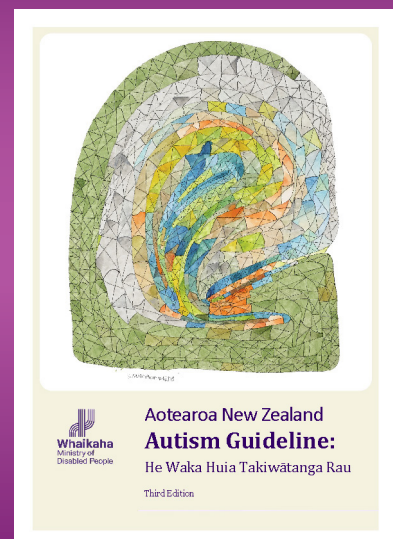
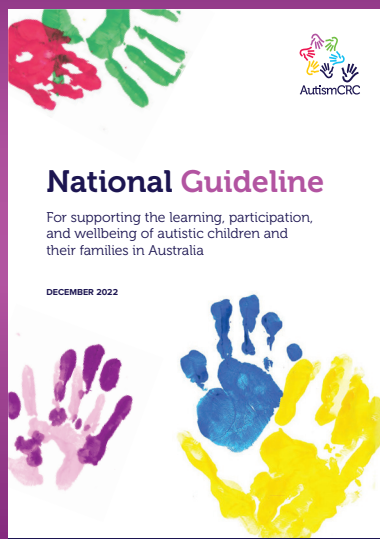
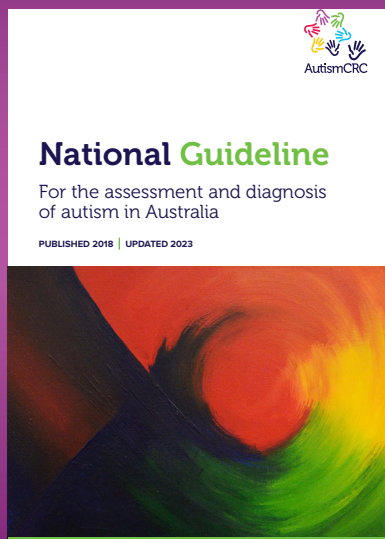


National Guidelines: Update and capacity building

Final Report

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September 2023



National Guidelines: Update and Capacity Building Final Report

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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.

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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.

autismcrc.com.au

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'.

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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.

1. Project Summary

This chapter presents a concise summary of the project, including the four sub-projects it entailed. The focus is on providing the context and the aims, methods, and Recommendations that span the four sub-projects. For specific information about one or more sub-projects, readers will be directed to the documents, reports, and resources that have been generated for each of the individual projects to ensure the most accurate and complete information is provided.

1.1 Background

In 2022, Autism CRC released a call for investment proposals from members for a series of short-term projects. Among the five projects outlined, two related specifically to updating and implementing clinical Guidelines, which provide an evidence-based framework for practitioners to deliver safe, effective, and desirable supports and services.

In Australia, Autism CRC has developed two Guidelines. The first was the National Guideline for assessment and diagnosis of autism in Australia (ADAG), first published in 2018 (Whitehouse et al., 2018) and the 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). In Aotearoa New Zealand, the Aotearoa New Zealand Autism Guideline (ANZG) was first published in 2008, updated as second edition in 2016, and most recently updated as a third edition in 2022 (Whaikaha, 2022).

For Guidelines to be effective, they must be developed, implemented, and updated in a systematic and rigorous manner, in accordance with international standards for best practice. A single cycle typically occurs over a period of several years, with planning for subsequent cycles an ongoing consideration and process. The process is also typically labour intensive and time consuming, and can be challenging, particularly where Guidelines must provide Recommendations in relation to issues for which little existing evidence exists, or that are emerging. The process requires deep engagement, collaboration, and partnership with a broad range of stakeholders, including foremost individuals whose lives the Guidelines will most directly affect, including autistic people and their families.

Recognising both the opportunities and challenges the process of developing, implementing, and updating Guidelines present, the project team sought to draw on the knowledge, experience, methods, and expertise accumulated across Australia and Aotearoa New Zealand in relation to Guideline development and implementation in proposing a set of four sub-projects that would address call for investment in a holistic and synergistic manner. Specifically, the team proposed to:

- Update the Autism CRC ADAG.
- Develop a suite of resources to support implementation of the Autism CRC SACG.
- Conduct research to inform implementation of the ANZG and other approaches in Aotearoa New Zealand.
- 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.

1.2 Approach

The project was coordinated by a team representing five organisations: Griffith University, Autism New Zealand, Telethon Kids Institute, Victoria University of Wellington, and Autism Queensland. Each sub-project was then delivered by a team comprising members from within and outside these five organisations, including autistic people, family members, practitioners, researchers, and other community members.

The specific methods used in each sub-project varied according to the sub-project aims:

- The update of the Autism CRC ADAG was conducted according to the National Health and Medical Research Council's (2016) Guidelines for Guidelines requirements and adhered to the international best practice GRADE methodology (Alonso-Coello et al., 2016) for moving from the development and revision of clinical questions, through to evidence gathering and synthesis, and updating of Recommendations. Key steps included: (a) establishing the Guideline Development Group; (b) revising the Guideline questions; (c) gathering evidence through research review and community consultation; (d) revising Recommendations in preparing the draft updated Guideline; (e) engaging in public consultation regarding the draft updated Guideline; and (f) making final edits and preparing the Guideline for submission to the National Health and Medical Research Council for approval of the updated Recommendations.
- The development of resources to support implementation of the Autism CRC SACG 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. Key steps included: (a) reviewing the SACG Dissemination and Implementation Plan that accompanied the Guideline; (b) critical review of the methods used and outcomes of the process used to develop the ADAG resources previously; and (c) an iterative process of developing, reviewing, and refining resources, with constant consideration of the needs of target users from across the autistic and autism communities. This process was supported by an external educational designer company and video editing services.
- The gathering of evidence to inform possible implementation activities for the ANZG and other approaches involved collaboration with the ANZG 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 as well as other approaches to autism support. Key steps included: (a) development of two research advisory groups (Autistic Advisory Group and Partnership Advisory Group) who provided input at each stage of the research; (b) developing a community views survey examining perceptions from members of the autistic and autism community of current supports and services as well as suggested approaches for the future, including implementation of the ANZG; and (c) analysis of survey findings and development of recommendations to inform implementation of the ANZG and other supportive approaches for the future.
- The development of the Guideline Lifecycle document involved the development of a series of practical Recommendations to inform the development and updating of future Guidelines. Key steps included: (a) reviewing the National Health and Medical Research Council's Guidelines for Guidelines requirements and GRADE methodology; (b) inviting project team members, research personnel, and members of Guideline Development Groups for the

ADAG update and SACG to review these requirements and offer practical Recommendations for how to achieve each of the requirements, taking into consideration the unique contextual considerations in the field of autism (e.g., available evidence, the critical importance of co-design and community consultation); and (c) reviewing and refining the document ahead of delivery to Autism CRC.

Common to all projects was a strong focus on community involvement in the project team and – where relevant – the gathering and use of the best available evidence from research, practice, and community consultation. Table 1 presents a summary of the approaches used.

Table 1: Summary of community involvement and research activities

| Document | Community Involvement | Research Evidence Review | Community Consultation |
|--|--|--|---|
| Update: Autism CRC National Guideline for assessment and diagnosis | Co-led by an autistic researcher with multiple members of the project team being autistic and/or having family members who are autistic. All activities and outputs were co-produced. | An umbrella review of 16 systematic reviews was completed. | 872 people participated in community consultation activities (online survey and focus groups). 339 individuals and 19 organisations provided feedback on the draft Guideline, which was also reviewed by international expert reviewers. |
| Implementation: Autism CRC National Guideline for supporting autistic children and their families | The project involved direct collaboration with autistic people and family members of autistic people, including in developing, reviewing, and refining resources. | All resources drew on the evidence gathered to inform the development of the Guideline, including an umbrella review of 48 systematic reviews. | All resources drew on the evidence gathered to inform the development of the Guideline, including evidence from extensive community consultation. |
| Implementation: Aotearoa New Zealand Guideline and other approaches | Co-led by autistic researchers, involvement of Autistic Advisory Group and Research Advisory Group as well as key stakeholders through each stage of the research. | Community views survey. | 1,042 people completed the survey (461 parents or caregivers of autistic people who are not autistic themselves; 296 autistic people; 242 professionals who work with autistic people; and 43 family or whānau members of autistic people). |
| Guideline Lifecycle | The development of the Guideline Lifecycle document was led by an autistic researcher, with multiple members of the project team being autistic and/or having family members who are autistic. | The document drew on learnings from the process of completing research evidence reviews for the ADAG and SACG. | The document drew on learnings from the process of completing community consultation activities conducted as part of the ADAG and SACG. |

1.3 Outcomes

The outcomes (deliverables) varied according to the sub-project aims but can be broadly categorised as the development of Recommendations (i.e., consensus-based Recommendations in a Guideline or Recommendations arising from research) and the development of resources (e.g., to support professional practice). The outcomes of the sub-projects are summarised in Table 2.

Table 2: Summary of deliverables

| Document | Recommendations | Resources |
|--|--|--|
| Update: Autism CRC National Guideline for assessment and diagnosis | The updated Guideline presents 66 consensus-based recommendations to guide clinical practice, as well as recommendations for implementation, future clinical and research directions, and for further updating the Guideline. | <ul style="list-style-type: none"> • Updated Guideline • Administration and Technical Report • Supporting Evidence • Public Consultation Summary • Easy Read version of Guiding Principles. |
| Implementation: Autism CRC National Guideline for supporting autistic children and their families | Members of the project team developed a formal proposal to support the dissemination and implementation of the resources developed in this project, as well as further updating and aligning resources developed to support implementation of the original and updated ADAG. | <ul style="list-style-type: none"> • Online Short Course • eLearning Lecture and Activity • Journey Planner for Caregivers • Guideline Overview for Practitioners. |
| Implementation: Aotearoa New Zealand Guideline | Findings from the project suggest investment and accountability for implementation of the ANZG and other approaches. | <ul style="list-style-type: none"> • Project report presenting the aims, methods, findings, and recommendations. |
| Guideline Lifecycle | The Guideline Lifecycle document comprises a suite of recommendations to support future guideline development, implementation, and updating. | <ul style="list-style-type: none"> • Guideline Lifecycle Document. |

1.4 Key Recommendations

The following Recommendations reflect critical reflection on the limitations of the project; implications for policy and practice; and current and future opportunities. The Recommendations focus holistically on the process of developing, implementing, and updating Guidelines. Although examples may be drawn from one or more specific sub-projects, the intention is to inform the implementation of an ongoing systematic process to continue to support professional practice and policy through clinical Guidelines.

1. **Living Guideline:** Through the process of updating the ADAG and drawing on the experience of project team members associated with the ANZG, we support the notion of ‘Living Guidelines’ whereby clinical questions, evidence gathering and synthesis, and revisions occur in a systematic manner, on an ongoing basis. There is an opportunity to learn from the experience of colleagues in Aotearoa New Zealand where this approach has been adopted. A number of subsequent Recommendations are consistent with this overarching notion, which requires longer term planning, funding, and coordination to achieve. A move to a living Guideline for the ADAG and SACG would see a team continue to monitor relevant research and gather evidence from the community periodically, to ensure the questions and Recommendations continue to be as relevant as possible.

2. **Coordinated Community Consultation:** Community consultation provides the foundation for consensus-based Recommendations and is a common fundamental feature across projects. Often, the questions project teams are seeking to answer - whether in developing, implementing, or updating a clinical Guideline or in other projects - are highly related. Furthermore, high quality qualitative research often involves asking people relatively broad questions about their lives, experiences, views, and preferences rather than specific questions, to allow for open expression. For example, people may be asked to reflect on what is, and is not positive, about their experience of accessing services and supports, working with practitioners, and engaging with service systems. We recommend exploring a more coordinated approach to engaging in community consultation across projects, to increase accessibility, increase engagement, reduce participant burden, and maximise efficiency. This could, for example, take the form of a twice-annual consultation process (e.g., an online survey, focus groups, expression through art) in defined periods (e.g., March and September) where participants can contribute their views on a range of issues, which are often related. Project teams would coordinate their efforts in developing the set of questions to be asked on each occasion, potentially share the workload in relation to data collection and analysis and provide timely and accessible feedback to participants in a coordinated manner. A purposive sampling approach should be adopted to help ensure a representative sample of all key community stakeholders, including over time, with appropriate compensation, and in ways that ensure accessibility needs are met.
3. **Long Term Partnerships:** We note the importance of genuine, broad, and deep community consultation, including with people who are commonly not represented in research and community consultation activities, such as Aboriginal and Torres Strait Islander Peoples, culturally and linguistically diverse communities, people living in rural and remote areas, people with intellectual disability, and people with complex communication needs. We also observe that the same groups of individuals and organisations may be approached at multiple timepoints for the same project (e.g., a single Guideline), at one or more timepoints for related projects (e.g., development and update of two related Guidelines), and/or at one or more time points for unrelated projects (e.g., with different aims and teams). We note that genuine consultation and collaboration requires the building of longstanding, positive, and trusting relationships, which in turn requires a coordinated and ongoing commitment. We encourage Autism CRC to continue to identify and strengthen relationships with key stakeholders in ways that promote long term collaboration, including facilitating awareness and coordination of activities across different projects and teams. We also support ongoing efforts within Autism CRC and the broader community to develop and improve methods for consulting people who are often marginalised from research.

4. **Guideline Capacity Building:** Developing, implementing, and updating clinical Guidelines requires a team with diverse knowledge, skills, and experience, including members with specialist knowledge of Guideline development and implementation methods and standards. Autism CRC has successfully supported the development of what has become a growing community of people with Guideline development experience, and we encourage the adoption of a deliberate strategy to ensure: (a) continued growth; (b) opportunities for people including early career researchers, practitioners, and community members to progress to positions of increasing responsibility within Guideline teams over time; and (c) succession planning to ensure continuity when it comes to updating each Guideline. Strategies to support such an approach may include: (a) adopting an expression of interest process when forming Guideline Development Groups to encourage broad engagement; (b) continuing to ensure diversity within Guideline Development Groups and broader project teams, including in relation to career stage and Guideline experience; and (c) in moving to the proposed 'Living Guideline' approach, establish panels to review evidence (gathered through research review and community consultation) that would provide further opportunities for members of the autistic and autism communities to contribute to Guideline development and updating while at the same time expanding capacity.

5. **Trans-Tasman and Regional Collaboration:** The approach and outcomes of this project demonstrate the benefits of trans-Tasman collaboration, which could be broadened within the region in the future. We should continue to seek opportunities to support such collaboration, in the interests of deepening connections; sharing knowledge, skills, and resources; and where appropriate aligning efforts.

1.5 Conclusion

The objectives of this project were achieved, resulting in an updated ADAG, the development of implementation resources for the SACG, the gathering of evidence to inform the future implementation of the ANZG and other approaches to autism support, and the development of a Guideline Lifecycle to support ongoing Guideline-related projects. The approach taken, in relation to coordination (i.e., bringing the projects and teams together) and methods used (e.g., co-production, extensive community consultation) have resulted in a complementary set of resources to support best practice in the field. Central to all approaches and outcomes, has been the essential involvement of a large number of people from across the autistic and autism communities, and for whom the project team extends our deepest and warmest gratitude.

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Our values



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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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