**

New solutions for long term challenges

**Independence**

Guided by evidence based research, integrity and peer review

**Cooperation**

Bringing benefits to our partners; capturing opportunities they cannot capture alone



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