

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

June 2020





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. <u>The New Zealand Autism Spectrum Disorder Guideline</u> (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 <u>The Health and Disability System Review</u>, <u>Well Child Tamariki Ora Review</u>, and the <u>Learning Support Action Plan</u>. 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.

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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.



autismcrc.com.au

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 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, evidencebased, 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 <u>The New Zealand Autism Spectrum Disorder Guideline</u> (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 <u>Living Guideline Group</u>. 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, speechlanguage 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].





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 Commonly, 6). health professionals advised about the pathway to pursue a diagnosis. For children, early





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.

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 primary satisfied. The 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 comorbidities, 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



Figure 11. Costs for private diagnoses

a diagnosis through private practice, indicating cost is very likely to be a barrier to adults accessing a diagnostic assessment.

"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

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



undertaken. Additionally, specific sensory, communication or other important aspects that could benefit from the expertise of clinicians from other disciplines, could be overlooked.

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.







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.



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 14. How clinicians provide a diagnosis



Figure 15. Multidisciplinary diagnosis process



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

(n=80)

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

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

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.

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

"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 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 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



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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





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 longterm 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

"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

diagnosis, and analysis reveals that (at least) the following factors may contribute:

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. Alarmingly, over one-third of children wait more than 7 months for their initial public assessment.







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.

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

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



"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

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



elapsed time from requesting an initial appointment to receiving a diagnosis. This 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 endpoint, 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:

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

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

Moderate overall satisfaction with th

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 whanau members.
- > They felt the pathway to a diagnosis was clear.

Figure 25. Overall stress during the diagnostic process



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

Figure 26. Overall satisfaction with the diagnostic process



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- They were more satisfied with initial help received and with the professional's manner when disclosing the diagnosis.
- They were more satisfied with the postdiagnostic 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 29. Overall coordination of postdiagnostic support



Figure 28. Overall satisfaction with post-diagnostic supports



Most clinicians offer follow-up after a diagnosis

While three-quarters (76%) of clinicians reported that they provided ongoing followup 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 "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

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.

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 indicated also 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.

ParentsweremoresatisfiedwhenDevelopmentalServices/ASDCoordinators 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 "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

improve service delivery, particularly with better uptake. However, qualitative comments also indicate they could be more effective and person-centred.



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

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

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.



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 (≥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 postdiagnostic 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 familyand 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.

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%

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

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 "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 nonstop panic attacks)." - Parent

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.





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 multidisciplinary 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 - <u>http://asdetect.org/</u>) 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, interministry, 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:		
	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	•	
2	All DHBs should have in place processes that ensure:	C	
	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		
2	d. All services are provided in a timely manner	1	
3	All children suspected of naving autism or another developmental delay should have an audiology assessment	V	
4	Preferably, a multidisciplinary team of health care practitioners experienced	В	
-	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		
5	Diagnostic assessment of young people and adults should be	С	
	comprehensive and involve the person concerned in interview and		
	observation.		
5.1	Standardised ASD assessment interviews and schedules should be used.	В	
	The intellectual, adaptive, and cognitive skills associated with ASD should		
	be seriously considered and, where possible and appropriate, formally		
	assessed		
6	Health care practitioners must have a good understanding of the different	В	
	forms of expression of autism symptomatology across developmental		
	stages and the symptomatology of common coexisting and alternative		
	diagnoses		
	Key recommendations for formulation, disclosure of diagnosis and		
	post-diagnosis support	-	
1.4.4	All diagnostic assessments should include a detailed written report	С	
	covering the person's strengths and weaknesses, developmental course,		
	ASD symptoms, recommendations for intervention and information on		
1.1.0	Support networks		
1.4.6	Information on ASD and support services should be available at all	В	
4 4 7	alagnostic disclosure interviews and through health and disability services	<u> </u>	
1.4./	Sources of post-diagnostic support should be identified for the person with		



	Key recommendations for support	
2	ASD-related counselling and/or advocacy services and education should	С
	be available to all family members and carers	
12	A coordinated approach to planning and implementing services should be	\checkmark
	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	\checkmark
1	Information packages in appropriate and relevant language about ASD	\checkmark
	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	\checkmark
	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. Fortyfour 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 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.