



AutismCRC

# The autism diagnostic process in New Zealand

## EXECUTIVE SUMMARY

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## Executive Summary

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

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

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## **A note on terminology**

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

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

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# Executive Summary

## Background

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

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

This project subsequently aimed to:

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

## Research Design and Methods

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

Workshops were held in Auckland, Hamilton and Wellington in October 2018. The workshops were attended by 17 professionals involved in autism assessment and/or post-diagnostic support

services, including medical professionals, allied health professionals, service providers and a researcher. The workshops centred around two key objectives: (1) discussing local experiences of the autism assessment process and implementation of national guideline recommendations; and (2) suggestions regarding the national online survey content, recruitment and administration. Workshops were audio recorded and summarised by a member of the research team, prior to undergoing thematic analysis.

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

## Findings

The findings from this project are presented in a series of appendices in their original format which can be read in full in the Final Report found at [https://www.autismcrc.com.au/knowledge-centre/reports/diagnostic\\_process\\_nz](https://www.autismcrc.com.au/knowledge-centre/reports/diagnostic_process_nz). The appendices cover:

- Appendix A – Autism/Takiwātanga: The Pathway to Diagnosis and Supports in New Zealand [Community Research Report]
- Appendix B – The Autism Diagnostic Process in New Zealand: A Cross-sectional Survey of Satisfaction amongst Autistic Adults [Embargoed Journal Manuscript]
- Appendix C – Strategies for Improving Satisfaction with the Autism Diagnostic Process in New Zealand – An Autistic Adult Perspective [Research Summary]
- Appendix D – The Autism Diagnostic Process in New Zealand: A Call for Action from Caregivers [Research Summary]
- Appendix E – The Clinical Landscape of Autism Diagnosis in New Zealand [Embargoed Journal Manuscript]
- Appendix F – Summary of Qualitative Themes from the Clinician Survey [Research Summary]
- Appendix G – Summary of Qualitative Themes and Suggestions from the Workshops [Research Summary]

- Appendix H – Autistic Adult and Caregiver Survey [Data Collection Instrument]
- Appendix I – Clinician Survey [Data Collection Instrument].

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

## Implications for Research and Practice

This project has added to the body of knowledge about the autism diagnostic process in New Zealand, from the perspectives of autistic adults, caregivers and clinicians. When the research findings are considered in the context of the broader research literature, it is apparent that the experiences within the New Zealand population studied are comparable to experiences reported internationally. This project has:

- Identified areas for future research include evaluating the implementation of recommended changes to the autism diagnostic process, such as awareness campaigns, formal screening systems, resources articulating / servicing a clear diagnostic pathway, coordination services and provision of post-diagnostic supports to meet unmet needs.
- Given a voice to autistic adults and caregivers regarding their experiences, unmet needs and suggestions for improving the autism diagnostic process in New Zealand in the future.
- Highlighted areas in which the autism diagnostic process has been successfully implemented in New Zealand, along with inconsistencies and unmet needs.
- Collected and compiled evidence to inform future revisions of the Guideline through the existing Living Guideline Group, along with a series of recommendations for additional resources and activities to enhance implementation of the Guideline across all regions, settings and sectors involved in the autism diagnostic process in New Zealand.

## Key Recommendations

1. Form an inter-ministry, inter-disciplinary, cross-sector, and consumer-oriented national steering committee to lead New Zealand's strategic and long-term approach to autism

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identification, diagnostic assessment and post-diagnostic supports. This steering committee should utilise a hub and spoke model, where it is supported by local stakeholder groups.

2. Increase awareness of autism among the general public (including parents), educators and clinicians. This should focus on providing education and training about signs and symptoms of autism (across the lifespan and for all genders), implementing Guideline recommendations for the autism diagnostic process (from the time of initial concerns until supports are in place), and effective supports for individuals on the autism spectrum and their families.
3. Develop and appropriately resource a clear pathway within the public sector that includes robust developmental surveillance and screening practices, equitable access to Developmental Services/ASD Coordinators, effective referral processes for initial assessments, specialist autism services and tertiary centres (as required), and linkage to required supports. This pathway should be person-centred, strengths-based, collaborative and informed by a comprehensive needs assessment.
4. Further investigate, and translate into practice, potential strategies that would promote the implementation of Guideline recommendations into standard practice across all regions, settings and populations across New Zealand. These strategies should be evaluated and revised over time.

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## Our values



### **Inclusion**

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



### **Innovation**

New solutions for long term challenges



### **Independence**

Guided by evidence based research, integrity and peer review



### **Cooperation**

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



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