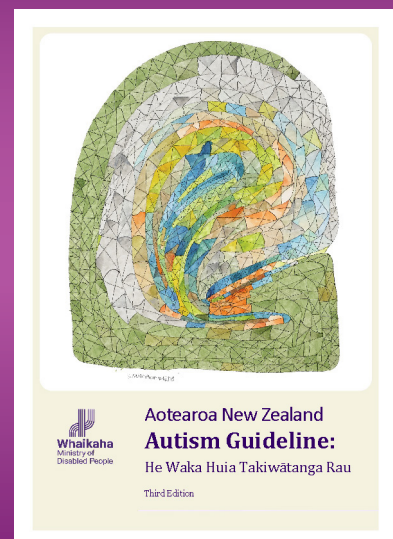
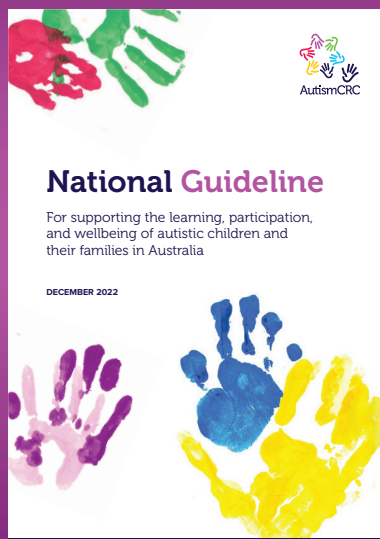
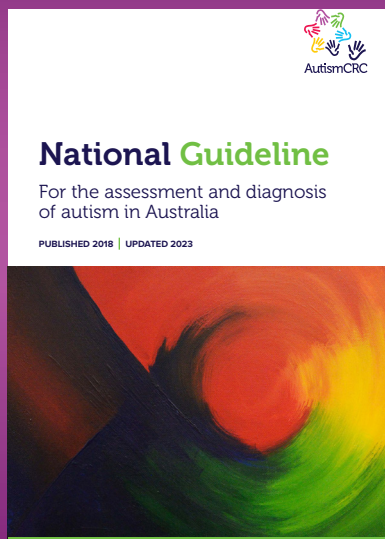


National Guidelines: Update and capacity building

Executive Summary

David Trembath, Cathy Franklin, Larah van der Meer, Hannah Waddington, Andrew Whitehouse

September 2023



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David Trembath

Griffith University | Telethon Kids Institute

Cathy Franklin

University of Queensland

Larah van der Meer

Autism New Zealand

Hannah Waddington

Victoria University of Wellington

Andrew Whitehouse

Telethon Kids Institute

ISBN: 978-1-922365-63-7

Citation: Trembath, D., Franklin, C., van der Meer, L., Waddington, H, Whitehouse, A. (2023). Autism CRC National Guidelines: Update and Capacity Building (Final Report). Brisbane, Autism CRC.

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

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Acknowledgements

The authors acknowledge the financial support of Autism CRC. Staff and non-staff in kind were provided by the five organisations involved in this project: Autism New Zealand, Griffith University, Telethon Kids Institute, University of Queensland, and Victoria University of Wellington. Given this project involved four sub-projects, the extensive contributions of autistic people, families, practitioners, researchers, and other members of the community who contributed to those projects have been acknowledged in the documents and resources arising from those projects.

Autism CRC

Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum.

We provide the national capacity to develop and deliver evidence-based outcomes through our unique collaboration with autistic people, families, professionals, services providers, researchers, and government. Together, we are addressing agreed needs and co-producing outputs with these stakeholders for the benefit of the community.

Autism CRC was established in 2013 as the world's first national, cooperative research effort focused on autism under the Australian Government's Cooperative Research Centres (CRC) Program. We receive funding from a number of sources, including the Australian Government. Autism CRC is no longer part of, or associated with, the CRC Program.

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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, 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'.

Executive Summary

Autistic people and their families commonly access practitioner provided services and supports, ranging from assessment and diagnostic services, through to the supports for learning, participation, and wellbeing in everyday life. It is essential that these services and supports are safe and effective, as well as desirable to individuals and their families.

The overarching aim of this project was to support the update and implementation of clinical Guidelines that have been developed to guide practitioners working with autistic people and their families. Clinical Guidelines provide an evidence-based framework to guide practitioners in their work, in order to promote the best possible for each individual and their family, and to protect against potential harms.

In Australia and Aotearoa New Zealand, there are three Guidelines for clinical practice:

- The National Guideline for assessment and diagnosis of autism in Australia (ADAG) which was first published in 2018 (Whitehouse et al., 2018)
- National Guideline for supporting the learning participation of autistic children and their families in Australia (SACG) which was first published in 2022 (Trembath et al., 2022)
- Aotearoa New Zealand Autism Guideline (ANZG) which was first published in 2008, updated as second edition in 2016, and most recently updated as a third edition in 2022 (Whaikaha, 2022).

Each Guideline was originally developed through a systematic process, which in broad terms involved: (a) forming a Guideline Development Group, (b) identifying the questions about clinical practice that need to be answered, (c) gathering evidence from research and through community consultation, (d) synthesising the evidence into a set of Recommendations and Good Practice Points, (e) submitting the Recommendations for public and peer review and making further edits, (f) publishing the Guideline, and (g) supporting its implementation in professional practice. To remain relevant, Guidelines must be updated periodically, given that community views and preferences, as well as research evidence, change over time.

The first specific objective of this project was to update the ADAG. The process followed the National Health and Medical Research Council (2016) Guidelines for Guidelines requirements and adhered to the international best practice GRADE methodology for moving from the development and revision of clinical questions, through to evidence gathering and synthesis, and updating of recommendations (Alonso-Coello et al., 2016). The project delivered an updated Guideline, an Administration and Technical Report, a Supporting Evidence document, a Public Consultation Summary, and an Easy Read version of the Guiding Principles presented in the Guideline. Moving forward, the updated Recommendations will be reviewed by the National Health and Medical Research Council, and existing resources to support its implementation will be updated and expanded where necessary.

The second specific objective of this project was to develop a suite of resources to support implementation of the SACG. The process broadly followed that used to successfully develop resources to support the implementation of the ADAG from 2019 to 2023, with a focus on the development of practical evidence-based resources that could be used by all members of the autistic and autism communities. The project delivered an online Short Course for use by all members of the autistic and autism communities, an eLearning Lecture and Activity for use in training and education contexts, a Journey Planner for Caregivers, a Guideline Overview for Practitioners. Moving forward, Autism CRC will support the dissemination and implementation of the SACG and accompanying resources, as the basis for improving supports provided to autistic children and their families.

The third specific objective of this project was to conduct research to inform implementation of the ANZG as well as future approaches to autism support in Aotearoa New Zealand. The process involved collaboration with the ANZG Guideline key stakeholder organisations and extensive community consultation to understand the needs and preferences of the autistic and autism communities regarding support for implementing the Guideline and other approaches. The project delivered a set of Recommendations, that can inform efforts to develop supportive approaches for policy makers, clinicians, educators, and family, and whānau.

The fourth specific objective of the project was to develop a Guideline Lifecycle document, in which the learnings from each specific project could be combined to inform the development and updating of future Guidelines. The Guideline Lifecycle features a series of practical Recommendations that draw on the methodological strengths of the individual projects and the experiences and insights of individual team members and complements the National Health and Medical Research Council's (2016) Guidelines for Guidelines and the GRADE methodology (Alonso-Coello et al., 2016).

Individually, and collectively, the outcomes of this project will result in positive changes in clinical practice, with the potential to inform policy and operational guidance across service systems including health, disability, and education. Furthermore, the development of a Guideline Lifecycle lays the foundation for a synergised system of Guideline development, implementation, and updating that has the potential to benefit autistic people and their families across Australia and Aotearoa New Zealand now and into the future.

Our values



Inclusion

Valuing lived experience



Innovation

Solutions for long term challenges



Evidence

Truth in practice



Independence

Integrity through autonomy



Cooperation

Capturing opportunities together



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