

The autism diagnostic process in New Zealand



Background

The New Zealand Autism Spectrum Disorder Guideline (the Guideline) was developed to provide evidence-based good practice in the identification, diagnosis, and ongoing supports for people on the autism spectrum.

Although there is good awareness of the Guideline in New Zealand, the autism community report some recommendations from the Guideline are not well implemented and little research has evaluated implementation of the Guideline.



Who took part?

640 total participants, including:

458  Parents/caregivers of children on the autism spectrum

70  Autistic adults

112  Clinicians



Aim

We aimed to understand the autism diagnostic process, spanning identification, diagnosis, and ongoing supports, in New Zealand. We also aimed to evaluate implementation of recommendations from the Guideline.

Results from this research led to recommendations for improving best practice in the identification, diagnosis, and ongoing supports for people on the autism spectrum.



How we did the research



Parents/caregivers of children on the autism spectrum and autistic adults completed a questionnaire exploring their experiences of, and satisfaction with, the autism diagnostic process.



Clinicians completed a questionnaire exploring the autism diagnostic process in both public and private settings.

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What did we find?



The autism diagnostic pathway varied between children and adults.



Children were more likely to receive their diagnosis through a multidisciplinary assessment within the public system and wait longer for their first appointment and diagnostic confirmation than adults.



Parents/caregivers and autistic adults reported that the autism diagnostic pathway is unclear and ongoing supports are lacking or uncoordinated.



Over half of parents/caregivers and autistic adults were satisfied with the autism diagnostic process overall.



However, only about a quarter of participants were satisfied with post-diagnostic supports.

Clinicians indicated good awareness of the Guideline, but implementation of recommendations varied. Results show work is needed to:

1. identify autism earlier and increase clarity in the autism diagnostic pathway
2. support implementation of recommendations from the Guideline to ensure diagnosis is timely, consistent and accurate
3. improve access to high-quality, coordinated and ongoing supports post-diagnosis.



Who did the research?



Autism New Zealand led this research.

Researchers were: Larah van der Meer (Autism New Zealand), Kiah Evans (Telethon Kids Institute), Lauren Taylor (Telethon Kids Institute / University of Western Australia), Andrew Whitehouse (Telethon Kids Institute / University of Western Australia)

We'd also like to acknowledge: Hiran Thabrew (The University of Auckland), Matthew Eggleston (Canterbury District Health Board), Hannah Waddington (Victoria University of Wellington) and Marty Flavall (Think Differently Solutions).

Find out more

Download the final report and executive summary on the Autism CRC website:

autismcrc.com.au/report/diagnosis-nz

Email Autism New Zealand:
research@autismnz.org.nz

